National Independent Study of the Administration on Developmental Disabilities Programs

Final Report – Volume II. Appendixes

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A. Memorandum from Director of OMB, Budget Guidance, August 17, 2011.
B. Working Version of Measurement Matrices (Benchmarks, Indicators, and Examples of Performance Standards)
C. Data Collection Instruments – Interview Guides
D. Notification of Sample Selection by ADD
E. Westat Email to Sampled Programs
F. Followup Letter from Westat to Confirm Program Visit Dates
G. Consent Forms
H. Findings Form Templates
I. Self-administered Questionnaire
J. Letter from ADD Commissioner to DD Network Programs on National Independent Study
K. Letter to obtain Draft Standards Panel Recommendations
L. Letter of Invitation from ADD Commissioner to Draft Standards Panel Members
M. Draft Standards Panel Members
N. Webinar Presentation PowerPoint to Draft Standards Panel Members
O. Draft Standards Rating Instructions
P. Draft Standards and Performance Criteria - Version 1

Volume II. Part 2 – Appendices Q through FF

Appendix

Q. Draft Standards Rating Form – Version 1
R. Draft Standards Version 1 Ratings
S. Rationale for Changes to Version 1
T. Cover letter for Version 2 Materials
U. Draft Standards and Performance Criteria - Version 2
V. Version 1 - Comments.doc
W. Version 2 Ratings
X. Cover letter - Version 3 materials
Y. Draft Standards and Performance Criteria – Version 3
Z. Version 2 Comments
AA. ADD Assessment Interview Guides
BB. Email to Stakeholders Requesting Participation in ADD Assessment
CC. Web Survey Findings – National Independent Study Participants Only
DD. Web Survey Questionnaire
EE. Letter from ADD Commissioner to Executive Directors on Web Survey
FF. Email to Executive Directors on Web Survey

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National Independent Study of the Administration on Developmental Disabilities Programs

Volume II. Appendices

Part 2. Appendix O through FF

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Appendix O. Rating Instructions

Rating Instructions – Electronic

1. This email contains the following attachments:

   - Instructions
   - DD Council/P&A/UCEDD Draft Standards and Performance Criteria – Version 1
   - Collaboration Draft Standard and Performance Criteria – Version 1
   - DD Council/P&A/UCEDD Rating Form - Version 1
   - List(s) of panel members
   - Collaboration Rating Form – Version 1

2. Open all files and save on your hard drive.

3. Read the list of Draft Standards and Performance Criteria all the way through.

4. To rate each draft standard:

   - Read each draft standard.
   - Decide whether you Agree, are Unsure, or Disagree that the program should be held to this standard.
   - Select the appropriate response by clicking in the box next to your response. Please provide **one rating** for each standard.
   - Provide comments **if you wish** in the COMMENTS box. Feel free to explain the reason for your rating, suggest alternative wording, or provide a different standard altogether.

5. To rate the performance criteria:

   - Read each performance criterion for the draft standard.
   - Decide whether you think the performance criterion should be required to meet the standard, exceeds the standard, or is not relevant to the standard.
   - Select the appropriate rating by clicking in the box next to your response. Please provide **one rating** for each performance criterion.
   - Provide comments **if you wish** in the COMMENTS box. Feel free to explain the reason for your rating, suggest alternative wording, or provide additional performance criteria.

6. At the end of each section (e.g., Planning, Self-Advocacy and Leadership, Individual Advocacy), provide comments **if you wish** in the COMMENTS box.

7. Save at the end of each section.

8. Once complete, email as an attachment to bibigollapudi@westat.com **by May 11, 2011.**

9. Please feel free to contact any one of the following individuals for assistance:

   - Linda Lynch: 1-800-837-8281, Ext. 4280 or lindalynch@westat.com
   - Bibi Gollapudi: 1-800-837-8281, Ext. 7558 or bibigollapudi@westat.com
   - Lynn Elinson: 1-800-837-8281, Ext. 5844 or lynnelinson@westat.com

Rating Instructions – Paper Copy

1. This package contains:

   - Instructions
   - DD Council/P&A/UCEDD Draft Standards and Performance Criteria – Version 1
   - Collaboration Draft Standard and Performance Criteria – Version 1
   - DD Council/P&A/UCEDD Rating Form - Version 1
   - Collaboration Rating Form – Version 1
   - List(s) of panel members
   - A postage paid envelope to return your completed ratings to Westat

2. Read the Draft Standards and Performance Criteria all the way through.

3. To rate each draft standard:

   - Read each draft standard.
   - Decide whether you Agree, are Unsure, or Disagree that the program should be held to this standard.
   - Put a check mark in the box next to the appropriate rating. Please mark **one rating** for each standard.
   - Provide comments **if you wish** in the COMMENTS box. Feel free to explain the reason for your rating, suggest alternative wording, or provide a different standard altogether.

4. To rate the performance criteria:

   - Read each performance criterion for the draft standard.
   - Decide whether you think the performance criterion should be required to meet the standard, exceeds the standard, or is not relevant to the standard.
   - Put a check mark in the box next to the appropriate rating. Please mark **one rating** for each performance criterion.
   - Provide comments **if you wish** in the COMMENTS box. Feel free to explain the reason for your rating, suggest alternative wording, or provide additional performance criteria.

5. At the end of each section (e.g., Planning, Self-Advocacy and Leadership, Individual Advocacy), provide comments **if you wish** in the COMMENTS box.

6. If you run out of room in the comments boxes, feel free to use extra sheets of paper.

7. Use the enclosed postage paid envelope to return your completed ratings to Westat **by May 11, 2011**.

8. If you have any questions or require assistance, please contact

   - Linda Lynch (1-800-837-8281, Ext.4280 or lindalynch@westat.com) or
   - Bibi Gollapudi (1-800-837-8281, Ext. 7558 or bibigollapudi@westat.com)
   - Lynn Elinson (1-800-837-8281, Ext. 5844 or lynnelinson@westat.com)

Appendix P. Draft Standards and Performance Criteria – Version 1

P1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

P2. PROTECTION AND ADVOCACY SYSTEMS

P3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

P4. COLLABORATION

P1. State Councils on Developmental Disabilities

A. Planning

Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory.

A Council that meets this standard:

1.1 Collects input for the State Plan from internal and external sources.

Examples of internal sources include DD Council staff, DD Council members, and DD Network partners in the state or territory.

Examples of external sources include the public, State agency staff, participants in DD Council activities (e.g., Partners in Policymaking), reports that contain valid and reliably collected data, and disability organizations and advocates.

1.2 Collects input for the State Plan from geographic regions across the state or territory.

1.3 Uses a variety of methods for collecting input for the State Plan (e.g., focus groups, surveys, social media outlets, the DD Council website, review and analysis of reports and studies).

1.4 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

1.5 Collects input for the State Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.

1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.

1.7 Gathers data for planning on an ongoing basis.

1.8 Has staff and DD Council members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.

Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for DD Council action.

A State Plan that meets this standard:

2.1 Reflects the internal and external input from the planning process.

2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life).

2.3 Drives all activities that the DD Council conducts and supports.

2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with DD Council resources, outside resources, and the potential impact of strategies that were considered.

B. Self-Advocacy and Leadership

Standard 3: DD Councils encourage and develop self-advocates and leaders among people with developmental disabilities (or their families) through education, training, and technical assistance.

A Council that meets this standard:

3.1 Actively recruits potential self-advocates and leaders from the broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities.

- Examples of ways to seek feedback include surveys and interviews.

Standard 4: Participants in DD Council self-advocacy and leadership development activities provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.

A Council that meets this standard:

4.1 Documents the self-advocacy and leadership development efforts of trainees to promote greater access to the community and improve the well-being of people with developmental disabilities.

These self-advocacy and leadership efforts include:

- Serving on the board of a disability-related organization (within the past 3 years),
- Advocating the state legislature to change or maintain services or access for people with developmental disabilities (within the past 3 years),
- Participating in training other people with a developmental disability in self-advocacy (within the past 3 years), and
- Obtaining a service or community access for oneself through self-advocacy (within the past 3 years).

4.2 Supports a statewide organization led by people with developmental disabilities.

C. Community Capacity Development

Standard 5. DD Councils improve community capacity through greater access, service delivery, choice and inclusion.

Examples of ways to improve community capacity include the following: achieve affordable transition housing for people with developmental disabilities, reasonable accommodations in the workplace, accommodations within community locations, and adaptive technology resources in schools.

A Council that meets this standard:

5.1 Provides information, training, and technical assistance to people and organizations in the community at large.

5.2 Conducts or supports at least one community capacity development activity each year.

5.3 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.

- Examples of targets include health care providers, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, and daycare workers.

5.4 Keeps track of participants in community capacity development activities, and uses the data for planning and evaluation.

5.5 Documents the success of efforts.

5.6 Demonstrates impact on increasing and improving services, choice, and inclusion for people with developmental disabilities within the past 5 years.

D. Systems Change

Standard 6: DD Councils use advocacy strategies to change systems to promote inclusion, choice, and better access to services for people with developmental disabilities and family members.

A Council that meets this standard:

6.1 Leads and participates in advocacy efforts that are expected to result in system changes that promote inclusion, choice, and better access to services for people with developmental disabilities.

6.2 Uses a variety of strategies to meet systems change objectives (e.g., providing funding to support systems change efforts, writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation).

6.3 Includes both Council members and staff in implementing advocacy activities.

6.4 Collaborates strategically to achieve systems change goals and objectives.

- Examples of strategic collaboration include maintaining or participating in a network of possible collaborators who are available to tap as appropriate issues arise and continually cultivating relationships for future systems change collaborations.

6.5 Makes sure State legislators and other policy makers personally know Council members and staff.

6.6 Evaluates its advocacy efforts throughout the year, and changes course as necessary.

6.7 Has evidence that its advocacy efforts have had an impact on legislation or public policy within the past 5 years.

6.8 Has evidence that its advocacy efforts have had an impact on community practice or services within the past 5 years.

6.9 Monitors implementation of systems change to ensure implementation adheres to a new policy, legislation, or procedures.

6.9 Monitors implementation of systems change to determine unintended consequences.

E. Demonstration of New Approaches to Services and Supports

Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members.

Examples of how DD Councils do this include: issuing requests for proposals, securing external funding to identify or test new or innovative practices, assisting community organizations in obtaining funding to identify or test promising practices, and partnering with other agencies or organizations in the state.

A Council that meets this standard:

7.1 Disseminates or promotes new or innovative practices the Council found to be effective.

7.2 Uses or tests new or innovative practices found to be effective by other DD Councils.

7.3 Collaborates with other DD Councils to try out or promote a new or innovative practice.

7.4 Disseminates information on practices found to be ineffective.

7.5 Can document that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.

7.6 Can document that other states or national programs are using the practices tested or disseminated by the DD Council.

F. Governance and Management

Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.

A Council that meets this standard:

8.1 Reflects the full range of the population of people with developmental disabilities in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups).

8.2 Fills all vacancies on the DD Council within 1 year.

8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.

8.4 Documents attendance in DD Council meeting minutes.

8.5 Has members who play an active role in meeting DD Council objectives.

- An active role includes membership or chairmanship of a sub-committee and participation in DD Council activities throughout the year.

8.6 Provides an orientation to new DD Council members.

- The orientation includes the principles and goals of the DD Act, background on the DD Council, DD Council goals and objectives, and the current State Plan.

8.7 Mentors new DD Council members.

8.8 Provides ongoing training on DD Council roles and responsibilities.

8.9 Provides all supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.

8.10 Provides funding for at least one DD Council member to attend a national meeting, conference, or training each year.

Standard 9. DD Councils are effective in fulfilling their mission.

A Council that meets this standard:

9.1 Reviews the performance of the Executive Director each year.

9.2 Conducts an independent review of itself every 3-5 years.

- An independent review does not need to be a formal evaluation.

9.3 Assigns a distinct role to every Council member.

9.4 Trains Council members on the core functions of their role.

9.5 Uses a fair, transparent, and effective process to select competent and experienced grantees.

- Evidence of a fair, transparent and effective process includes adherence to procedures for selecting grantees; adherence to procedures for handling unsolicited proposals; the inclusion of outside expertise during the proposal review process, as necessary; and the selection of grantee projects that reflect the goals and priorities stipulated in the State Plan.

P2. Protection and Advocacy (P&A) Systems

Draft Standards and Performance Criteria

A. Planning and Priority Setting

Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities and family members in the state or territory.

A P&A that meets this standard:

1.1 Collects input for the Statement of Goals and Priorities (SGP) from internal and external sources.

- Examples of internal sources include P&A staff, Board of Directors or Commission members, and DD Network partners in the state or territory.
- Examples of external sources include data from P&A activities (e.g., intake and assistance, outreach and community education), state agency staff, research and other reports that contain valid and reliably collected data, and state and territory disability organizations and advocates.

1.2 Collects input for the SGP from geographic regions across the state or territory.

1.3 Uses a variety of methods for collecting input for the SGP (e.g., focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies).

1.4 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

1.5 Collects input for the SGP using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.

1.5 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.

1.6 Gathers data on the needs of people with developmental disabilities on an ongoing basis.

1.7 Has staff and Board of Directors (or Commission) members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.

Standard 2: P&A SGPs reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for P&A action.

A P&A SGP that meets this standard:

2.1 Reflects the internal and external input from the planning process.

2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life), as well as protection from abuse and neglect.

2.3 Drives all primary activities that the P&A conducts and supports.

2.4 Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with P&A resources, outside resources, and the potential impact of strategies that were considered.

A. Intake and Assistance

Standard 3: The P&A intake process is equitable, efficient, and effective.

A P&A that meets this standard:

3.1 Maintains written intake procedures that describe how to determine an applicant's service needs and preferred mode of communication.

3.2 Maintains written procedures for documenting client information in a computerized database.

3.3 Maintains written procedures for priority case selection.

3.4 Provides training on the written intake procedures to all new intake staff.

3.5 Annually updates the intake process (e.g., intake forms, procedures, training, and orientation) to reflect changes in P&A goals and priorities and Federal and State policy and legislation.

3.6 Monitors staff adherence to intake procedures periodically.

3.7 Provides immediate corrective action of problems with adherence to intake procedures.

3.8 Directs callers to the appropriate level of assistance (e.g., referral, provision of information and resources, possible individual advocacy).

3.9 Periodically applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process (e.g., a survey of every caller for a period of 2 weeks, a followup telephone call to a random selection of callers).

3.10 Provides intake staff with access to ongoing professional development through the National Disability Rights Network [NDRN] or other organizations.

B. Individual Advocacy

Standard 4: P&A caseload reflects the priorities set in the SGP

A P&A that meets this standard:

4.1 Maintains written procedures for selecting and processing individual advocacy cases.

4.2 Selects individual advocacy cases that are consistent with goals and priorities in the SGP.

4.3 Conducts ongoing reviews of staff caseloads to ensure that the balance in the SGP priorities is achieved.

- A balanced caseload would consist of the P&A addressing approximately equal numbers of priority issues throughout the year.

Standard 5: P&A provides high quality representation.

A P&A that meets this standard:

5.1 Provides staff with formal opportunities (e.g., regularly scheduled meetings) to discuss and review cases.

5.2 Requires supervisory staff to provide frequent staff oversight (at least weekly).

5.3 Encourages use of the NDRN listServ and other resources, and provides staff with easy access.

Standard 6: Individual advocacy meets client objectives

A P&A that meets this standard:

6.1 Ascertains accommodation and communication needs at intake.

6.2 Commits resources to support all clients being served (e.g., language line, interpreters, staff that speak a language other than English, policy for including a support person for clients with cognitive disabilities if needed) so that individual advocacy staff is able to communicate with any client whose case is taken.

6.3 Provides a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.

6.4 Requires individual advocacy staff to update representation agreements when issues or approaches require a modification.

6.5 Sends or gives clients a closing letter documenting actions taken, results, and notification that the case is closed.

6.6 Informs callers of the grievance process if a case is turned down for individual advocacy.

6.7 Informs clients of the grievance process when the case is closed.

6.8 Documents success in resolving a majority of issues in favor of P&A clients.

6.9 Routinely follows up clients to determine whether decisions made on behalf of a client are being followed and the client issue has truly been resolved.

Standard 7: P&A strictly adheres to confidentiality.

A P&A that meets this standard:

7.1 Has a written confidentiality policy with well-delineated requirements.

- Examples of confidentiality requirements include checking with clients about whether phone messages can be left, turning off the computer at the end of the day, and storing files in a cabinet or drawer so they are not left in view of someone walking through the office.

7.2 Has written confidentiality procedures (including for working at home).

7.3 Has structures in place to maintain confidentiality (e.g., shredding capability, private offices, email encryption, locking file cabinets).

7.4 Has structures in place to help staff meet confidentiality requirements (e.g., email reminders to change passwords, alerts to tell people there is a stranger in the office so special care can be taken with client files).

7.5 Monitors periodically to ensure confidentiality procedures are being followed (e.g., inspects periodically to see if client files are left around or computers are turned off at end of day).

7.6 Requires a confidentiality pledge to be signed by anyone who is privy to client information. (e.g., P&A staff, students, interpreters).

7.7 Includes information about confidentiality requirements in all orientations (e.g., new staff, students, Board of Directors or Commissioners).

C. Systemic Advocacy

Standard 8: P&A systemic advocacy increases inclusion and choice for people with developmental disabilities and reduces abuse and neglect.

Systemic advocacy consists of systems change efforts on behalf of groups (e.g., group advocacy, investigations, monitoring, court-ordered monitoring, systemic or class action litigation) and results in changes to infrastructure, legislation, or policy.

A P&A that meets this standard:

8.1 Leads and participates in systemic advocacy activities to increase inclusion, improve access to supports and services, and to prevent abuse and neglect.

8.2 Regularly monitors databases from residential facilities, community services, intermediate care facilities, social service agencies, and other sources to identify and follow up on abuse and neglect issues.

8.3 Collaborates strategically to achieve systemic advocacy goals and objectives.

- Examples of strategic collaboration include maintaining or participating in a network of possible collaborators who are available to tap as appropriate issues arise; continually cultivating relationships for future systemic advocacy collaborations; and cultivating relationships with regulatory and enforcement agencies to effectively respond to emergency protection situations.

8.4 Effects systems change through a variety of means.

- Examples of means to effect systems change include writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation, securing pro bono assistance in class action suits from legal firms, filing amicus briefs, monitoring residential facilities, and following up on identified patterns of abuse and neglect).

8.5 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on legislation or public policy.

8.6 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on community practice or services.

8.7 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on inclusion and choice for people with developmental disabilities.

8.8 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on reduction in abuse and neglect.

8.9 Conducts ongoing monitoring to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.

D. Outreach and Community Education

Standard 9: P&As engage in effective and equitable outreach activities.

Outreach is defined as efforts made to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of outreach is to identify typically unserved and underserved populations that might benefit from P&A services and programs.

A P&A that meets this standard:

9.1 Conducts ongoing outreach activities.

9.2 Targets populations that are underrepresented or unserved.

9.3 Maintains a budget and designated trained staff for outreach activities.

9.4 Employs a variety of strategies to conduct outreach.

- Examples of outreach strategies include use of the P&A website, brochures, presentations at community events on the P&A and P&A services, and visits to group homes and other facilities that house people with developmental disabilities.

9.5 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.

9.6 Obtains feedback on outreach activities.

9.7 Reviews outreach activities between planning cycles so that outreach plans and strategies can be revised as needed.

9.8 Includes Board of Directors (or Commission) members in outreach activities.

9.9 Documents that outreach efforts have increased the number of callers and clients from typically unserved and underserved populations.

Standard 10: P&As have an impact on access to services, inclusion, and choice for people with developmental disabilities through the provision of community education.

Community education consists of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

A P&A that meets this standard:

10.1 Provides education, training, and technical assistance activities.

10.2 Makes community education available to a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).

10.3 Targets community education to those in the community at large who can increase and improve services, choice and inclusion (e.g., health care providers, residential facility operators, employers, local government officials, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, daycare workers) for people with developmental disabilities.

10.4 Delivers community education through a variety of modes (e.g., classes, workshops, webinars, and online courses).

10.5 Delivers culturally appropriate and targeted community education activities.

10.6 Maintains a budget and designated trained staff for community education activities.

10.7 Determines recipient satisfaction.

10.8 Documents that community education efforts led to improved access to services, choice, or inclusion for people with developmental disabilities within the past 5 years.

E. Governance and Management

Standard 11: P&A maintains an infrastructure that enables them to conduct all key functions efficiently and effectively.

A P&A that meets this standard:

11.1 Fills all vacancies on the Board of Directors (or Commission) within 1 year.

11.2 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues.

11.3 Includes Board of Directors (or Commission) members who are knowledgeable about the full range of the developmental disabilities population (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

11.4 Familiarizes all new Board Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.

11.5 Includes Board of Directors (or Commission) members who attend public events on issues related to developmental disabilities such as community meetings, legislative hearings, or non-profit organizations' events.

11.6 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.

11.7 Conducts an annual performance review of all staff members.

11.8 Receives an unqualified audit finding (i.e., clean audit with no findings, no notice of noncompliance) each year.

11.9 Budgets for professional development for staff.

Standard 12: P&A governance adheres to the principles and goals of the DD Act.

A P&A that meets this standard:

12.1 Maintains complete independence from the Governor and the developmental disabilities service system of the state or territory.

12.2 Provides supports needed to ensure meaningful participation by Board of Directors (or Commission) members.

12.3 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available to each member in accessible format.

12.4 Funds at least one Board or Commission member's attendance at a developmental disabilities-related national meeting each year.

P3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)

Draft Standards and Performance Criteria

A. 5-Year Planning

Standard 1: UCEDDs identify the key issues, needs, and priorities of people with developmental disabilities and family members in their state or territory.

A UCEDD that meets this standard:

1.1 Collects input for the 5-Year Plan from internal and external sources.

- Examples of internal sources include UCEDD faculty and staff, the Consumer Advisory Committee (CAC), students, and DD Network partners in the state or territory.
- Examples of external sources include people with developmental disabilities receiving services from the UCEDD, data from UCEDD activities (e.g., community services), research and other reports that contain valid and reliably collected data, and state and territory disability organizations and advocates.

1.2 Collects input for the 5-Year Plan from geographic regions across the state or territory.

1.3 Uses a variety of methods for collecting input for the 5-year Plan (e.g., focus groups, surveys, social media outlets, the UCEDD website, and review and analysis of reports and studies).

1.4 Collects input for the 5-Year Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

1.5 Collects input for the 5-Year Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.

1.6 Leverages its own planning efforts with the planning efforts of DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.

1.7 Gathers data for planning on an ongoing basis throughout the planning cycle.

1.8 Has faculty and staff who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.

Standard 2: UCEDD 5-Year Plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for UCEDD action.

A 5-Year Plan that meets this standard:

2.1 Reflects the internal and external input from the planning process.

2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access, inclusion, choice, basic human rights, quality of life).

2.3 Drives the activities that the UCEDD conducts and supports.

2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with UCEDD resources, outside resources, and the potential impact of strategies that were considered.

B. Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3: UCEDDs prepare students to implement an interdisciplinary approach to serving people with developmental disabilities and family members.

An interdisciplinary approach requires interaction among multiple disciplines to resolve a common problem.

A UCEDD that meets this standard:

3.1 Offers developmental disabilities-related courses or trainings based on content from a variety of disciplines.

3.2 Offers developmental disabilities-related courses or trainings taught by faculty and staff from multiple disciplines.

3.3 Offers developmental disabilities-related courses or trainings to students from multiple disciplines.

3.4 Involves students in the conduct of research and reporting.

3.5 Assists students in finding work, career or educational options that benefit the quality of life of people with developmental disabilities.

3.6 Infuses disability-related content into courses outside the department and school in which the UCEDD is housed.

3.7 Lists UCEDD-developed courses in more than one department in the university.

3.8 Develops courses that are adopted by other universities.

3.9 Impacts the community by having former students enter a disability-focused field or line of work.

3.10 Prepares students to apply a multidisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.

Standard 4: UCEDDs prepare students to reach a diverse population of people with developmental disabilities.

A UCEDD that meets this standard:

4.1 Recruits students from culturally and linguistically diverse backgrounds.

4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities (e.g., serving as lead instructors, co-instructors, curriculum developers).

4.3 Provides students with coursework that leads to an understanding of the daily lives of people with developmental disabilities and their families.

4.4 Provides pre-service and graduate students with opportunities to interact with people with developmental disabilities and family members.

Standard 5: UCEDDs improve the knowledge, skills, and strategies of service providers and practitioners through a continuing education program.

A UCEDD that meets this standard:

5.1 Provides continuing education course work to a variety of professionals in the community.

5.2 Provides continuing education on topics of interest to service providers and practitioners.

5.3 Bases continuing education course topics on documented needs in the state or territory.

5.4 Develops continuing education programs (including courses) that are adopted by other states or internationally.

5.5 Develops continuing education that becomes part of a state requirement or certification.

5.6 Can document that participants in continuing education impact the developmental disabilities community.

C. Basic and Applied Research

Standard 6: UCEDD faculty and staff conduct research that is relevant to improvements in the lives of people with developmental disabilities or family members.

A UCEDD that meets this standard has research faculty and staff who:

6.1 Conducts basic research, evaluation, or policy analysis relevant to improvements in the lives of people with developmental disabilities or family members.

6.2 Involves people with developmental disabilities in the development, design, or implementation of the research (e.g., identify research topics, assist with the design of data collection instruments, help to ensure that research materials are in accessible and understandable formats, recruit people with developmental disabilities and family members as study participants).

6.3 Can document that their research has had a direct impact on people with developmental disabilities in the past 5 years.

Standard 7: UCEDD faculty members and staff are leaders in their field of research.

A UCEDD that meets this standard has faculty members and staff who:

7.1 Publish research findings on developmental disabilities in peer-reviewed journals.

7.2 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.

7.3 Are members of a peer-reviewed journal's editorial board.

7.4 Participate on a grant review panel (either for the University or for an outside organization).

D. Community Services

Standard 8: UCEDDs provide or support community services through education, training, or technical assistance.

A UCEDD that meets this standard:

8.1 Supports community services or at times provides direct services to people with developmental disabilities and family members.

8.2 Provides training or technical assistance to service providers.

8.3 Implements community services that are endorsed or funded by state agencies.

8.4 Can demonstrate that the community services provided or supported by the UCEDD for people with developmental disabilities and family members were integrated into training and research activities of the UCEDD in the past 5 years.

8.5 Can demonstrate that the training, technical assistance or other community services it provides has resulted in increased and improved services for people with developmental disabilities and their families in the past 5 years.

E. Dissemination

Standard 9: UCEDD dissemination activities address the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.

A UCEDD that meets this standard:

9.1 Provides publications, material and other resources in accessible formats.

9.2 Provides accessible training and technical assistance activities.

9.3 Seeks input on materials and resources from people with developmental disabilities and family members (e.g., CAC members, advisory groups connected with research and community service activities).

9.4 Provides materials and other resources in formats appropriate for people with cognitive impairments.

9.5 Maintains and routinely updates a fully accessible website.

9.6 Evaluates dissemination activities and results on an ongoing basis (e.g., monitors number of website hits, conducts targeted surveys, monitors the use of materials).

9.7 Makes its products, resources, and materials available to DD Network programs in its own state or territory.

9.8 Makes its products, resources and materials available to UCEDDs, DD Councils, and P&As in other states and territories.

Standard 10. UCEDD dissemination activities bridge the gap between research and practice.

A UCEDD that meets this standard:

10.1 Publishes on developmental disability-related issues in professional newsletters and other publications for providers and practitioners.

10.2 Uses a variety of distribution modes (e.g., electronic, in-person, and print) and strategies (mass mailings, YouTube videos, seminar series) to disseminate information and research findings to providers and practitioners.

10.3 Makes effective use of practitioner organization networks, listServs, and contact lists to expand its dissemination range.

10.4 Disseminates the work of other UCEDDs to providers and practitioners.

10.5 Uses the national developmental disabilities organizations to disseminate to other UCEDDs, P&As, and DD Councils.

- The national developmental disabilities organizations are the National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD).

10.6 Integrates UCEDD research findings into the preparation and continuing education of pre-service interdisciplinary trainees.

10.7 Disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.

10.8 Makes materials, resources, and information on developmental disabilities available to the University community (e.g., publishes in the university newspaper, organizes and presents at a University-wide seminar).

F. Governance and Management

Standard 11: UCEDDs leverage funding to support and maintain its programs.

A UCEDD that meets this standard:

11.1 Leverages funds that amount to at least three times the amount of the ADD grant.

11.2 Leverages funds and in kind resources (e.g., space, use of University infrastructure) from the University in which it is housed.

Standard 12: UCEDDs maintain and support involvement from CACs.

A UCEDD that meets this standard:

12.1 Fills all vacancies on the CAC within 1 year.

12.2 Continuously maintains CAC membership that includes people who are knowledgeable about the full range of the developmental disabilities population in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).

12.3 Involve CAC members in the development and implementation of the 5-Year Plan.

12.4 Seeks and incorporates the input of the CAC into UCEDD activities throughout the planning cycle.

12.5 Supports its CAC for a minimum of two meetings each year.

12.6 Supports its CAC for more than two meetings each year.

12.7 Provides CAC members with any supports that are needed to ensure meaningful participation.

P4. Collaboration

Draft Standards and Performance Criteria

Standard 1: All DD Network programs in the state or territory achieve common goals through collaboration.

DD Network programs in a state or territory are the State Council on Developmental Disabilities (DD Council), the Protection and Advocacy (P&A) System, and one or more University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).

DD Network programs in a state or territory that meet this standard:

1.1 Identify and acknowledge a common goal or goals.

1.2 Articulate dedicated activities or tasks for each DD Network program.

1.3 Demonstrate a united front on key (identified) issues.

1.4 Talk with a common voice on key (identified) issues.

1.5 Include staff from all three DD Network programs in collaborative planning meetings and implementation activities.

1.6 Include members of the DD Council, Consumer Advisory Committee (CAC) and P&A Board of Directors (or Commission) in collaborative planning meetings and implementation activities.

1.7 Can demonstrate that they have achieved common goals in the past 5 years through their collaborative efforts.

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Appendix Q. Draft Standards and Performance Criteria – Version 1: Rating Forms

Q1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

Q2. PROTECTION AND ADVOCACY SYSTEMS

Q3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

Q4. COLLABORATION

Appendix Q1. State Councils on Developmental Disabilities

Q1-1. Planning

Q1-2. Self-Advocacy and Leadership

Q1-3. Community Capacity

Q1-4. Systems Change

Q1-5. Demonstration of New Approaches to Services and Supports

Q1-6. Governance and Management

Q1-1. Planning

Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory.	
1. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 1.1 Collects input for the State Plan from internal and external sources. ■ Examples of internal sources include DD Council staff, DD Council members, and DD Network partners in the state or territory. ■ Examples of external sources include the public, State agency staff, participants in DD Council activities (e.g., Partners in Policymaking), reports that contain valid and reliably collected data, and disability organizations and advocates.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.2 Collects input for the State Plan from geographic regions across the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.3 Uses a variety of methods for collecting input for the State Plan (e.g., focus groups, surveys, social media outlets, the DD Council website, review and analysis of reports and studies).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.4 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.5 Collects input for the State Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.7 Gathers data for planning on an ongoing basis.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 1.8 Has staff and DD Council members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for DD Council action.	
2. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A State Plan that meets this standard: 2.1 Reflects the internal and external input from the planning process.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A State Plan that meets this standard: 2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A State Plan that meets this standard: 2.3 Drives all activities that the DD Council conducts and supports.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A State Plan that meets this standard: 2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with DD Council resources, outside resources, and the potential impact of strategies that were considered.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR PLANNING.

Q1-2. Self-Advocacy and Leadership

Standard 3: DD Councils encourage and develop self-advocates and leaders among people with developmental disabilities (or their families) through education, training, and technical assistance.	
3. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 3.1 Actively recruits potential self-advocates and leaders from the broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities. ■ Examples of ways to seek feedback include surveys and interviews.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 4: Participants in DD Council self-advocacy and leadership development activities provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.	
4. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard:

4.1 Documents the self-advocacy and leadership development efforts of trainees to promote greater access to the community and improve the well-being of people with developmental disabilities.

- These self-advocacy and leadership efforts include:
  - Serving on the board of a disability-related organization (within the past 3 years),
  - Advocating the state legislature to change or maintain services or access for people with developmental disabilities (within the past 3 years),
  - Participating in training other people with a developmental disability in self-advocacy (within the past 3 years), and
  - Obtaining a service or community access for oneself through self-advocacy (within the past 3 years).

PLEASE CHECK ONE.	COMMENTS:
☐ This should be required to meet the standard.	
☐ This exceeds the standard.	
☐ This is not relevant to the standard.	

A Council that meets this standard:

4.2 Supports a statewide organization led by people with developmental disabilities.

PLEASE CHECK ONE.	COMMENTS:
☐ This should be required to meet the standard.	
☐ This exceeds the standard.	
☐ This is not relevant to the standard.	

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR SELF-ADVOCACY AND LEADERSHIP.

Q1-3. Community Capacity

Standard 5. DD Councils improve community capacity through greater access, service delivery, choice and inclusion. ■ Examples of ways to improve community capacity include the following: achieve affordable transition housing for people with developmental disabilities, reasonable accommodations in the workplace, accommodations within community locations, and adaptive technology resources in schools.	
5. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 5.1 Provides information, training, and technical assistance to people and organizations in the community at large.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 5.2 Conducts or supports at least one community capacity development activity each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 5.3 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities. ■ Examples of targets include health care providers, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, and daycare workers.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 5.4 Keeps track of participants in community capacity development activities, and uses the data for planning and evaluation.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 5.5 Documents the success of efforts.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 5.6 Demonstrates impact on increasing and improving services, choice, and inclusion for people with developmental disabilities within the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR COMMUNITY CAPACITY DEVELOPMENT.

Q1-4. Systems Change

Standard 6: DD Councils use advocacy strategies to change systems to promote inclusion, choice, and better access to services for people with developmental disabilities and family members.	
6. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 6.1 Leads and participates in advocacy efforts that are expected to result in system changes that promote inclusion, choice, and better access to services for people with developmental disabilities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.2 Uses a variety of strategies to meet systems change objectives (e.g., providing funding to support systems change efforts, writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.3 Includes both Council members and staff in implementing advocacy activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.4 Collaborates strategically to achieve systems change goals and objectives. ■ Examples of strategic collaboration include maintaining or participating in a network of possible collaborators who are available to tap as appropriate issues arise and continually cultivating relationships for future systems change collaborations.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.5 Makes sure legislators and other policy makers personally know the Council members and staff.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.6 Evaluates its advocacy efforts throughout the year, and changes course as necessary.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.7 Has evidence that its advocacy efforts have had an impact on legislation or public policy within the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.8 Has evidence that its advocacy efforts have had an impact on community practice or services within the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.9 Monitors implementation of systems change to ensure implementation adheres to a new policy, legislation, or procedures.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 6.10 Monitors implementation of systems change to determine unintended consequences.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR SYSTEMS CHANGE.

Q1-5. Demonstration of New Approaches to Services and Supports

Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members. ■ Examples of how DD Councils do this include: issuing requests for proposals, securing external funding to identify or test new or innovative practices, assisting community organizations in obtaining funding to identify or test promising practices, and partnering with other agencies or organizations in the state.	
7. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 7.1 Disseminates or promotes new or innovative practices the Council found to be effective.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 7.2 Uses or tests new or innovative practices found to be effective by other DD Councils.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 7.3 Collaborates with other DD Councils to try out or promote a new or innovative practice.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 7.4 Disseminates information on practices found to be ineffective.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 7.5 Can document that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 7.6 Can document that other states or national programs are using the practices tested or disseminated by the DD Council.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR DEMONSTRATION OF NEW APPROACHES TO SERVICES AND SUPPORTS.

Q1-6. Governance and Management

Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.	
8. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 8.1 Reflects the full range of the population of people with developmental disabilities in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.2 Fills all vacancies on the DD Council within 1 year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.4 Documents attendance in DD Council meeting minutes.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.5 Has members who play an active role in meeting DD Council objectives. ■ An active role includes membership or chairmanship of a sub-committee and participation in DD Council activities throughout the year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.6 Provides an orientation to new DD Council members. ■ The orientation includes the principles and goals of the DD Act, background on the DD Council, DD Council goals and objectives, and the current State Plan.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: Mentors new DD Council members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:
A Council that meets this standard: 8.7 Provides ongoing training on DD Council roles and responsibilities	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.8 Provides all supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 8.9 Provides funding for at least one DD Council member to attend a national meeting, conference, or training each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 9: DD Councils are effective in fulfilling their mission.	
9. DD Councils should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A Council that meets this standard: 9.1 Reviews the performance of the Executive Director each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 9.2 Conducts an independent review of itself every 3-5 years. ■ An independent review does not need to be a formal evaluation.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 9.3 Assigns a distinct role to every Council member	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard: 9.4 Trains Council members on the core functions of their role.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A Council that meets this standard:

9.5 Uses a fair, transparent, and effective process to select competent and experienced grantees.

- Evidence of a fair, transparent and effective process includes adherence to procedures for selecting grantees; adherence to procedures for handling unsolicited proposals; the inclusion of outside expertise during the proposal review process, as necessary; and the selection of grantee projects that reflect the goals and priorities stipulated in the State Plan.

PLEASE CHECK ONE.	COMMENTS:
☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR GOVERNANCE AND MANAGEMENT.

Appendix Q2. Protection and Advocacy Systems

Q2-1. Planning and Priority Setting

Q2-2. Intake and Assistance

Q2-3. Individual Advocacy

Q2-4. Systemic Advocacy

Q2-5. Outreach and Community Education

Q2-6. Governance and Management

Q2-1. Planning and Priority Setting

Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities and family members in the state or territory.	
1. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 1.1Collects input for the Statement of Goals and Priorities (SGP) from internal and external sources. ■ Examples of internal sources include P&A staff, Board of Directors or Commission members, and DD Network partners in the state or territory. ■ Examples of external sources include data from P&A activities (e.g., intake and assistance, outreach and community education), state agency staff, research and other reports that contain valid and reliably collected data, and state and territory disability organizations and advocates.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.2 Collects input for the SGP from geographic regions across the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.3 Uses a variety of methods for collecting input for the SGP (e.g., focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.4 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.5 Collects input for the SGP using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.7 Gathers data on the needs of people with developmental disabilities on an ongoing basis.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 1.8 Has staff and Board of Directors (or Commission) members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 2: P&A SGPs reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for P&A action.	
2. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A SGP that meets this standard: 2.1 Reflects the internal and external input from the planning process.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A SGP that meets this standard: 2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life), as well as protection from abuse and neglect.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A SGP that meets this standard: 2.3 Drives all primary activities that the P&A conducts and supports.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A SGP that meets this standard: 2.4 Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with P&A resources, outside resources, and the potential impact of strategies that were considered.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR PLANNING AND PRIORITY SETTING.

Q2-2. Intake and Assistance

Standard 3: The P&A intake process is equitable, efficient, and effective.	
3. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 3.1 Maintains written intake procedures that describe how to determine an applicant's service needs and preferred mode of communication.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.2 Maintains written procedures for documenting client information in a computerized database.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.3 Maintains written procedures for priority case selection.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.4 Provides training on the written intake procedures to all new intake staff.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.5 Annually updates the intake process (e.g., intake forms, procedures, training, and orientation) to reflect changes in P&A goals and priorities and Federal and State policy and legislation.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.6 Monitors staff adherence to intake procedures periodically.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.7 Provides immediate corrective action of problems with adherence to intake procedures.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.8 Directs callers to the appropriate level of assistance (e.g., referral, provision of information and resources, possible individual advocacy).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.9 Periodically applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process (e.g., a survey of every caller for a period of 2 weeks, a followup telephone call to a random selection of callers).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 3.10 Provides intake staff with access to ongoing professional development through the National Disability Rights Network [NDRN] or other organizations.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR INTAKE AND ASSISTANCE.

Q2-3. Individual Advocacy

Standard 4: P&A caseload reflects the priorities set in the SGP.	
4. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 4.1 Maintains written procedures for selecting and processing individual advocacy cases.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 4.2 Selects individual advocacy cases that are consistent with goals and priorities in the SGP.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 4.3 Conducts ongoing reviews of staff caseloads to ensure that the balance in the SGP priorities is achieved. ■ A balanced caseload would consist of the P&A addressing approximately equal numbers of priority issues throughout the year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 5: P&A provides high quality representation.	
5. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 5.1 Provides staff with formal opportunities (e.g., regularly scheduled meetings) to discuss and review cases.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 5.2 Requires supervisory staff to provide frequent staff oversight (at least weekly).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 5.3 Encourages use of the NDRN listServ and other resources, and provides staff with easy access.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 6: Individual advocacy meets client objectives.	
6. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 6.1 Ascertains accommodation and communication needs at intake.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.2 Commits resources to support all clients being served (e.g., language line, interpreters, staff that speak a language other than English, policy for including a support person for clients with cognitive disabilities if needed) so that individual advocacy staff is able to communicate with any client whose case is taken.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.3 Provides a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.4 Requires individual advocacy staff to update representation agreements when issues or approaches require a modification.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.5 Sends or gives clients a closing letter documenting actions taken, results, and notification that the case is closed.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.6 Informs callers of the grievance process if a case is turned down for individual advocacy.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.7 Informs clients of the grievance process when the case is closed.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.8 Documents success in resolving a majority of issues in favor of P&A clients.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 6.9 Routinely follows up clients to determine whether decisions made on behalf of a client are being followed and the client issue has truly been resolved.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 7: P&A strictly adheres to confidentiality.	
7. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 7.1 Has written confidentiality procedures (including for working at home).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 7.2 Has written confidentiality procedures (including for working at home).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 7.3 Has structures in place to maintain confidentiality (e.g., shredding capability, private offices, email encryption, locking file cabinets).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 7.4 Has structures in place to help staff meet confidentiality requirements (e.g., email reminders to change passwords, alerts to tell people there is a stranger in the office so special care can be taken with client files).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 7.5 Monitors periodically to ensure confidentiality procedures are being followed (e.g., inspects periodically to see if client files are left around or computers are turned off at end of day).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 7.6 Requires a confidentiality pledge to be signed by anyone who is privy to client information. (e.g., P&A staff, students, interpreters).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 7.7 Includes information about confidentiality requirements in all orientations (e.g., new staff, students, Board of Directors or Commissioners).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR INDIVIDUAL ADVOCACY.

Q2-4. Systemic Advocacy

Standard 8: P&A systemic advocacy increases inclusion and choice for people with developmental disabilities and reduces abuse and neglect. ■ Systemic advocacy consists of systems change efforts on behalf of groups (e.g., group advocacy, investigations, monitoring, court-ordered monitoring, systemic or class action litigation) and results in changes to infrastructure, legislation, or policy.	
8. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 8.1 Leads and participates in systemic advocacy activities to increase inclusion, improve access to supports and services, and to prevent abuse and neglect.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.2 Regularly monitors databases from residential facilities, community services, intermediate care facilities, social service agencies, and other sources to identify and follow up on abuse and neglect issues.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.3 Collaborates strategically to achieve systemic advocacy goals and objectives. ■ Examples of strategic collaboration include maintaining or participating in a network of possible collaborators who are available to tap as appropriate issues arise; continually cultivating relationships for future systemic advocacy collaborations; and cultivating relationships with regulatory and enforcement agencies to effectively respond to emergency protection situations.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.4 Effects systems change through a variety of means. ■ Examples of means to effect systems change include writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation, securing pro bono assistance in class action suits from legal firms, filing amicus briefs, monitoring residential facilities, and following up on identified patterns of abuse and neglect).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.5 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on legislation or public policy.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.6 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on community practice or services.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.7 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on inclusion and choice for people with developmental disabilities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.8 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on reduction in abuse and neglect.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 8.9 Conducts ongoing monitoring to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR SYSTEMIC ADVOCACY.

Q2-5. Outreach and Community Education

Standard 9: P&As engage in effective and equitable outreach activities. ■ Outreach is defined as efforts made to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of outreach is to identify typically unserved and underserved populations that might benefit from P&A services and programs.	
9. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 9.1 Conducts ongoing outreach activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.2 Targets populations that are underrepresented or unserved.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.3 Maintains a budget and designated trained staff for outreach activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.4 Employs a variety of strategies to conduct outreach. ■ Examples of outreach strategies include use of the P&A website, brochures, presentations at community events on the P&A and P&A services, and visits to group homes and other facilities that house people with developmental disabilities	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.5 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.6 Obtains feedback on outreach activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.7 Reviews outreach activities between planning cycles so that outreach plans and strategies can be revised as needed.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.8 Includes Board of Directors (or Commission) members in outreach activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 9.9 Documents that outreach efforts have increased the number of callers and clients from typically unserved and underserved populations.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 10: P&As have an impact on access to services, inclusion, and choice for people with developmental disabilities through the provision of community education. ■ Community education consists of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.	
10. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 10.1 Provides education, training, and technical assistance activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.2 Makes community education available to a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.3 Targets community education to those in the community at large who can increase and improve services, choice and inclusion (e.g., health care providers, residential facility operators, employers, local government officials, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, daycare workers) for people with developmental disabilities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.4 Delivers community education through a variety of modes (e.g., classes, workshops, webinars, and online courses).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.5 Delivers culturally appropriate and targeted community education activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.6 Maintains a budget and designated trained staff for community education activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.7 Determines recipient satisfaction.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 10.8 Documents that community education efforts led to improved access to services, choice, or inclusion for people with developmental disabilities within the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR OUTREACH AND COMMUNITY EDUCATION.

Q2-6. Governance and Management

Standard 11: P&As maintain an infrastructure that enables them to conduct all activities efficiently and effectively.	
11. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 11.1 Fills all vacancies on the Board of Directors (or Commission) within 1 year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.2 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.3 Includes Board of Directors (or Commission) members who are knowledgeable about the full range of the developmental disabilities population (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.4 Familiarizes all new Board Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.5 Includes Board of Directors (or Commission) members who attend public events on issues related to developmental disabilities such as community meetings, legislative hearings, or non-profit organizations' events.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.6 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.7 Conducts an annual performance review of all staff members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.7 Receives an unqualified audit finding (i.e., clean audit with no findings, no notice of noncompliance) each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 11.8 Budgets for professional development for staff.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 12: P&A governance adheres to the principles and goals of the DD Act.	
1. P&As should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A P&A that meets this standard: 12.1 Maintains complete independence from the Governor and the developmental disabilities service system of the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 12.2 Provides supports needed to ensure meaningful participation by Board of Directors (or Commission) members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 12.3 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available to each member in accessible format.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A P&A that meets this standard: 12.4 Funds at least one Board or Commission member's attendance at a developmental disabilities-related national meeting each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR GOVERNANCE AND MANAGEMENT.

Appendix Q3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

Q3-1. 5-Year Planning

Q3-2. Interdisciplinary Pre-Service Preparation and Continuing Education

Q3-3. Basic and Applied Research

Q3-4. Community Services

Q3-5. Dissemination

Q3-6. Governance and Management

Q3-1. 5-Year Planning

Standard 1: UCEDDs identify the key issues, needs, and priorities of people with developmental disabilities and family members in their state or territory.	
1. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 1.1 Collects input for the 5-Year Plan from internal and external sources. ■ Examples of internal sources include UCEDD faculty and staff, the Consumer Advisory Committee (CAC), students, and DD Network partners in the state or territory. ■ Examples of external sources include people with developmental disabilities receiving services from the UCEDD, data from UCEDD activities (e.g., community services), research and other reports that contain valid and reliably collected data, and state and territory disability organizations and advocates.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.2 Collects input for the 5-Year Plan from geographic regions across the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.3 Uses a variety of methods for collecting input for the 5-year Plan (e.g., focus groups, surveys, social media outlets, the UCEDD website, and review and analysis of reports and studies).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.4 Collects input for the 5-Year Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.5 Collects input for the 5-Year Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.6 Leverages its own planning efforts with the planning efforts of DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.7 Gathers data for planning on an ongoing basis throughout the planning cycle.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 1.8 Has faculty and staff who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 2: UCEDD 5-Year Plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for UCEDD action.	
2. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A 5-Year Plan that meets this standard: 2.1 Reflects the internal and external input from the planning process.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A 5-Year Plan that meets this standard: 2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access, inclusion, choice, basic human rights, quality of life).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A 5-Year Plan that meets this standard: 2.3 Drives the activities that the UCEDD conducts and supports.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A 5-Year Plan that meets this standard: 2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with UCEDD resources, outside resources, and the potential impact of strategies that were considered.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR 5-YEAR PLANNING.

Q3-2. Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3: UCEDDs prepare students to implement an interdisciplinary approach to serving people with developmental disabilities and family members. ■ An interdisciplinary approach requires interaction among multiple disciplines to resolve a common problem.	
3. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 3.1 Offers developmental disabilities-related courses or trainings based on content from a variety of disciplines.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.2 Offers developmental disabilities-related courses or trainings taught by faculty and staff from multiple disciplines.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.3 Offers developmental disabilities-related courses or trainings to students from multiple disciplines.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.4 Involves students in the conduct of research and reporting.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.5 Assists students in finding work, career or educational options that benefit the quality of life of people with developmental disabilities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.6 Infuses disability-related content into courses outside the department and school in which the UCEDD is housed.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.7 Lists UCEDD-developed courses in more than one department in the university.	
PLEASE CHECK ONE.	COMMENTS:

☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	

A UCEDD that meets this standard: 3.8 Develops courses that are adopted by other universities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.9 Impacts the community by having former students enter a disability-focused field or disability-focused line of work.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 3.10 Prepares students to apply a multidisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 4: UCEDDs prepare students to reach a diverse population of people with developmental disabilities.	
4. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 4.1 Recruits students from culturally and linguistically diverse backgrounds.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities (e.g., serving as lead instructors, co-instructors, curriculum developers).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 4.3 Provides students with coursework that leads to an understanding of the daily lives of people with developmental disabilities and their families.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 4.4 Provides pre-service and graduate students with opportunities to interact with people with developmental disabilities and family members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 5: UCEDDs improve the knowledge, skills, and strategies of service providers and practitioners through a continuing education program.	
5. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 5.1 Provides continuing education course work to a variety of professionals in the community.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 5.2 Provides continuing education on topics of interest to service providers and practitioners.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 5.3 Bases continuing education course topics on documented needs in the state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 5.4 Develops continuing education programs (including courses) that are adopted by other states or internationally.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 5.5 Develops continuing education that becomes part of a state requirement or certification.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 5.6 Can document that participants in continuing education impact the developmental disabilities community.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR INTERDISCIPLINARY PRE-SERVICE PREPARATION AND CONTINUING EDUCATION.

Q3-3. Basic and Applied Research

Standard 6: UCEDD faculty and staff conduct research that is relevant to improvements in the lives of people with developmental disabilities or family members.	
6. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard has faculty members and staff who: 6.1 Conduct basic research, evaluation, or policy analysis relevant to improvements in the lives of people with developmental disabilities or family members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard has research faculty and staff who: 6.2 Involve people with developmental disabilities in the development, design, or implementation of the research (e.g., identify research topics, assist with the design of data collection instruments, help to ensure that research materials are in accessible and understandable formats, recruit people with developmental disabilities and family members as study participants).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard has research faculty and staff who: 6.3 Can document that their research has had a direct impact on people with developmental disabilities in the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 7: UCEDD faculty members and staff are leaders in their field of research.	
7. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard has faculty members and staff who: 7.1 Publish research findings on developmental disabilities in peer-reviewed journals.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard has faculty members and staff who: 7.2 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard has faculty members and staff who: 7.3 Are members of a peer-reviewed journal's editorial board.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard has faculty members and staff who: 7.4 Participate on a grant review panel (either for the University or for an outside organization).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR BASIC AND APPLIED RESEARCH.

Q3-4. Community Services

Standard 8: UCEDDs provide or support community services through education, training, or technical assistance.	
8. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 8.1 Supports community services or at times provides direct services to people with developmental disabilities and family members.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 8.2 Provides training or technical assistance to service providers.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 8.3 Implements community services that are endorsed or funded by state agencies.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 8.4 Can demonstrate that the community services provided or supported by the UCEDD for people with developmental disabilities and family members were integrated into training and research activities of the UCEDD in the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 8.5 Can demonstrate that the training, technical assistance or other community services it provides has resulted in increased and improved services for people with developmental disabilities and their families in the past 5 years.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR COMMUNITY SERVICES.

Q3-5. Dissemination

Standard 9: UCEDD dissemination activities address the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.	
9. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 9.1 Provides publications, material and other resources in accessible formats.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.2 Provides accessible training and technical assistance activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.3 Seeks input on materials and resources from people with developmental disabilities and family members (e.g., CAC members, advisory groups connected with research and community service activities).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.4 Provides materials and other resources in formats appropriate for people with cognitive impairments.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.5 Maintains and routinely updates a fully accessible website.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.6 Evaluates dissemination activities and results on an ongoing basis (e.g., monitors number of website hits, conducts targeted surveys, monitors the use of materials).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.7 Makes its products, resources, and materials available to DD Network programs in its own state or territory.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 9.8 Makes its products, resources and materials available to UCEDDs, DD Councils, and P&As in other states and territories.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 10. UCEDD dissemination activities bridge the gap between research and practice.	
10. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 10.1 Publishes on developmental disability-related issues in professional newsletters and other publications for providers and practitioners.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.2 Uses a variety of distribution modes (e.g., electronic, in-person, and print) and strategies (mass mailings, YouTube videos, seminar series) to disseminate information and research findings to providers and practitioners.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.3 Makes effective use of practitioner organization networks, listServs, and contact lists to expand its dissemination range.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.4 Disseminates the work of other UCEDDs to providers and practitioners.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.5 Uses the national developmental disabilities organizations to disseminate to other UCEDDs, P&As, and DD Councils. ■ The national developmental disabilities organizations are the National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.6 Integrates UCEDD research findings into the preparation and continuing education of pre-service interdisciplinary trainees.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.7 Disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 10.8 Makes materials, resources, and information on developmental disabilities available to the University community (e.g., publishes in the university newspaper, organizes and presents at a University-wide seminar).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR DISSEMINATION.

Q3-6. Governance and Management

Standard 11: UCEDDs leverage funding to support and maintain its programs.	
11. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 11.1 Leverages funds that amount to at least three times the amount of the ADD grant.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 11.2 Leverages funds and in kind resources (e.g., space, use of University infrastructure) from the University in which it is housed.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

Standard 12: UCEDDs maintain and support involvement from CACs.	
12. UCEDDs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

A UCEDD that meets this standard: 12.1 Fills all vacancies on the CAC within 1 year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 12.2 Continuously maintains CAC membership that includes people who are knowledgeable about the full range of the developmental disabilities population in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 12.3 Involve CAC members in the development and implementation of the 5-Year Plan	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 12.4 Seeks and incorporates the input of the CAC into UCEDD activities throughout the planning cycle.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 12.5 Supports its CAC for a minimum of two meetings each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 12.6 Supports its CAC for more than two meetings each year.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

A UCEDD that meets this standard: 12.7 Provides CAC members with any supports that are needed to ensure meaningful participation.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

FURTHER COMMENTS; ADDITIONAL STANDARDS OR PERFORMANCE CRITERIA FOR GOVERNANCE AND MANAGEMENT.

Appendix Q4. Collaboration

Standard 1: All DD Network programs in the state or territory achieve common goals through collaboration. ■ DD Network programs in a state or territory are the State Council on Developmental Disabilities (DD Council), the Protection and Advocacy (P&A) System, and one or more University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).	
1. The DD Network programs should be held to this standard. PLEASE CHECK ONE. ☐ Agree ☐ Unsure ☐ Disagree	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.1 Identify and acknowledge a common goal or goals.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.2 Articulate dedicated activities or tasks for each DD Network program.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.3 Demonstrate a united front on key (identified) issues.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.4 Talk with a common voice on key (identified) issues.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.5 Include staff from all three DD Network programs in collaborative planning meetings and implementation activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.6 Include members of the DD Council, Consumer Advisory Committee (CAC) and P&A Board of Directors (or Commission) in collaborative planning meetings and implementation activities.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

DD Network programs in a state or territory that meet this standard: 1.7 Can demonstrate that they have achieved common goals in the past 5 years through their collaborative efforts.	
PLEASE CHECK ONE. ☐ This should be required to meet the standard. ☐ This exceeds the standard. ☐ This is not relevant to the standard.	COMMENTS:

COMMENTS ON COLLABORATION: Please feel free to add additional standards or performance criteria for Collaboration:

Appendix R. Version 1 Ratings

R1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

R2. PROTECTION AND ADVOCACY SYSTEMS

R3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

R4. COLLABORATION

R1. Draft Standards and Performance Criteria – Version 1, State Councils on Developmental Disabilities, Rating Results*

Draft standards/ performance criteria (PC) – Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory	23	0	2	1
1.1 Collects input for the State Plan from internal and external sources.	21	3	1	1
1.2 Collects input for the State Plan from geographic regions across the state or territory.	22	1	1	2
1.3 Uses a variety of methods for collecting input for the State Plan (e.g., focus groups, surveys, social media outlets, the DD Council website, review and analysis of reports and studies).	19	4	1	2
1.4 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	21	4	0	1
1.5 Collects input for the State Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.	20	3	1	2
1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.	17	5	3	1
1.7 Gathers data for planning on an ongoing basis.	16	4	5	1
1.8 Has staff and DD Council members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.	12	9	4	1

*26 individuals rated the draft standards and performance criteria for the State Councils on Developmental Disabilities.

R1. Draft Standards and Performance Criteria – Version 1, State Councils on Developmental Disabilities, Rating Results (continued)

Draft standards/ performance criteria (PC) – Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for DD Council action.	21	2	2	1
2.1 Reflects the internal and external input from the planning process.	23	0	1	2
2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life).	24	0	0	2
2.3 Drives all activities that the DD Council conducts and supports.	21	3	1	1
2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with DD Council resources, outside resources, and the potential impact of strategies that were considered.	14	4	6	2
Standard 3: DD Councils encourage and develop self-advocates and leaders among people with developmental disabilities (or their families) through education, training, and technical assistance.	23	2	0	1
3.1 Actively recruits potential self-advocates and leaders from the broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	19	3	2	2
3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities.	19	2	3	2
Standard 4: Participants in DD Council self-advocacy and leadership development activities provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.	18	4	3	1
4.1 Documents the self-advocacy and leadership development efforts of trainees to promote greater access to the community and improve the well-being of people with developmental disabilities.	14	7	4	1
4.2 Supports a statewide organization led by people with developmental disabilities	19	4	1	2
Standard 5. DD Councils improve community capacity through greater access, service delivery, choice and inclusion.	14	8	3	1

R1. Draft Standards and Performance Criteria – Version 1, State Councils on Developmental Disabilities, Rating Results (continued)

Draft standards/ performance criteria (PC) – Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
5.1 Provides information, training, and technical assistance to people and organizations in the community at large.	24	0	1	1
5.2 Conducts or supports at least one community capacity development activity each year.	12	6	7	1
5.3 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.	16	4	4	2
5.4 Keeps track of participants in community capacity development activities, and uses the data for planning and evaluation.	15	6	4	1
5.5 Documents the success of efforts.	17	4	2	3
5.6 Demonstrates impact on increasing and improving services, choice, and inclusion for people with developmental disabilities within the past 5 years.	17	4	3	2
Standard 6: DD Councils use advocacy strategies to change systems to promote inclusion, choice, and better access to services for people with developmental disabilities and family members.	22	1	2	1
6.1 Leads and participates in advocacy efforts that are expected to result in system changes that promote inclusion, choice, and better access to services for people with developmental disabilities.	22	1	1	2
6.2 Uses a variety of strategies to meet systems change objectives (e.g., providing funding to support systems change efforts, writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation).	20	4	1	1
6.3 Includes both Council members and staff in implementing advocacy activities.	14	4	5	3
6.4 Collaborates strategically to achieve systems change goals and objectives.	24	1	0	1
6.5 Makes sure State legislators and other policy makers personally know Council members and staff.	11	9	5	1
6.6 Evaluates its advocacy efforts throughout the year, and changes course as necessary.	16	3	5	2
6.7 Has evidence that its advocacy efforts have had an impact on legislation or public policy within the past 5 years.	16	7	2	1

R1. Draft Standards and Performance Criteria – Version 1, State Councils on Developmental Disabilities, Rating Results (continued)

Draft standards/ performance criteria (PC) – Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
6.8 Has evidence that its advocacy efforts have had an impact on community practice or services within the past 5 years.	14	6	4	2
6.9 Monitors implementation of systems change to ensure implementation adheres to a new policy, legislation, or procedures.	14	9	2	1
6.10 Monitors implementation of systems change to determine unintended consequences.	12	9	2	3
Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members.	19	2	4	1
7.1 Disseminates or promotes new or innovative practices the Council found to be effective.	22	0	1	3
7.2 Uses or tests new or innovative practices found to be effective by other DD Councils.	9	10	5	2
7.3 Collaborates with other DD Councils to try out or promote a new or innovative practice.	7	11	5	3
7.4 Disseminates information on practices found to be ineffective.	10	7	6	3
7.5 Can document that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.	12	10	1	3
7.6 Can document that other states or national programs are using the practices tested or disseminated by the DD Council.	6	13	5	2
Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.	24	0	1	1
8.1 Reflects the full range of the population of people with developmental disabilities in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups).	19	4	2	1
8.2 Fills all vacancies on the DD Council within 1 year.	10	10	5	1
8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.	19	4	1	2
8.4 Documents attendance in DD Council meeting minutes.	21	0	4	1
8.5 Has members who play an active role in meeting DD Council objectives.	22	1	1	2
8.6 Provides an orientation to new DD Council members.	23	0	1	2
8.7 Mentors new DD Council members.	20	3	2	1

R1. Draft Standards and Performance Criteria – Version 1, State Councils on Developmental Disabilities, Rating Results (continued)

Draft standards/ performance criteria (PC) – Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
8.8 Provides ongoing training on DD Council roles and responsibilities.	20	3	2	1
8.9 Provides all supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.	21	3	0	2
8.10 Provides funding for at least one DD Council member to attend a national meeting, conference, or training each year.	16	7	2	1
Standard 9. DD Councils are effective in fulfilling their mission.	18	4	2	2
9.1 Reviews the performance of the executive director each year.	22	1	2	1
9.2 Conducts an independent review of itself every 3-5 years.	18	4	3	1
9.3 Assigns a distinct role to every Council member.	7	9	9	1
9.4 Trains Council members on the core functions of their role.	18	2	4	2
9.5 Uses a fair, transparent, and effective process to select competent and experienced grantees.	22	1	1	2

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results*

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities and family members in the state or territory.	18	2	1	0
1.1 Collects input for the Statement of Goals and Priorities (SGP) from internal and external sources.	19	2	0	0
1.2 Collects input for the SGP from geographic regions across the state or territory.	18	2	1	0
1.3 Uses a variety of methods for collecting input for the SGP (e.g., focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies).	15	3	1	2
1.4 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	15	4	2	0
1.5 Collects input for the SGP using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.	14	4	3	0
1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.	9	10	1	1
1.7 Gathers data on the needs of people with developmental disabilities on an ongoing basis.	16	3	1	1
1.8 Has staff and Board of Directors (or Commission) members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.	6	10	5	0

*21 individuals rated the P&A draft standards and performance criteria.

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 2: P&A SGPs reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for P&A action.	16	2	3	0
2.1 Reflects the internal and external input from the planning process.	19	0	2	0
2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life), as well as protection from abuse and neglect.	19	1	1	0
2.3 Drives all primary activities that the P&A conducts and supports.	18	2	1	0
2.4 Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with P&A resources, outside resources, and the potential impact of strategies that were considered.	12	1	7	1
Standard 3: The P&A intake process is equitable, efficient, and effective.	19	1	1	0
3.1 Maintains written intake procedures that describe how to determine an applicant's service needs and preferred mode of communication.	14	5	1	1
3.2 Maintains written procedures for documenting client information in a computerized database.	17	1	0	3
3.3 Maintains written procedures for priority case selection.	18	0	2	1
3.4 Provides training on the written intake procedures to all new intake staff.	16	2	2	1
3.5 Annually updates the intake process (e.g., intake forms, procedures, training, and orientation) to reflect changes in P&A goals and priorities and Federal and State policy and legislation.	9	8	4	0
3.6 Monitors staff adherence to intake procedures periodically.	15	3	3	0
3.7 Provides immediate corrective action of problems with adherence to intake procedures.	9	7	5	0
3.8 Directs callers to the appropriate level of assistance (e.g., referral, provision of information and resources, possible individual advocacy).	17	2	1	1

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
3.9 Periodically applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process (e.g., a survey of every caller for a period of 2 weeks, a followup telephone call to a random selection of callers).	9	12	0	0
3.10 Provides intake staff with access to ongoing professional development through the National Disability Rights Network [NDRN] or other organizations.	14	3	2	2
Standard 4: P&A caseload reflects the priorities set in the SGP.	16	4	0	1
4.1 Maintains written procedures for selecting and processing individual advocacy cases.	19	1	0	1
4.2 Selects individual advocacy cases that are consistent with goals and priorities in the SGP.	19	1	1	0
4.3 Conducts ongoing reviews of staff caseloads to ensure that the balance in the SGP priorities is achieved.	6	7	7	1
Standard 5: P&A provides high quality representation.	18	3	0	0
5.1 Provides staff with formal opportunities (e.g., regularly scheduled meetings) to discuss and review cases.	18	2	1	0
5.2 Requires supervisory staff to provide frequent staff oversight (at least weekly).	6	14	1	0
5.3 Encourages use of the NDRN listServe and other resources, and provides staff with easy access.	11	5	5	0
Standard 6: Individual advocacy meets client objectives.	16	4	0	1
6.1 Ascertains accommodation and communication needs at intake.	17	1	2	1
6.2 Commits resources to support all clients being served (e.g., language line, interpreters, staff that speak a language other than English, policy for including a support person for clients with cognitive disabilities if needed) so that individual advocacy staff is able to communicate with any client whose case is taken.	17	3	1	0
6.3 Provides a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.	15	5	1	0

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
6.4 Requires individual advocacy staff to update representation agreements when issues or approaches require a modification.	14	4	2	1
6.5 Sends or gives clients a closing letter documenting actions taken, results, and notification that the case is closed.	17	3	1	0
6.6 Informs callers of the grievance process if a case is turned down for individual advocacy.	18	1	2	0
6.7 Informs clients of the grievance process when the case is closed.	16	1	4	0
6.8 Documents success in resolving a majority of issues in favor of P&A clients.	12	7	2	0
6.9 Routinely follows up clients to determine whether decisions made on behalf of a client are being followed and the client issue has truly been resolved.	7	14	0	0
Standard 7: P&A strictly adheres to confidentiality.	20	1	0	0
7.1 Has a written confidentiality policy with well-delineated requirements.	19	1	1	0
7.2 Has written confidentiality procedures (including for working at home).	12	2	0	7
7.3 Has structures in place to maintain confidentiality (e.g., shredding capability, private offices, email encryption, locking file cabinets).	19	1	1	0
7.4 Has structures in place to help staff meet confidentiality requirements (e.g., email reminders to change passwords, alerts to tell people there is a stranger in the office so special care can be taken with client files).	9	7	4	1
7.5 Monitors periodically to ensure confidentiality procedures are being followed (e.g., inspects periodically to see if client files are left around or computers are turned off at end of day).	12	6	3	0
7.6 Requires a confidentiality pledge to be signed by anyone who is privy to client information. (e.g., P&A staff, students, interpreters).	15	5	1	0
7.7 Includes information about confidentiality requirements in all orientations (e.g., new staff, students, Board of Directors or Commissioners).	14	7	0	0
Standard 8: P&A systemic advocacy increases inclusion and choice for people with developmental disabilities and reduces abuse and neglect.	14	4	3	0

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
8.1 Leads and participates in systemic advocacy activities to increase inclusion, improve access to supports and services, and to prevent abuse and neglect	17	2	0	2
8.2 Regularly monitors databases from residential facilities, community services, intermediate care facilities, social service agencies, and other sources to identify and follow up on abuse and neglect issues.	7	9	1	4
8.3 Collaborates strategically to achieve systemic advocacy goals and objectives.	15	4	0	2
8.4 Effects systems change through a variety of means.	19	1	0	1
8.5 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on legislation or public policy.	14	3	3	1
8.6 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on community practice or services.	15	4	1	1
8.7 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on inclusion and choice for people with developmental disabilities.	15	5	0	1
8.8 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on reduction in abuse and neglect.	11	9	0	1
8.9 Conducts ongoing monitoring to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.	15	2	3	1
Standard 9: P&As engage in effective and equitable outreach activities.	17	2	2	0
9.1 Conducts ongoing outreach activities.	21	0	0	0
9.2 Targets populations that are underrepresented or unserved.	19	2	0	0
9.3 Maintains a budget and designated trained staff for outreach activities.	12	7	2	0
9.4 Employs a variety of strategies to conduct outreach.	17	2	1	1
9.5 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.	19	2	0	0
9.6 Obtains feedback on outreach activities.	14	5	1	1
9.7 Reviews outreach activities between planning cycles so that outreach plans and strategies can be revised as needed.	14	5	1	1

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
9.8 Includes Board of Directors (or Commission) members in outreach activities.	4	14	3	0
9.9 Documents that outreach efforts have increased the number of callers and clients from typically unserved and underserved populations.	15	6	0	0
Standard 10: P&As have an impact on access to services, inclusion, and choice for people with developmental disabilities through the provision of community education	12	3	6	0
10.1 Provides education, training, and technical assistance activities.	16	1	1	3
10.2 Makes community education available to a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).	15	3	0	3
10.3 Targets community education to those in the community at large who can increase and improve services, choice and inclusion (e.g., health care providers, residential facility operators, employers, local government officials, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, daycare workers) for people with developmental disabilities.	8	9	0	4
10.4 Delivers community education through a variety of modes (e.g., classes, workshops, webinars, and online courses).	12	4	1	4
10.5 Delivers culturally appropriate and targeted community education activities.	12	4	1	4
10.6 Maintains a budget and designated trained staff for community education activities.	12	4	0	5
10.7 Determines recipient satisfaction.	14	3	0	4
10.8 Documents that community education efforts led to improved access to services, choice, or inclusion for people with developmental disabilities within the past 5 years.	6	10	0	5
Standard 11: P&A maintains an infrastructure that enables them to conduct all key functions efficiently and effectively.	19	2	0	0
11.1 Fills all vacancies on the Board of Directors (or Commission) within 1 year.	11	8	0	2

R2. Draft Standards and Performance Criteria – Version 1, Protection and Advocacy Systems, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
11.2 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues.	17	2	1	1
11.3 Includes Board of Directors (or Commission) members who are knowledgeable about the full range of the developmental disabilities population (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	14	3	1	3
11.4 Familiarizes all new Board Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.	20	1	0	0
11.5 Includes Board of Directors (or Commission) members who attend public events on issues related to developmental disabilities such as community meetings, legislative hearings, or non-profit organizations' events.	6	10	4	1
11.6 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.	20	1	0	0
11.7 Conducts an annual performance review of all staff members.	19	2	0	0
11.8 Receives an unqualified audit finding (i.e., clean audit with no findings, no notice of noncompliance) each year.	14	6	1	0
11.9 Budgets for professional development for staff.	17	4	0	0
Standard 12: P&A governance adheres to the principles and goals of the DD Act.	20	0	0	1
12.1 Maintains complete independence from the Governor and the developmental disabilities service system of the state or territory.	17	3	1	0
12.2 Provides supports needed to ensure meaningful participation by Board of Directors (or Commission) members.	20	0	1	0
12.3 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available to each member in accessible format.	18	1	2	0
12.4 Funds at least one Board or Commission member's attendance at a developmental disabilities-related national meeting each year.	6	12	3	0

R3. Draft Standards and Performance Criteria – Version 1, University Centers for Excellence in Developmental Disabilities Education, Research, and Service, Rating Results*

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 1: UCEDDs identify the key issues, needs, and priorities of people with developmental disabilities and family members in their state or territory.	16	0	3	0
1.1 Collects input for the 5-Year Plan from internal and external sources	18	1	0	0
1.2 Collects input for the 5-Year Plan from geographic regions across the state or territory.	11	6	2	0
1.3 Uses a variety of methods for collecting input for the 5-year Plan (e.g., focus groups, surveys, social media outlets, the UCEDD website, and review and analysis of reports and studies).	11	6	1	1
1.4 Collects input for the 5-Year Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.	9	7	2	1
1.5 Collects input for the 5-Year Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.	9	6	2	2
1.6 Leverages its own planning efforts with the planning efforts of DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.	13	3	2	1
1.7 Gathers data for planning on an ongoing basis throughout the planning cycle.	7	6	6	0
1.8 Has faculty and staff who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.	9	7	3	0

*19 panel members rated the draft standards and performance criteria.

R3. Draft Standards and Performance Criteria – Version 1, UCEDDs, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 2: UCEDD 5-Year Plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for UCEDD action.	14	3	2	0
2.1 Reflects the internal and external input from the planning process.	17	0	1	1
2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access, inclusion, choice, basic human rights, quality of life).	19	0	0	0
2.3 Drives the activities that the UCEDD conducts and supports.	16	2	1	0
2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with UCEDD resources, outside resources, and the potential impact of strategies that were considered.	10	2	6	1
Standard 3: UCEDDs prepare students to implement an interdisciplinary approach to serving people with developmental disabilities and family members.	13	1	5	0
3.1 Offers developmental disabilities-related courses or trainings based on content from a variety of disciplines.	16	1	0	2
3.2 Offers developmental disabilities-related courses or trainings taught by faculty and staff from multiple disciplines.	15	2	0	2
3.3 Offers developmental disabilities-related courses or trainings to students from multiple disciplines.	15	2	0	2
3.4 Involves students in the conduct of research and reporting.	13	4	2	0
3.5 Assists students in finding work, career or educational options that benefit the quality of life of people with developmental disabilities.	6	12	1	0
3.6 Infuses disability-related content into courses outside the department and school in which the UCEDD is housed.	8	9	2	0
3.7 Lists UCEDD-developed courses in more than one department in the university.	6	10	3	0
3.8 Develops courses that are adopted by other universities.	1	13	5	0
3.9 Impacts the community by having former students enter a disability-focused field or line of work.	9	6	4	0

R3. Draft Standards and Performance Criteria – Version 1, UCEDDs, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
3.10 Prepares students to apply a multidisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.	13	3	3	0
Standard 4: UCEDDs prepare students to reach a diverse population of people with developmental disabilities.	16	3	0	0
4.1 Recruits students from culturally and linguistically diverse backgrounds.	13	3	3	0
4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities (e.g., serving as lead instructors, co-instructors, curriculum developers).	14	5	0	0
4.3 Provides students with coursework that leads to an understanding of the daily lives of people with developmental disabilities and their families.	16	2	1	0
4.4 Provides pre-service and graduate students with opportunities to interact with people with developmental disabilities and family members.	17	0	2	0
Standard 5: UCEDDs improve the knowledge, skills, and strategies of service providers and practitioners through a continuing education program.	15	3	1	0
5.1 Provides continuing education course work to a variety of professionals in the community.	15	1	2	1
5.2 Provides continuing education on topics of interest to service providers and practitioners.	13	3	3	0
5.3 Bases continuing education course topics on documented needs in the state or territory.	13	4	2	0
5.4 Develops continuing education programs (including courses) that are adopted by other states or internationally.	2	11	6	0
5.5 Develops continuing education that becomes part of a state requirement or certification.	2	14	3	0
5.6 Can document that participants in continuing education impact the developmental disabilities community.	6	10	3	0

R3. Draft Standards and Performance Criteria – Version 1, UCEDDs, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 6: UCEDD faculty and staff conduct research that is relevant to improvements in the lives of people with developmental disabilities or family members.	17	2	0	0
6.1 Conducts basic research, evaluation, or policy analysis relevant to improvements in the lives of people with developmental disabilities or family members.	15	2	0	2
6.2 Involves people with developmental disabilities in the development, design, or implementation of the research (e.g., identify research topics, assist with the design of data collection instruments, help to ensure that research materials are in accessible and understandable formats, recruit people with developmental disabilities and family members as study participants).	13	4	2	0
6.3 Can document that their research has had a direct impact on people with developmental disabilities in the past 5 years.	9	10	0	0
Standard 7: UCEDD faculty members and staff are leaders in their field of research.	12	5	2	0
7.1 Publish research findings on developmental disabilities in peer-reviewed journals.	15	3	0	1
7.2 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.	18	1	0	0
7.3 Are members of a peer-reviewed journal's editorial board.	6	11	2	0
7.4 Participate on a grant review panel (either for the University or for an outside organization).	7	9	3	0
Standard 8: UCEDDs provide or support community services through education, training, or technical assistance	16	3	0	0
8.1 Supports community services or at times provides direct services to people with developmental disabilities and family members.	12	3	4	0
8.2 Provides training or technical assistance to service providers.	17	0	2	0
8.3 Implements community services that are endorsed or funded by state agencies.	3	11	5	0

R3. Draft Standards and Performance Criteria – Version 1, UCEDDs, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
8.4 Can demonstrate that the community services provided or supported by the UCEDD for people with developmental disabilities and family members were integrated into training and research activities of the UCEDD in the past 5 years.	8	6	3	2
8.5 Can demonstrate that the training, technical assistance or other community services it provides has resulted in increased and improved services for people with developmental disabilities and their families in the past 5 years.	12	4	1	2
Standard 9: UCEDD dissemination activities address the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.	19	0	0	0
9.1 Provides publications, material and other resources in accessible formats.	19	0	0	0
9.2 Provides accessible training and technical assistance activities.	16	0	3	0
9.3 Seeks input on materials and resources from people with developmental disabilities and family members (e.g., CAC members, advisory groups connected with research and community service activities).	17	2	0	0
9.4 Provides materials and other resources in formats appropriate for people with cognitive impairments.	14	4	0	1
9.5 Maintains and routinely updates a fully accessible website.	16	3	0	0
9.6 Evaluates dissemination activities and results on an ongoing basis (e.g., monitors number of website hits, conducts targeted surveys, monitors the use of materials).	14	5	0	0
9.7 Makes its products, resources, and materials available to DD Network programs in its own state or territory.	16	2	1	0
9.8 Makes its products, resources and materials available to UCEDDs, DD Councils, and P&As in other states and territories.	10	8	1	0
Standard 10. UCEDD dissemination activities bridge the gap between research and practice.	14	2	3	0
10.1 Publishes on developmental disability-related issues in professional newsletters and other publications for providers and practitioners.	15	1	1	2

R3. Draft Standards and Performance Criteria – Version 1, UCEDDs, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
10.2 Uses a variety of distribution modes (e.g., electronic, in-person, and print) and strategies (mass mailings, YouTube videos, seminar series) to disseminate information and research findings to providers and practitioners.	15	3	0	1
10.3 Makes effective use of practitioner organization networks, listServs, and contact lists to expand its dissemination range.	13	2	2	2
10.4 Disseminates the work of other UCEDDs to providers and practitioners.	4	11	3	1
10.5 Uses the national developmental disabilities organizations to disseminate to other UCEDDs, P&As, and DD Councils.	9	6	3	1
10.6 Integrates UCEDD research findings into the preparation and continuing education of pre-service interdisciplinary trainees.	11	4	2	2
10.7 Disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.	11	7	0	1
10.8 Makes materials, resources, and information on developmental disabilities available to the University community (e.g., publishes in the university newspaper, organizes and presents at a University-wide seminar).	10	7	1	1
Standard 11: UCEDDs leverage funding to support and maintain its programs	15	1	2	1
11.1 Leverages funds that amount to at least three times the amount of the ADD grant.	6	11	1	1
11.2 Leverages funds and in kind resources (e.g., space, use of University infrastructure) from the University in which it is housed.	14	2	3	0
Standard 12: UCEDDs maintain and support involvement from CACs.	17	1	1	0
12.1 Fills all vacancies on the CAC within 1 year.	14	3	2	0
12.2 Continuously maintains CAC membership that includes people who are knowledgeable about the full range of the developmental disabilities population in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).	14	3	2	0
12. Involve CAC members in the development and implementation of the 5-Year Plan.	19	0	0	0

R3. Draft Standards and Performance Criteria – Version 1, UCEDDs, Rating Results (continued)

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
12.4 Seeks and incorporates the input of the CAC into UCEDD activities throughout the planning cycle.	17	1	1	0
12.5 Supports its CAC for a minimum of two meetings each year.	17	0	1	1
12.6 Supports its CAC for more than two meetings each year.	3	10	4	2
12.7 Provides CAC members with any supports that are needed to ensure meaningful participation.	17	1	0	1

R4. Draft Standards and Performance Criteria – Version 1, Collaboration, Rating Results*

Draft standard/performance criteria (PC) - Version 1	Agree/ PC required	Unsure/ exceeds the standard	Disagree/ not relevant	Missing
Standard 1. All DD Network programs in the state or territory achieve common goals through collaboration.	42	8	4	0
1.1 Identify and acknowledge a common goal or goals.	49	4	0	1
1.2 Articulate dedicated activities or tasks for each DD Network program.	40	6	5	3
1.3 Demonstrate a united front on key (identified) issues.	31	17	6	0
1.4 Talk with a common voice on key (identified) issues.	27	19	6	2
1.5. Include staff from all three DD Network programs in collaborative planning meetings and implementation activities.	39	10	2	3
1.6 Include members of the DD Council, Consumer Advisory Committee (CAC) and P&A Board of Directors (or Commissions) in collaborative planning meetings and implementation activities.	28	18	5	3
1.7 Can demonstrate that they have achieved common goals in the past 5 years through their collaborative efforts.	42	10	1	1

*52 panel members rated the draft standards and performance criteria for collaboration among the three DD Network programs.

Appendix S. Rationale for Changes to Version 1

State Councils on Developmental Disabilities

Planning. On the whole, the ratings were relatively high for the planning section. All but three people agreed with Standard 1 (*DD Councils identify key issues, needs and priorities of people with developmental disabilities and family members in their state or territory*). Standard 2 (that the resulting *State Plans reflect the needs of people with developmental disabilities and is used to drive all DD Council activities*) was agreed to by 21 out of 26 panel members (81 percent).

We eliminated Performance Criterion (PC) 1.8 under Standard 1 (*DD Council has staff and members who serve on community and agency boards and committees...*). Although one panel member thought this PC "added depth" to the Council and another noted that it is "important to stay connected to other initiatives," we were persuaded by other comments that this PC could be too directive, especially for small Councils with few staff, and that conflict of interest could become a problem.

Wording changes were made to both standards and all remaining PCs, based on panel members' suggestions.

As suggested by one panel member, when a list of examples was provided, we noted that all items were not required and that others might be used. We also followed the suggestion of one panel member to be consistent in the formatting of examples.

Self-advocacy and Leadership. The self-advocacy and leadership section had two standards. Standard 3 (*DD Councils encourage and develop self-advocates and leaders among people with developmental disabilities [or their families] through education, training, and technical assistance*) obtained agreement from 23 panel members. However, as suggested by a number of commenters, we took "or their families" out of parentheses and changed "or" to "and" to recognize the vital support played by family members. The PCs under Standard 3 received considerable agreement (19 for each one), but wording changes were made, particularly to the PC that called for active recruitment from the *broad population of people with developmental disabilities*. In our examples, we took out "all" types of developmental disabilities and added a few other examples that were suggested.

Standard 4 and the two PCs under the standard remained. We incorporated wording changes as recommended by panel members.

Community Capacity Development. The one standard (Standard 5) under Community Capacity Development was agreed upon by 13 panel members. The comments indicated agreement with the concept but concern with the language and examples that were provided. Thus, we changed the wording of the standard to "DD Councils improve the capacity of communities to include and support community members with developmental disabilities," as suggested by one panel member. We provided different examples.

For the PCs under the re-worded Standard 5, we eliminated PC 5.2 (*Conducts or supports at least one community capacity development activity each year*) since only 11 thought this PC should be required to meet the standard. Three PCs that were intended to address the concept of evaluation of community capacity activities were combined. The result was one PC requiring that DD Councils document the outcomes of their efforts.

Systems Change Through Advocacy. Despite the fact that two panel members had strong feelings about the approach of this section ("Systems change is not just advocacy and not just legislative related activities which this standard and criteria implies..." and "Standard 6 does not reflect our systems change mission – it focuses almost entirely on advocacy. They are NOT the same..."), 22 panel members agreed with Standard 6 on Systems Change. In addition, while we recognize that advocacy is not the only way to achieve systems change, we also noted in our program visits to 20 DD Councils as part of the National Independent Study of the ADD Programs that advocacy activities were a large part of what DD Councils do. Thus, we kept the basic concept of the standard and changed the section name to "Systems Change Through Advocacy."

Rating results were mixed on the PCs listed to meet this standard. Twenty-one (21) panel members thought DD Councils should *lead and participate in advocacy efforts that are expected to result in system changes that promote inclusion, choice, and better access to services* (PC 6.1). It was pointed out that this wording overlapped with the wording of the standard, however, so we used the wording of the PC to revise the wording of the standard. In addition, 20 panel members thought the use of a variety of strategies should be used (PC 6.2), and 24 agreed that collaboration should be used to achieve system change goals and objectives (PC 6.4). Again, we combined PCs that were intended to address the concept of evaluation of advocacy efforts into one PC, resulting in one PC that reads "Documents the outcomes and effects of its advocacy efforts."

Demonstration of New Approaches to Services and Supports. Standard 7 under Section D addressed the work that many Councils support on testing, promoting, and providing information

on promising practices for the delivery of services. There was agreement on this standard by 19 panel members so it was not eliminated. Twenty-two (22) panel members thought that disseminating or promoting new or innovative practices would be one way to meet this standard (PC 7.1). Elimination or wording changes were made to the remainder of the PCs under Standard 7.

Governance and Management. Finally, the Governance and Management section contained two standards (Standard 8 and 9). Most panel members agreed with both standards. We changed the wording of Standard 9 to read "DD Councils are effective in fulfilling their governing responsibilities," as suggested by one panel member. Except for PC 8.2 under Standard 8 (*Fills all vacancies on the DD Council within 1 year*) and PC 9.3 under Standard 9 (*Assigns a distinct role to every Council member*), we kept all PCs. Changes in wording and examples were made based on comments and suggestions of panel members. Two PCs were added under Standard 9 at the suggestion of panel members.

Protection and Advocacy

Planning and Priority Setting. The section on planning and priority setting consisted of one standard on the planning and priority setting process and one on the outcome (i.e., the result of the process – a Statement of Goals and Priorities that truly reflects the needs of people with developmental disabilities in the state or territory). More than 65 percent of panel members (i.e., 13 or more) agreed with both standards, although with certain caveats. Thus, for Standard 1 (***P&As identify the key issues, needs, and priorities of people with developmental disabilities and family members in the state or territory***) and Standard 2 (***P&A SGPs reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for P&A action***), we took out "and family members" to recognize that the person with a developmental disability is the P&A client and not the family member.

Performance criteria (PC) under Standard 1 address the need to ensure that P&As obtain a broad and comprehensive perspective. A number of panel members saw the examples as prescriptive or, alternatively, suggested additional examples. Since we think this document should be able to stand on its own as much as possible, we left in the examples. However, we inserted a footnote for all examples indicating that not all examples are required, and other examples could also be used. We eliminated PC 1.8 (***Has staff and Board or Directors [or Commission] members who serve on community and agency boards and committees***). Although we saw this as a way to obtain ongoing input into the needs of people with developmental disabilities, we recognized the concern expressed

by some panel members on the issue of conflict of interest, as well as time constraints and limited resources.

Although there was low agreement on PC 1.6, we re-worded this PC instead of eliminating it entirely. Our intent for PC 1.6 was to provide P&As with the opportunity to be more efficient and use the information obtained from other planning efforts in the state or territory if appropriate. Hopefully, this PC is now more clear. Our intent for PC 2.4 (***Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with P&A resources, outside resources, and the potential impact of strategies that were considered***) had been to suggest that P&As look not only at the needs of people with developmental disabilities but also whether they have the resources to make something their own priority and whether other organizations in the community have also made it a priority. However, there are likely many more considerations to be made in SGP priority setting, so we eliminated this PC.

Finally, because a number of panel members indicated that the SGP needs to be flexible to account for emerging or emergency issues, we added a PC using the words suggested by one panel member: "Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statutes, regulations, or priorities."

Intake and Assistance. The one standard under Intake and Assistance was acceptable to most panel members (19 out of 21 or 90 percent). There was a question on the meaning of "equitable" which we tried to explain by adding "By equitable we mean that anyone contacting the P&A will be able to be served."

Two PCs were eliminated (PC 3.5 and PC 3.7). We agreed with commenters that these seemed to be overly prescriptive and should be left to the discretion of management. PC 3.9 (***Periodically applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process***) had agreement from only 9 panel members (40 percent), and 12 thought it exceeded the standard. However, having been told by a number of P&As we visited as part of the National Independent Study of the Developmental Disabilities Programs that feedback on satisfaction is typically sporadic and nonrepresentative, we decided to try again in Version 2. Although we recognize the difficulty with limited resources, we think that every so often P&As need to obtain accurate, representative data on customer satisfaction because this would be an excellent way for a P&A to judge the outcome of its intake and assistance activities. Thus, we kept the general intent of the PC and re- worded it to indicate that the frequency does not need to be yearly, but instead can be every 3 to 5 years. With certain word changes suggested by panel members, the remainder of the PCs was kept.

Individual Advocacy. There were three standards under Individual Advocacy. Standard 4 (***P&A caseload reflects the priorities set in the SGP***) received agreement from 16 panel members (80 percent). Eighteen (18) panel members agreed to Standard 5 (***P&A provides high quality representation***). Standard 6 (***Individual Advocacy meets client objectives***) was agreed to by 16 of the panel members.

There was high agreement with PC 4.1 and 4.2 under Standard 4. However, there was concern about the possible loss of flexibility in the case of emerging or emergency issues. Thus, we changed the wording to allow for such flexibility. Seven (7) panel members reported that PC 4.3 was not relevant to the standard so we eliminated it.

Panel members generally agreed that P&A individual advocacy staff should be provided with opportunities to discuss and review cases (PC 5.1) but thought that weekly provision of oversight (PC 5.2) was either too frequent, arbitrary, or should be a management decision. Thus, PC 5.2 was eliminated. PC 5.3 was reworded to indicate that a P&A should provide accessible resources to staff and encourage them to use them without prescribing which resources.

There was high agreement for most PCs under Standard 6 (***Individual advocacy meets client objectives***), with certain caveats. Therefore, most remain, with rewordings as suggested by panel members. PC 6.8 (***Documents success in resolving a majority of issues in favor of P&A clients***) was re-worded. The intent of this PC was to address the outcome of individual advocacy. We found in our study of 20 P&As that many P&As achieve much more than a 51 percent success rate. Thus, a requirement that all P&As at least meet the majority of objectives of its clients does not appear to be unreachable. Thus, PC 6.8 now indicates that P&As should resolve a majority of issues in favor of P&A clients.

We eliminated PC 6.9 (P&As follow up clients to determine whether decisions made on behalf of a client are being followed and the client issue has truly been resolved). Although we came across a number of P&As that implemented such a practice, we were convinced by panel members that not all P&As would have the resources to fulfill this criterion.

We reduced the number of PCs under Standard 7 on confidentiality from seven to four, and then added one more. PCs now indicate that all P&As should have a written confidentiality policy and procedures that cover onsite staff, staff working at home, students, volunteers, and contracted staff. Moreover, there needs to be structures in place to maintain confidentiality, adherence to policy and

procedures needs to be demonstrated, and orientations need to review the confidentiality requirements. The additional PC in Version 2, recommended by a panel member, relates to obtaining client feedback and satisfaction.

Systemic Advocacy. Although there was considerable agreement with the Systemic Advocacy standard and PCs, we tried to clarify the language, based on panel members' suggestions, and reduce the number of PCs by combining a number that related to systemic advocacy outcomes. Thus, the standard starts with an outcome – ***P&As systemic advocacy improves access to State systems and community practice and reduces abuse and neglect***. The first PC now calls for the use of a variety of systemic advocacy strategies, none of them required. The second PC calls for documentation that illustrates that outcomes have been achieved within the past 5 years. We left in the time period of 5 years to indicate that P&As need to document at least one outcome every 5 years. The final PC has one wording change (we changed "monitoring" to "reviewing") and calls for P&As to make sure that any outcomes that have been achieved are being implemented appropriately and that the P&A is aware of any unintended consequences.

Outreach and Community Education. The outreach and community education standards posed some difficulties to panel members. Although there was disagreement on the definition of outreach, there was agreement among 17 out of 21panel members that outreach should take place, that it should be conducted on an ongoing basis (all 21 agreed), and that it should target populations that are underrepresented or unserved (19 agreed). We revised Standard 9 to indicate that the outcome of such outreach activities is the identification of unserved and underserved populations. We see this outcome as different than the outcome of community education, so we did not combine Standard 9 and 10, as suggested by one panel member. Under Standard 9 we eliminated PC 9.8 (***Includes Board of Directors [or Commission] members in outreach activities***) and included it as an example with other strategies from PC 9.4 in PC 9.1.

The original intent of Standard 10 on community education was to focus on P&A activities targeted not only to people with developmental disabilities and family members, but also to those in the community who require a better understanding of the rights and value of people with developmental disabilities (e.g., employers, teachers, local government officials, health care providers). Although we saw some excellent examples of community education in our program visits to 20 P&As, we recognize that not all P&As have the resources to target such a wide audience. Thus, we have changed the name of this section to "Outreach and Education" in Version 2 of the draft standards.

In addition, the PCs address only the education activities targeting people with developmental disabilities and family members. We also deleted PC 10.2 (***Makes communication education available to a broad population of people with developmental disabilities...)*** since we think community education should be relevant to the priorities in the SGP and not necessarily to a broad population of people with developmental disabilities and PC 10.8 (***Documents that community education efforts led to improved access to services, choice, or inclusion for people with developmental disabilities within the past 5 years)***. Other PCs require measurement of recipient satisfaction (14 panel members agreed with this PC) and documentation of the achievement of outcomes on improved access to services and community participation.

Governance and Management. The section on Governance and Management contained two standards (Standard 11 and 12) which received agreement from most panel members. Thus, they were not changed. Although some panel members were troubled by the potential infringement of management's role of some PCs under these standards, a large majority of panel members agreed with most of them. Those that received low agreement (e.g., PC 11.5 and 12.4) were eliminated. Others were re-worded, as suggested by panel members, to address some panel members' concerns. We removed the requirement to fill Board of Directors (Commission) vacancies within 1 year and instead required a P&A to actively work toward filling vacancies in a timely manner and to document its efforts to do so (a suggestion from one panel member). We combined two PCs on the composition of the Board of Directors (Commission) and called for expertise in fiscal, policy, and legal issues, as well as members who are knowledgeable about the developmental disabilities population and issues.

Although there were some suggestions on changes to PC 11.4 (***Familiarizes all new Board of Directors [or Commission] members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A***), 20 out of 21 agreed with this PC. Thus, we left it alone. We also did not revise PC 11.6 (***Maintains a staff infrastructure with well-defined supervisory roles and responsibilities)***) because of high agreement. Although 14 panel members agreed with PC 11.8 on independent audits, there was consistency on some of its problems, so we attempted to address those problems by revising the wording. The PC on audits now indicates that P&As need to receive an annual independent audit and immediately address any issues that are found. Since 17 out of 21 panel members agreed with PC 11.9 (***Budgets for professional development for staff***), we left that PC intact.

Under Standard 12, we eliminated PC 12.4 to fund at least one Board of Commission member's attendance at a developmental disabilities-related national meeting each year since only 6 panel

members agreed with this PC and 12 thought it exceeded the standard. We made small wording changes to all other PCs under Standard 12, as suggested by panel members.

Finally, one panel member suggested adding a standard "the Board of Directors (or Commission) sets policy and long range goals for the P&A, and holds the executive director accountable for adhering to the policies and goals." We made that the first standard under Government and Management, added a new PC ("Conducts an annual performance review of the Executive Director"), and moved a few PCs from other standards to this new standard.

UCEDDs

Five-year Planning. The section on 5-year planning consisted of one standard on the planning process and one on the outcome (i.e., the results of the process – a 5-year plan resulting from that process). More than 70 percent of panel members agreed with both standards. However, a number of panel members indicated in their comments that the planning section was too similar to what was required of State Developmental Disabilities Councils (DD Councils) instead of building on it. Thus, we went back to the wording of the DD Act. Standard 1 now reads "UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and the goals in the DD Council State Plan. Standard 2 (*UCEDD 5-year plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for UCEDD action)* was changed to reflect that 5-year plans are a "guide" for UCEDD action (a term preferred by some panel members).

Performance criteria (PCs) under Standard 1 address the need to ensure that UCEDDs obtain a broad and comprehensive perspective. A number of panel members saw the examples as prescriptive or, alternatively, suggested additional examples. Since we think this document should be able to stand on its own as much as possible, we left in many examples throughout the document. However, we inserted a footnote for all examples indicating that not all examples are required, and other examples could also be used.

Under the first standard, we eliminated PC 1.7 (*Gathers data for planning on an ongoing basis throughout the planning cycle*) and PC 1.8 (*Has faculty and staff who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members*) because of low agreement. The

remaining PCs were combined or reworded, consistent with some of the suggestions of panel members.

Under Standard 2, our intent for PC 2.4 (*Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with UCEDD resources, outside resources, and the potential impact of strategies that were considered*) had been to suggest that UCEDDs look not only at the needs of people with developmental disabilities but also whether they have the resources to address a particular issue and whether other organizations might be addressing it. However, there are likely many more considerations to be made in UCEDD priority setting, including having more than one UCEDD in a state (as pointed out by one panel member) so we eliminated this PC. Other PCs under Standard 2 were re-worded, based on panel members' suggestions.

Interdisciplinary Pre-service Preparation and Continuing Education. Although there were many comments on the interdisciplinary pre-service preparation and continuing education section, ratings for standards under this function were relatively high.

We tried to address many of the concerns of commenters, including the definition of "interdisciplinary approach" which was given to us by a UCEDD working group member during Phase 1 of this study. We were unable to find any other definition, so instead, have taken it out and followed many other suggestions of panel members. Standard 3 under Interdisciplinary Pre-Service Preparation and Continuing Education (*UCEDDs prepare students to implement an interdisciplinary approach to serving people with developmental disabilities and family* members) is now re-worded as "UCEDDs advance practice, scholarship, and policy that impacts the lives of people with developmental disabilities and their families." Standard 4 (*UCEDDs prepare students to reach a diverse population of people with developmental disabilities*) was reworded slightly to indicate that UCEDDs prepare students "to work on behalf of" a diverse population of people with developmental disabilities" instead of to "reach" them. For Standard 5, we added in-service training and technical assistance to better describe continuing education at UCEDDs.

Under Standard 3, we eliminated PC 3.5 (*Assists students in finding work, career or educational options that benefit the quality of life of people with developmental disabilities*). In program visits to 20 UCEDDs, as part of the National Independent Study of State Developmental Disabilities Programs, we found a number of UCEDDs that were doing this. However, we recognize that not all UCEDDs will have the resources. We also re-worded or added a number of PCs under Standard 3, based on panel member suggestions.

Under Standard 4, we combined PCs 4.3 (*Provides students with coursework that leads to an understanding of the daily lives of people with developmental disabilities and their families*) and PC 4.4 (*Provides pre-service and graduate students with opportunities to interact with people with developmental disabilities and family members*) and made word changes to the remaining PCs, as suggested by panel members.

We eliminated three PCs under Standard 5 on continuing education because of low ratings—PC 5.4: *Develops continuing education programs [including courses] that are adopted by other states or internationally*; PC 5.5: *Develops continuing education that becomes part of a state requirement of certification*; and PC 5.6: *Can document that participants in continuing education impact the developmental disabilities community.* The two remaining PCs capture panel members comments that continuing education is provided to professionals in the community, and content is based on needs that are documented in the 5-year plan.

Basic and Applied Research. There was strong agreement (17 out of 19 panel members or 89 percent) with Standard 6 on Basic and Applied Research (*UCEDD faculty and staff conduct research that is relevant to improvements in the lives of people with developmental disabilities or family members*). Agreement with Standard 7 (*UCEDD faculty members and staff are leaders in their field of research*) was borderline. Although we found a number of leaders in their field of research among many of the UCEDDs we visited, we ended up eliminating this standard and moved some of Standard 7's PCs under a slightly re-worded Standard 6. We eliminated PC 6.3 (*Can document that their research has had a direct impact on people with developmental disabilities in the past 5 years*), PC 7.3 (*Are members of a peer-reviewed journal's editorial board*), and PC 7.4 (*Participate on a grant review panel [either for the University or for an outside organization*]) due to low agreement that they should be used to meet the standard and high agreement that they exceeded the standard. Remaining PCs were mostly reworded based on panel members' suggestions.

Community Services. Although 16 out of 19 panel members agreed with Standard 8 on community services, we revised it to be more consistent with the wording of the DD Act. We eliminated two PCs under this standard because of low agreement – PC 8.3: *Implements community services that are endorsed or funded by state agencies*; and PC 8.4: *Can demonstrate that the community services provided or supported by the UCEDD for people with developmental disabilities and family members.* PC 8.5 (*Can demonstrate that the training, technical assistance or other community services it provides has resulted in increased and improved services for*

people with developmental disabilities and their families in the past 5 years) received agreement from 12 out of 19 panel members. However, a number of commenters indicated the difficulty in operationalizing such a requirement. Therefore, we revised this PC to require reporting on community services targets. The remaining PCs were added or re-worded, based on panel members' suggestions.

Dissemination. Standards 9 and 10 in Version 1 (*UCEDD dissemination activities address the principles and purpose of the DD Act by reaching people with developmental disabilities and family members*; and *UCEDD dissemination activities bridge the gap between research and practice*) had high agreement, although a number of panel members suggested switching the order, which we did.

Under Standard 9 in Version 1, all PCs had high ratings except for PC 9.8 (*Makes its products, resources and materials available to UCEDDs, DD Councils, and P&As in other states and territories*). We combined PC 9.8 with PC 9.7 (*Makes its products, resources, and materials available to DD Network programs in its own state or territory*) so the PC now reads "Makes its products, resources, and materials available to other DD Network programs." Other PCs under Standard 9 were combined or re-worded to be consistent with panel members' suggestions.

The PCs under Standard 10 in Version 1 (*UCEDD dissemination activities bridge the gap between research and practice*) either became examples, were re-worded slightly to conform with panel members' suggestions, or were eliminated due to low ratings. We eliminated PC 10.4 (*Disseminates the work of other UCEDDs to providers and practitioners*), PC 10.5 (*Uses the national developmental disabilities organizations to disseminate to other UCEDDs, P&As, and DD Councils*), and PC 10.8 (*Makes materials, resources, and information on developmental disabilities available to the University community [e.g., publishes in the university newspaper, organizes and presents at a university-wide seminar]).* Although the percentage of panel members who agreed with PC 10.7 (*Disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers*) was less than 65 percent, we kept it in since it is a requirement of the DD Act. However, we added in a phrase, suggested by a panel member, to indicate that UCEDDs also need to comply with their university guidelines on dissemination of information to policymakers.

Governance and Management. The two standards under Governance and Management relate to UCEDDs leveraging funding and maintenance and support of the CAC. Both received high enough ratings to remain, but commenters expressed a few caveats on both. We saw Standard 11 (*UCEDDs*

leverage funding to support and maintain its programs) as a way to address the fact that funding from ADD is not meant to run the entire UCEDD program but instead, as noted by ADD, is considered to be seed money. Commenters appeared to agree, but reluctantly. Only six panel members were in agreement with PC 11.1 (*Leverages funds that amount to at least three times the amount of the ADD grant*), and 11 thought it exceeded the standard. We took it out, but, in fact, findings from the National Independent Study revealed that all 19 UCEDDs that provided information on this issue would meet that standard and most far exceeded it. We replaced the PC with a process instead of an outcome criterion – "Documents the degree to which the UCEDD leverages ADD and university funds."

Standard 12 (*UCEDDs maintain and support involvement from CACs*) received agreement from 17 out of 19 panel members, although one panel member did not think it should be placed under Governance and Management. However, since many of the PCs that remained under this standard are management responsibilities, we left it there.

We eliminated PC 12.6 under Standard 12 (*Supports its CAC for more than two meetings each year*). The remainder are still included in Version 2, although some have been re-worded. Because of high ratings, PC 12.3 (*Involves CAC members in the development and implementation of the 5-year plan*) and 12.5 (*Supports its CAC for a minimum of two meetings each year*) remain exactly the same. We borrowed the wording from the DD Council draft standards to now say for what was PC 12.1 (*Fills all vacancies on the CAC within 1 year*) that a UCEDD needs to actively work to fill CAC vacancies in a timely manner and document efforts to do so. Instead of the wording in PC 12.2 (*Continuously maintains CAC membership that includes people who are knowledgeable about the full range of the developmental disabilities population in the state or territory...*), which received agreement from 14 panel members, the PC now says "Maintains a diverse CAC membership," as recommended by a UCEDD panel member. Although 17 UCEDD panel members agreed that UCEDDs should *provide CAC members with any supports.*

Collaboration

The draft standard on collaboration received agreement from 42 (78 percent) panel members. Comments were generally supportive of this standard, with some caveats. Some noted the difficulty of the three DD Network programs in a state or territory achieving common goals and the different roles each program plays. It was also noted that collaboration should be wider than just the three DD Network programs. One panel member suggested incorporating the concept of collaboration

into other DD Council standards and performance criteria (PCs). In addition, it was stated that there has been on overemphasis on collaboration lately and that there should be a federal law or regulation regarding collaboration.

We agree that collaboration needs to be wider than just the three DD Network programs in a state or territory and included PCs that recognize that. Moreover, this particular standard on collaboration does not preclude DD Network programs from collaborating with other organizations and agencies. We did not revise the standard.

Although there was some agreement on PC 1.3 and 1.4 (programs should ***demonstrate a united front*** and ***talk with a common voice*** on key issues), some panel members indicated that programs have different perspectives and need to be able to express them. It was also noted that these two PCs could be combined. Thus, we re-worded PC 1.3 and eliminated PC 1.4. The re-worded PC indicates that the "united perspective" is related to the common goal(s) that have been identified by the three programs.

We also eliminated PC 1.6 (to include Council, CAC and P&A Board of Director members in collaboration activities), which was agreed to by 27 panel members but was felt to be difficult to achieve for volunteer Council members and perhaps very costly. Instead, we combined the concept with PC 1.5 (***Include staff from all three DD Network programs*** in collaborative meetings) and made some other wording changes, as suggested.

The remaining PCs were agreeable to 70 percent or more of panel members, so we kept the PC but made some wording changes, as suggested by panel members.

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Appendix T. Cover Letters for Version 2

T1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

T2. PROTECTION AND ADVOCACY SYSTEMS

T3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

T1. State Councils on Developmental Disabilities

June 1, 2011

Dear DD Council Panel Member:

Thank you for providing your ratings of the DD Council Draft Standards and Performance Criteria – Version 1, as well as your comments and suggestions. Based on those ratings, comments, and suggestions, we have revised Version 1 and present you with Version 2 for further rating and comments. This package contains the following:

- Rating Results – DD Councils
- DD Council Draft Standards and Performance Criteria – Version 2 (in tracking)
- DD Council Draft Standards and Performance Criteria – Version 2 (no tracking)
- Rating materials for Version 2
- DD Council Panel member comments (no one is identified)
- Postage paid return envelope

Approach to Making Changes to Version 1

Twenty-six (26) panel members rated the DD council Draft Standards and Performance Criteria – Version 1.

For the standards,

- If 65 percent[1] or more (17+) agreed with a standard, we kept the standard.
- If 35 percent or more (9+) disagreed with a standard, we eliminated the standard.
- We received comments from 26 panel members. We reviewed the comments to see if we could clarify or improve the wording for those standards that remained.
- In general, we tried to keep the same wording for those standards for which 17 or more people agreed that it should be a standard. However, in many cases, comments and suggestions were an improvement to the original standard. Thus, we followed a number of suggestions from panel members. On the other hand, if the number of panel members who agreed with a standard was particularly high (20 or more), we tried not to make major changes.

For the performance criteria,

- If 65 percent or more (17+) indicated that the performance criterion (PC) is required to meet the standard, we kept the performance criterion.
- If 35 percent or more (9+) indicated that the PC would exceed the standard or was not relevant, we eliminated it.
- We received comments from 26 panel members. We reviewed the comments to see if we could clarify or improve the wording for those PCs that remained.

[1] We used 26 as the denominator in the calculation of percentages.

- In general, we tried to keep the same wording for those PCs for which 17 or more people agreed that it should be a standard. However, in many cases, panel members' suggestions were an improvement to the original wording. Thus, we followed a number of suggestions from panel members. On the other hand, if the number of panel members who thought the performance criterion was required to meet the standard was particularly high (20 or more), we tried not to make major changes.

Summary of Comments

We received many helpful comments and suggestions. A brief summary of the ratings and comments for each section are contained in Appendix A.

Return Ratings for Version 2

We would appreciate it if you would return your ratings in the enclosed postage paid envelope by **June 20, 2011**.

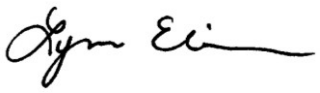
To avoid packages becoming too cumbersome, please note that we are sending out panel materials separately for each panel and collaboration. The collaboration package will contain a reimbursement form for you to complete if you are able to receive an honorarium.

If you received assistance for Version 1 from a Westat staff member, we will call you to see whether you would like to receive assistance again.

If you have any questions, please feel free to contact me (1-800-937-8281, Ext. 5844 or lynnelinson@westat.com) or Bibi Gollapudi (1-800-937-8281, Ext. 7558 or bibigollapudi@westat.com).

Again, we would like to thank you for your assistance.

Sincerely,



Lynn Elinson, Ph.D.
Associate Director, Health Studies

Appendix A. Summary of Ratings and Comments

A. Planning

On the whole, the ratings were relatively high for this section. All but three people agreed with Standard 1 (DD Councils identify key issues, needs and priorities of people with developmental disabilities and family members in their state or territory). Standard 2 (that the resulting State Plans reflect the needs of people with developmental disabilities and is used to drive all DD Council activities) was agreed to by 21 out of 26 panel members (81 percent).

We eliminated Performance Criterion (PC) 1.8 under Standard 1 (DD Council has staff and members who serve on community and agency boards and committees...). Although one panel member thought this PC "added depth" to the Council and another noted that it is "important to stay connected to other initiatives," we were persuaded by other comments that this PC could be too directive, especially for small Councils with few staff, and that conflict of interest could become a problem.

Wording changes were made to both standards and all remaining PCs, based on panel members' suggestions.

As suggested by one panel member, when a list of examples was provided, we noted that all items were not required and that others might be used. We also followed the suggestion of one panel member to be consistent in the formatting of examples.

B. Self-Advocacy and Leadership

This section had two standards. Standard 3 (DD Councils encourage and develop self-advocates and leaders among people with developmental disabilities [or their families] through education, training, and technical assistance) obtained agreement from 23 panel members. However, as suggested by a number of commenters, we took "or their families" out of parentheses and changed "or" to "and" to recognize the vital support played by family members. The PCs under Standard 3 received considerable agreement (19 for each one), but wording changes were made, particularly to the PC that called for active recruitment from the broad population of people with developmental disabilities. In our examples, we took out "all" types of developmental disabilities and added a few other examples that were suggested.

Standard 4 and the two PCs under the standard remain. We incorporated wording changes as recommended by panel members.

C. Community Capacity Development

The one standard (Standard 5) under Community Capacity Development was agreed upon by 13 panel members. The comments indicated agreement with the concept but concern with the language and examples that were provided. Thus, we changed the wording of the standard to "DD Councils

improve the capacity of communities to include and support community members with developmental disabilities," as suggested by one panel member. We provided different examples.

For the PCs under the re-worded Standard 5, we eliminated PC 5.2 (*Conducts or supports at least one community capacity development activity each year*) since only 11 thought this PC should be required to meet the standard. Three PCs that were intended to address the concept of evaluation of community capacity activities were combined. The result was one PC requiring that DD Councils document the outcomes of their efforts.

D. Systems Change

Despite the fact that two panel members had strong feelings about the approach of this section ("Systems change is not just advocacy and not just legislative related activities which this standard and criteria implies..." and "Standard 6 does not reflect our systems change mission – it focuses almost entirely on advocacy. They are NOT the same..."), 22 panel members agreed with Standard 6 on Systems Change. In addition, while we recognize that advocacy is not the only way to achieve systems change, we also noted in our program visits to 20 DD Councils as part of the National Independent Study of the ADD Programs that advocacy activities were a large part of what DD Councils do. Thus, we kept the basic concept of the standard and changed the section name to "Systems Change Through Advocacy."

Rating results were mixed on the PCs listed to meet this standard. Twenty-one (21) panel members thought DD Councils should *lead and participate in advocacy efforts that are expected to result in system changes that promote inclusion, choice, and better access to services* (PC 6.1). It was pointed out that this wording overlapped with the wording of the standard, however, so we used the wording of the PC to revise the wording of the standard. In addition, 20 panel members thought the use of a variety of strategies should be used (PC 6.2), and 24 agreed that collaboration should be used to achieve system change goals and objectives (PC 6.4). Again, we combined PCs that were intended to address the concept of evaluation of advocacy efforts into one PC, resulting in one PC that reads "Documents the outcomes and effects of its advocacy efforts."

E. Demonstration of New Approaches to Services and Supports

Standard 7 under Section D addresses the work that many Councils support on testing, promoting, and providing information on promising practices for the delivery of services. There was agreement on this standard by 19 panel members so it was not eliminated. Twenty-two (22) panel members thought that disseminating or promoting new or innovative practices would be one way to meet this standard (PC 7.1). Elimination or wording changes were made to the remainder of the PCs under Standard 7.

F. Governance and Management

The Governance and Management section contained two standards (Standard 8 and 9). Most panel members agreed with both standards. We changed the wording of Standard 9 to read "DD Councils are effective in fulfilling their governing responsibilities," as suggested by one panel member. Except

for PC 8.2 under Standard 8 (*Fills all vacancies on the DD Council within 1 year*) and PC 9.3 under Standard 9 (*Assigns a distinct role to every Council member*), we kept all PCs. Changes in wording and examples were made based on comments and suggestions of panel members. Two PCs were added under Standard 9 at the suggestion of panel members.

T2. Protection and Advocacy Systems

Dear P&A Panel Member:

Thank you for providing your ratings of the P&A Draft Standards and Performance Criteria – Version 1, as well as your comments and suggestions. Based on those ratings, comments, and suggestions, we have revised Version 1 and present you with Version 2 for further rating and comments. This package contains the following:

- P&A Rating Results – Version 1
- P&A Draft Standards and Performance Criteria – Version 2 (in tracking)
- P&A Draft Standards and Performance Criteria – Version 2 (no tracking)
- Rating form for Version 2
- P&A Panel member comments (no one is identified)
- Postage paid return envelope

Approach to making changes to Version 1

Twenty-one (21) individuals rated the P&A Draft Standards and Performance Criteria – Version 1.

For the standards,

- If 65 percent or more (14+) agreed with a standard, we kept the standard. [Note: We used 21 as the denominator in the calculation of percentages.]
- If 35 percent or more (7+) percent disagreed with a standard, we eliminated the standard.
- We received comments from all 21 panel members who provided ratings. We reviewed the comments to see if we could clarify or improve the wording for those standards that remained.
- In general, we tried to keep the same wording for those standards for which 14 or more people agreed that it should be a standard. However, in many cases, suggestions for re-wording were an improvement to the original standard. Thus, we followed a number of suggestions from panel members. On the other hand, if the number of panel members who agreed with a standard was particularly high (18 or more), we tried not to make major changes.

For the performance criteria,

- If 65 percent or more (14+) indicated that the performance criterion (PC) is required to meet the standard, we kept the performance criterion.
- If 35 percent or more (7+) indicated that the PC would exceed the standard or was not relevant, we eliminated it.
- We received comments from all 21 panel members who provided ratings. We reviewed the comments to see if we could clarify or improve the wording for those PCs that remained.
- In general, we tried to keep the same wording for those PCs for which 14 or more people agreed that it should be a standard. However, in many cases, panel member

suggestions for re-wording were an improvement to the original wording. Thus, we followed a number of suggestions from panel members. On the other hand, if the number of panel members who thought the performance criterion was required to meet the standard was particularly high (18 or more), we tried not to make major changes.

Summary of Comments

We received many helpful comments and suggestions. A brief summary of the ratings and comments for each section are contained in Appendix A below.

Return Ratings

If you complete the ratings electronically, we would appreciate it if you would email the completed ratings to bibigollapudi@westat.com **by June 22, 2011.**

To avoid emails becoming too cumbersome, please note that we are sending out separate emails for each panel and collaboration. The collaboration email contains a reimbursement form for you to complete if you are able to receive an honorarium. Hard copy versions are also being sent to you.

If you received assistance for Version 1 from a Westat staff member, we will call you to see whether you would like to receive assistance again.

If you have any questions, please feel free to contact me (1-800-937-8281, Ext. 5844 or lynnelinson@westat.com) or Bibi Gollapudi (1-800-937-8281, Ext. 7558 or bibigollapudi@westat.com).

Again, we would like to thank you for your assistance.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies

Attachments

Appendix A. Summary of Ratings and Comments

A. Planning and Priority Setting

The section on planning and priority setting consisted of one standard on the planning and priority setting process and one on the outcome (i.e., the result of the process – a Statement of Goals and Priorities that truly reflects the needs of people with developmental disabilities in the state or territory). More than 65 percent of panel members (i.e., 13 or more) agreed with both standards, although with certain caveats. Thus, for Standard 1 (*P&As identify the key issues, needs, and priorities of people with developmental disabilities and family members in the state or territory*) and Standard 2 (*P&A SGPs reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for P&A action*), we took out "and family members" to recognize that the person with a developmental disability is the P&A client and not the family member.

Performance criteria (PC) under Standard 1 address the need to ensure that P&As obtain a broad and comprehensive perspective. A number of panel members saw the examples as prescriptive or, alternatively, suggested additional examples. Since we think this document should be able to stand on its own as much as possible, we left in the examples. However, we inserted a footnote for all examples indicating that not all examples are required, and other examples could also be used.

We eliminated PC 1.8 (*Has staff and Board or Directors [or Commission] members who serve on community and agency boards and committees*). Although we saw this as a way to obtain ongoing input into the needs of people with developmental disabilities, we recognized the concern expressed by some panel members on the issue of conflict of interest, as well as time constraints and limited resources.

Although there was low agreement on PC 1.6, we re-worded this PC instead of eliminating it entirely. Our intent for PC 1.6 was to provide P&As with the opportunity to be more efficient and use the information obtained from other planning efforts in the state or territory if appropriate. Hopefully, this PC is now more clear.

Our intent for PC 2.4 (*Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with P&A resources, outside resources, and the potential impact of strategies that were considered*) had been to suggest that P&As look not only at the needs of people with developmental disabilities but also whether they have the resources to make something their own priority and whether other organizations in the community have also made it a priority. However, there are likely many more considerations to be made in SGP priority setting, so we eliminated this PC.

Finally, because a number of panel members indicated that the SGP needs to be flexible to account for emerging or emergency issues, we added a PC using the words suggested by one panel member – "Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statutes, regulations, or priorities."

B. Intake and Assistance

The one standard under Intake and Assistance was acceptable to most panel members (19 out of 21 or 90 percent). There was a question on the meaning of "equitable" which we tried to explain by adding "By equitable we mean that anyone contacting the P&A will be able to be served."

Two PCs were eliminated (PC 3.5 and PC 3.7). We agreed with commenters that these seemed to be overly prescriptive and should be left to the discretion of management. PC 3.9 (*Periodically applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process*) had agreement from only 9 panel members (40 percent), and 12 thought it exceeded the standard. However, having been told by a number of P&As we visited as part of the National Independent Study of the Developmental Disabilities Programs that feedback on satisfaction is typically sporadic and non-representative, we decided to try again in Version 2. Although we recognize the difficulty with limited resources, we think that every so often P&As need to obtain accurate, representative data on customer satisfaction because this would be an excellent way for a P&A to judge the outcome of its intake and assistance activities. Thus, we kept the general intent of the PC and re-worded it to indicate that the frequency does not need to be yearly, but instead can be every 3 to 5 years.

With certain word changes suggested by panel members, the remainder of the PCs was kept.

C. Individual Advocacy

There were three standards under Individual Advocacy. Standard 4 (*P&A caseload reflects the priorities set in the SGP*) received agreement from 16 panel members (80 percent). Eighteen (18) panel members agreed to Standard 5 (*P&A provides high quality representation*). Standard 6 (*Individual Advocacy meets client objectives*) was agreed to by 16 of the panel members.

There was high agreement with PC 4.1 and 4.2 under Standard 4. However, there was concern about the possible loss of flexibility in the case of emerging or emergency issues. Thus, we changed the wording to allow for such flexibility. Seven (7) panel members reported that PC 4.3 was not relevant to the standard so we eliminated it.

Panel members generally agreed that P&A individual advocacy staff should be provided with opportunities to discuss and review cases (PC 5.1) but thought that weekly provision of oversight (PC 5.2) was either too frequent, arbitrary, or should be a management decision. Thus, PC 5.2 was eliminated. PC 5.3 was reworded to indicate that a P&A should provide accessible resources to staff and encourage them to use them without prescribing which resources.

There was high agreement for most PCs under Standard 6 (*Individual advocacy meets client objectives*), with certain caveats. Therefore, most remain, with rewordings as suggested by panel members. PC 6.8 (*Documents success in resolving a majority of issues in favor of P&A clients*) was re-worded. The intent of this PC was to address the outcome of individual advocacy. We found in our study of 20 P&As that many P&As achieve much more than a 51 percent success rate. Thus, a requirement that all P&As at least meet the majority of objectives of its clients does not appear to be unreachable. Thus, PC 6.8 now indicates that P&As should resolve a majority of issues in favor of P&A clients.

We eliminated PC 6.9 (*P&As follow up clients to determine whether decisions made on behalf of a client are being followed and the client issue has truly been resolved*). Although we came across a number of P&As that implemented such a practice, we were convinced by panel members that not all P&As would have the resources to fulfill this criterion.

We reduced the number of PCs under Standard 7 on confidentiality from seven to four, and then added one more. PCs now indicate that all P&As should have a written confidentiality policy and procedures that cover onsite staff, staff working at home, students, volunteers, and contracted staff. Moreover, there needs to be structures in place to maintain confidentiality, adherence to policy and procedures needs to be demonstrated, and orientations need to review the confidentiality requirements.

The additional PC in Version 2, recommended by a panel member, relates to obtaining client feedback and satisfaction.

D. Systemic Advocacy

Although there was considerable agreement with the Systemic Advocacy Standard and PCs, we tried to clarify the language, based on panel members' suggestions, and reduce the number of PCs by combining a number that related to systemic advocacy outcomes. Thus, the standard starts with an outcome – *P&A's systemic advocacy improves access to State systems and community practice and reduces abuse and neglect*. The first PC now calls for the use of a variety of systemic advocacy strategies, none of them required. The second PC calls for documentation that illustrates that outcomes have been achieved within the past 5 years. We left in the time period of 5 years to indicate that P&As need to document at least one outcome every 5 years. The final PC has one wording change (we changed "monitoring" to "reviewing") and calls for P&As to make sure that any outcomes that have been achieved are being implemented appropriately and that the P&A is aware of any unintended consequences.

E. Outreach and Community Education

Although there was disagreement on the definition of outreach, there was agreement among 17 out of 21panel members that outreach should take place, that it should be conducted on an ongoing basis (all 21 agreed), and that it should target populations that are underrepresented or unserved (19 agreed). We revised Standard 9 to indicate that the outcome of such outreach activities is the identification of unserved and underserved populations. We see this outcome as different than the outcome of community education, so we did not combine Standard 9 and 10, as suggested by one panel member. Under Standard 9 we eliminated PC 9.8 (*Includes Board of Directors [or Commission] members in outreach activities*) and included it as an example with other strategies in PC 9.1.

The original intent of Standard 10 on community education was to focus on P&A activities targeted not only to people with developmental disabilities and family members, but also to those in the community who require a better understanding of the rights and value of people with developmental disabilities (e.g., employers, teachers, local government officials, health care providers). Although we saw some excellent examples of community education in our program visits to 20 P&As, we recognize that not all P&As have the resources to target such a wide audience. Thus, we have

changed the name of this section to "Outreach and Education" in Version 2 of the draft standards. In addition, the PCs address only the education activities targeting people with developmental disabilities and family members.

We also deleted PC 10.2 (*Makes communication education available to a broad population of people with developmental disabilities...)* since we think community education should be relevant to the priorities in the SGP and not necessarily to a broad population of people with developmental disabilities and PC 10.8 (*Documents that community education efforts led to improved access to services, choice, or inclusion for people with developmental disabilities within the past 5 years)*. Other PCs require measurement of recipient satisfaction (14 panel members agreed with this PC) and documentation of the achievement of outcomes on improved access to services and community participation.

F. Governance and Management

The two standards under this section (Standard 11 and 12) received agreement from most panel members. Thus, they were not changed.

Although some panel members were troubled by the potential infringement of management's role of some PCs under these standards, a large majority of panel members agreed with most of them. Those that received low agreement (e.g., PC 11.5 and 12.4) were eliminated. Others were re-worded, as suggested by panel members, to address some panel members' concerns.

We removed the requirement to fill Board of Directors (Commission) vacancies within 1 year and instead required a P&A to actively work toward filling vacancies in a timely manner and to document its efforts to do so (a suggestion from one panel member). We combined two PCs on the composition of the Board of Directors (Commission) and called for expertise in fiscal, policy, and legal issues, as well as members who are knowledgeable about the developmental disabilities population and issues.

Although there were some suggestions on changes to PC 11.4 (*Familiarizes all new Board of Directors [or Commission] members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A*), 20 out of 21 agreed with this PC. Thus, we left it alone. We also did not revise PC 11.6 (*Maintains a staff infrastructure with well-defined supervisory roles and responsibilities*) because of high agreement. Although 14 panel members agreed with PC 11.8 on independent audits, there was consistency on some of its problems, so we attempted to address those problems by revising the wording. The PC on audits now indicates that P&As need to receive an annual independent audit and immediately address any issues that are found. Since 17 out of 21 panel members agreed with PC 11.9 (*Budgets for professional development for staff*), we left that PC intact.

Under Standard 12, we eliminated PC 12.4 to fund at least one Board of Commission member's attendance at a developmental disabilities-related national meeting each year since only 6 panel members agreed with this PC and 12 thought it exceeded the standard. We made small wording changes to all other PCs under Standard 12, as suggested by panel members.

Finally, one panel member suggested adding a standard "the Board of Directors (or Commission) sets policy and long range goals for the P&A, and holds the Executive Director accountable for adhering to the policies and goals." We made that the first standard under Government and

Management, added a new PC ("Conducts an annual performance review of the Executive Director"), and moved a few PCs from other standards to this new standard.

Finally, since all but one PC under Standard 12 was moved, we eliminated Standard 12 and converted PC 12.1 on independence from the state to a standard since there was high agreement.

T3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

June 10, 2011

Dear UCEDD Panel Member:

Thank you for providing your ratings of the Draft Standards and Performance Criteria – Version 1, as well as your comments and suggestions. Based on those ratings, comments, and suggestions, we have revised Version 1 and present you with Version 2 for further rating and comments. This package contains the following:

- UCEDD Rating Results – Version 1
- UCEDD Draft Standards and Performance Criteria – Version 2 (in tracking)
- UCEDD Draft Standards and Performance Criteria – Version 2 (no tracking)
- Rating form for Version 2
- UCEDD Panel member comments (no one is identified)
- Postage paid return envelope

Approach to making changes to Version 1

Nineteen (19) individuals rated the UCEDD Draft Standards and Performance Criteria – Version 1.

For the standards,

- If 65 percent or more (12+) agreed with a standard, we tried to keep the standard or its general intent.*
- If 35 percent or more (7+) percent disagreed with a standard or there was low agreement (≤7), we eliminated the standard.
- We received comments on the draft standards from 16 panel members who provided ratings. We reviewed the comments to see if we could clarify or improve the wording for those standards that remained.
- In general, we tried to keep the same wording for those standards for which 12 or more people agreed that it should be a standard. However, in many cases, suggestions for rewording were an improvement to the original standard. Thus, we followed a number of suggestions from panel members. On the other hand, if the number of panel members who agreed with a standard was particularly high (17 or more), we tried not to make major changes.

*We used 19 as the denominator in the calculation of percentages.

For the performance criteria,

- If 65 percent or more (12+) indicated that the performance criterion (PC) is required to meet the standard, we tried to keep the PC or its general intent.
- If 35 percent or more (7+) indicated that the PC would exceed the standard or was not relevant, we eliminated it. We also eliminated those with low agreement (≤7).
- We received comments on PCs from 18 panel members who provided ratings. We reviewed the comments to see if we could clarify or improve the wording for those PCs that remained.
- In general, we tried to keep the same wording for those PCs for which 12 or more people agreed that it should be a standard. However, in many cases, panel member suggestions for re-wording were an improvement to the original wording. Thus, we followed a number of suggestions from panel members. On the other hand, if the number of panel members who thought the performance criterion was required to meet the standard was particularly high (17 or more), we tried not to make major changes.
- In a few cases, additional PCs were suggested. We added some of those to Version 2.

Summary of Comments

We received many helpful comments and suggestions. A brief summary of the ratings and comments for each section are contained in Appendix A.

Return Ratings

We would appreciate it if you would return your ratings for Version 2 in the enclosed postage paid envelope by **June 27, 2011**.

To avoid packages becoming too cumbersome, please note that we are sending out panel materials separately for each panel and collaboration. The collaboration package contains a reimbursement form for you to complete if you are able to receive an honorarium.

If you received assistance for Version 1 from a Westat staff member, we will call you to see whether you would like to receive assistance again.

If you have any questions, please feel free to contact me (1-800-937-8281, Ext. 5844 or lynnelinson@westat.com) or Bibi Gollapudi (1-800-937-8281, Ext. 7558 or bibigollapudi@westat.com).

Again, we would like to thank you for your assistance.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies
Attachments

Appendix A. Summary of Ratings and Comments

A. 5-year Planning

The section on 5-year planning consisted of one standard on the planning process and one on the outcome (i.e., the results of the process – a 5-year plan resulting from that process). More than 70 percent of panel members agreed with both standards. However, a number of panel members indicated in their comments that the planning section was too similar to what was required of State Developmental Disabilities Councils (DD Councils) instead of building on it. Thus, we went back to the wording of the DD Act. Standard 1 now reads "UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and the goals in the DD Council State Plan.

Standard 2 (*UCEDD 5-year plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for UCEDD action)* was changed to reflect that 5-year plans are a "guide" for UCEDD action (a term preferred by some panel members).

Performance criteria (PCs) under Standard 1 address the need to ensure that UCEDDs obtain a broad and comprehensive perspective. A number of panel members saw the examples as prescriptive or, alternatively, suggested additional examples. Since we think this document should be able to stand on its own as much as possible, we left in many examples throughout the document. However, we inserted a footnote for all examples indicating that not all examples are required, and other examples could also be used.

Under the first standard, we eliminated PC 1.7 (*Gathers data for planning on an ongoing basis throughout the planning cycle*) and PC 1.8 (*Has faculty and staff who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members*) because of low agreement. The remaining PCs were combined or reworded, consistent with some of the suggestions of panel members.

Under Standard 2, our intent for PC 2.4 (*Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with UCEDD resources, outside resources, and the potential impact of strategies that were considered*) had been to suggest that UCEDDs look not only at the needs of people with developmental disabilities but also whether they have the resources to address a particular issue and whether other organizations might be addressing it. However, there are likely many more considerations to be made in UCEDD priority setting, including having more than one UCEDD in a state (as pointed out by one panel member) so we eliminated this PC. Other PCs under Standard 2 were re-worded, based on panel members' suggestions.

B. Interdisciplinary Pre-Service Preparation and Continuing Education

Although there were many comments, ratings for standards under this function were relatively high. We tried to address many of the concerns of commenters, including the definition of "interdisciplinary approach" which was given to us by a UCEDD working group member during phase 1 of this study. We were unable to find any other definition, so instead, have taken it out and

followed many other suggestions of panel members. Standard 3 under Interdisciplinary Pre-Service Preparation and Continuing Education (*UCEDDs prepare students to implement an interdisciplinary approach to serving people with developmental disabilities and family* members) is now re-worded as "UCEDDs advance practice, scholarship, and policy that impacts the lives of people with developmental disabilities and their families." Standard 4 (*UCEDDs prepare students to reach a diverse population of people with developmental disabilities*) was reworded slightly to indicate that UCEDDs prepare students "to work on behalf of" a diverse population of people with developmental disabilities" instead of to "reach" them. For Standard 5, we added inservice training and technical assistance to better describe continuing education at UCEDDs.

Under Standard 3, we eliminated PC 3.5 (*Assists students in finding work, career or educational options that benefit the quality of life of people with developmental disabilities*). In program visits to 20 UCEDDs, as part of the National Independent Study of State Developmental Disabilities Programs, we found a number of UCEDDs that were doing this. However, we recognize that not all UCEDDs will have the resources. We also re-worded or added a number of PCs under Standard 3, based on panel member suggestions.

Under Standard 4, we combined PCs 4.3 (*Provides students with coursework that leads to an understanding of the daily lives of people with developmental disabilities and their families*) and PC 4.4 (*Provides pre-service and graduate students with opportunities to interact with people with developmental disabilities and family members*) and made word changes to the remaining PCs, as suggested by panel members.

We eliminated three PCs under Standard 5 on continuing education because of low ratings – PC 5.4: *Develops continuing education programs [including courses] that are adopted by other states or internationally;* PC 5.5: *Develops continuing education that becomes part of a state requirement of certification*; and PC 5.6: *Can document that participants in continuing education impact the developmental disabilities community.* The two remaining PCs capture panel members comments that continuing education is provided to professionals in the community, and content is based on needs that are documented in the 5-year plan.

C. Basic and Applied Research

There was strong agreement (17 out of 19 panel members or 89 percent) with Standard 6 on Basic and Applied Research (*UCEDD faculty and staff conduct research that is relevant to improvements in the lives of people with developmental disabilities or family members*). Agreement with Standard 7 (*UCEDD faculty members and staff are leaders in their field of research*) was borderline. Although we found a number of leaders in their field of research among many of the UCEDDs we visited, we ended up eliminating this standard and moved some of Standard 7's PCs under a slightly re-worded Standard 6. We eliminated PC 6.3 (*Can document that their research has had a direct impact on people with developmental disabilities in the past 5 years*), PC 7.3 (*Are members of a peer-reviewed journal's editorial board*), and PC 7.4 (*Participate on a grant review panel [either for the University or for an outside organization*]) due to low agreement that they should be used to meet the standard and high agreement that they exceeded the standard. Remaining PCs were mostly reworded based on panel members' suggestions.

D. Community Services

Although 16 out of 19 panel members agreed with Standard 8 on community services, we revised it to be more consistent with the wording of the DD Act. We eliminated two PCs under this standard because of low agreement – PC 8.3: *Implements community services that are endorsed or funded by state agencies*; and PC 8.4: *Can demonstrate that the community services provided or supported by the UCEDD for people with developmental disabilities and family members.* PC 8.5 (*Can demonstrate that the training, technical assistance or other community services it provides has resulted in increased and improved services for people with developmental disabilities and their families in the past 5 years*) received agreement from 12 out of 19 panel members. However, a number of commenters indicated the difficulty in operationalizing such a requirement. Therefore, we revised this PC to require reporting on community services targets.

The remaining PCs were added or re-worded, based on panel members' suggestions.

E. Dissemination

Standards 9 and 10 in Version 1 (UCEDD dissemination activities address the principles and purpose of the DD Act by reaching people with developmental disabilities and family members; and UCEDD dissemination activities bridge the gap between research and practice) had high agreement, although a number of panel members suggested switching the order, which we did.

Under Standard 9 in Version 1, all PCs had high ratings except for PC 9.8 (Makes its products, resources and materials available to UCEDDs, DD Councils, and P&As in other states and territories). We combined PC 9.8 with PC 9.7 (Makes its products, resources, and materials available to DD Network programs in its own state or territory) so the PC now reads "Makes its products, resources, and materials available to other DD Network programs." Other PCs under Standard 9 were combined or re-worded to be consistent with panel members' suggestions.

The PCs under Standard 10 in Version 1 (UCEDD dissemination activities bridge the gap between research and practice) either became examples, were re-worded slightly to conform with panel members' suggestions, or were eliminated due to low ratings. We eliminated PC 10.4 (Disseminates the work of other UCEDDs to providers and practitioners), PC 10.5 (Uses the national developmental disabilities organizations to disseminate to other UCEDDs, P&As, and DD Councils), and PC 10.8 (Makes materials, resources, and information on developmental disabilities available to the University community [e.g., publishes in the university newspaper, organizes and presents at a university-wide seminar]). Although the percentage of panel members who agreed with PC 10.7 (Disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers) was less than 65 percent, we kept it in since it is a requirement of the DD Act. However, we added in a phrase, suggested by a panel member, to indicate that UCEDDs also need to comply with their university guidelines on dissemination of information to policymakers.

F. Governance and Management

The two standards under Governance and Management relate to UCEDDs leveraging funding and maintenance and support of the CAC. Both received high enough ratings to remain, but commenters expressed a few caveats on both. We saw Standard 11 (UCEDDs leverage funding to support and maintain its programs) as a way to address the fact that funding from ADD is not meant to run the entire UCEDD program but instead, as noted by ADD, is considered to be seed money. Commenters appeared to agree, but reluctantly.

Only six panel members were in agreement with PC 11.1 (Leverages funds that amount to at least three times the amount of the ADD grant), and 11 thought it exceeded the standard. We took it out, but, in fact, findings from the National Independent Study revealed that all 19 UCEDDs that provided information on this issue would meet that standard and most far exceeded it. We replaced the PC with a process instead of an outcome criterion – "Documents the degree to which the UCEDD leverages ADD and university funds."

Standard 12 (UCEDDs maintain and support involvement from CACs) received agreement from 17 out of 19 panel members, although one panel member did not think it should be placed under Governance and Management. However, since many of the PCs that remained under this standard are management responsibilities, we left it there.

We eliminated PC 12.6 under Standard 12 (Supports its CAC for more than two meetings each year). The remainder are still included in Version 2, although some have been re-worded. Because of high ratings, PC 12.3 (Involves CAC members in the development and implementation of the 5-year plan) and 12.5 (Supports its CAC for a minimum of two meetings each year) remain exactly the same. We borrowed the wording from the DD Council draft standards to now say for what was PC 12.1 (Fills all vacancies on the CAC within 1 year) that a UCEDD needs to actively work to fill CAC vacancies in a timely manner and document efforts to do so. Instead of the wording in PC 12.2 (Continuously maintains CAC membership that includes people who are knowledgeable about the full range of the developmental disabilities population in the state or territory...), which received agreement from 14 panel members, the PC now says "Maintains a diverse CAC membership," as recommended by a UCEDD panel member. Although 17 UCEDD panel members agreed that UCEDDs should provide CAC members with any supports that are needed to ensure meaningful participation (PC 12.7), we took out the word "any" in Version 2.

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Appendix U. Draft Standards and Performance Criteria - Version 2

U1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

U2. PROTECTION AND ADVOCACY SYSTEMS

U3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

U4. COLLABORATION

U1. State Councils on Developmental Disabilities

A. Planning

Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory to lead meaningful and productive lives.

A Council that meets this standard:

1.1 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities in the state or territory.

- Examples of members of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

1.2 Collects input for the State Plan from a variety of sources.

- Examples of sources include DD Council staff, DD Council members, DD Network partners in the state or territory (i.e., P&A and UCEDD[s]), results from the previous 5-year plan, focus group results from other agency needs assessments, the public, State agency staff, participants in DD Council supported activities, and disability organizations and advocates*

  *Note: These are examples. Not all are required. Others may be used.

1.3 Collects input for the State Plan from the various geographic regions across the state or territory.

1.4 Uses a variety of methods for collecting input for the State Plan.

- Examples of methods include focus groups, surveys, social media outlets, serving on Boards and committees in the state or local community, the DD Council website, collection of formal testimony through DD Council organized summits, and the review and analysis of reports and studies.*

  *Note: These are examples. Not all are required. Others may be used.

1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include in person discussions, electronic surveys, written surveys, use of pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

1.6 Uses information from the planning efforts of other organizations in the State or territory to increase planning efficiency.

- Examples of other organizations may include P&A, UCEDD(s), developmental disabilities partners, disability specific state agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

1.7 Gathers input on needs on an ongoing basis.

Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and is a guide to DD Council action.

A State Plan that meets this standard:

2.1 Is consistent with the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

- Examples include self-determination, independence, productivity, integration, and inclusion in all facets of community life.*

  *Note: These are examples. Not all are required. Others may be used.

2.2 Is consistent with the input received from the planning process.

2.3 Drives activities that the DD Council conducts and supports.

2.4 Contains priorities that consider the needs of people with developmental disabilities and family members, DD Council resources, and what is already taking place in the state and local communities.

B. Self-Advocacy and Leadership

Standard 3: DD Councils develop self-advocates and leaders among people with developmental disabilities and family members through the support of activities that provide exposure, education, training, and technical assistance.

A Council that meets this standard:

3.1 Actively reaches out to people with developmental disabilities from the broad population of people with developmental disabilities in the state or territory to participate in education, training, and technical assistance activities.

- Examples of members of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups, and both men and women.*

  *Note: These are examples. Not all are required. Others may be used.

3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities to inform the effectiveness of Council self-advocacy and leadership activities.

- Examples of ways to seek feedback include surveys and interviews.*

  *Note: These are examples. Not all are required. Others may be used.

Standard 4: Participants in DD Council self-advocacy and leadership development activities exercise self-determination and provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.

A Council that meets this standard:

4.1 Can document that participants in self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.

- Examples of the use of such knowledge and skills include:*
  - Serving on the board of a disability-related organization (within the past 3 years),
  - Advocating policymakers to change or maintain services or access for people with developmental disabilities (within the past 3 years),
  - Participating in training other people with a developmental disability in self-advocacy and/or leadership (within the past 3 years),
  - Demonstrating the use of self-advocacy/leadership skills developed (within the past 3 years), and
  - Participating on a board of a generic community organization, such as a church or disability specific state agency.

  *Note: These are examples. Not all are required. Others may be used.

4.2 Supports and helps to grow at least one statewide organization led and staffed by people with developmental disabilities.

C. Community Capacity Development

Standard 5. DD Councils improve the capacity of communities to include and support community members with developmental disabilities.

- Examples of improving the capacity of communities include increasing community awareness, knowledge, skills, and abilities and improving the infrastructure for service delivery throughout the State or territory.*

  *Note: These are examples. Not all are required. Others may be used.

A Council that meets this standard:

5.1 Supports information, training, and technical assistance to people and organizations in the community at large.

5.2 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.

- Examples of target audiences include health care providers, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, daycare workers, social service providers, and employers.*

  *Note: These are examples. Not all are required. Others may be used.

5.3 Documents the outcomes of efforts.

D. Systems Change through Advocacy

Standard 6: DD Councils support, lead and participate in advocacy efforts that are expected to result in system changes that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life for people with developmental disabilities.

A Council that meets this standard:

6.1 Uses a variety of strategies to meet systems change objectives.

- Examples include provision of funding to support systems change efforts; writing position papers or other reports; obtaining press coverage; educating policy makers; giving public testimony; and promoting changes in law, policy, and practice).*

  *Note: These are examples. Not all are required. Others may be used.

6.2 In addition to partners and collaborators, includes both Council members and staff in implementing advocacy activities.

6.3 Makes sure policy makers personally know some Council members or staff.

6.4 Evaluates its advocacy efforts throughout the year, and makes adjustments as necessary.

6.5 Documents the outcome and effects of its advocacy efforts.

E. Demonstration of New Approaches to Services and Supports

Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members.

- Examples of how DD Councils do this include issuing requests for proposals, securing external funding to identify or test new or innovative practices, assisting community organizations in obtaining funding to identify or test promising practices, and partnering with other agencies or organizations in the state.*

  *Note: These are examples. Not all are required. Others may be used.

A Council that meets this standard:

7.1 Disseminates or promotes new or innovative practices demonstrated to be effective.

7.2 Documents that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.

- Examples of documentation include journal articles, newspaper and magazine articles, websites, and reports from state agencies and organizations.*

  *Note: These are examples. Not all are required. Others may be used.

F. Governance and Management

Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.

A Council that meets this standard:

8.1 Reflects the range of the population of people with developmental disabilities in the state or territory.

- Examples include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

8.2 Actively works to fill Council vacancies in a timely manner and documents efforts to do so.

8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.

8.4 Documents attendance in DD Council meeting minutes.

8.5 Has members who play an active role in meeting DD Council objectives.

- An active role includes membership or chairmanship of a sub-committee and participation in DD Council activities throughout the year.*

  *Note: These are examples. Not all are required. Others may be used.

8.6 Provides an orientation to new DD Council members.

- The orientation includes the principles and goals of the DD Act, background on the DD Council, DD Council goals and objectives, and the current State Plan.

- If necessary, the orientation should be provided in more than one format to meet Council member needs.

8.7 Mentors new DD Council members.

8.8 Provides supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.

8.9 Supports at least one DD Council member to attend a national meeting, conference, or training each year.

Standard 9. DD Councils are effective in fulfilling their governing responsibilities.

A Council that meets this standard:

9.1 Reviews the performance of the Executive Director each year.

9.2 Reviews itself every 3-5 years.

9.3 Trains and supports Council members on the core functions of their roles and responsibilities.

9.4 Uses a fair, transparent, and effective process to select competent and experienced grantees.

- Evidence of a fair, transparent and effective process includes adherence to procedures for selecting grantees; adherence to procedures for handling unsolicited proposals; the inclusion of outside expertise during the proposal review process, as necessary; and the selection of grantee projects that reflect the goals and priorities stipulated in the State Plan.*

  *Note: These are examples. Not all are required. Others may be used.

9.5 Maintains a system to manage grants and measure grantee results.

U2. Protection and Advocacy Systems

A. Planning and Priority Setting

Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities in the state or territory.

A P&A that meets this standard:

1.1 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities in the state or territory.

- Examples of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

1.2 Collects input for the Statement of Goals and Priorities (SGP) from a variety of sources.

- Examples of sources include people with developmental disabilities, family members, P&A staff, Board of Directors or Commission members, DD Network partners in the state or territory, data from P&A activities (e.g., intake and assistance, outreach and education), research and other reports that contain valid and reliably collected data, community gatherings, church affiliated events, and examples of first-hand accounts through state and territory disability organizations, advocates, and self-advocacy groups.*

  *Note: These are examples. Not all are required. Others may be used.

1.3 Collects input for the SGP from geographic regions across the state or territory.

1.4 Uses a variety of methods for collecting input for the SGP.

- Examples of methods include focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies.*

  *Note: These are examples. Not all are required. Others may be used.

1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

1.6 Uses information from the planning efforts of other organizations in the state or territory to increase planning efficiency.

- Examples of other organizations may include the DD Council, UCEDD(s), developmental disabilities partners, disability specific state agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

1.7 Gathers information on the needs of people with developmental disabilities on an ongoing basis.

Standard 2: P&A SGPs reflect the needs of people with developmental disabilities in the state or territory and is a guide to P&A action.

A P&A SGP that meets this standard:

2.1 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

- Examples of some of the goals and principles in the DD Act include self-determination, independence, productivity, integration, and inclusion in all facets of community life.*

  *Note: These are examples. Not all are required. Others may be used.

2.2 Reflects the input from the planning process.

2.3 Drives primary activities that the P&A conducts and supports.

2.4 Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statues, regulations, or priorities.

B. Intake and Assistance

Standard 3: The P&A intake process is equitable, efficient, and effective.

By equitable we mean that anyone contacting the P&A will be able to be served.

A P&A that meets this standard:

3.1 Maintains written intake procedures that include but are not limited to:

- Procedures for documenting client information in a computerized database, and
- Procedures for priority case selection.

3.2 Provides training on the intake procedures to new intake staff.

3.3 Monitors staff adherence to intake procedures periodically.

3.4 Directs callers and others who seek assistance from the P&A to the appropriate level of assistance.

- Examples of the different levels of assistance include referral, provision of information and resources, possible individual advocacy.*

  *Note: These are examples. Not all are required. Others may be used.

3.5 Applies a rigorous methodology to assess satisfaction with the P&A intake and assistance process every 3 to 5 years.

- Examples of such rigorous methodologies (i.e., those that achieve high response rate and obtain representative data) include a survey of every caller for a period of 2 weeks or a followup telephone call to a random selection of callers.*

  *Note: These are examples. Not all are required. Others may be used.

3.6 Provides intake staff with access to ongoing professional development.

C. Individual Advocacy

Standard 4: P&A casework reflects the priorities set in the SGP.

A P&A that meets this standard:

4.1 Maintains written procedures to guide the selection and processing of individual advocacy cases.

4.2 Selects individual advocacy cases that are consistent with but not limited to the goals and priorities in the SGP.

Standard 5: P&A provides high quality representation.

A P&A that meets this standard:

5.1 Provides staff with individualized ways to discuss and review cases.

5.2 Provides and encourages use of easily accessible resources.

Standard 6: Individual advocacy meets client objectives.

A P&A that meets this standard:

6.1 Ascertains accommodation and necessary support services at intake.

6.2 Commits resources to support all clients being served so that individual advocacy staff is able to communicate with any client whose case is taken.

- Examples include availability of a language line and/or interpreters, staff that speaks a language other than English, a policy for including a support person for clients with cognitive disabilities if needed.*

  *Note: These are examples. Not all are required. Others may be used.

6.3 Except in the case of an emergency or time-limited circumstances, provides and updates a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.\

6.4 Sends or gives clients a closing letter in simple language documenting actions taken, results, and notification that the case is closed.

6.5 Informs the following individuals about the grievance process in writing:

- Those who contact the P&A and whose case is turned down for individual advocacy, and

- Clients whose case is closed.

6.6 Resolves a majority of issues in favor of P&A clients.

6.7 Has a mechanism for gathering and assessing client feedback and satisfaction with P&A services.

Standard 7: P&A strictly adheres to confidentiality.

A P&A that meets this standard:

7.1 Has a written confidentiality policy -- covering onsite staff, staff working at home, students, volunteers, and contracted staff -- with well-delineated requirements.

- Examples of confidentiality requirements include checking with clients about whether phone messages can be left, turning off the computer at the end of the day, and storing files in a cabinet or drawer so they are not left in view of someone walking through the office.*

  *Note: These are examples. Not all are required. Others may be used.

7.2 Has structures in place to maintain confidentiality.

- Examples of structures include shredding capability, private offices, email encryption, locking file cabinets.*

  *Note: These are examples. Not all are required. Others may be used.

7.3 Requires demonstrable compliance with the P&As written confidentiality policies and procedures by anyone who is privy to client information.

7.4 Reviews confidentiality requirements in orientations to new staff, students, contracted staff, volunteers, and Board of Directors or Commissioners.

D. Systemic Advocacy

Standard 8: P&A systemic advocacy improves access to State systems and community practice and reduces abuse and neglect.

A P&A that meets this standard:

8.1 Uses a variety of strategies to meet systemic advocacy objectives.

- Examples of strategies to effect systems change include writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation, securing pro bono assistance in class action suits from legal firms, filing amicus briefs, monitoring residential facilities, monitoring existing databases, collaborating with developmental disabilities partners, and following up on identified patterns of abuse and neglect).*

  *Note: These are examples. Not all are required. Others may be used.

8.2 Provides documentation that illustrates outcomes within the past 5 years that are associated with its systemic advocacy efforts.

8.3 Conducts ongoing review to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.

E. Outreach and Education

Standard 9: P&As engage in effective outreach activities to identify unserved and underserved populations.

A P&A that meets this standard:

9.1 Conducts ongoing outreach activities.

- Examples of outreach activities include use of the P&A website, distribution of brochures, presentations at community events on the P&A and P&A services, and Board of Director (or Commissioner) networking.*

  *Note: These are examples. Not all are required. Others may be used.

9.2 Targets populations that are underrepresented or unserved.

9.3 Maintains a budget for outreach activities.

9.4 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.

9.5 Reports on measureable targets and outreach activities.

9.6 Periodically reviews outreach activities so that outreach plans and strategies can be revised as needed.

Standard 10: P&As have an impact on access to services and community participation for people with developmental disabilities through the provision of education training, and technical assistance.

A P&A that meets this standard:

10.1 Provides culturally appropriate and targeted education, training, and technical assistance activities to people with developmental disabilities and family members.

10.2 Maintains a budget for education, training, and technical assistance activities.

10.3 Measures recipient satisfaction with education activities.

F. Governance and Management

Standard 11: P&A Board of Directors or Commission sets policy and long range goals for the P&A and holds the Executive Director accountable for adhering to the policies and goals.

A P&A that meets this standard:

11.1 Conducts an annual performance review of the Executive Director.

11.2 Actively works to fill Board of Directors (Commission) vacancies in a timely manner and documents efforts to do so.

11.3 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues, and who are knowledgeable about the developmental disabilities population and issues.

11.4 Familiarizes all new Board of Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.

11.5 Provides supports needed to facilitate meaningful participation by Board of Directors (or Commission) members.

11.6 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available in accessible format for each member who requires them.

Standard 12: P&As maintain an infrastructure that enables them to conduct key functions efficiently and effectively.

A P&A that meets this standard:

12.1 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.

12.2 Conducts an annual performance review of all staff members.

12.3 Receives an independent audit each year, and immediately addresses qualified findings.

12.4 Budgets for professional development for staff.

Standard 13: P&A maintain operational independence from the Governor and the developmental disabilities service system of the state or territory.

U3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

A. 5-Year Planning

Standard 1: UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and the goals contained in the DD Council State Plan.

A UCEDD that meets this standard:

1.1 Collects input for the 5-Year Plan from a variety of sources.

- Examples of sources include people with developmental disabilities, family members, UCEDD faculty and staff, the Consumer Advisory Committee (CAC), students, DD Network partners in the state or territory, data from UCEDD activities (e.g., community services), research and other reports that contain valid and reliably collected data, state developmental disability agency and other policy makers, service providers, and state and territory disability organizations and advocates.*

  *Note: These are examples. Not all are required. Others may be used.

1.2 Obtains input for the 5-Year Plan that covers various geographic regions across the state or territory.

1.3 Uses a variety of methods for collecting input for the 5-year Plan.

- Examples include focus groups, surveys, social media outlets, the UCEDD website, serving on Boards and committees in the state or local community, and review and analysis of reports and studies.*

  *Note: These are examples. Not all are required. Others may be used.

1.4 Gathers input for the 5-year plan from or about a wide cross-section of the state or territory's disability population representing many different segments of the community.

1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

1.6 Uses information from the planning efforts of other organizations to increase planning efficiency.

- Examples of other organizations may include the DD Council, P&A, and other UCEDDs in the state, developmental disabilities partners, disability specific state agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

Standard 2: UCEDD 5-Year Plans are a guide for UCEDD action.

A 5-Year Plan that meets this standard:

2.1 Reflects the input from the planning process.

2.2 Reflects the goals and principles in the DD Act.

- Examples include self-determination, independence, productivity, integration, and inclusion in all facets of community life.*

  *Note: These are examples. Not all are required. Others may be used.

2.3 Guides the activities that the UCEDD conducts and supports, while including provisions for responding to emergency needs and opportunities.

B. Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3: UCEDDs advance practice, scholarship and policy that impacts the lives of people with developmental disabilities and their families.

A UCEDD that meets this standard:

3.1 May offer training that leads to the award of an academic degree, professional certificate, or advanced academic credential.

3.2 Advances the academic or professional credentials of trainees.

3.3 Offers developmental disabilities-related courses, clinical experiences, mentorings, or trainings based on content from a variety of disciplines.

3.4 Offers developmental disabilities-related courses, clinical experiences, mentoring, or trainings taught by faculty and staff from multiple disciplines.

3.5 Offers developmental disabilities-related courses, clinical experiences, mentoring, or trainings to students from multiple disciplines.

3.6 Teaches students about the conduct and interpretation of research.

3.7 Integrates UCEDD research findings into interdisciplinary pre-service preparation and continuing education activities.

3.8 Can document the percentage of graduates who are engaged in work related to people with developmental disabilities and their families 5 years after training.

3.9 Can document the percentage of graduates in leadership positions related to developmental disabilities.

3.10 Prepares students to apply an interdisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.

Standard 4: UCEDDs prepare students to work on behalf of a diverse population of people with developmental disabilities.

A UCEDD that meets this standard:

4.1 Enrolls students from culturally and linguistically diverse backgrounds.

4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities.

4.3 Provides students with experiences that lead to an understanding of the daily lives of people with developmental disabilities and their families.

- Examples include the provision of opportunities to interact with people with developmental disabilities and family members.*

*Note: These are examples. Not all are required. Others may be used.

Standard 5: UCEDDs improve the knowledge and skills of service providers and practitioners through continuing education, inservice training, and technical assistance.

A UCEDD that meets this standard:

5.1 Provides continuing education to a variety of professionals in the community.

5.2 Bases continuing education on documented needs in the state or territory, as identified in the 5-year plan.

C. Basic and Applied Research

Standard 6: UCEDD faculty and staff conduct research that is relevant to the lives of people with developmental disabilities and family members.

A UCEDD that meets this standard has research faculty and staff who:

6.1 Conduct basic or applied research, evaluation, or policy analysis relevant to the lives of people with developmental disabilities or family members.

6.2 Involve people with developmental disabilities in the development, design, or implementation of the research.

- Examples of involvement include identifying research topics, assisting with the design of data collection instruments, helping to ensure that research materials are in accessible and understandable formats, recruiting people with developmental disabilities and family members as study participants.*

  *Note: These are examples. Not all are required. Others may be used.

6.3 Publish research findings on developmental disabilities in peer-reviewed journals and other venues.

6.4 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.

D. Community Services

Standard 7: UCEDDs provide community services through training or technical assistance for people with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community.

And may provide services, supports, and assistance through demonstration and model activities.

A UCEDD that meets this standard:

7.1. Addresses topics that allow professionals to maintain professional credentials, expand their knowledge base, and stay up-to-date on new developments.

7.2 Provides community services that address issues across the range of the population of people with developmental disabilities in the state or territory.

- Examples include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

7.3 Provides continuing education training and technical assistance that promote the principles of the DD Act.

7.4 Integrates community services with training, research and/or dissemination functions.

7.5 Provides participants in continuing education activities with certificates of completion or continuing education units (CEUs).

7.6 Can document that recipients of training and technical assistance use the knowledge and skills they obtained from these activities.

E. Dissemination

Standard 8. UCEDD dissemination bridges the gap between research and practice.

A UCEDD that meets this standard:

8.1 Uses a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners.

- Examples include electronic, in-person, and print; mass mailings, YouTube videos, and seminar series; use of practitioner organization networks, listServs, contact lists to expand its dissemination range; and publication on developmental disability-related issues in professional newsletters and other publications for providers and practitioners.*

  *Note: These are examples. Not all are required. Others may be used.

8.2 Within university guidelines, disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.

Standard 9: UCEDD dissemination addresses the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.

A UCEDD that meets this standard:

9.1 Provides publications, materials and other resources in accessible formats.

9.2 Provides easily accessible training and technical assistance activities.

9.3 Seeks input on materials and resources from people with developmental disabilities and family members.

Evaluates dissemination activities and results on an ongoing basis.

- Examples include monitoring number of website hits, conducting targeted surveys, following up the use of materials.*

*Note: These are examples. Not all are required. Others may be used.

9.4 Makes its products, resources, and materials available to other DD Network programs.

F. Governance and Management

Standard 10: UCEDDs leverage ADD funding and in-kind resources to achieve the goals of the 5-year plan.

A UCEDD that meets this standard:

10.1 Documents the degree to which the UCEDD leverages ADD and university funds.

Standard 11: UCEDDs maintain and support involvement from CACs.

A UCEDD that meets this standard:

11.1 Actively works to fill CAC vacancies in a timely manner and documents efforts to do so.

11.2 Maintains a diverse CAC membership.

11.3 Involves CAC members in the development and implementation of the 5-year plan.

11.4 Supports its CAC for a minimum of two meetings each year.

11.5 Provides CAC members with supports that are needed to ensure meaningful participation.

U4. Collaboration

Standard 1: All DD Network programs in the state or territory achieve common goals through collaboration.

DD Network programs in a state or territory are the State Council on Developmental Disabilities (DD Council), the Protection and Advocacy (P&A) System, and one or more University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).

DD Network programs in a state or territory that meet this standard:

1.1 Identify and acknowledge a common goal or goals.

1.2 Identify roles, activities and tasks for each DD Network program supporting the common goal or goals that are identified.

1.3 Demonstrate a united perspective on key issues related to common goals.

1.4 Involve representatives from all three DD Network programs in collaborative meetings.

1.5 Document the outcomes of collaborative efforts.

Appendix V. Version 1 Comments

V1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

V2. PROTECTION AND ADVOCACY SYSTEMS

V3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

V4. COLLABORATION

Appendix V1. State Councils on Developmental Disabilities

State Councils on Developmental Disabilities (DD Councils)
Draft Standards and Performance Criteria – Version 1

Panel Member Comments

A. Planning

Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory.

Comment
Modify to say family members "of minor children" or you may be beholden to VOR.
I would consider all of the criteria identified below as important to collecting input and perspectives for the state plan and on-going planning. However, neither this standard, nor standard #2, reflect the analysis and prioritization of all the data and information, and subsequent development of Council initiatives to address the key issues, needs and priorities. The only focus is on data/information/ and input gathering.
I think that the second standard says this much better. We use the five year plan as a way to identify issues, needs and priorities but that in itself is not a standard - more about how the information is used.
How will this be measured? Is it pass fail? If so will not provide meaningful information. This is clearly required in state plan development so it seems a bit redundant. In general without knowing how these standards will be used (in the webinar it was saying will likely not replace PPR outcomes) it is very difficult to judge whether the standard is appropriate or not. In general these standards and methods are all very process oriented.
Should also state identify key issues for people with developmental disabilities and their families to lead full meaningful productive lives.
General: Either have examples of each standard or don't. Having some examples(standard 5, but no others) makes those standards appear more important. And the examples are really helpful, so I urge you to include examples for all standards.
We have found that the expectations people with DD and families are as important as 'needs'. You probably cannot add that term but when we analyzed public input, the frustration came from unmet expectations of how people are treated (dignity, respect)
Include 'needs of communities' in order to capture Councils' responsibility for capacity building. Examples: recreational institutions like YMCA; banking industry for home ownership opportunities; business & industry.

1.1 Collects input for the State Plan from internal and external sources.

Comment
Not sure DD Network partners are "internal."
I almost checked exceeds the standard, as exec. Guides the director to bring "mini workshops" as part of the DD Council meetings to help train and members to be aware of the tools, needs & training that is made available to consumers, training centers & staff. The reason I did not check it was because only a select few have the 'time' to attend additional workshops outside the DD Council meetings.
Throughout document either remove all e.g., 's or clearly indicate that program not required to do all.
The first two statements are fine. The example in the third statement is probelmatic. There is no way for the Council to establish the "reliability" of all of the data and reports we receive short of doing a methodology study on each item. This is not possible within given staffing and resources. WE can only vouch for our own processes of gathering/analyzing dat
Should also explicitly include local service providers, policy makers and legislative committees.

Comment
My concern is staff turnover who may not have a clear idea to give an accurate internal response.
We can solicit input but may not actually receive it. 'Solicit' vs. 'Collects'.
Delete reference to partners in policymaking or add other examples.
I object to the terms "internal and external sources." Org. boundaries are much more permeable. It implies a value i.e., the network is more important. I don't know that People who participate in Council projects are any more or less outside than the P&P. The state DD agency – a source of data that is essential to the planning process – is suggested to be an "outside" i.e., lessor source.
I like that there are examples of how the Council meets this standard. There should be examples for each performance measure, and the format should be the same: Examples of ….NOT e.g., (as in 1.5) Many people with see e.g., as i.e., There is no advantage in inconsistency here.
Add to the criterion "There is a process in place to gather facts and…" Add internal sources – results from the previous 5-year plan. External – focus group results from other agencies needs assessments.
This statement & examples are too narrow and don't represent sources for the state plan. Change to read 'collects broad input for the state plan'. Examples include: DD Council, DD Network & other disability organizations; individuals with developmental disabilities & family members; non-disability organizations and community members.
These criteria should include a requirement to obtain information from persons with disabilities and their families, friends etc. unless that is implied

1.2 Collects input for the State Plan from geographic regions across the state or territory.

Comment
We agree this important but while the Councils can attempt to gather input from geographic regions through focus groups, surveys, etc., some councils may not have the capacity to tabulate data on a regional basis. In addition, while we may solicit input, we cannot guarantee that we will receive the requested feedback.
Again, 'solicits' vs. 'collects'
This should say, "Collects input …from the various geographic regions across the state" to be clear that all regions need to be incluced.
Combine this std with 1.4 below.

1.3 Uses a variety of methods for collecting input for the State Plan (e.g., focus groups, surveys, social media outlets, the DD Council website, review and analysis of reports and studies).

Comment
At this particular time the website is only a minute part of collecting input. Our state is more rural and personal.
Remove e.g., or indicate not all required.
As long as the Council demonstrates that they do this, is it necessary to do this using a variety of methods?
Would be okay if clear that all of the above would not be required
As noted earlier, many of these items are strategies. This particular one is redundant to 1.1 and could be combined.
Should include the collection of formal testimony through DDC organized summits.
Make sure self advocates have accessibility and support they need to give real input.
Data collection must be in accessible formats and venues for people with ADD to participate meaningfully. Costs cannot be prohibitive for minimum allotment states. Travel freezes from DSA can affect some states.
Do not use the e.g., format. Instead say, "Examples of various methods include focus groups, surveys, social media outlets, Council website, review and analysis of reports and studies."
Other sources include Past 5Year plan results – ADD required; customer satisfaction results – ADD required; outcomes from council work; customer contacts; compliments and complaints file.
More efficient to combine with 1.5 below, looking at modes and methods together.

1.4 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

Comment
They should strive to achieve this. They may not be able to get all of the catagories.
Yes!
Same e.g., Comment, also "all disability types" too broad.
Use of the word "all" in the example creates an unrealistic expectation.
Word "all" makes this difficult to accomplish - would representative of different age groups, ages, living etc be a better way to state?
Unless ADD plans to provide additonal resources to Councils it is beyond council capacity to collect input from all disaiblyt types,age groups, living arrangements, ethnic and nationality groups. Again, we can conduct focus groups, hold hearings, solicit written input with no guarantee of feedback. Trying to get into all living arrangmeents (nursing homes, faiclities, individual homes, community facilities, foster care) and address all nationalities, all disabilities would require extensive financial and staff resources that do not exist.
Should include SES as a defined group variable.
What about families? Esp. of children. Use of the word 'all' is very problematic. Consider 'diverse'. It is extremely difficult to collect info/data from people w/ complex intellectual disabilities. Language barriers, once we pass Spanish complicate this. Costs?
Do not use the e.g., format.
'Age groups' means families must be mentioned for children. 'Nationality" – how do you know nationality? Clarify all disabilities types that compose a developmental disability which is a functional definition. I would delete Nationality. In [State], it would be Swedish, German, Norwegian, Finnish – not sure if it's the intent. Clarify as 'ethnic and racial' groups.
This should not stand alone - it is better combined with 1.2 above.
Councils should do everything possible to meet this standard but bear in mind that certain ethnic and minority groups may be difficult to reach due to cultural beliefs about disability.

1.5 Collects input for the State Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.

Comment
This is too prescriptive.
Again, if possible.
The idea of providing reasonable accommodations for individuals with disabilities and ensuring that language accommodations are provided and that surveys, etc. are culturally competent is something Councils need to be doing. What is reasonable is the question. Again there is a resource issue of potential translation into multiple languages. reaching cultures that are not interested in hearing from us, addressing transportation issues in rural areas as an accommodation, etc. Reasonable efforts within available resources should be part of 1.5.
Voice (telephone, chatrooms)
This should also be targeted for expert technical assistance from ADD - more than peer-to-peer assistance is needed.
I think this one and 1.3 could be combined
Be clear that it includes ADA accessibility
Delete "people facing geographic, language, or cultural barriers." Add "Has a process in place to accommodate a range of communication methods". Change wording to communicate the process of accommodation without specifying what the methods are.

Comment
Combine with 1.3 above.
This is vital to gaining accurate and valid feedback from persons with disabilities.

1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.

Comment
Need to clarify/take care on what we mean by leverages. This requires genuine ideals and good relationships. Other partners must act in good faith to succeed.
I feel the [State] Council does an excellent job of working with other agencies. These agencies know that the Council will work with them for our consumers and their families. The Council strives to have a good working relationship with these entities.
Although this would be optimal, often the "three sisters" are on different planning cycles making this difficult to impossible to do.
While working with the DD Network is important, it does not relate to collecting data about needs or planning
We understand the concept but feel this should be rewritten. It would be better to say coordinates or partners vs. "leverages". It is also unclear what is meant by planning "efficiency". This is redundant to 6.4 and with the 1.1 in the collaboration standard. DD Councils cannot do their work without collaboration and erffecitiveness vs. efficiency would seem the more appropriate objectives. Sometimes partnering actually decreases efficiency in terms of time spent planning and engaging and resources used but increases the effectiveness of the endeavor.
I am referring to the P&A & UCEDD only. For DD Network programs, does this mean P&A & UCEDD or state agencies? – needs to be clear.
This should be targeted for ADD techical assistance.
I feel this is captured in collaboration criteria
This is very hard to understand
While we attempt to work w/ADD network programs this is feasible. The P&A target pop is broader than that of councils. UCEDD may condition its participation on council funding
Could be mis-interpreted to mean Councils must develop their plan with other DD network programs. Consider changing language to "Using information from the planning efforts of other DD Network programs..." The different planning cycles make it difficult to coordinate plans.
Good god. Timeliness and goals do not consistently allow occurring – thus being mandatory as a measure is not reasonable.
The state DD agency should be explicitly included—required.
There should be two additional standards requiring planning with 1) disability specific state agencies, and 2) relevant generic agencies, such as housing, transportation, labor, education, and so on.
"Leverages" – "Coordinates"? ADD needs to synchronize planning cycles in order to increase efficiency. The P&A does not plan – they have a single page of priorities. Do not know what the term "Leverage" means. Are you asking that a Council verify that it has consulted with the other network programs?
Could you simplify the language...' Collaborates assessment & planning activities with DD Network, disability organizations and other community groups'
Councils need to be strongly encouraged to demonstrate this criterion

1.7 Gathers data for planning on an ongoing basis.

Comment
Define ongoing
This is always part of the 'plan' when the director and exec. Committee attends training, listening sessions, and sponsored events.
If you want to use this standard you will need further explanation of what this means.

Comment
This is vague; what data?
This best reflects the issue that Councils should be gathering data but not dictating how or what kind. Will be different based on states and issues.
In a revised form. What is meant by "ongoing." Annually, monthly, weekly? If it is for state plan updates and implies all of the data that are required in the new state plan template than this would be a resource issue for most councils. If it is simply collecting data on our activiites and making sure it is utilized effectively, then that is fine. We cnanot do our job without data collection. Many of these recommendations are "operational" in nature. More like apple pie. The emphasis should be on achieving outcomes and demonstrating how you got there, not on process.
Certainly to strive for...but requires significant staffing capacity. Also tends to dilute the sense of urgency and importance
There is no definition of "ongoing." If the plan is completed every 5 yrs, the data should be current. That would be adequate. The Council may look at data over a multiyear period to assess trends.
Reword "Has a process in place to receive review data to improve the planning process" Clarify – Does this refer to collecting voice of the customer data or does this refer to ongoing environmental scanning of reports, initiatives, media, etc.
This doesn't relate directly to the standard - it is too prescriptive. The schedule a council uses for gathering data shouldn't matter.

1.8 Has staff and DD Council members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.

Comment
Too prescriptive
We only have one staff person, the director. But individuals on the Council serve on community and agency boards.
Concern for conflict of interest on 'agency' or provider boards
Although i am sure this happens for many Council members, making it a requirement is unnecessary, particularly for families and people with disabilities who are already "volunteering" their time to participate in the many facets of the DD Council (e.g., Council meetings, committee meetings, proposal review, etc.
This is one of multiple strategies that could be utilized to gather information and data. While our Council does this, strategies should not be dictated. Every state is different in terms of what will work best and what their resources permit. Strategies should be reported on. I should make it clear that we would have no difficulty meeting the vast majority of these but the time and resource burden to provide this level of detail on process (again vs. outcomes) will be time mis-spent.
This would really add depth to the council and I think it rarely happens.
While this is extermely useful and desirable, one has to realize that our members, especially those with intellectual disabilities, can not spread themselves too thin with commitments or they will not be effective DDC members.
Important to stay connected to other initiatives
Council membership is not within control of council; gubernatorial appointments. Councils cannot require members to serve on boards and committees though certainly many do. We do not generally attempt to seat staff on boards since we are a funder. 'Serve on' vs. 'gather information from'
Depending on type of data, much can be collected electronically. Anecdotal data is often collected but in face-to-face meetings. One method vs. another shouldn't be predetermined.
This should include the word "dissemination" in the performance criteria, as in , "...agency boards and committees to complement information collection and dissemination about the needs..." And it would be nice to have a "further Comments" box for each standard in the planning section.

Comment
This seems like the standards is dictating behavior. Cautions – State ethics laws and conflict of interest policies may prevent staff from serving on certain boards. Be very careful that the Council members are not placed in positions that conflict with fiduciary responsibilities. It seems that the federally mandated state agency reps could be expected to serve as 'go betweens' for their plans and the Council plans.
This is already accomplished through earlier criteria and is too prescriptive - one way of many to accomplish the standard.

Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for DD Council action.

Comment
Again modify family members 'of minors'
All of the above criteria are important for Council State Plans.
Are we asking: Are the blueprints for council action in the State Plan consistent with the needs of people?
This best reflects the intent of the DD Act concerning the role of Councils and planning
The word blueprint is problematic. It implies that we have a step by step way in which to conduct activities and guide change. The state plan needs to be a guide to activity that is able to change based on changing circumstances within the state. The new state plan template is clearly not a blueprint. It is a guide to action. The first part of the standard is clearly relevant.
MUST ADD to this standard –> ". . . within available financial resources." All states, but especially minimum allotment states, must have boundaries on what can be done realistically with the small amount of funding provided to DDCs.
5 years is a long time. A great deal changes in 5 years. The plan must be amended and modified to respond to strategic issues during the 5 years. In fact, the concept of 5 year strategies plans the management ____ has been abandoned in favor of ongoing strategic thinking.
But this is two standards: one that is about reflecting needs and a separate one that is about serving as a blueprint. This should be broken down into two.
Indicator 2.2 below should be the standard. This statement is on the level of an indicator.

2.1 Reflects the internal and external input from the planning process.

Comment
State agencies and stake holders; as well as consumers are given opportunities to have input.
Seems covered in 1.1
Qualification: 'Reflect' is not subject to ready interpretation. 'Document' internal and external input is better verb
Again, I object to the designation of 'internal"/"external."
But I think this should be standard 2.2 and I've suggested further re-organization.

2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life).

Comment
I would balance this with the ideas of systems change, capacity building and advocacy as well as the outcomes expected in the DD Act: independence, productivity, inclusion and integration and self determination
A better term would be consistent with the goals and principles of the DD Act.
This reflection should be explicit.
Examples provided are pretty limiting - broaden the examples or delete them entirely.

Comment
Again what does 'reflect' mean? Goals and principles are evident on the face of the document
'Principles' too ill defined with multiple interpretations. "Choice" to work in a sheltered workshop violates our "inclusion" value. This as well as the importance of values varies among network as well as community partners, families, and PwDD.
But I think this should be standard 2.1
I would insert the outcomes of the federal law (independence, productivity, self determination, integration, and inclusion) rather than the list given above.
This should be the standard.

2.3 Drives all activities that the DD Council conducts and supports.

Comment
With flexibility to take on new and emerging issues.
Don't know of any other way to issue RFP's.
As noted in 2.1, there is a need for flexibility and to conduct activities based on changing priorities and new opportuniites. To say that all activities are driven by the state plan (unless the state plan is extremely broad) is to eliminate the opportunity to react to change. We have annual updates to the state plan which then reflect changing priorities. In addition, some states receive other funding (state funds, etc). that may be used to support activities consistent with the DD ACt but perhaps not in the state plan per se..
I'd like to see this rephrased: state plan should be the focus of all council activities
"all": We conduct certain activities as a staff, that are exploratory and may impact revisions to the plan
This should be in all caps!!!
Great standard. Interpretation of when policy/grant is within specific Plan goal can cause contention.
Once again, the DD council should have the capacity to respond to strategic issues as they arise during the 5 year period.
No, 'all' is not realistic or practical given opportunities that arise. 'drives activities' is okay. There are also disasters that cannot be anticipated.

2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with DD Council resources, outside resources, and the potential impact of strategies that were considered.

Comment
Again modify family members 'of minors'
This is totally umnclear. What is this meant to say amnd how might it be measured?
vague and difficult to define "balance"
This is very unclear. Balancing priorities with available resources is an operational/management issue. Goals are aspirtation. If you develop goals that are only realistic given resources, goals would be very limited. Objectives under the goals are where you determine what is doable based on current funding. It is unclear what is meant by "poptential impact of strategies being considered." Suggest rethinking this one.
Not sure "balance" is the best term perhaps "address" or "link."
Inclusion of this performance criteria is critical, however, is not adequate to address the point made above for standard 2.
"resources and known effectiveness, outside"
I think 2.2 covers this
Reword: Balance family vs. self advocates? Or both with resources? How would this 'balance' be assessed? What is the proper 'balance'? I believe this standard, while admirable, will create controversy
Hard to measure, evaluate.
Will need further interpretation.

Comment
Both individuals and their families, not just one or the other.
But I think this should be standard 2.4
It should be better clarified
Delete “outside resources….” I think you are asking about prioritization given Council resources. Please note: Out DD Division has 15,000 times more resources than the Council; Special Ed has 10,000 times more resources.

2.5 Additional comments, standards and criteria for planning

Comment
Each year when the Council is deciding which RFP’s we would want to issue, it is with the state plan before us at all times. Of course, we take into consideration what is still working for people with disabilities and their families from previous state plans. We take information from listening sessions that are in the state plan to help drive us.
Standard #1 should be eliminated and the focus should be on standard #2. Focus needs to be on how the state plan reflects the DD Acts intent of systems change, capacity building and advocacy as a route to accomplish the individual outcomes of independence (I would change to interdependence) productivity (I would change to economic self-sufficiency) inclusion and integration and self determination.
Planning needs to be all inclusive
These are very good. I believe it is important to find the right language for how Councils interact with network partners when developing their plans. There is a relationship around network collaborative activities but that is only a piece of the plan. Otherwise network partners should have no more influence on the Council's plan than any other source.
But I think this should be standard 2.3. Also, what does the phrase, "the potential impact of strategies that were considered" mean? Is ADD looking for a list of everything the Council thought of but rejected? Surely not.
Sometimes the Council can get in the way of this work and this _
Sample questions: “Was the state plan submitted on time? Was the state plan complete? Was the state plan approved by the Council and the DSA? Did the budget reflect the priorities? Perhaps ADD’s process for review of state plans can be reviewed? Timeliness is the primary problem experienced by Councils (waiting for ADD approval)

B. Self-Advocacy and Leadership

Standard 3: DD Councils encourage and develop self-advocates and leaders among people with developmental disabilities (or their families) through education, training, and technical assistance.

Comment
Council director has been instrumental in helping the self-advocates for change.
Do not give same weight to leadership development of individuals with disabilities and family members - more to PWD
The criteria for this standard do not adequately address the standard. The criteria only focus on recruitment of and input from self advocates. They do not address developing leaders or leadership skills of individuals with developmental disabilities and families. Note, the criteria for standard #3 also does not address this important element.
I suggest: DD councils develop and support people to be effective advocates and leaders through education, training ...
I believe this needs to be reworded to state DD Councils encourage and develop self-advocates AS leaders among people with developmental disabilities (remove or their families) . . . . By definition, families are not self advocates. This does not exclude Councils from supporting families to become leaders but not within a standard around self advocacy.
(or their families) change "or" to "and" If this is a standard – there needs to be clear benchmarks to measure this.
"Or" or "and their families"? The family is always the unit of intervention whenever minor children are concerned. Families remain a vital support across the life span
Consider adding 'support'.
(or their families) change to 'and their families'. Both individuals and families – not just the one or the other
Consideration of other local/statewide advocacy groups with similar work would be appropriate. [State] has eleven ARC units, a cross disability coalition, etc. unlike many other states, where ARCs provide direct services, not advocacy.
DD Councils should be sure to work with the state advocacy organizations to develop self advocates shouldn't do it without them
But the standard should say,"...(or their families) through exposure, educ ation, training, and technical assistance". For many people who might like to become more active advocates, there has never been an opportunity to for them to even observe.
Children are represented by families. Please acknowledge families. Change "or their families" to 'and their families".
The indicator could be clearer. please consider a change to: DD Councils support opportunities for leadership development among individuals with developmental disabilities and their family members

3.1 Actively recruits potential self-advocates and leaders from the broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

Comment
All disability types too broad
I would not use "all" in the example.
What are we recruiting for? It this suggests individuals for Council membership there will be an issue because Governor's appoint members and some Governor's want Council input and others do not.

Comment
We assume you mean recruiting for the activities listed in the standard. Again, requiring recruitment of all disability types, living arrangements and ethnicity/nationality groups via targeted vs. more broad activities beyond the resources of most Councils. In addition, there are some places that we cannot easily access (i.e., nursing homes). A general standard re broad recruitment, asking for what was done and then providing feedback on whether action was certificate is fair but requiring this type of effort is beyond the scope.
After living arrangements, SES levels
This need to be reworded to have more action… recruits self advocates to do what? To train other self advocates, to influence state policy?
? Council request from institutions, group homes and persons who own their own residence? All other characteristics are logical. I don't understand the "living arrangement."
Should read "Actively reaches out to or includes"
What is a "potential self advocate"? Everyone from this population is a potential self advocate. Why not say instead, "provides support and training for those people with DD and families who are interested in developing further their self advocacy skills"?
Delete "nationality". DD is a functional definition and not linked to categories to clarify if you mean a range of disabilities that constitute developmental disabilities rather than the broadest def. of disability. In this case gender should be mentioned since women are disproportionately represented in leadership classes. Some of us sponsor special cultural outreach and leadership programs – consider that.
consider change to read: "establishes or strengthens a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities" This is directly from the Act and a clearer indicator.
This should be an intentional ongoing activity to increase the number and diversity of self advocates across the state and the nation

3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities.

Comment
We have a diverse board with self advocates for change and self advocates having a good representation for the council, who have given us great backgrounds for their needs.
Why is this different from ANY council funded activities?
Would change to read "Seeks feedback from participants in DD Council SUPPORTED OR FUNDED self-advocacy and leadership activities.
This is covered under A.1.4
no sense and is captured in planning process
What is the definition of a 'self-advocacy and leadership' activity? Attendance at a Council meeting? Leadership training? Going to the legislatures? Are 'participants' only self advocates? We fund 'leadership' activities for the next generation of professionals. Two more issues: Council itself vs. grantees. The grantee if often responsible for this, e.g., w/Partners in Policymaking. As to the Council itself, we ask for a 'member survey' after each quarterly council meeting and provide assistance to fill it out at the members' request. Not clear what you mean here. Council funded activities or Council's own activities? Both?
Question: To inform what? Consider clarifying how this feedback is to be used. "to inform the effectiveness of Council efforts".
What about seeking feedback from self-advocates/individuals beyond DD Council initiatives? We did that for the ADD Envisioning the Possibilities Self Advocacy summit and emerged with some fantastic new partnerships

Comment
As mentioned earlier, I think the exmples for each performance criteria are very useful. I think there need to be two more performance criteria for Standard 3: The first is 3.3: Supports self advocates as they participate in meetings, hearings, etc. and the second additional performance criteria is 3.4: Encourages all state agencies to include people with DD on their agency advisory groups.
To what end? Needs clarification: 1. Do you mean customer satisfaction surveys? 2. Do you mean pre/post learning surveys? 4. Do you mean to track leadership activities?
This indicator as written relates to evaluation vs. self advocacy & leadership development. Pls consider this indicator: "support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders" (Directly from the DD Act)
This criterion should also include focus groups

Standard 4: Participants in DD Council self-advocacy and leadership development activities provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.

Comment
I believe SD self-advocates have the training and supports to speak to the issues that are important to them. In the 2010-2011 Leg. Session, many self advocacy came to give solid testimony in how budget cuts and issues affect the disability community.
Neither Standard #4 or #3 capture the development and growth in individuals exercising self-determination (i.e., control, choice and responsibility), only how to utilize the leadership and advocacy capacity developed.
This is very hard to measure, especially with the recommended performance criteria. It will take many years of follow up to get real data about how many people participate in a training (input) and how many actually use it to improve the lives of people with developmental disabilities other than there own life.
The Councils can track participation in advocacy activities by program participants. We have no control over and often no way to judge whether these activities are effective or whether the outcome was due to the advocacy of the individual in most cases. There are exceptions, where someone promotes a policy before a school board that is accepted. In many cases, not so clear cut and we are dependent on people reporting to us.
The second bullet on legislative advocacy is far too limiting to cover all direct advocacy efforts. Some DDCs do not do legislative advocacy but do have a full advocacy agenda with a variety of different policy makers, including State Executive staff, state agency leaders, service provider agency leadership, and leadership of statewide organization and provider associations, etc. where they have more success and better outcomes than legislative advocacy.
needs to be reworded the standard does not make sense almost is redundant
One may provide 'effective leadership' but fail for reasons beyond one's control to 'improve the lives of people w/DD'. How many people? How does one measure 'effective leadership'? Perhaps some wording such as 'Activities provide participants an opportunity to learn and demonstrate the skills associated with effective leadership…" "…issues identified in the State Plan as important to people with DD and their families"
But I don't think "effective" helps much here. This is a place where examples of "effective leadership" would make this standard clearer.
Lately with budget cuts – success is defined as not regressing and holding onto what is in place. In good times, it is easier to 'improve lives'. I would ask that you link this back to IPSII – the outcomes in the DD Act – greater independence, product, self determination, integrity, and inclusion
This is somehat judgemental and subjective. The first step in self advocacy is learning to represent yourself. For indicators in self advocacy I respectfully recommend the specific items mentioned in the DD Act.

4.1 Documents the self-advocacy and leadership development efforts of trainees to promote greater access to the community and improve the well-being of people with developmental disabilities.

Comment
Too prescriptive. Too detailed.
This seems natural; yes this should be the standard!
Is it realistic to say that either these bullets together define leadership? Does someone have to do all? What if they did 2 of 4? Or a different one?
This requires a level of data collection that may be difficult to collect, even during the past 3 years. If the Council contracts out for self-advocacy activity, they would need to require grantees to collect this information.
Again, this will require many years of longitudinal studies to get the data required to determine if people are doing what is expected. I would also question if these are the real outcomes we are trying to get at which is about systems change, not about "getting services for oneself"
May be difficult to document with reasonable cost
With caveat. As noted above, we can report numbers but we are dependent on indivudals providing us the information. In most cases it is easier to track within a 1 year period not a 3 year period. Participants are enthusiastic for a year in terms of reporting. Most continue their work after that but are less diligent about reporting to the council. We can survey, call, email, etc. but cannot control the folow of information from participants. Information therefore will be incomplete and not fully represent achievements of these individuals..
These are important activities but documenting these efforts is not important. Supporting these efforts is more important.
The term "supports" must be defined more broadly than providing funds - there are many different ways to support that do not necessarily mean transfer of funds.
Advocacy can be interpreted as lobbying
I think it should say “documents and supports…”
Level of policy/decision making included in Council’s Plan may/may not include a legislative effort. Could be a rule-making and early stages of development of policy. Expand this change strategy and the effort would capture wider efforts.
Consider re-writes.
“Serving on the board of a disability organization”: why limit to disability boards? Why not generic boards or groups? Why limit to state legislation? Include local, state, and federal government. I think the promotion of greater access and improved well being is way beyond the control of some trainees. Where is the responsibility of the larger systems compared to a group of self advocates? Is acquisition of a service the end result? Be careful in advocating for more services

4.2 Supports a statewide organization led by people with developmental disabilities.

Comment
Define “support”. Give option or use broad definitions. Broaden “a statewide…” to include coalitions, networks, SA-led initiatives. Don’t tie down to a simple “support a SA …” This leads to unintended consequences.
I think this can become burdensome for both and it is hard to provide funding without exerting control, and then it is no longer led by the people with developmental disabilities.
More clarification around what is meant by Supports is needed.
To push it a little we could say … organization led by and staffed by people with DD.
This standard should grow out of individual state plans and not be a requirement a priori. It directly impacts funds if we set this standard.

Comment
The term "supports" must be defined more broadly than providing funds - there are many different ways to support that do not necessarily mean transfer of funds.
financially support a statewide self advocacy organization to train and educate people with developmental disabilities
Define support. Does support = fund? What does support mean? We, e.g., afford our Association of Self-Advocates with space, admin. Support, and pay the salary of the ED.
At least one?
I think this can be done in many ways and the focus on a single statewide organization rather than a variety of methods/strategies limits efficacy/encourages divisiveness (e.g., People First vs. Autism Society; self advocates vs. other groups
Nice wide interpretation of "support" makes this workable.
This should include people with all types of disabilities, not just DD
I think "support" is too narrow. And it just means "fund forever" often. I would like to see, "supports and help to grow".
There are multiple self advocacy groups in states. Why limit to only one statewide group?

4.3 Additional comments, standards, criteria for self advocacy and leadership

Comment
The Council is supportive and inclusive to self-advocates and their supportive families. I feel this is strength to the people who need to have their own voice. I believe this should be a natural overflow, or by product, as it were, resulting in listening to self-advocates and their families, that the Council would be supportive.
Although I fully support the efforts ADD is taking around self-advocacy, I feel that the responsibility to promote leadership among parents (and perhaps even siblings) is waning. Self-advocacy should NOT be promoted to the exclusion of oter critical leadership.
This standard and performance criteria needs to be better defined around outcomes and not inputs - training is an input that does not really tell us if we are accomplishing systems change. We will need to think about collection of data other than straight data collection to really understand the outcomes of self advocacy activities including the use of story telling and collaborative inquiry.
An artificial delineation was used to separate standards #3 & 4 - they actually should be combined and the 4 performacne standards shuld be combined under the single standard. Furthermore, using the parens for –> (or their family members) would definitely be seen as a slight by our DDC Members - they would not want to be referred to as an add-on, fail to have their importance recognized, or be excluded. Completely missing from these standards are the importance of family advocacy, network development (including getting self-advocates involved in borader advocacy efforts), and assistance and support for priorities idnetified by self-advocates. I am distressed to see that our family members have been given so little regard - they also are advocates and deserve more consideration in these standards for the extensive time that they devote. Our membership and our advocacy work are more than self-advocates and self-advocacy. There needs to be both recognition and balance. Consider renaming this section to Advocacy and Leadership and then having two standards one that focuses on our advocacy work and one focusing on our support of self-advocacy.
Collaborates with other network partners and the state DD agency to support a state wide self-advocacy org and to involve the state-wide self-advocacy organization, in their organizational activities: advisory group, workgroups, etc. Provide training and coaching for advisors of self-advocacy org.
The federal law section about self advocacy has been difficult to implement because some people have read it to mean pass through money to only one group. State law requires competitive bidding. I would ask that you review this section carefully against what the law says.

Comment
Add the following as an indicator: supports and expands participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions

C. Community Capacity Development

Standard 5. DD Councils improve community capacity through greater access, service delivery, choice and inclusion.

Comment
I believe the council should work with other stake holders, agencies and support providers to help improve community capacity.
This standard and criteria below appear to focus on building the capacity of the broader (non-disability) community to support and include individuals with developmental disabilities. While this is an important aspect of capacity building, what is missing is building the capacity of the developmental disabilities providers to support individuals with developmental disabilities in inclusive communities.
I like a standard on “community capacity” building but this wording is vague and confusing. Are we saying “DD councils improve the capacity of communities to include and support members with DD?”
Lots of questions about how this standard gets at the idea of community capacity. First, it is too focused on the "service system" and not the community and all that it offers for people with disabilities. Access, service delivery, choice and inclusion are bad words and then "transition housing" accomodations in the workplace is not about what Councils are doing or should be doing. How are we defining choice and inclusion - is it okay if there is a choice of segregated housing? Isn't this more about DD Councils improve community capacity by creating places that welcome everyone and utilize each person's gifts and talents. This can be through community resources and the publicly funded system.
Very broad standard - could mean almost anything
We promote and support expansion of community capacity through policy change, education, occasionally grant programs, etc. We don't directly improve community capacity. It is other agencies, the legislature, etc. that does this.
The concept is acceptable; the language is not. The standard needs to be re-written to cover "acess to, availability of, and delivery of services, supports and other assistance."
I think this is a very hard standard to fulfill in many states with many rural areas
These are not good examples! Add “funding or advocating for policies and practices that” to “DD Councils improve community capacity through…” “build community capacity seems more objective than ‘improve’. Councils do not provide direct services. The examples tend to suggest that. Councils advance policies or practices that build community capacity
This is generally ok but 'service delivery' needs to be clear that it is referring to the delivery system, not the Council. Consider dropping the term.
Examples are pretty limited—doesn’t talk about relationships/choices for participation, sense of welcome, improved quality of support.
The goal is unrealistic. These areas of capacity can only be impacted through other public agencies—housing authorities, VR, DD agency, education, etc.
While I like having examples of the standards, I don't know what "affordable, transitional housing" is. Why not just say, "affordable housing"?
“Service delivery”: this is system not the ‘community’. ‘adaptive technology’: Do you mean assistive technology? The DD Act does not make us responsible for providing reasonable accommodations within the work area. There is no requirement in the DD Act about community capacity – there is a permissive section entitled ‘supporting and educating communities”.

Comment
I disagree with use of the term 'community capacity'. This term is not in the DD Act. 'Capacity building' is the term used in the DD Act. Capacity building is not defined in the Act, but in general can be applied to public and private organizations and to communities at large - though I would expect even then that capacity building would be aimed at an organization. The examples are too specific. What a Council provides depends on the needs of the organization that the Council is trying to help. A Council should be asked to give examples of who/what organization they assisted by building the organization's capacity and how they accomplished this. An option: DD Councils increase capacity of public or private organizations so that they are more accessible to individuals with developmental disabilities and increase the individuals' independence, productivity and inclusion in the community.

5.1 Provides information, training, and technical assistance to people and organizations in the community at large.

Comment
"Community at large". We changed policy at the State level to increase access to housing stock. Not sure if this is 'information' to orgs. In the 'community at large'. We advocated for that change, offering information to policymakers.
This is important, and I think it should speak to the Council doing this alone as well as with existing community organizations. This would help make the Councils more part of the fabric of the community rather than being seen as a separate entity.
This is reasonable and achievable.
Restate: Provides information, training and technical assistance to people and organizations in order to increase their capacity to support individuals with developmental disabilities.

5.2 Conducts or supports at least one community capacity development activity each year.

Comment
Again, more clarity is required here.
I don't think we should mandate activities in this process.
Did not know that we were required to do anything except fund self advocacy. May want to include this same performance criteria in each of the programmatic sections. You will also need to define community capacity development activity
Too specific and directive
DDCs have state plans to guide their activities and their frequency and duration. Unless an annual activity is included in the DD Act, it shuold ne be included as performance criteria.
I don't like the idea that it required for each year.
can be done in 5.3
'Capacity building' is not defined in the Act. It may be a subset of systems change or a step towards it. For this reason, it should not be mandated. Invites 'hair splitting' w/o a definition to work against.
Delete 'community capacity development' with generic organizations to include people with DD in community activities. The community is not broken according to John McKnight. This reads like a 'systems' viewpoint.
This is arbitrary and risks setting a low standard for Councils to achieve. Please delete this as an indicator.

5.3 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.

Comment
Too detailed. 5.2 is sufficient. Flexibility/broad mandate is better here.
Interesting concept. Not sure it should be the standard for rural states. The council always has a presence at conventions and seminars that are held for the above, i.e., a booth giving out materials and answering questions. But target? Interesting food for thought.
Remove 'and' replace with 'or'. Same concern about e.g.s
How is this different from 5.2?
There needs to be discussion that increasing capacity around the community at large may not focus on the publicly funded system.
This is a strategy. Strategies must vary by need, program, project, priority. This is why we exist. It is both overly simplistic and overly detailed. It is rare that the "community at large" increase community capacity. It is policymakers, decision makers, etc., not building managers, teachers, and daycare workers that develop community capacity.
I think these activities are appropriate BUT not required for all Council
Change 'in the community at large' to 'those policies, practices that can…" Again target may be policies 'on the books' that delimit capacity. Not clear that 'community at large' contemplates this.
Please do not give lists like this. This is way beyond the DD Act. Encourage councils to fund activities that enable people with DD to be part of the community (Present and participating)
The indicator is ok but the examples are too specific, too limiting. We should state that Councils assist a variety of types of organizations to become more accessible for individuals with developmental disabilities.
Additional examples that should be included in this criteria are social service providers and employees

5.4 Keeps track of participants in community capacity development activities, and uses the data for planning and evaluation.

Comment
Many councils have little if any staff. This criteria can only work if sufficient staffing.
I am not sure what this will tell us over and above 5.5
We are unclear as to what this means. Who are participants in community capacity development activities and how are councils to track them. We can track participants in programs/projects we fund. We have to do this anyway as part of our reporting activities. Keeping track of participants is not relevant to the standard of improving community capacity. IT is relevant for planning which is a different standard.
This is a huge effort in terms of data collection and therefore staffing and funding. Is this talking about participants in DDC funded activities or a general population?
Be sure this means that our grantees and contractors can be the trackers of participants - not necessarily the DDC itself. Otherwise, this would be an incredibly burden for DDCs with extensive capacity building agendas.
I don't think this should be specifically required BUT can be documented.
Give examples—are there straightforward ways to collect this data? Is it feasible for Councils to do this?
I think data is critical, but this standard is vague. What does "keep track of" mean? What data is to be collected? This performance measure would be better stated as "records number of participants in community capacity development activites." I don't think more needs to be said.
This is way beyond the capacity and resources of Councils
Keeping track of participants in activities doesn't seem to be a meaningful indicator, and it is not clear how this informs planning & evaluation, or for what.
Question: Keep track of participants, how?

5.5 Documents the success of efforts.

Comment
The standard is to improve community capacity. Documenting the success of efforts does not improve community capacity. This is what we do in our Program Performance Report. We cannot get funded without documenting our efforts, both successes and failures. We also do this through our comprehensive assessment. This is so broad as to not have any meaning.
Within council funded activities
I think this AGAIN can be documented as performance BUT not required every year.
Outcomes vs. success – I prefer the former. 'success' is rather subjective
And some example of what "success" might be would be helpful here.
"a process in place to document results", without dictating the tracking system
This statement could be deleted - the next indicator (5.6) is more substantive and presumably would be documented.
Question: document success, how?

5.6 Demonstrates impact on increasing and improving services, choice, and inclusion for people with developmental disabilities within the past 5 years.

Comment
I don't understand how this would/could be measured. It may be possible in some projects but not others.
I think the focus here should be on demonstrating whether or not a community better understands, supports and includes its members with DD.
We report annually in our PPR on the impact of increasing and improving services and for the 5 year state plan this is th en tabulated fore the 5 year period. If this is meant to reuqire a 5 year evaluation beyond the comprehensive assessment, this will be a resource issue. If we knew the purpose of the standards, i.e., this replaces the PPR, it would be easier to judge whether a standard was relevant and appropritate.
Part of Standard A
services AND supports (and other assistance)
Same feeling as before. Can be used if relevant in the Council's Plan!
Can't prove causal connection
Often difficult to determine whether such changes in services are correlated to council efforts or caused by these. Councils' are catalysts for change. E.g. technical assistance, information, policy analysis may spark a series of events that results in change
Again, examples would be great here.
This isn't the role of the Council.
Replace "services…inclusion" with IPSII. Align to the federal law.

5.7 Additional comments, standards and criteria for community capacity development

Comment
The use of the word "service" is a problem here. First, are we talking about DD services and supports or other generic, community based services? Data seems to suggest that even when a person gets all the supports and services they need does not mean they are more involved or included in the community.
Too much emphasis on improving the "publicly funded system of services" which we might not be able to impact and might be relied upon too much. Not sure about some of the definitions that will make it difficult to report on. I also wonder about how [State]'s Real Communities Initiative would be measured against these criteria. It is an effort to create community capacity but not through choice or the "system" but by bringing communities together. Would not fit within most of this.
DDCs are directed to do capacity building - not specifically Community Capacity Development. The entire focus of Standard 5 needs to reflect that point and the terminology changed. We should be buidling capacity in all aspects of the service delivery and community systems - not limiting it to a single aspect.
This standard's focus is services. Small allocations to Councils are unlikely to result in dramatic shifts in numbers served, included

Comment
I think this sections suffers from a lack of mention of collaboration. Councils cannot do this work on their own, and in fact, should not. Community capacity building should result from a partnership of many pllayers, among whom the Council plays a vital role. Also, such efforts take a lot of time, so measure outputs here might be more relevant to ADD's purpse that only looking at outcomes.
The DD Act section dealing with community is permissive not mandatory.
Please rethink this standard and indicators. Capacity building is central to Council work. The term 'community capacity' is not synonymous with capacity building, the term used in the DD Act. The standards should not change terminology used in the DD Act.
Councils should also focus on increasing their own capacity to provide PWD access to assistive technology that facilitate and enhance participation in Council activities. If the council cannot do this, there needs to engage community resources to provide assistance. The standard should also include a continuous improvement clause or statement

D. Systems Change

Standard 6: DD Councils use advocacy strategies to change systems to promote inclusion, choice, and better access to services for people with developmental disabilities and family members.

Comment
Systems change is not just advocacy and not just legislative related activities which this standard and criteria implies. As noted in my initial Comments, there are several elements to accomplishing system change including identification of barriers, building coalitions (and not just for the purposes of advocacy), etc.. The Route to Success model (which is only one model for thinking about and creating system change) was based on multi year retrospective examination of the activities/strategies that resulted in system change which included improving knowledge base, selecting social strategies, creating stakeholder will, etc.
Agree with the idea of systems change but need to define it. Also need to figure out how we tie together the ideas of community capacity and advocacy for the purpose of creating systems change
However, why is it just limited to advocacy strategies. And should the standard be on the types of "strategies" we are using or on the outcome of effecting systems change. Again, the focus is on process vs. outcome.
Standard 6 does not reflect our systems change mission - it focuses almost entirely on advocacy. They are NOT the same. This standard and all the performance criteria needs to be re-worked to make that distinction. Advocacy and systems change aer two spearate and distinct functions which sometime (maybe frequently) are needed to work "hand in glove" to achieve a desired end.
There is no definition of systems change in the DD Act. Use DD Act's Independence, Productivity, Integration, Inclusion, self-determination language vs. 'inclusion, choice…" by the way, some interpret 'choice' to mean the 'choice' to live in an institution or other ICF-MR setting even when HCBS is available.
We have no definition of 'system change' – open to accusations of 'doing nothing' without measure to definition and communication thereof.
I think this is THE CRITICAL WORK that Councils do.
Align to DD Act. Promote IPSII. The outcomes in the federal law. Do we want more services? The commissioner is preaching for inclusion, not more services.
Advocacy strategies are not the only strategies used to change systems. This standard seeks to define systems change too narrowly. Inclusion, choice and access are not the only outcomes that Councils promote. This list is too narrow. What about practices and policies that are yet to be discovered in our field? Suggested rewording: DD Councils use systems change strategies to promote improved policies and practices for individuals with developmental disabilities and family members.

6.1 Leads and participates in advocacy efforts that are expected to result in system changes that promote inclusion, choice, and better access to services for people with developmental disabilities.

Comment
Believe the council should be supportive to people and stakeholders and agencies that promote the above.
Again, difficult to measure.
6.1 is redundant with the standard itself.
Standard 6 does not reflect our systems change mission - it focuses almost entirely on advocacy. They are NOT the same. This standard and all the performance criteria needs to be re-worked to make that distinction. Advocacy and systems change aer two spearate and distinct functions which sometime (maybe frequently) are needed to work "hand in glove" to achieve a desired end.
Do you mean the Council itself and its grantees? I would use 'promotes' vs. 'leads and participates' in. IPIIS language
Give examples
This performance measure should be 6.2. The first measure should be: "Adopts and uses a system change model or framework that informs all Council activites in this area." Many models are available, and Councils should use one of them to guide the system change work they undertake, resulting in more connectedness and less disparate funding.
Align to the federal act outcomes - IPSII
Reword: "Leads and participates in systems changes that result in....." Delete reference to advocacy efforts. Confusing, too narrow, not clear enough.

6.2 Uses a variety of strategies to meet systems change objectives (e.g., providing funding to support systems change efforts, writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation).

Comment
Too detailed. Maybe that one or two solid strategies accomplish the goal.
I believe the council should be supportive of people who give public testimony and who draft legislation. Not sure that it's the council's job to do so.
This would need to be measured by grantees - a reporting format would be helpful. Look at the one developed by HSRI in collaboration with the PA Council.
Feel that drafting legislation may be beyond the scope.
Process and strategy. We already report on state plan and PPR what strategies we are using for each activity. with the standard focus on using "advocacy strategies" this is again redundant with the strategy. It just lists what t hose strategies might be.
The concept is fine for s systems change standard but the examples are largely advocacy so they need to be reworked.
Don't use 'drafting' legislation; better 'promoting changes in law, policy, and practice' i.e., something broader than 'drafting'
Good examples.
Please add community organizing and coalition building as secondary, less direct, effective strategies.-
The goal is very directly linked to E. Demonstrate New Approaches to Services.
Again, use "examples include" and lose the e.g.
Why not use the list of strategies in the federal law? Emphasizing compliance with the DD Act strategies instead of an incomplete list.
Drafting legislation may be beyond the scope of Council's activities. However, it can certainly Advise on the content and language of the legislation

6.3 Includes both Council members and staff in implementing advocacy activities.

Comment
How would this be measured?
This is a governance issue
Not sure how this is relevant to the standard, in terms of who is used to implement a strategy as long as it works.
Pretty prescriptive – probably will be fulfilled anyway.
There are costs associated with involving members in activities – these may be prohibitive. Some activity in which staff engage (e.g., policy analysis) may be more difficult ones in which to 'include' members
Critical
This is important, but there should be an additional standard here: "Recruits interested others to be involved in advocacy activites." There is no advantage to limiting this to Council staff and members.
Council members govern, set direction. They do not implement. In addition to the staff, note grantees, consultants, contractors, self advocates, trainees and volunteers
This indicator is too narrow. If we believe it is necessary to name who will be involved in Council systems change activities, we should emphasize broad, diverse participation, including Council members and staff, DD Network, other advocacy groups and non- disability groups or individuals.
It seems to me that if the Council is charged with using a variety of strategies to bring about systems change then it stands to reason that a wide range of people would be involved including the Council and staff. Doesn't need to be stated.

6.4 Collaborates strategically to achieve systems change goals and objectives.

Comment
Should be working with IL in their state.
Collaboration is key to success. Not sure how you evaluate "strategic collaboration." That will be in the eye of the beholder.
'Strategically'? How to assess?
This puts a lot of pressure on staff is Council members can't/don't do this. It's a worthy goal but may be drilling down too specifically into what a Council can do of all partners aren't engaged.
Agree with modification, otherwise it's not relevant. By system and _____ we mean the public service system. The goal should more specifically name DD agencies, ED, VR, etc as the targets for collaboration.
Another place where having examples is very helpful. Examples also help various reviewrs maintain an inter-rater consistency.

6.5 Makes sure State legislators and other policy makers personally know Council members and staff.

Comment
Laudable, but again, too prescriptive.
At least the leadership on council and staff.
Revise to 'personally know some council members or staff'
Why would this be a requirement?
My concern is about Councils that are prhobitted from these kinds of activities by Governor's, agencies and legislatures. ADD will need to back this up with written support before this can be something all Councils are judged on.
Legislators will know the Chair, the ED, and perhaps some key staff but making sure that legislators and policymakers know Council members and all staff is neither feasible, reasonable, or productive. We have a 40 member Council. Message needs to be controlled and consistent to be effective.
Why?
Probably happens – but required NO.

Comment
Unnecessary and ?
not always easy to accomplish
Legislators – state? Federal? All? Some? Not feasible. We have 40 Council members. Our policy analyst, not all staff, works with specific members around specific issues in the legislature
Consider 'making sure…know about the Council, its purpose and priorities.'
This puts a lot of pressure on staff if council members can't/don't do this. It's a worthy goal but may be drilling down too specifically into what a council can do if all partners are not engaged
Again, if plan calls for training leaders, for example, who may later have legislative contact, the impact of efforts would be at a different level in the hierarchy of decision-makers – not always at legislative level.
Should specifically mention state disability organizations: VR, DD agency, etc.
Note out state policies prohibit 'lobbying'. Need a definition of 'personally know'. Why limit to legislators? There are policymakers at all levels of government.
This is not relevant and not useful. It's subjective and goes beyond what should be demonstrated to show systems change impact and results.

6.6 Evaluates its advocacy efforts throughout the year, and changes course as necessary.

Comment
"throughout" is too vague. Change to "at least annually."
Although I think this happens naturally, how would one propose to measure it?>
Advocacy may not be part of a Council's portfolio so they could not evaluate it or may not have anything going on during the current year.
This is important to do but not relevant to the standard of using advocacy strategies to effect change. It is also inconsistent with the standard earlier about using the state plan as a blueprint. What type of documentation of this would be required. Going back to the mom and apple pie standard. No council can do its job without continually refining its efforts and strategies to meet needs. This may be formal or informal and not specifically documented.
The concept of evaluating systems change efforts (not advocacy efforts) throughout the course of an initiative is appropriate as is change course as necessary
evaluate in many different ways, i.e., Online survey, focus groups, state conference
"changes course" – "adjusts activities". Throughout the year may create staff burden. 'Evaluates' means what? 'Assesses?' 'Evaluates' tends to suggest formal evaluation. When grantees are doing work under PA or contract, 'changing course as necessary' can be less than simple.
Great – too rarely considered
Replace 'change course' with 'make adjustments as needed'. Needs greater clarity. Are you asking whether a process is in place for every advocacy effort?
This might be better placed in governance & management. Relates more to evaluation.
This ability is important. If a Council can change course easily, it will then be able to take advantage of new opportunities as they arise

6.7 Has evidence that its advocacy efforts have had an impact on legislation or public policy within the past 5 years.

Comment
This is difficult to prove. Prefer "provides documentation that may include news articles, memoranda, testimonials, etc that demonstrate impact on legislation or public policy. with past 5 years."
Legislation from start to finish may take up to 10 years to pass. Holding Councils to this standard may not be feasible. In addition, many Councils believe this to be a lobbying effort and will not get involved in this type of lawmaking at all.

Comment
We report on this annually now. This is PPR outcome reporting now . The use of the word advocacy again may need to be reconsidered unless being used in the broadest sense. There are other activities that impact legislation or public policy including education, training, demonstration projects, research, etc.
This should be documented in the planning (Standard A)
again see above - systems change means focusing on systems change strategeis (of which advocacy is only one strategy) - the concept is appropriate (having evidence) but the statement as written is mis-guided.
I would prefer not to have this required BUT available for documentation.
Incontrovertible evidence of unique impact is almost impossible to prove
May be able to combine with 6.6
What constitutes evidence? I just sent out 14 articles on a complex topic. What would be 'evidence' that they impact legislation or policy? We have provided extensive consultation and TA to our Div. of Medical Assistance and Div. of MH/DD/SAs on the same topic. I would hope our division staff would state that these has had an impact, but I could not promise that. 'advocacy efforts': How many? How much evidence? Costs of gathering evidence
Very challenging in our State with its political climate despite heroic efforts.
"or" allow flex a range of necessary options to change course, if necessary
Examples of the kinds of evidence that ADD is looking for would be a great help here. And I don't think "has" is the right verb. How about "Collects"?
In collaboration, the Council will rarely 'take credit'.
The above indicators already get at this - this indicator is not necessary.
This standard is a reasonable demonstration of systems change growth, movement of success

6.8 Has evidence that its advocacy efforts have had an impact on community practice or services within the past 5 years.

Comment
See previous Comment.
I firmly believe that the DD Council, P&A, University Center and the State Independent Living Council and Centers for Independent Living should all be working together.
I think it's hard to show the evidence; as system change is ongoing.
Again, How would this be measured?
It is relatively simple to determine statewide impact of an advocacy effort. It is much more challenging to have "evidence" of change in community practice or service. Virginia is a large state and services and programs are under local, not state control. We would not have the resources to meet this and there is no way for us to measure local impact except on a project that we have specifically funded and only for the 2 year period in which we can require the grantee to report pot grant data.
Same response as on 6.7
again see above - systems change means focusing on systems change strategeis (of which advocacy is only one strategy) - the concept is appropriate (having evidence of impact on community ractice or service) bu the statement as written is mis-guided.
There is simply no way to find the requisite degree of evidence
May be able to combine with 6.6.
Prefer 'outcomes' to 'evidence'
Good to include both community practice and services.
Again, "Collects" evidence would be better wording, and this is another place where examples of such evidence would help people know what ADD is looking for.
"community practice or services" – Rewrite. Advocacy has an impact on people. This seems to ignore all the individual advocacy that occurs because of Council efforts.

Comment
Systems change advocacy that has a definite impact on community practice or services can be very hard to measure.

6.9 Monitors implementation of systems change to ensure implementation adheres to a new policy, legislation, or procedures.

Comment
Take out 'to ensure' and 'adheres to;
Measured how?
Monitoring implementation is beyond the capacity and scope of a DD Council other than with our funded activities or through our comprehensive assessment. We do not have the capacity or resources to "ensure" adherence to policies, legislation or procedures. We are certainly able to report to relevant agencies if we find through our activities that an agency or organization is not complying with law, regulations, etc. but we cannot proactively seek out this information.
within the boundaries of our state plans
Pretty hard to enforce – so what if not happened
I think this should be part of P & A role
Council efforts are short-term by requirement and design. Monitoring could require a Council to maintain an objective over many more years to track inplementation. Consider a standard that requires Councils to encourage and support other advocates to monitor.
This should be limited to projects the council funds.
Who owns implementation? Who own enforcement? Seems beyond the limited resources of the Council

6.10 Monitors implementation of systems change to determine unintended consequences.

Comment
Concern with capacity/strategy issues laudable, but not as easy as it seems.
How does a council monitor this?
Measured how?
This is an important area and through policy work we (and I'm sure other councils) seek to identify unintended consequences. However, this is too broad and not feasible to implement. It is reliant on data from other agencies who are actually implementing and it can take years to determine unintended consequences. This is already done in part through the comprehensive assessment.
A council could fund a grant to do this but I don't think it has the capacity (or should have it) otherwise.
within the boundaries of our state plans
Beyond the capacity of most Councils – and most researchers!
See 6.9 Comments.
This doesn't seem to be necessary if the 3 ADD partners and other groups are working together to analyze implications of policy as they move forward.
I see intent, but wording may mislead unintended consequence by definition can't be seen – work change (but what?) is necessary
This exceeds the capacity of Councils and our limited resources.
This should be the UCEDD's responsibility.
Just does not seem germane to the standard.
This is a strength of the DD Councils and its network of programs

6.11 Additional comments, standards and criteria for systems change

Comment
You may want Council to do something about unintended consequences or policies not being adhered to
Although many of these standards are admirable, it os virtually impossible to imagine how Councils would collect this information short of hiring an evaluator or contracting for evaluation services. Look at Route to Success developed by HSRI. It is a much less prescriptive process to look at systems change.
This standard should not be called systems change it should be called advocacy because that is its entire focus.
You are "mixing apples and oranges." Standard 6 does not reflect our systems change mission - it focuses almost entirely on advocacy. They are NOT the same. And advocacy is only one of many systems change strategies .This standard and all the performance criteria needs to be re-worked to make that distinction. Advocacy and systems change aer two spearate and distinct functions which sometime (maybe frequently) are needed to work "hand in glove" to achieve a desired end.
We should make an effort to stick to requirements of the DD Act and not have indicators go outside the focus of the Act.

E. Demonstration of New Approaches to Services and Supports

Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members.

Comment
This ofter goes nowhere. I think the resources can be better utilized internally.
Once again this is too focused on the publicly funded system and not really about new approaches to having people as part of their community.
The word "try out" should be changed. If the examples are things that we are required to do, they are problematic. What does securing external funding mean? ARe you talking about match funds for grants we give out? Are you talking about applying for grants? Our council and many others I'm sure do not have the capacity to do this. Assisting communtiy organizations to obtain funds? Are we supposed to help[other orgnaizations write grant proposals or just provide letters of support. To accomplish all of this would require additonal funding and staff.
Demonstration of new approaches is one systems change strategy. In the best of all worlds this needs to be reflected in a systems change standard performance criterion not as a standalone Standard.
Pilot demonstration in a climate of limited economic resources is ill advised in many cases. The 'system' may not have the funds to pick up certain 'new or innovative practices' when Council funds end. Councils should not be required to fund in this area try out- 'Identify' and 'promote' is another matter
Issuing RFPs is not needed. The goal is to test.
Here is a place where the examples segment is so useful. Such a section would be advantageous throughout the document.
This is permissive in the federal law and should not be made mandatory through performance standards
Leave out term 'try out'. Reword: DD Councils promote trends and most promising practices in their states.

7.1 Disseminates or promotes new or innovative practices the Council found to be effective.

Comment
State plan should drive the RFP.
We assume but are not sure that this refers to practices that we have funded or to simple dissemination of information regarding promising practices. If the standard implies that we have done an evaluation of the practice to determine its effectiveness, that is beyond the scope of our capacity and would mean that we would be unable to disseminate information. A better standard would be disseminate or promotes information on effective, new or innovative practices.
The Council found to be effective is delimiting. We are ,e.g., promoting resource allocation methodologies used effectively in other states. We are providing research done in other states – and not done with council funds. NADDDDS has been helpful in identifying to the field evidence based and promising practices. Try 'practices demonstrated to be effective'.
delete 'the Council'. The practice may be found to be effective by another group/entity, such as UCEDD or other.
Councils and its programs should do more promoting of approaches and best practices within their own networks, across, the state and country

7.2 Uses or tests new or innovative practices found to be effective by other DD Councils.

Comment
Why reinvent the wheel? Good to get ideas from other council's that have the same demographics.
May nit be consistent with priopirities of this Council.
May not be a priority or issue in another state. Also, too many differences in the state to be able to judge based on another states efforts..
This would require an effort by ADD to provide information to DD Councils on new and innovative practices by other DD Councils. We do not currently receive that information. What works in one state may not work in another. Information gained at conferences (when Councils can afford to attend them) is not adequate to this purpose. In addition, just because something is effective in one state does not mean it will be effective in another. Evaluating whether a practice may be workable in your state would be a more appropriate first step.
Should not be a requirement- might be a good strategy.
We can and do this but it should not be required - we find ideas from a lot of different places.
Then it wouldn't be 'new or innovative' would it?
We do this as a matter of course. Other Councils do not. It should not be required. States and their priorities are unique.
Could be reworded to remove the reference to DD Councils and just note 'by others'.
This assumes there are enough new and innovative activities coming out of Councils that could also get each State's individual plan. I don't think this needs to be so prescriptive— we have taken innovative ideas outside the ADD/ disability counseling services, community development field, general education field, etc.
"Use & testing" is implementation only. Add to allow for a totally new idea by learning and exploring new idea prior to 'use and testing' the practice.
The council should look far and wide for new and innovative practices. Other councils are but one source of idea but not so innovative that a council should have to demonstrate they have used other council ideas. This is controversial.
This performance measure needs to have a data component; otherwise, the testing is meaningless. So added onto the end I suggest: "and collects and uses the data from these tests."
I would urge adoption of innovation from anyone and everyone. Why limit to other Councils?
This seems redundant with above indicator. It doesn't seem necessary/relevant to specify where the Councils get new ideas, just that they do it.

7.3 Collaborates with other DD Councils to try out or promote a new or innovative practice.

Comment
No requirements for this in the DD Act and would be nice, but as a standard?
Great idea but sometimes it is difficult to blend funding.
As noted above, information would need to be provided by ADD on a formal basis regarding the work of other DD Councils and there would need to be some mechanism for sharing and collaboration with resources attached to it if inter-state collaboration is desired.
We can do this but working across state systems is extremely difficult. Making this a requirement (i.e., performacne criterion) is not appropriate.
See above
Love this, but it is an 'exceeds'.
This could be a method but shouldn't be a requirement. It's better as an example for 7.2.
Great idea— but may be far prescriptive—many States aren't even working with this ADD partners.
Mandate is permissive – a good idea but may just not work at times. Our DSA only allows out-of-state travel with very tightly defined circumstances, so we have a huge barrier to implementation.
Again, the "try out" should require that data be collected; otherwise, why try it out?
Why limit to other DD Councils? It should be anyone and everyone that has something new and innovative.
If collaboration is the key concept here, broaden the scope to include other organizations that Councils collaborate with to promote most promising practices.

7.4 Disseminates information on practices found to be ineffective.

Comment
This may be tricky as such dissemination may be viewed as negatively affecting a grantee.
Not our job to do this kind of scientific research to determine if practices are ineffective.
It is unclear how disseminating information on ineffective practices would be helpful except in the case where the Council knows that an agency is considering a practice that has been proven beyond a shadow of a doubt not to work. Sometimes practices that are ineffective in one organization or situation will work in another. Documenting a lack of success in grant or policy work is important to not repeat mistakes but that is a more limited scope. We cannot see the value with people already loaded with information on disseminating information on practices that don't work.
This is novel. Could be a huge undertaking – easier to identify EBP or practice-based evidence rather than identify all the non-EBP related to all types of disabilities (e.g., autism ineffective practice is huge!)
Best practice to show ineffectiveness – But not basic requirement.
in accessible and alternative formats
Only so many hours in the day… Are you referencing re: out own funded initiatives or state policy/practice in general?
Good idea- but too prescriptive.
By promoting effective practices, DD council can send the right message. While a council may occasionally do this to counter some nefarious initiatives it should not be so common as to be a standard.
Doesn't make sense.
Please be careful – if we criticize certain practices, cures, etc. we can get sued.
The standard has to do with demonstration of best practice/trends. This is outside the scope of that standard and may not be a good use of Council resources.
This criterion is important so that social service systems do not continue to design service delivery modalities that don't meet the needs of the people with DD

7.5 Can document that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.

Comment
DD Council cannot assure integration into practice
Impossible to measure
There are issues of sustainability and being able to fund projects longer than five years that may impact ability to measure this
We are able to request post grant data for 2 years, a 5 year time frame is a long time. We understand the desire and need to show sustainable change but it may not be feasible to collect 5 year data. As noted earlier, the term community practice should be defined.
Best practice but not basic requirement.
Five years is a very short span of time
Change 'found to be effective' to 'promoted'. The 'you can lead a horse to water' standard. State has integrated practices we have advanced, that that we ourselves did not 'find to be effective' e.g., use of AAIDDDs SIS. P.S. it took considerably longer than five years for our state to adopt self-directed services and supports – but we 'came to this game' early
Ideal but can't force community partners to adopt practices/programs.
Has to be a goal, but acknowledge factors beyond Council control impact service implementation..i.e., if it involvesnew $ to implement – or leadership not buying into practice – i.e., provision of sheltered workshops, institutions
see no reason for "can document". Why not just say, Documents that new..."? I expect ADD cares less about the ability to document that it does about actually documenting. And here is another place where examples of docmenting would be very useful.
Need definition of community practice.
Reword: Can document sustainability of new practice in state/community service system.
This again will be very difficult to quantify because funding as well as the desire to serve people with DD drives service delivery. The pace of this type of change is very slow.

7.6 Can document that other states or national programs are using the practices tested or disseminated by the DD Council.

Comment
This is something that ADD should do. DD Councils do not have the funding or resources to promote their practices and programs nationally.
Copying is not a test of utility
Great – but definitely exceeds. Also sometimes less than clear, when the practice is modified that I is 'ours'.
It is not a state Council's responsibility to advocate for use of its successful practices in other states. That's ADD's responsibility.
Can't force others to adopt our programs.
See 7.2 Need flex for local decision making characteristics of stakeholders, $, culture
While something interesting to track, it is only fair to measure performance within the domain(state) they are operating.
I see no reason for "can document". Why not just say, Documents that new..."? I expect ADD cares less about the ability to document that it does about actually documenting. And here is another place where examples of docmenting would be very useful.
With our limited resources such tracking is beyond our capability
This exceeds the scope of the standard. This might be a standard for ADD.
Again the timetable for communicating positive results from best practices or programs supported by the Council is very slow

7.7 Additional comments, standards and criteria for demonstration of new approaches to services and supports

Comment
Again, the issues of measuring performance within these standards will be close to impossible.
Demonstration of new approaches is one systems change strategy. In the best of all worlds, this needs to be reflected in a systems change standard performance criterion not as a stand alone Standard.
As I thought about all this overnight, I am nervous for those smallest Councils who only have 1 or 2 staff. I think that we should have like a very BASIC minimum requirement and that could be exceeded (of course) but not required for every council. As I rated things, it seems like I leaned toward not "requiring" formal collaboration with sister agencies....so this at first thought – seemed like it could be the easiest/less critical components to let up on standards. This section as well might be one place to "give the smaller" councils some slack. Just some thoughts....
These are all great ideas – I worry there's ? too much for our small agency to accomplish if all of these are required.
The criteria for demonstration of new approaches to supports and services is admirable. However the criteria for this standard need to reflect the fact that change can be very slow. Councils and network programs may be doing great things, but may not be able to meet the standard

F. Governance and Management

Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.

Comment
Governors appoint council members and occasionally appoint people who are unable or unwilling to meet their responsibilities. Gov's should be accountable too.
The standard and half of the sub-standards do not match. Most of the subs below relate to management and operation of the Council not to whether council members can effectively fulfill their role and meet their responsiblities. If you take out the word "members" and say that the DD Council has the capacity to fulfil its role and meet its repsonsibiliteis then 8.1 - 8.4 apply and the rest don't. If you leave the standard as is, then 8.5 on applies but 8.1 - 8.4 do not.
Capacity is not a good word to use in the world of ID. 'members are provided the training and supports to.." would be preferable.
Examples here would be a big help, espcially around words like "capacity", "effectively".
Add "under the DD Act" at the end. Tie this standard back to the DD Act requirements.
Reword: DD Councils members effectively fulfill their governance roles and responsibilities. Don't think we should judge whether they have the capacity.

8.1 Reflects the full range of the population of people with developmental disabilities in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups).

Comment
Again, governors need to be responsible too.
All disability types too broad
I would add geographic diversity within the state.
I would not use "all" in this example.
Councils do not have control over members who are appointed by the Governor.

Comment
Again would suggest using "representative of"
We agree this is important for the Council as a whole but it is not relevant to the ability of Council members to do their job.
& SES levels. Disability is highly correlated with poverty and most councils only reflect middle class disability populations and issues.
. . . . within reason and wherever possible. However, the political nature of Gubernatorial appointsments is a major inhibitor - so unless tructural changes to the DD Act occur surrounding DDC membership, in reality, we may be in a position of choosing one over the other.
"full range": No – we attempt to do this but remember that the governor not council appoints. All disability types pushes us toward a diagnosis-based definition. DD is a 'functional' definition. We nominate a slate of members and provide boards and commissions with a spreadsheet re: demographics, along many lines
See earlier Comment on 'living arrangements.'
Well, since Councils don't control this, I think this is unfair to hold them to this measure. Governors often take their own sweet time, and may appoint people who do not meet this criteria. Better to say, "Documents Council attempts to insure representation of full range of the population, ..."
"disability types", "nationality" – same as before. DD is a functional definition – clarify if you mean all disability types that constitute DD and not the broad definition of disability. Delete 'nationality'. The council membership regulations are dictated in federal law. Use that section. The DD Act has one of the most complicated membership list of regulations compared to compared to hundreds of other state appointed councils.

8.2 Fills all vacancies on the DD Council within 1 year.

Comment
Again, this depends on governors.
Should be filled immediately.
Take out 'within one year' substitute 'according to operating principles'
Having been a Council member and knowing the process in the Governor's Office, I would say that 1 year is not reasonable - perhaps 2 years?
Governor appoints members thus filling vacancies. Council can recruit screen, interview and recommend in a timely way but appointments are done by Governor.
Again, this is related to the Governor appointing members and Councils may not have control over this.
We agree this is important for the Council as a whole but it is not relevant to the ability of Council members to do their job. It is relevant for the Council as a whole to being able to fulfill its responsibilities. Further in our state, the Governor has sole control over the filling of vacancies.
I say exceeds – I know some DDP Councils have to wait on Gov slowing down their process. It is not them.
As long as governor holds the authority to appoint, this is not within Council control. We nominate timely
Councils don't control appointments. Consider a standard such as 'Actively works to fill Council vacancies in a timely manner and documents efforts to do so.'
Can't force governor to appoint.
But sometimes is hard to find good quality people in a short period of time
Same issue here - Governors do what they will. Say instead, "Documents efforts to fill vacancies within one year."
Our council has absolutely no control over the governor's process and state laws governing appointments.
Not appropriate to set this arbitrary number. For many Councils, this is too long, lowers the bar. We should delete this and deal with problems that arise with specific Councils vs. setting an arbitrary length of time that is actually too lenient for most Councils.

8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.

Comment
In [State], there is no enforcement mechanism if you do not attend.
We agree this is important for the Council as a whole but it is not relevant to the ability of Council members to individually fulfill their role. It is relevant for the Council as a shole to fulfill its responsibilities.
Minimum attendance standards may have a disparate effect on some disability groups
Our governor's office on Boards and Commissions 'requires' attendance at 75% of meetings. 3 of 4. We accept excused meetings
Communicates and enforces policy, by-law. Without enforcement, existence of communication does not lead to attendance /expectations.
State laws and operating policies are usually written re: absences. A member cannot exceed X number of absences then a process kicks in with the governor's office.
Reword: "Has a written attendance policy.....". The word 'communicates' is unnecessary. We should simply call for a policy.
Councils must meet often enough so that participants/members are aware of, and engaged in, and supportive of its business

8.4 Documents attendance in DD Council meeting minutes.

Comment
We agree this is important for the Council as a whole but it is not relevant to the ability of Council members to individually fulfill their role. It is relevant for the Council as a shole to fulfill its responsibilities.
Need 8.4 to implement 8.3 merge?
If an attendance policy is required, we don't need to tell Councils to take attendance. Suggest that we deal with problems with specific Councils that arise vs. setting indicators that are simplistic and don't illustrate a quality measure.
Addition in 8.4 wording Documents attendance in DD Council meeting minutes and action taken to remedy serial absences.

8.5 Has members who play an active role in meeting DD Council objectives.

Comment
the examples given are pretty limiting and need to be expanded or deleted all together
For at least there is an open invite, support, and encouragement by Council staff.
What are other ways to encourage this – add to this only to serve goal is met. Dept reps on Council have no term limits effectively because Depts. determine who gets on Council, not our membership committee, Council as a whole, or 600 appt. Dept _____expertise from yrs on the Council. Can overpower the 60% intent of the DD Act.
"Meeting DD Council Objectives": No, this is handled by grantees, contractors, and consultants. "subcommittee": Please don't dictate how a Council is organized. Confusion of governance with implementation. Are you asking whether members have a list of duties and are engaged as members?
Perhaps reword: DD Council members fill leadership roles on the Council.
Council members should be involved in either a subcommittee or other council projects

8.6 Provides an orientation to new DD Council members.

Comment
& council committees and WIC groups
The performance measure should say that the orientation is presented in a variety of formats to meet COuncil member needs.
Reword: Council members receive new member orientation and on-going training while on the Council.
This criterion is necessary so that Council members know what is expected of them as Council members

8.7 Mentors new DD Council members.

Comment
Mentoring is only one strategy for learning about DDCwork and assimilating new members - if this criterion remains it needs to be broadened beyond mentoring.
Member-to-member mentoring? What does 'mentor' mean?
9.3 should be moved here.
Do you mean 'has a process in place to assist members become active? Don't dictate the 'how'.
This will help members fit in and learn policies, procedures, and were their energies, skills, and talents can be used best.

Provides ongoing training on DD Council roles and responsibilities.

Comment
This one area we strive to provide to the council; ongoing trainings.
this must also take into account informal and well as formal training
We provide annual, formal training and ongoing informal training. We provide support to self advocates at meetings to enhance their participation
There are a variety of training topics not just 'roles and 'responsibilities'. Check best practices, DD Act, innovation.
Combine with previous standard on training.

8.8 Provides all supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.

Comment
suggest dropping word "all"
Reword - Provide supports needed to ensure meaningful participation by DD Council members. "all supports" and "one-to-one assistance" exceeds the realities of life and the DDC worl - they are options not requirements
this needs to be enforced
'All Supports' that are 'needed' is not the same as 'supports that are necessary (e.g., ADA accommodations). A member may believe they 'need' something that would break the bank
This is critical. Supports need to be available to all members, whether or not they have disability, when the supports are needed, rather than at specific times only.
No need to add 'one to one assistance' especially if you believe in natural supports and creating an inclusive community.
Reword: Provide supports that are needed to ensure participation on the Council.
This criteria is appropriate because people learn at different rates. Also some questions are best handled on an individual basis

8.9 Provides funding for at least one DD Council member to attend a national meeting, conference, or training each year.

Comment
Budget and travel restrictions may make this impossible even if the council would like to.
Issues of state limits on travel and Councils with small budgets
Too broadly stated

Comment
To what end? This absolutely has to be a state discretion -an option but not a requirement/standard.
State travel priorities may not make this possible
Many states struggle with DSAs that freeze travel. 'Allocates funding' vs. 'provides funding'. Good idea...we send members to a variety of events. We may be, however, an exception. We have a Council development fund for this purpose. We regularly bring in to the state national presentations and speakers. We hold member development forums with national experts presenting innovations in the field. Usually invite guests and other stakeholders to these meetings.
Consider a standard such as 'Supports at least one...' Funding for participation can be leveraged through other sources. In addition, this is an arbitrary burden to place on low allotment Councils.
We cannot do this/meet standard as PSA considers no work 60% budget restriction provisionary no out-of-state travel (for anyone with strict exceptions). If included in a standard, we could use as a rationale in our out-of-state travel request. We have many extra dollars in this line item – no way to implement.
We have had a hard travel ban/freeze in place and no one travels. This exceeds what a Council can do.
This should be subsumed under Council assuming leadership role on the Council.. It is too prescriptive, too specific.
Council members need regular training on issues facing people with DD

Standard 9. DD Councils are effective in fulfilling their mission.

Comment
Are we talking about the big mission of "advocacy, capacity building and system change" or some other mission? I suggest "councils are effective in fulfilling their governing responsibilities.
This statement is about the state plan not about governance and management
Way too vague. Needs more specifciity. This says very little. We report on our effectiveness in the PPR every year. The numbers below relate to operations and management which may but do not necessarily denote effectiveness in fulfilling the mission. If this section is about governance/management, the the standard should relate to that and be about that. The standard as written is programmaticlaly oriented..
The performance criterion that follow provides a pretty slim operationalization of "effective in fulfilling their mission"
Effective? By what standard?
This is redundant. Other standard requires evaluation. This is so global as to be meaningless.
gain, example of "effective" would be helpful here. It would provide a way to say outputs are good sometimes, outcomes are good sometimes, and measuring is good all the time.
This section does not mention continuous improvement, results, measurement, evaluation, surveys, baselines, benchmarks etc. seems to miss 'effectiveness'.
This is vague and subjective. Could we more clearly tie it to Governance & management? Since the previous subsection deals with governance/council members; this section should address staffing, resources, operations. Reword: DD Council resources are effectively managed and tied to the Council mission.

9.1 Reviews the performance of the Executive Director each year.

Comment
This is a management/operational issue and does not relate to the standard. Reviewing the performance of the ED does not guarantee or even necessarily relate to the effectiveness of the Council itself. If the standard is changed to relate to governmance and management, then 9.1 is fine.
Annual is nice but periodic is more reasonable. If everything gets done on an annual basis, there is no time for new work. These people are volunteers and have a life outside the DDC.

Comment
I personally have trouble getting their follow-up written performance. Really – I have had no control over volunteer Council members. This has happened thru 3 Chairs.
Because I am a state employee, the DSA and Chair of the Council collaborate in evaluating my performance. The DSA does not want other volunteers (often council members) doing the work plan ratings, other members of the council provide input to the Chairman
This should be performance measure 9.2 and should say "all staff", not just the Executive. Performance measure 9.1 should be, "Reviews the mission on a regular basis and amends it as necessary."
Rewrite "This Council has a process in place to evaluate the performance of the Exec Dir each year
reword: The Executive Director and Council staff receive regular performance evaluations.

9.2 Conducts an independent review of itself every 3-5 years.

Comment
This is valuable and shows an effort to exceed minimum requirements. However, some states, especially small states likely would not have the funds for this.
What does independent evlauation mean. If it does not mean a formal evaluation, then it is unclear. Does independent mean an outside resources has to conduct the evaluation? If so that is a resource issue. This does not directly relate to the effectivneess in achieving mission. If the standard is changed to relate to governmance and management, then 9.2 is fine if there is clarifcation on what "independent" means..
I would say every 5 years (not 3)
Nice thought but not realistic without a fair increase in funding - we, but minimum allotment states in particular, would spend all our funds on that independent review and be found wanting because we had no or little funds to do our work.
What is an 'independent review'?
The Council should have a system in place to collect, analyze, and improve itself in a continuous manner. Once every 3-5 years makes no sense.
Reword: The Council conducts a self-evaluation and has a plan for evaluating its work.

9.3 Assigns a distinct role to every Council member.

Comment
There should be expectations of the responsibility of each and every council member, but I do not agree that a distinct role should be assigned.
Don't know what this means. Is it a role beyond Council Member and Committee Member?
Not clear.
This is not reasonable and it is vague. We have a 40 member Council. If the standard is meant to imply that everyone is assgined a committee, then that's fine. But assigning a distinct role to every council member implies that every council member has their own responsibility. This is not feasible nor relevant to the standard.
Our members should all have roles but not distinct - they function as a body. Yes, their roles and responsibilities should be clearly defined.
Not necessary.
Consider re-wording to 'identifying roles and encouraging participation of every citizen Counvil member.' We have limits on the activities of Council members who are state agency reps, and to some extent, Council members representing the other DD network prgrams.
unclear "role. Chair, e.c., membership committee, fiscal, policy, planning choices ? just guesses
9.3 Assigns a distinct role to every council member and has a written role description.
What does "distinct" mean here? Each Council member should have a role, but several members may have the same role. I think the measure should say, "assigns a role to each Council member."

Comment
Needs greater explanation. No one assign 'roles'. Members are performing duties and play a variety of roles bases on interests.
This is inappropriate. It doesn't reflect standard practice for boards, governing bodies. We cover Council member involvement under members assuming leadership roles. "Assigning" members a role is prescriptive and assumes this leads to a meaningful outcome related to the DD Act.
There may not be specific roles for each member at a given time. However, members should be encouraged to participate in Council sub-committee and projects.

9.4 Trains Council members on the core functions of their role.

Comment
How is this different from the council member orienation?
This belongs in Standard 8 on ensuring that Council members are properly trained and educated to perform their responsibilities. IT is impossible for every Council member to have a distinct role as noted in 9.3 above.
as long as formal and informal training are recognized.
This is difficult to do. We do annual training for new members – open to others. Our officers/Executive Committee gets more training than other members.
Duplicates 8.8
Again, one time training may not be enough. This should say, "trains and supports Council members on the core functions of their roles."
This makes no sense. A person has only one role? Members are trained and develop progress and become even more skilled across a variety of competencies.
Training for Council members is already covered.

9.5 Uses a fair, transparent, and effective process to select competent and experienced grantees.

Comment
Good
ASsujming these are just examples. Councils should not be dictated to in terms of how to set procedures for proposal review, etc as long as the process is fair, trasnparent and effective.
Delete 'experienced'. Delete 'unsolicited proposals'. State law does not allow. Conflict of interest policy is specified in the federal law but not mentioned here. In addition, you want an ongoing supplier management system in place after grants are awarded.
This needs rewording: DD Council establishes operational policies and procedures for awarding grants that follow state and federal administrative regulations.
The councils should be held to the above practices regarding grants and grantees.

9.6 Additional comments, standards or criteria for governance and management

Comment
See attached concept paper from NACDD. Thanks.
This standard is about governance - not really management and certainly not about mission. It is important that members know their roles and have information to do their jobs which some of the criteria support. In addition, needs to be something in here about Councils utilizing state of the art or best practices in management and organizational development.
There should be a performance criterion in this section about meeting the stipulations of the DD Act in the composition of the DDC membership (i.e., individuals, family members, provider, statutory agencies - and percent consumer vs. agency). This is one of the most directive sections of the law and there is not mention of it in the performance criterion.
It is critical that DDC's involved and listen to people with DD and family members and ensure they have an active role. I wish councils could get rid of the word consumer.

Comment
Please reconsider this section and add in something about ongoing measurement of results etc.

Appendix V2. Protection and Advocacy Systems

Protection and Advocacy
Draft Standards and Performance Criteria – Version 1

Panel Member Comments

A. Planning and Priority Setting

Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities and family members in the state or territory.

Comments
Self evident
DD Act says our clients are people with DDs, not family members.
This is Council function: Standard should complement but not wholly repeat Council function
This is a good standard, but remember the P&A's serve a population of people with disabilities that goes beyond "developmental disabilities". ADD might want to ask how people with DD are served in the larger group. Also be cautious not to imply that the P&A's represent the families. Our client is the person with the disability and not necessarily the family member's wishes.
Too specific or _____
Would be okay if "or" were used to indicate that all were not required
Disagree as written. Delete 'family members' and replace with 'their representatives'.
This standard appears to be designed to reflect the priorities of people with DD, not for people with DD. Additional performance criteria should be written to ensure that the priorities are those of persons with DD, not P&A professionals alone.
Add the term systemic trends to the list.
We should support families whenever possible. However, our client is the person with a disability. Therefore, their needs and interests are our first priority, especially in the event of a conflict with family.

A P&A that meets this standard:

1.1 Collects input for the Statement of Goals and Priorities (SGP) from internal and external sources.

- Examples of internal sources include P&A staff, Board of Directors or Commission members, and DD Network partners in the state or territory.

- Examples of external sources include data from P&A activities (e.g., intake and assistance, outreach and community education), state agency staff, research and other reports that contain valid and reliably collected data, and state and territory disability organizations and advocates.

Comments
Exceeds only because examples seem likely to become prescriptive.
You might want to drop the limiting examples and simply ask how it is done..

Comments
Main source should be people with disabilities and their families.
This Performance Criterion would meet standards if the examples were deleted. The P&A administration is best able to determine the internal and external sources for its system.
Include examples of internal sources.
Eliminate the examples. Instead, require that a process be in place for collecting input and adherence to it documented. Clarify timelines and frequency - how often are P & As required to collect input from internal/external sources?
Eliminate the examples. Listing a series of examples may lead to future reviewers viewing these examples as requirements. So, if for example, I don't think state agency staff can offer much w/regard to the P&A priorities, I may find myself HAVING to seek their input to satisfy this standard.
I suggest that the examples be eliminated as they often become a checklist to demonstrate compliance. I also have concerns about the specific inclusion of state agency' staff. Because of our work, we often can not discuss needs because of litigation activities.
Rewrote line 1.1: "Examples……territory, state agency staff. Examples of external sources include data from P&A activities (e.g., intake and assistance, outreach and community education), research and other reports that contain valid and reliably collected data, and examples of firsthand accounts (e.g., state and territory disability organizations and advocates) Prioritize the representation of 1st hand needs and priorities. Often overlooked by other resources in this category.

1.2 Collects input for the SGP from geographic regions across the state or territory.

Comments
Especially from rural parts of the state and also small towns. Texas has a lot of rural areas and small towns.
1. It might be better to simply ask how the P&A gets state wide input and what are the results of their efforts. 2. This implies that grography may be more critical than issues.
Require that a process be in place for collecting input and adherence to it documented.
Strategize how geo. Regions are determined so as to target needs that may be specific to certain communities/culture bases (ex: Native American reservations)

1.3 Uses a variety of methods for collecting input for the SGP (e.g., focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies).

Comments
The examples are likely to become prescriptive. I would delete.
Include UCEDD in this group and a content analysis of the state council's state plan.
I like this one.
Exceeds as written. This would meet the standard if you delete the examples following e.g., "Uses a variety of methods for collecting input for SGP" would be acceptable
Also collect input from schools, students and families, "Mom and Pop" support groups and traditional settings such as sheltered workshops (even if owners resist letting P & A into the SWs).
All P&As will encounter resource problems year to year using multiple methods. Both time consuming and costly. Take the examples out. Examples have a way of becoming THE STANDARD instead of just illustrations. Examples have to go.
Eliminate the examples. Instead, require that a process be in place for collecting input and adherence to it documented. Clarification: are focus groups / public herings required?
Again, the laundry list of examples is unnecessary. There may be years when there are no reports and studies to analyze, for example.
Again, I worry about a list of examples becoming a checklist that would require all of the above.

Comments
Important detail – though examples given may still be exclusive to some communities; not sure of an appropriate reference (term) to use but community gatherings, church affiliated events, etc. may tap into folks not represented here (e.g. Focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies)

1.4 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

Comments
The examples aren't really example when you say all.
Again, this could imply that geography, living arrangements and ethnicity play a more critical role that the presenting issues. This will show up if there is a disconnect between the input and how P&A budgets target the key issues. Key issues and geography may not match.
Too specific as written
Exceeds as written. This would meet the standard if all the examples following the e.g., are deleted. "Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities" meets the standard
Also set input from self-advocacy groups and "People First" groups. Be sure to get out to rural areas in [State].
With language focusing on developmental disabilities
Surveys only ask for priority information. The survey will be long and cumbersome if we start surveying for age group, disability, living arrangement, etc. The goal is to set priorities with public feedback, not conduct a census of the Arizonans with disabilities with our limited PADD resources each year.
Eliminate the examples. Instead, require that a process be in place for collecting input and adherence to it documented.
Modifiers exceed the standard and DD Act mandate
Rewrote 1.4" Collects input for the SGP from a broad population of people with developmental disabilities (e.g., diverse disability types, age groups, living arrangements, and ethnic and nationality groups, economic conditions) in the state or territory.

1.5 Collects input for the SGP using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.

Comments
Again, please delete examples.
In some states, language translation needs are quite extensive, e.g., California. Judgment needs to be used on feasible translations for "major groups."
This just seems to be common sense as a reasonable accomodation to get imput from the people whom we are least likely to hear from with traditional communication. Might be better to ask how this is done.
this is a duplication of 1.3
This criterion is unnecessary since the response to 1.3 would address the variety of methods. The example suggests that what is being sought is a 'variety of media' rather than 'modes'
Be sure language/messages used are simple and not so bureaucratic – explain "alphabet soup" terms.
Is appropriate if focused on persons with DD and their families
Each P&A is required under the law to provide reasonable accommodation and to provide information for limited English proficient communities based on U.S. DOJ guidelines. I would rewrite 1.5 based on the law, not as you have written it.

Comments
Eliminate the examples. Instead, require that a process be in place for collecting input and adherence to it documented.
I think this level of detail is becoming too prescriptive and potentially burdensome. If we get input as described in the previous two components, we would have had to already do this in order to do those.
Various modes OK. Modifiers in parentheses too prescriptive
Add 1.5: (e.g., spoken/conversational in person, electronic…."

1.6 Leverages its own planning efforts with the planning efforts of other DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.

Comments
I would prefer coordinates efforts…P&A's gather data beyond DD consumers, so not always possible to leverage. And, planning cycles are different w/UCEDD's & P&A's.
UCEDDs are by definition connected to survey expertise and should be utilized.
Could be encouraged but not required. Issue focus of partners may be very different.
But clarity as "leverage"
The DD network is a critical part of the process but not the only source of information.
Not practical. Confusion of mission.
Also should hear from other disability groups (non-DD) because they share common interests. Need to work together, not against each other.
While we often use information gathered by our DD Network partners to inform our priority setting process, we want the community to have access to the P&As independently. There could be confusion of mission and conflicts of interest when leveraging planning efforts. We are obligated to collect data on all persons with disabilities, not just persons with DD because of other fed grants.
To the extent possible. However, each of the network partners plays a different role in the system. Therefore, some of the information collected and how we is used will necessarily be different.
This creates a requirement over which the P&A has no control. If, for example, the state has a weak or ineffcient DDC or UCED, the P&A would not be able to use their planning efforts to enhance its own.
Please remember that the P&A does not plan for I/DD in isolation. For example, last fall we held 18 listening sessions that included ALL types of disabilities, attempting to focus/advertise for I/DD would have had a chilling effect on other disability populations thus increasing the financial burden.
Important stuff but not necessary to have here. Measurement of the P&A (along with other DD Network Programs) should not be dependent/based on other outside sources

1.7 Gathers data on the needs of people with developmental disabilities on an ongoing basis.

Comments
Don't agree it needs to be ongoing. We are required to do annually, that seems sufficient.
Self evident.
There should be an ongoing analysis of the calls that come into the agency as well as an analysis of the calls turned away because they do not meet "priorities". It would be more interesting to know "how" it is done rather than "IF" it is done.
but keep it practical requiring too much data collection takes away from client work expecially minimum allotment states.
The Act requires that the strategic plan be data driven but it isn't clear how this criterion as written corresponds to the planning process. To be relevant to the planning process recommend: "The P&A collects and analyzes reliable data to identify issues, needs and priorities"
Include perspective to ensure the point of view of persons with disabilities is reflected.

Comments
Not sure where this is coming from. Again, the P&A system is not the U.S. Census Bureau. It feels like there is mission creep/DD Act creep and we are being asked to do more in terms of data collection through the Westat process.
Require that a process be in place for collecting input and adherence to it documented.

1.8 Has staff and Board of Directors (or Commission) members who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.

Comments
This is too prescriptive for Board members, most of whom are very busy and do not have time to commit to other board.
Would be helpful to more fully explain this standard; e.g., what is meant by "complement"?; also, what proportion of staff and board should be represented from outside DD?
This ignored the conflict of interest issues which could compromise the independence of the P&A. Same P&As bylaws (appropriately) prohibit Board members of provider agencies.
Again, be careful on the "family members". Their needs may be in conflict with the individual with a disability. This question will be problematic related to "Pragmatic Conflicts of Interest". Not sure how this can be re-worded.
May be a conflict. Retain independence.
We don't want to have staff and boardmembers serving on boards we would limit the number of people with disabilities who could serve on those committees.
This overlooks the potential conflicts of interest for both staff and Board members. Also, Board Members are volunteers and to require these volunteers to join other committees or Boards is an unreasonable expectation.
Encourage staff to share what the barriers are and what else they see are problems/issues when they are serving people. They are on the "front lines" and see a lot.
Issues of conflict of interest.
Unnecessary. Staff and board members contribute relevant information to the planning process regardless of its origin.
While I think this would be true more often than not, I don't think this should be a requirement upon which a P&A should be evaluated.
Because of the conflict of interest disclosures/requirements that the P&A be independent of services providers and because of how the service provision network in this state are organized, this demonstration of the standard may be difficult especially as it relates to staff. this does not limit our ability to collect input.
Again, important, but not something suitable for accountability of service provision. Instead: Has staff and Board of Directors (of the P&A itself) who provide sound representation of diverse views and experiences (e.t., pwd, people having experienced institutionalization, people having experienced group homes, etc.)

Standard 2: P&A SGPs reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for P&A action.

Comments
Delete "blueprints for P&A action" too prescriptive.
What if needs of PWD and family members are in conflict?
Needs of people with DDs = Yes. Needs of family members = Not always (e.g., same families want to keep person in institution)
Yes BUT drop the "and family members".

Comments
After the P&A identifies issues, needs, and priorities, pursuant to Standard 1, it then implements a plan that addresses the goals and priorities identified. A blueprint is a very detailed workplan and the SGP is not intended to be a work plan. Recommend Standard 2 be rewritten to state P&A SGP implements a plan that addresses the goals and priorities identified.
Should also reflect needs of people who are "non-traditional" DD community members.
Should reflect the needs of persons with disabilities, not family members.
We should support families whenever possible. However, our client is the person with a disability. Therefore, their needs and interests are our first priority, especially in the event of a conflict with family.
Good concept but it is only relevant if these blueprints were collected from truly diverse representation which includes gathering input in ways not always customary to traditional means, such as surveys and file review, etc. but rather person-to-person discussion, community events, religious activities, etc. Checked Agree – but only if there can be some assurance of true cross representation in determining what the "blueprints" are.

2.1 Reflects the internal and external input from the planning process.

Comments
Self evident but vague.
Not relevant as written. Recommend it be rewritten to state Input from internal and external sources is included in the P&A plan
This should ask "how?" and what are the results rather than "if".

2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access to services, inclusion, choice, basic human rights, quality of life), as well as protection from abuse and neglect.

Comments
These are not the only DD goals.
Absolutely. But again the "how" it is done and the outcome of the efforts are more important than simply stating that the goals and principles are reflected.
But does not require that all goals are addressed. Do you mean that the guiding principles are stated in the plan or reflected in all the goals?
The problem is with the word 'reflects' which is rather passive. Omit the examples. Recommend this be rewritten to state: The P&A plan addresses the requirements of the Act
Participants concerned about people in group homes.
Must have the flexibility to emphasize different aspects based on public input, emerging issues, or resources.
Items in parentheses do not have enough specificity in terms of DD Act – stick to DD Act language
Insert 2.2: deinstitutionalization

2.3 Drives all primary activities that the P&A conducts and supports.

Comments
The input from people with disabilities should drive the agenda but the standard gives equal weight to the needs of the families. These two inputs may pull in opposit directions.
Most but not all
Exceeds as written. Delete 'all' and this would meet the standard
Must have the flexibility to emphasize different aspects based on public input, emerging issues, or resources.
This is confusing. Our SGP focuses on our case selection criteria but does not include on-going functions like information & referral, monitoring and investigations.

2.4 Contains priorities that balance the needs of people with developmental disabilities and family members in the state or territory with P&A resources, outside resources, and the potential impact of strategies that were considered.

Comments
We serve people w/DD. We do not have to balance w/ family members, particularly those whose values are inconsistent w/DD Act.
The standard is quite vague. What if PWDD and family members don't agree? I suggest rewording and/or dividing into two standards.
"Balance" is a problematic term. It could imply an arbitrary equalizing of efforts across multiple needs. "Reflect" is a better word.
This one is very problematic. It appears to be micro-management and it looks like we need to balances the needs of people with disabilities and their family. I think I inderstand the intent here but this doesn't get there.
Not much room for "special" initiatives that throw the P&A out of balance Need exception – exclude family members
vague and not definable
Change balance to considers because this could have as balance could cause a problem when trying to address systemic issues.
This criterion includes factors that are not required to be balanced. P&A would not balance individual needs against family members need. How would you measure potential impact of strategies that were considered but not used?
Possible—All goals and priorities should be realistic and achievable based on resource availability and program capacity. Not sure if this needs to be a separate criteria or a clarifying statement.
Use the term "considers" instead of "balance" and exclude the phrase "family members." We represent people with disabilities. Adding family members as a standard builds in conflicts of interests that are not there now.
Seems like an internal question that would be subjected and difficult to evaluate from the outside.
I wouldn't state this in just this way. Perhaps a better way to state this would be: "Contains priorities that are both responsive to the needs of pwdd (leave out family members)
First of all the P&A does not represent family members only the person with I/DD. I am also alarmed about the term balance. It implies that our resources will be spread equally. In reality, because of a variety of factors - including the likelihood of impact and potential harm, one specific priority may take a larger percentage of the resources. I am also not clear about how 'outside resource'
Unclear. If you want to reference a priority setting process, be clearer

2.5 Additional Comments or Standards and Criteria for Planning

Comments
It seems to me that the State DD Councils "State Plan" is the definite plan and the P&A, Council & UCEDD should collaborate to produce that plan, and to execute it.
All the items in A. add up to a lot of process requirements. Looking at the overall instrument, make sure the process requirements don't outweigh the outcome standards.
The questions and examples seem to be strictly process driven, making the assumption that if all of these things are done, the P&As will have impeckable input on the needs of the community and they will expend their energies and budget addressing those needs. It might be better to ask; "How does the P&A assure broad input on the issues facing people with disabilies and what are the stratigies and the outcome of those stratigies to address the identified needs?"
Standard 2 should be rewritten to state P&A SGP addresses the goals and priorities identified. Criterion 2.1 should be Input from internal and external sources is included in the plan. 2.2 the P&A plan addresses the requirements of the Act. 2.3 the SGP directs the primary activities of the P&A. 2.4 should be omitted.

Comments
Include provisions for revising goals and priorities during the year to reflect new or changing conditions, statutes, regulations, or priorities.
in the state and reflective of the resources available to the P&A.
I think with all of the standards how we will be expected to demonstrate them will be critical - also how they will be used is important. I assume that they will play a role in any federal reviews but how else? The formatting is not accepting all of my Comments. I suggest changing the above statement to the following " contains priorities that reflect the needs of people with DD through the allocation of its resources."
2.5) Same as above but family member specific—there is a distinct difference here when it comes to accountability and fulfillment.

B. Intake and Assistance

Standard 3: The P&A intake process is equitable, efficient, and effective.

Comments
Should be efficient and effective. Equitable is unclear and not sure how you measure.
?
"Equitable" seems difficult to measure, especially when intake has no control over the calls it receives.
Checked Agree – w/need for a way to truly fulfill These are great to have but at present they are w/o a translucent means of measure that can be compared with other states and/or improved over time.

3.1 Maintains written intake procedures that describe how to determine an applicant's service needs and preferred mode of communication.

Comments
On this portion only (that describe how to determine an applicant's service needs and preferred mode of communication). This portion too detailed & prescriptive. Many things intake procedures should measure these are not necessarily the most important.
Some P&As address this through training without having lengthy written procedures.
This seems way too detailed. This should be covered in Casework Standards and internal training/supervision.
Written? Why
A client's service needs would include preferred mode of communication. 3.1 would meet the standard if 'preferred mode of communication' was deleted.
See above.
We do this. Do not need a written standard.
Eliminate the two specific items as they are not the only ones necessary or of interest.
While I think written intake procedures are a must, I don't think they necessarily have to explain how the intake staff determine the applicant's mode of communication. It would be enough to simply state: "Maintains written intake procedures"

3.2 Maintains written procedures for documenting client information in a computerized database.

Comments
Casework standards should cover this. It appears too intrusive and micro managed from ADD.
Also a hardcopy file or backup of some kind of client files in case computers crash.
Optional – included in previous question.

Comments
On Please check one: Comment “it depends.” We need to come up with a universal understanding of what this info is for, ways to record and compare to other info so as to utilize it to the fullest on behalf of the clients and the P&As..

3.3 Maintains written procedures for priority case selection.

Comments
The procedures should permit some flexibility/judgment as to provide case selection by the P&A Director with the concurrence of the board.
Absolutely. This should be a measure.
The written requirement should be the priorities themselves. I'm not sure that written procedures for priority case selection is meaningful. In fact, I'm not sure what this means.

3.4 Provides training on the written intake procedures to all new intake staff.

Comments
(to all new intake staff) : Too prescriptive; not only people who should be trained.
This should drop the word "written". Proper training for all new staff is critical but this standard needs to stay away from personnel issues or how the training is done.
And Board members too.
Also should train staff about our particular region and make-up differences from other regions in state.
Is there interest in documentation of the training as well as the documentation of the intake procedures? Seems more like an internal personnel management matter.
I'm not sure this belong here or it needs to be repeated. I would prefer the latter. I think that there does need to be a standard related to staff training across functions (Intake, adovcates & attorneys, fiscal staff, etc.
Internal need for sure, but doesn’t seem fitting here.

3.5 Annually updates the intake process (e.g., intake forms, procedures, training, and orientation) to reflect changes in P&A goals and priorities and Federal and State policy and legislation.

Comments
(e.g., intake forms, procedures, training, and orientation): No need to update process annually except for goals; priorities.
If the process is working, the only thing that may require an annual update is case selection priorities.
Too detailed. The goals, priorities, State/federal policy may not change on a yearly basis.
Why annually? Update priority info maybe instead.
needs to include updating intake process as needed.
‘Annual’ updates are not relevant to the standard. Recommend it be rewritten to state: “All P&A standard intake documents are updated as needed’
You should add, "if necessary." If there are no changes, then there is no need to update the process.
Is there interest in documentation of the updates? Again, seems more like an internal matter. Annual updates may not be necessary.
The intake process does not need to be updated annually. If the priorities change or if case selection critieria change then, of course, intake staff need to be trained about those changes. To state that this HAS to be done annually is overkill.
A management decision as appropriate
Same as above.

3.6 Monitors staff adherence to intake procedures periodically.

Comments
This is a personnel matter.
This is an internal management and personnel issue.
This is an issue that involves personal management styles.
This is more an administrative function than part of the intake process
Perhaps require a quality control process be in place and adherence to it documented. Define "periodically", perhaps "annually"?

3.7 Provides immediate corrective action of problems with adherence to intake procedures.

Comments
This is a personnel matter.
"Corrective action" sounds like a personnel sanction. "Immediately addresses problems..." would be better phrasing.
This is a personnel issue
Only mention of corrective action
And brings this to the attention of the Board.
Immediate corrective action suggests a human resource performance assessment rather than a part of the intake process
As amended.
Crossed a line into personnel management.
again, seems more like an internal matter.
This appears to be addressing how the P&A deals with staff who are not following procedure. Seems out of place in a document such as this. It appears to be the only place in the document that addresses "corrective actions"
This interferes with personnel practices and may violate confidentiality and privacy issues.

3.8 Directs callers to the appropriate level of assistance (e.g., referral, provision of information and resources, possible individual advocacy).

Comments
(delete the examples). These are not the only things intake staff should do.
This is good, but the outcome of this activity shold be reflected in the clients' satisfaction with the levels of support they recieve.
difficult to determine
Not clear— For all calls on only calls for "eligible" callers.
The examples following the e.g., should be omitted
Optional
Perhaps have a quality assurance process in place and document adherence to it, instead.
Rewrote by adding at end of line "and supports them in understanding next steps of action."

3.9 Periodically applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process (e.g., a survey of every caller for a period of 2 weeks, a followup telephone call to a random selection of callers).

Comments
If we do 2 week follow-up, we will either need increased dollars or will save fewer people. Cannot do both w/current PADD grant.
Opinions may differ on that "rigorous" means. I suggest "an effective methodology."

Comments
This is far too intrusive into the process of gathering information. It might be better to ask; how caller satisfaction is gathered and what happens with the information.
Define
Requires training and resources. Would be good if there are models available.
Big resource drain. Already have to have methods to asses impact of I & R.
A rigorous methodology goes far beyond equitable, efficient, and effective intake process. It would be within the standard to provide for a method of assessing client satisfaction but there is no showing that the examples given would be part of a valid methodology
The survey should be annually to a random selection of callers.
Publishes results of the periodic assessment of public document or annual report. The P&A needs to set an example of transparency.
Resource issue for the P&A program. It is burdensome and we would have to redirect limited PADD resources to this effort.
Eliminate the examples. Require a process be in place to gauge caller satisfaction and use the information obtained to improve practices and procedures.
While I agree that this is best practice, it may not always be feasible. With diminishing resources from the federal government (Louisiana has received a cut every year since Hurricane Katrina because of relative population shifts in the country, for example) we may have to use limited resources to deliver services rather than evaluating the services we've already delivered.
While I applaud the concept, this would potentially divert valuable resources from client services - especially the e.g., list. Also the word rigorous is very subjective.
-delete 'rigorous' -delete examples too prescriptive
Rewrote 3.8: "Applies a rigorous methodology to assess caller satisfaction with the P&A intake and assistance process once/year (e.g., a survey of every caller for a period of 2 weeks, a followup telephone call to a random selection of callers)."

3.10 Provides intake staff with access to ongoing professional development through the National Disability Rights Network [NDRN] or other organizations.

Comments
Remove example (through the NDRN or other organizations)
P&A's should promote professional development. Directing specific activities to occure does not indicate any improvement in service.
Why highlight NDRN— should say— through professionally accredited on sanctioned entities.
It would exceed standards to specify which listservs a P&A should use. Recommend just: Provides intake staff with access to ongoing professional development opportunities
Or internal training.
I would word this differently. "Provides intake staff with ongoing professional development" would be enough. This seems to imply that the P&A has to give intake personnel staff outside training to meet this standard. Again, because of resources, this may not be possible.
We already have a standard about staff development - this seems redundant.

3.11 Further comments additional standards or criteria for intake and assistance

Comments
This section does not look at the benifit any of these activities has on people with developmental disabilities recieving needed advocacy support or protection. The standards are all worded to reflect "activity" instead of "outcome".

C. Individual Advocacy

Standard 4: P&A caseload reflects the priorities set in the SGP.

Comments
The case load should reflect the priorities however the cases that do not meet the priority should be used as a "feedback loop" to identify what issues are missed by the current priorities.
Caseload can be affected by other factors rather than priorities. Autism may be an example
Not sure how this would be measured. Recommend it be rewritten to state P&A caseload is consistent with SGP
Must have the flexibility to respond to demand, emerging issues, or resource constraints
I suggest changing the word caseload to casework.
Rewrote 4: "P&A caseload supports but are not limited to the priorities set in the SGP. Predetermining these services could go against the need. Info gained by callers needs could influence future priorities.

4.1 Maintains written procedures for selecting and processing individual advocacy cases.

Comments
There should be written Case Work Standards and internal operating proceedures to pay attention to the agreed upon priorities.
Suggest that the words "written procedures" be struck in favor of the word "guidance" to ensure staff have flexibility in selecting cases.

4.2 Selects individual advocacy cases that are consistent with goals and priorities in the SGP.

Comments
"Yes/but" Yes, these should match, but there needs to be an allowance for "Wild Cards". Asking about how the P&A responds to unanticipated issues, might be a good standard.
And provides this information in summary within the annual report.
However, sometimes issues arise which need to be addressed immediately and may not be in the SGP.
Recommend "The selection process utilized results in advocacy cases consistent with the goals and priorities in the SGP"
If there is a person with a disability that can serve as a peer mentor for each case, that would also be good.
Need to include procedures as reference to a procedure for referring cases not taken to other sources of information, support or advocacy.
Must have the flexibility to respond to demand, emerging issues, or resource constraints.
Rewrote 4.2: "Selects individual advocacy cases that are consistent with but not limited to goals and priorities in the SGP.

4.3 Conducts ongoing reviews of staff caseloads to ensure that the balance in the SGP priorities is achieved.

- A balanced caseload would consist of the P&A addressing approximately equal numbers of priority issues throughout the year.

Comments
Standard cannot be about balance. Our SGP sets forth minimums we will do in each area
I don't think "priority issues" are inherently equal. Therefore, I question the standards utility since it inhibits sound executive judgment.

Comments
But "balance caseload" as defined is too rigid. There are some case priority areas where we can't find as many cases as we can in other areas (e.ga., withholding of medical treatment in jail)
This is a personnel issue.
Not every priority may result in casework.
Don't know that this is realistic.
Last sentence creates a problem. Just because you set priorities doesn't mean that priority will result in cases.
Equal number of priority issues has no relevance to a balanced caseload. Recommend "Conducts reviews of staff caseloads to ensure priorities are addressed"
No. We can't guarantee that each priority we have gets the same number of cases. Too much variability. Not every priority will have the same number of cases. Maybe one priority will result in one caes that results in one large systemic change. Another will result in hundreds of individual cases.
Must have the flexibility to respond to demand, emerging issues, or resource constraints.
The P&A's priorities may not require equal caseloads. A priority may not require any caseload at all. So, while the P&A should conduct ongoing reviews of caseloads, this review should focus on things like quality and timely service, caseload numbers for individual case handlers, and so forth. It would not focus on equal numbers of cases across priorities.
The statement is fine but the "a balanced caseload would..." unrealistic. Casework is too variable. One big case in federal court does not equal 25 short term assistance.
These are management decisions not appropriate for standards
Agree with this need process for sure but this sort of "balance" seems not truly balanced at all with the needs of the folks being served.

Standard 5: P&A provides high quality representation.

Comments
The devil is in the details as to what "high quality" means in the content of abundant caseloads of varying caseloads.
"Yes, but" This should be a standard, but how and who decides if the representation is "high quality"? Consumer satisfaction should indicate the quality.
Too vague. Reword.
Delete 'high' so that the standard reads "P&A provides quality representation'
I not sure that the items below ensure high quality as they seem more process related.

5.1 Provides staff with formal opportunities (e.g., regularly scheduled meetings) to discuss and review cases.

Comments
Delete example (e.g., regularly scheduled meetings). Many ways to do this.
This is an internal management and personnel management issue.
With whom? A senior member of staff management? Add— Management will review data at last quarterly to look for trends and needs for system's change.
This would meet the standard if the examples are deleted
Again, seems like an internal matter. Perhaps require a case review process be in place and adherence to it documented.
Rewrote 5.1: "Provides staff with effectively individualized ways to discuss and review cases.

5.2 Requires supervisory staff to provide frequent staff oversight (at least weekly).

Comments
Rewrote line 5.2: Requires supervisory staff to provide staff oversight. Amount of supervision depends on skill level of staff. We have clear standards but not weekly for all staff.
(Micromanagement in some cases) "At least weekly" might be deleted and replaced with "as needed."
"At least weekly" is too rigid. It may not be appropriate for some veteran advocates. "As appropriate" would be a better phrase.
Too prescriptive
This is far too intrusive into management and personnel issues within the P&A.
Weekly shouldn't be mandated. P & A should be able to show the work that is done.
This would meet standard if 'frequent' was deleted and replaced with 'regular'
The staff oversight can be individual or as a group. Instead of weekly, I will say bi-monthly or as needed.
The amount and character of the supervisor should be determined by the supervisor in consultation with the supervisee.
Arbitrary standard. A supervisor may not need to meet with a 25 year lawyer with the same frequency as a new lawyer or advocate. Crossing a line into personnel management.
Eliminate "at least weekly." Seems like an internal management issue.
This exceeds the standard only in the way it is written. There should be regular oversight of cases, but the frequency may vary depending on how experienced staff is or on other factors. The individual P&A should set the standard for frequency of oversight and even this may vary from staff member to staff member.
At least weekly is overly prescriptive and does not allow for the fact that different staff need different levels of supervision. Delete (at least weeky)
Supervision – yes. ? re weekly not appropriate
Rewrote 5.2: "Requires supervisory staff to provide personalized forms of staff oversight."

5.3 Encourages use of the NDRN list Serve and other resources, and provides staff with easy access.

Comments
This seems too prescriptive. Should encourage use of resources, NDRN is one but should not be required.
Borderline micromanagement
Not sure how this connects to providing quality representation.
Why do you solely promote NDRN? What is the outcome" Rewrite.
Exceeds the standard to designate a specific listserv. Recommend "Provides staff with easy access to relevant resource services and encourages the use of available resources"
Not sure how to objectively measure "encourages use" - and how to document adherence to this standard.
this is a good thing to do but not sure it is relevant
Requirement of encouragement
Rewrote 5.3: "Encourages use of resources with easy access. Not sure why NDRN needs to be specifically referred to here; good site (NDRN) but lots of others.

Standard 6: Individual advocacy meets client objectives.

Comments
"yes/but" Client objectives must have legal merit.
Rewrote line 6: advocacy meets "outcomes identified by the person with a disability" client objectives.
Suggests it reads "Advocacy meets client objectives'

Comments
Generally I agree, but some clients may have objectives that go beyond those that can be addressed through legal means. Substituting the word "address" may permit greater flexibility.

6.1 Ascertains accommodation and communication needs at intake.

Comments
These seem too small of a detail. Important but not the only item that will ensure you meet objective.
Does this belong in intake?
The advocate generally does not become involved with the client needs during the intake process. See 3.1. Recommend "Reviews intake to ensure client has appropriate accommodations"
this was already addressed in the intake section and so redundant here.
Rewrote 6.1: "Ascertains accommodations and necessary support services at intake.

6.2 Commits resources to support all clients being served (e.g., language line, interpreters, staff that speak a language other than English, policy for including a support person for clients with cognitive disabilities if needed) so that individual advocacy staff is able to communicate with any client whose case is taken.

Comments
But also, again, focus on communication rather than outcome. Good communication does not ensure good outcome.
This may be a challenge in many states with multilingual populations.
Depends if the P&A has adequate resources – This is uncertain.
ADA compliance issue. The way this is worded begs the question as to what level of resources is sufficient.
All languages? Urdu?
Omit examples. Recommend this be rewritten to state "P&A utilizes resources to ensure appropriate accommodations are available to best serve clients"
Reflects the needs of the particular community, within resource limitations.
As with other Comments above, I don't think the list of examples is helpful and may be interpreted by reviewers as mandatory.
Change to read ensure regular and access communication with clients - take out the e.g.
On "so that individual advocacy staff is able to communicate with any client whose case is taken" not sure this phrase is necessary; consider omitting.

6.3 Provides a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.

Comments
Retainers do not need to address this. Other part of standard is fine.
Not always necessary for brief cases. If problem can/must be resolved on same day client calls, written agreement may be a problematic bottleneck.
Retainer agreements are critical so that it is clear that P&A is representing the individual and so there is a clear understanding of what P&A agrees to do. I like this one.
For brief cases this isn't appropriate; And in those cases needs to be allowance that notation in the file that client verbally consents not acceptable here can cause problems.

Comments
As written exceed standards. Not every client contact requires a representation agreement. Recommend "Memorializes agreement with the client as to the objectives and anticipated outcome in a format appropriate to the representation"
Good practice
Perhaps consider an exception for time sensitive issues or when an issue may be able to be resolved through a quick phone call or conversation. Require representation agreements except when not possible (e.g., death investigations, clients who cannot read / write / communicate)
A written retainer should be required in almost all cases. However, there may be times when a verbal retainer is necessary in order to state the process of representation in a timely manner.
Appropriate only for/when representation provided not advice or referral
Rewrote 6.3: "Provides a representation agreement in a method/means by which both the client and staff are of full understanding of the methods, procedures, and process/progression.

6.4 Requires individual advocacy staff to update representation agreements when issues or approaches require a modification.

Comments
This level of process will not get you good outcomes.
Only appropriate for in-depth cases.
The wording needs to be changed to make this a requirement of the agency as a Standard Operating Proceedure. The wording on this sound like a staff evaluation process which is a personnel issue.
Suggest just 'Requires individual advocacy staff to update representation agreements as needed'
Make sure these updates are simply and completely explained so that client really understands impact of modification.
Add "asrequestedbytheclientor" when issues or approaches……
Updates to case strategy would seem to be something better documented internally rather than in the representation agreement.
Include in the standard 6.3
See 6.3
Rewrote 6.4: "Requires individual advocacy staff and clients an opportunity to update representation agreements when issues or approaches require a modification. Ideally, agreements would be written in a way that they're flexible enough to not need this…However, if needed then cool with edit.

6.5 Sends or gives clients a closing letter documenting actions taken, results, and notification that the case is closed.

Comments
Not necessary for cases that get resolved some day as request. Or opening letter closing letter could be all-in-one.
I like this one
The P&A has a procedure in place to properly notify the client when the case is closed.
Should clearly explain in simple language what the result is and what it means for client.
(Isn't this standard practice?)
Sometimes we have to move faster and this would keep us from being able to act quickly.
Is e-mail okay?
Not only appropriate

Comments
Rewrote 6.5: "Sends or gives clients a closing letter documenting actions taken, results, and notification that the case is closed, after some form of person-to-person communications assuming a full understanding of the content of the letter."

6.6 Informs callers of the grievance process if a case is turned down for individual advocacy.

Comments
Do not use "caller" not everyone will call.
This is currently a requirement in the PAIMI Program.
Combine with 6.7
6.6 and 6.7 could probably be combined. The P&A has a written procedure to notify clients of its grievance procedure when closing or declining a case.
The information to callers of the grievance process should be in writing/ a letter.
The standard should additionally require that individuals requesting representation/advocacy are, upon denial, referred to other resources for information, assistance, and support.
Consolidate 6.6. and 6.7 - as both are 'closures'

6.7 Informs clients of the grievance process when the case is closed.

Comments
If outcome is achieved, don't believe necessary to inform when close.
Combine with 6.6
This is good practice, not always practical.
6.6 and 6.7 could probably be combined. The P&A has a written procedure to notify clients of its grievance procedure when closing or declining a case.
Inform in writing.

6.8 Documents success in resolving a majority of issues in favor of P&A clients.

Comments
If you consistently take on the hardest issues, your success rate may be less than 51%.
Good business
Delete majority
How about documents, success and failures?
Need to also praise and recognize staff who resolved an issue and document staff achievement in resolving a case.
This is a goal and should be reported in the P&A annual performance report.
Take out the word "majority." We meet client objectives 80-90% of the time. We don't win every case but we try. Sometimes a judge or hearing officer just won't rule in clients' favor. I don't think you can mandate "majority."
Perhaps the criterion would be more realistic if it read something like, "Documents actions taken, outcome achieved, and reasons for outcome."
Specifying that a MAJORITY of issues should be resolved in the client's favor may be problematic in some circumstances. For example, maybe the inability to resolve issues under a certain priority is an indication that a law or regulation needs to be changed, work that may commence in the following year.
take out majority -
Is standard about documenting or resolving? P&A cannot control resolution only quality of representation
Rewrote 6.8: "Documents success in resolving a majority of issues in favor of P&A clients through 1st person accounts as well as statistical documentation."

6.9 Routinely follows up clients to determine whether decisions made on behalf of a client are being followed and the client issue has truly been resolved.

Comments
Should instead require regular communication with the client. Not prescribe what is discussed.
For some/many clients this is paternalistic. Most clients are capable of contacting the P&A if there is a problem.
The grievance process and request to "call back if there are additional issues". should suffice. We really do not have time to follow-up unless the client calls back. Also many of our clients don't want our continues intrusion once the problems are solved.
Too costly, some can do it but not all.
For how long? At least once at or before 60 days—
To cumbersome takes away from serving people with developmental disabilities.
Routinely – should be defined. How frequent should be followed?
Rewrote 6.9 "Routinely follows up with clients to determine whether decisions made on behalf of the client are being followed and the client's issue has truly been resolved.
Difficult to do with limited resources. We would have to divert direct service dollars to this effort. Would be even more burdensome for minimum allotment states.
What does "routinely" mean? Could be extremely resource intensive. Perhaps a better approach would be to require that an ongoing client satisfaction process be in place and that its results are documented.
Again, while this may be best practice, available resources may mitigate against fulfilling this requirement.
This level of follow up would take quite a bit of resources limiting our ability to serve more and our expereince is that they let us know if things are not working. also because of our 'friend-building' activities we are will aware of the level of satisfaction of former clients.

Standard 7: P&A strictly adheres to confidentiality.

Comments
Strongly agree

7.1 Has a written confidentiality policy with well-delineated requirements.

- Examples of confidentiality requirements include checking with clients about whether phone messages can be left, turning off the computer at the end of the day, and storing files in a cabinet or drawer so they are not left in view of someone walking through the office.

Note: Text from 7.2 accidentally used in the ratings forms distributed to the panel members

Comments
Example only. Took out from 7.1: including for working at home.
Mistake? Standards document reads "Has a written confidentiality policy with well-delineated requirements"
Isn't this the same as 7.1?
Signed by all staff and board annually.
Rewrote 7.1: "Has written confidentiality procedures (including for working at home, w/ contracted staff and office interns."

7.2 Has written confidentiality procedures (including for working at home).

Comments
Duplicate.
This is a repeat of the one before
Duplication of 7.1
Duplicate
Same as above
This is the same as 7.1. Please proofread version 2
Duplicate to 7.1

7.3 Has structures in place to maintain confidentiality (e.g., shredding capability, private offices, email encryption, locking file cabinets).

Comments
Examples only
Not sure if this is necessary – seems obvious
Eliminate specific examples. Require that structures to maintain confidentiality are spelled out and adherence to them documented.
This is part of the procedures so if we meet 7.1 then this is part of that. Also this is all about equipment. The next one 7.4 is part of 7.3

7.4 Has structures in place to help staff meet confidentiality requirements (e.g., email reminders to change passwords, alerts to tell people there is a stranger in the office so special care can be taken with client files).

Comments
Example about strangers in office makes no sense.
Could be combined with 7.3. This standard has a lot of process requirements.
Too detailed and micro managed
Remove all.
Eliminate specific examples. There must be a balance between the ideal and the practical. The criterion feels like it may be going a bit overboard.
7.4 through 7.7 could be eliminated. If the P&A has good confidentiality procedures in place, there is no need to expound further on exactly what they should be.
Same as 7.3
this is part of the procedures so if we meet 7.1 then this is part of that. Also this is all about equipment. The next one 7.4 is part of 7.3

7.5 Monitors periodically to ensure confidentiality procedures are being followed (e.g., inspects periodically to see if client files are left around or computers are turned off at end of day).

Comments
Examples only
This is a management issue. This standard is too intrusive into the daily operations of the agency.
Remove all.
Examples are ? and not appropriate
Should be in an internal policy/procedure because of the office rather than here.

7.6 Requires a confidentiality pledge to be signed by anyone who is privy to client information. (e.g., P&A staff, students, interpreters).

Comments
Too prescriptive. Should require that all staff, volunteers, etc. comply with policy; policy should state that it so requires.
Licensed interpreters in my state have already made a confidentiality pledge.
This is a "best Practice" but may be too detailed for a Standard.
Remove all.
At least annually
Eliminate specific examples. Require demonstrable compliance with agency's written confidentiality policies and procedures.

7.7 Includes information about confidentiality requirements in all orientations (e.g., new staff, students, Board of Directors or Commissioners).

Comments
Instead say review confidential policy.
We never share client-specific information with the Board (i.e., no client names used).
This too is a management issue. It is a "Best Practice" but too detailed for a standard.
Part of the explantion to 7.6 and so seems redundant
Rewrote 7.7: "Includes information about confidentiality requirements in all orientations (e.g.., new staff, students and interns, Board of Directors or Commissioners). "

7.8 Further comments, additional standards or criteria for individual advocacy

Comments
Standard 5 was thin. We should be able to define "high quality representation" as well and as thoroughly as we define adherence to confidentiality.
Most, of the standards in this Section reflect process, not outcomes. From the standards listed it would be difficult to determine if the P&A has made any positive impact in the lives of people with disabilities.
7.1-7.3 all adequate to achieve this
A discussion between the P&A and the client should take place to assure client is comfortable providing details about case, comfortable revealing personal information, and that client can choose what information can be given to other people and what cannot be shared outside P&A. Make them feel comfortable working with the P&A and comfortable that information will be kept confidential unless client gives permission for release. Clients may feel uncomfortable, frightened, embarrassed, etc. revealing info to a stranger at P&A.
Should include a requirement that the P&A has a mechanism for gathering and assessing client feedback and satisfaction w/ P&A services. The assessment should be performed by an external entity or organization not affiliated with the P&A. And the results should be made public.

D. Systemic Advocacy

Standard 8: P&A systemic advocacy increases inclusion and choice for people with developmental disabilities and reduces abuse and neglect.

Systemic advocacy consists of systems change efforts on behalf of groups (e.g., group advocacy, investigations, monitoring, court-ordered monitoring, systemic or class action litigation) and results in changes to infrastructure, legislation, or policy.

Comments
Yes but not sure that advocacy only increases those 3 things. Should also increase accusations to services.
The list of inclusion, choice, abuse, and neglect should be more open-ended. What object, denial of service/benefits, racial discrimination and ADA issues?
This standard assumes that "CHOICE" and "INCLUSION" are synonomous — they are not. Choice is the process and includion may be the outcome. A standard to evaluate the Systemic outcomes of the P&A are needed, but the wording here is problematic.
Not all programs will have adequate capacity for monitoring or class action litigation.
Group homes are always a problem, hard to get access, promote change.
Add to line 8: "community participation," (between increases and inclusion and delete "and" before the word choice. Delete word "changes to" and substitute "improvement in" to last line of 8. This is a definition of systemic advocacy not a standard. Should be re-written as a performance standard.
These two elements should be separate. Confusion about criteria vs. standards

8.1 Leads and participates in systemic advocacy activities to increase inclusion, improve access to supports and services, and to prevent abuse and neglect.

Comments
But here you delete Choice or and see above Comment.
Should be required but there may be other important issues that the P&A must respect to, in order to comply with Standard 2.
Be aware that we have significant restrictions that prevent P&As from lobbying to secure systemic reform. The defination stated above includes "legislation or policy reform. P&A's may not be permitted to meet this standard as worded.
Too limited only 3 areas[illegible]
As part of leading, need to educate system first sometimes
Rewrote 8.1: "leads and/or participates in systemic advocacy activities to increase community participation, "
Abuse and neglect should be an example.
Limits systemic work
Should be noted that increasing inclusion, improving access to supports and services and preventing abuse and neglect are just some of the examples of the goals of systems advocacy.
so will this be measured by whether or not we go to lots of meetings?
Rewrote 8.1: "Leads and participates in systemic advocacy activities that include but are not limited to increase inclusion, improve access to supports and services, promote deinstitutionalization and present abuse and neglect.

8.2 Regularly monitors databases from residential facilities, community services, intermediate care facilities, social service agencies, and other sources to identify and follow up on abuse and neglect issues.

Comments
Current law does not provide access to such data base.
P&As do not have access to all these databases, and if we did "it might mean boxes of reports to read every month. That may not be the best use of P&A staff time
Not sure what is meant by "regularly monitor"
Do not have such access.
need to be more specific on what data is being reveiwed and what "regular" means.
Based on resources available.
Regularly – should be established monthly, every six months, etc.
If available

Comments
Not a reasonable standard. The P&As don't have access to all of the information.
Could be resource intensive. Have had difficulty gaining access to these types of information sources. Perhaps ADD could mandate access?
This may not be required in some years. Whether the P&A monitors databases is soley dependant on the specific goals and activities for any given year.
We don't access to databases from all of these places. I think as an alternative, we should have protocals in place to determining when we and where we monitor as will as how we respond to allegations of abuse or neglect.

8.3 Collaborates strategically to achieve systemic advocacy goals and objectives.

- Examples of strategic collaboration include maintaining or participating in a network of possible collaborators who are available to tap as appropriate issues arise; continually cultivating relationships for future systemic advocacy collaborations; and cultivating relationships with regulatory and enforcement agencies to effectively respond to emergency protection situations.

Comments
But delete examples.
The examples are too perscriptive. It would be better to ask; "How does the P&A stratigically coolaborate with others to achieve systemic reform?"
Add to line 8.3 "....emergency protection situations, cultivating relationships with the state DD agency ____ key state policy makers and others to improve communication and explore areas of mutual interest and concern."
Collaboration is a valuable methodolgy in certain circumstances. Under other circumstances attempting to collaborate is needlessly time consuming and inefficient. I don't believe P&As should be held to collaboration as a standard of performance. They should collaborate in instance in which such collaboration makes their advocacy more effective.

8.4 Effects systems change through a variety of means.

- Examples of means to effect systems change include writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation, securing pro bono assistance in class action suits from legal firms, filing amicus briefs, monitoring residential facilities, and following up on identified patterns of abuse and neglect).

Comments
But delete examples.
Add: "commissioning special studies"
The examples may imply these are the requirements. I suggest eliminating the examples and ask "How?".
This is a given.
again get rid of the examples

8.5 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on legislation or public policy.

Comments
Should delete (within the past 5 years) and (on legislation or public policy. Should continue timeframe and limit on legislation public policy.
Instead of provides “evidence” provides “documentation that illustrates”
This may not be permitted with the current restrictions on Lobbying.
Put in annual report.
Be sure to ask staff members if they see change/impacts, not just Exec. Dir. Or Board members.
(But changed) Difficult to verify and validate. Suggest providing documentation of the advocacy activities that have taken place and the related changes that have occurred in state policy, statute, regulation, and practice.
Require evidence of active and sustained engagement in the public policy arena. However, the impact or success of these efforts depends on external factors, such as the political and fiscal environment.
I think the P&A should be able to show outcomes of its systems advocacy work. I'm not sure it is necessary that the outcomes have to fall under the categories of legislation or public policy.

8.6 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on community practice or services.

Comments
Very hard to demonstrate impact on community practice. See prior Comment.
See prior Comment
and ties back to the sated goals and priorities of the DD Network Programs
Require evidence of active and sustained engagement around issues of community practice or services. However, the impact or success of these efforts depends on external factors, such as the availability of resources and the willingness of other actors to collaborate.
I would combine this with the one above and simply state that the P&A is able to show concrete outcomes that result from its systems advocacy activities.
Methods by which this evidence is gathered and assessed may need updating as well?

8.7 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on inclusion and choice for people with developmental disabilities.

Comments
Both delete timeframe.
This overlaps with 8.5 & 8.6. Could they be merged?
See prior Comment
Again the issues of "choice" and " inclusion" need to separated. It is possible to have one without the other.
Rewrote 8.7: “have had an impact on community participation, inclusion…”
Require evidence of active and sustained efforts to promote and expand inclusion. However, the impact or success of these efforts depends on external factors, such as the availability of resources and the willingness of other actors to collaborate.
We can do a lot of work but might not be able to impact changes in laws or regualtions.
Same as above.

8.8 Provides evidence that its systemic advocacy efforts within the past 5 years have had an impact on reduction in abuse and neglect.

Comments
Not possible to demonstrate actual reduction in abuse.
Hard to prove. Not all abuse & neglect is counted in official reports.
This will be difficult to measure. A reduction may indicate less reporting
Difficult to prove.

Comments
We can do the best we can but I'm not sure how we demonstrate a "reduction."
Require evidence of active and sustained efforts to reduce abuse and neglect. However, the impact or success of these efforts depends on external factors, such as the availability of resources and the willingness of other actors to collaborate.
Impossible to prove a negative

8.9 Conducts ongoing monitoring to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.

Comments
What is being monitored is unclear.
If resources allow
"Ongoing Monitoring" is impossible to qualify
Replaced “monitoring” with “review “in line 8.9
Rewrote 8.9: “Conducts ongoing monitoring to ensure appropriate implementation of new policies.”

8.10 Further comments, additional standards or criteria for systemic advocacy

Comments
The systemic advocacy role of the P&A systems is absolutly important and needs to be a standard, however there needs to be real caution so that P&A's are not held accountable to a process like lobbying, in which they are restricted from engaging.nI appriciate the attempts to have identifiabe outcomes in this section, but the outcomes need to be measurable.
-Sheltered workshops should be a target systems change so that workers can get jobs outside of sheltered workshops. -P&As should do a quality of life survey to see if people who have transitioned from an institution to community are being successful. -Monitor individuals who transition to be sure they are okay. Make sure these people know services of P&A.

E. Outreach and Community Education

Standard 9: P&As engage in effective and equitable outreach activities.

- Outreach is defined as efforts made to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of outreach is to identify typically unserved and underserved populations that might benefit from P&A services and programs.

Comments
Don’t agree our outreach should focus on general public. Also do not believe equitable is right criteria.
Focus should be on persons with developmental disabilities.
Delete " outreach is defined... programs and services." Define "equitable" Perhaps: P&As engage in a variety of outreach activities aimed at identifying unserved and underserved populations.
Standard OK. Definition is inappropriate
I would like to see outreach and community education cobined in one standard since there is little difference.

9.1 Conducts ongoing outreach activities.

Comments
Activities are great but the P&A should be looking at the outcome or result of the activities.
Need to clarify what outreach activities should include.
Rewrote line 9.1: "Conducts ongoing outreach activities to improve the ability of the P&A to meet the needs of individuals with DD and their families. Added "as amended" to the line "This should be required to meet the standard.
Require reporting on measurable targets and outcomes
Great goal but another that is necessary to be creative with so as to really reach underserved populations.

9.2 Targets populations that are underrepresented or unserved.

Comments
This standard may be interpreted based on race, gender, ethnicity or geography and attempts to address the targets may ignore the key issues facing people with disabilities. Input on priorities may indicate that incarceration of people with developmental disabilities is a key issue. As such the population served may be predominantly male. Would this standard imply more females should be served?
Should also reach out to people with other disabilities (i.e., non-DD) because there might be some common problems/issues.
Focus should be on persons with DD.
Require reporting on measurable targets and outcomes
Same as previous page.

9.3 Maintains a budget and designated trained staff for outreach activities.

Comments
Exceeds standards in some of the small states possibly?
It is possible to incorporate outreach into the job of many attorneys, advocates and other without having a separate budget and designated outreach staff. This could be particularly had for same minimum allotment. P&As.
This is a management decision on resource allocation.
Resources should be available but not necessarily designated staff (i.e., it may be same staff who represent client. It would be a luxury to have designated outreach staff who do only that.
It goes too far to designate staff for this. We have a small staff and we ask all staff to participate.
This criterion may not be practical for all P&As. A more reasonable approach may be to require a procedure to ensure that staff members with expertise relevant to the audience conduct engage in the specific outreach activity.
-Budget OK -Designation of staff is a management decision
Rewrote 9.3: "Maintains a budget for outreach activities." All staff should have the FYI here.

9.4 Employs a variety of strategies to conduct outreach.

- Examples of outreach strategies include use of the P&A website, brochures, presentations at community events on the P&A and P&A services, and visits to group homes and other facilities that house people with developmental disabilities.

Comments
Delete examples. Standard is fine.
Eliminate the examples.

Comments
Line 9.4: DELETED "and visits to group homes and other facilities that house people with developmental disabilities
Relevant, but not necessary to be solo. This could be condensed into/represented by other standards.

9.5 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.

Cultural competency and ADA best practices is a good thing. It might be good to ask how it is done and is it effective.
Rewrote 9.5: "Host cultural sensitivity trainings and ___inclusion trainings.

9.6 Obtains feedback on outreach activities.

Comments
Why feedback here; not other areas.
We already ask a lot of questions at intake without adding "How did you hear about the P&A?" If we're serving more of the under-represented groups, isn't that feedback enough?
Added to line 9.6 after outreach activities "from persons with DD and their families, service providers and the state DD agencies.
This is going too far. We get feedback on training events but not outreach events. Our resources are too limited to survey people on our outreach booth.
Feedback from staff? audiences? both? What type of feedback? formal (e.g., surveys) informal?
Again, this may depend on available resources. Good practice but not always feasible.
Does this need to be a sub objective? Not assumed?

9.7 Reviews outreach activities between planning cycles so that outreach plans and strategies can be revised as needed.

Comments
Rewrote line 9.7: Periodically, reviews outreach activities so that outreach plans and strategies can be revised as needed. As amended.
As necessary
We have a lot on our plate. Doing this once a year at annual planning is enough.

9.8 Includes Board of Directors (or Commission) members in outreach activities.

Comments
Should not prescribe board role.
Too vague
Should not be a requirement. It is a strategic option. We expect Board members to do a lot of other things.
This should be reflected in the standard about "a varity of stratigies to outreach.
Not sure if this is a good idea.
When appropiate should be added.
They should be included but is not required to attend.
The P&A should provide outreach to itself?
Goes too far. Board members are volunteers.
If interest is expressed and the setting is appropriate.

Comments
While one of the duties of board members is to represent the agency to the general public, I am not sure that this would fall under "outreach" activities.
please remember that our board members are volunteers so if this stays in then add to the extent possible

9.9 Documents that outreach efforts have increased the number of callers and clients from typically unserved and underserved populations.

Comments
No way to prove.
Rewrite: Documents the effects of the outreach efforts for unserved and underserved populations.
Rewrote 9.9 efforts have "been associated with increases in " the number…
P&A should conduct an analysis of their outreach activities and the outcomes realized by this activity. However, it may be difficult to show a direct causal relationship between outreach activities and an increased number of callers from underserved and unserved.
The effectiveness of outreach is not ? calls
Rewrote 9.9: "Tracks new outreach efforts impacted by the number of callers and clients from typically unserved and underserved populations and the needs felt by those communities."

Standard 10: P&As have an impact on access to services, inclusion, and choice for people with developmental disabilities through the provision of community education.

Community education consists of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

Comments
Delete "the public at large" line 10. Do not believe P&As should spend resource informing public at large.
Our priority should be education and training for people with disabilities and families. In a big state that's enough of a challenge.
As written, I am not sure how this can be measured.
But too broad.
this is certainly needed but unclear if it is the role of the PA
Somewhat concerned that this could be too broad.
Added "community participation after services and before inclusion But difficult to measure. Improved access to services could be the result of a wide range of different activities by different groups that may or may not have anything to do with the P&A.
We conduct self-advocacy legal rights training and it is geared to people with disabilities, not the public at large. They may gain access to the information but including them as part of the goal is beyond the scope of the DD Act.
What is the P&As role in relation to that of the DD Council and the UCEDD?
My only reservation is the part of the statement that references the public at large. Again, this may be a resource issue. If not even enough funds to educate persons w/ DD, then would be unable to conduct education activities for the general population.
Exceeds the role in DD Act. Confuses criteria and standard
See Comment for standard 9. I believe these should be combined.

10.1 Provides education, training, and technical assistance activities.

Comments
It's a strategic option if it helps to achieve a systemic goal.
Rewrite: Provides education, training, and technical assistance activities. Makes available and provides.
Try to educate legislature and policy people especially about barriers and issues DD community face.
Document objectives and measurable outcomes

10.2 Makes community education available to a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).

Comments
delete examples
Outreach activities must support the goal plan. Must have the flexibility to respond to public input, emerging issues, or resource limitations.

10.3 Targets community education to those in the community at large who can increase and improve services, choice and inclusion (e.g., health care providers, residential facility operators, employers, local government officials, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, daycare workers) for people with developmental disabilities.

Comments
Do not believe this is primary P&A role.
It's a strategic option if it will be effective in achieving specific goals.
Should be based on needs assessment and plan
If used this would need to be more focused, it suggests that P & As would be providing training to the community and less to people with disabilties.
Optional: The P&A is not always in the best position to provide broad based community education. It should focus on legal, protection and advocacy issues.
Our resources are to be used to help people with developmental disabilities. The statute would have to change to permit us to use funds that primarily serve a different population.
Eliminate the specific examples. Outreach activities must support the goal plan Must have the flexibility to target outreach in response to public input, emerging issues, or resource limitations.
This may or may not fall within a strategy. I don't this it should be expected each and every year.
As long as there is a dup. sub-objective noting that these same edu opp are focused spec for pwd.

10.4 Delivers community education through a variety of modes (e.g., classes, workshops, webinars, and online courses).

Comments
Delete examples otherwise fine.
It depends whether the P&A has decided to use community education as a strategy.
The role of the P&A is to Advocate and protect the rights of people with disabilities. They may have more effective stratigies to achieve this standard than the examples listed above.
Use more interactive education techniques that personalize experiences of DD persons and their barriers. Boring, complicated lectures or slide presentations may make it difficult for participants to learn much or relate info to their personal lives.
Optional
We are moving in this direction. It takes an investment of resources to set up the equipment for webinars. Minimum allotment states may not be able to meet the goal as written.
These methods could be much stronger with updated means of provision.

10.5 Delivers culturally appropriate and targeted community education activities.

Comments
Same Comment as 10.4.
Optional
Not necessary alone. Should be understood as a piece of all other sub-ob.

10.6 Maintains a budget and designated trained staff for community education activities.

Comments
(if feasible in small states)
Same Comment as 10.4 plus this can be part of the job of attorney and advocate staff.
Resource management issue.
Reword 10.6: Maintains a budge and assigns or provides staff for community education activities. Budget yet. "Designated?" Perhaps a different word.
Staff should go to conferences to learn new things and share experiences with other states at these conferences.
Optional
This criterion may not be practical for all P&As. A more reasonable approach may be to require a procedure to ensure that staff members with expertise relevant to the audience conduct engage in the specific community education activity.
Rewrote 10.6: "Maintains a budget for community split across staff education activities."

10.7 Determines recipient satisfaction.

Comments
With what?
Whenever feasible - This standard would apply to trainings/presentations? Community education is broader than trainings and presentations.
Rewrote 10.7: "Measures recipient satisfaction."

10.8 Documents that community education efforts led to improved access to services, choice, or inclusion for people with developmental disabilities within the past 5 years.

Comments
Cannot directly document that education increased success.
Too hard to prove the cause and effect.
Difficult to do; reward?
How to measure this
May be difficult to document.
I like this however it could be hard gain information to determine if the training you provided actually had the desired result. May need to narrow.
Our surveys can't document success for the past 5 years.
Require evidence of active and sustained efforts to improve access to services, choice, or inclusion. However, the impact or success of these efforts depends on external factors, such as the availability of resources and the willingness of other actors to collaborate.
May be impossible to ascertain

10.9 Further comments, additional standards and criteria for community education and outreach

Comments
I had real problems with this section. As written, it seems to contradict the priority setting process. Outreach is well covered in how Priority setting is done. This section only confuses the issues.
Staff and board should attend community meetings, trainings that aren't just focused on DD, for example go to a school board meeting on budget or transportation issues to find out what is available, what is changing, etc. in the community that may affect DD persons.

F. Governance and Management

Standard 11: P&A maintains an infrastructure that enables them to conduct all key functions efficiently and effectively.

Comments
Contingent on adequate resources from federal, state, and local sources.

11.1 Fills all vacancies on the Board of Directors (or Commission) within 1 year.

Comments
But note this is a different requirement than PAIMI.
Suggest "a reasonable period of time, preferably one year)
Many P&As have bylaws that specify a range in size of Board, e.g., 12-16 members. This requirement is too rigid.
The P&A should comply with the structure in their by-laws. This standard may be impossible for P&As that are internal to State Government.
May not need to fill if a range of numbers ___ Board members
Replace 1 year with 3 months.
Bylaws may have a range of board members on a maximum which doesn't have to be achieved at all times. There should be at least a minimum requirement which should be maintained.
No. We have a by-law that states a range. We don't need to fill vacancies unless we get below a certain number. The Board should be permitted to operate the way it wants too. This is micromanaging the Board.
May be unrealistic given the size of an turnover on some boards. Should be internally addressed within the Board's bylaws.
This statement should read something like this: "The P&A fill board vacancies in accordance with its bylaws."

11.2 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues.

Comments
Just not clear since Boards must be majority family, consumer not clear what expertise means.
Good to have these and other disciplines on the Board but there needs to be clear role definations between the Board and the Management. Attorneys on the Board need to understand their role as a Board Member, not a staff attorney. Conflicts of interest must be carefully managed.
The Board of Directors should have expertise in various issues besides the legal and fiscal. For example, in outreach, diversity, inclusion, etc.
Rewrote 11.2: "Maintains….policy, legal issues, and/or 1st person experience, specifically in the disability rights arena, and with some personal connection to the rights of pwd."

11.2 Includes Board of Directors (or Commission) members who are knowledgeable about the full range of the developmental disabilities population (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

Comments
Rewrote line 11.3: Includes Board of Directors (or Commission) members who are knowledgeable about developmental disabilities population and issues. Strike thru not relevant, rest is fine.
No one knows the "full range of the developmental disabilities population". We'd never find Board members who meet this qualification.
Replace “who are knowledgeable” with “who are or become knowledgeable.”
Should also include members outside the system, who don’t know much about DD. This way more people can learn about and become more interested in DD issues.
For me 11.2 and 11.3 is similar and can be merged into one standard.
To the extent possible
take out developmental since we serve all disabilities
On 11.3, circled “about the full range of the” Not sure if realistic—perhaps having some folks like this is good but also having those with specific expertise is only a few of these areas would be a +.

11.3 Familiarizes all new Board Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.

Comments
Not sure critical to be familiar w/DD Act (and by inference therefore goals of all & federal statutes.
They should be informed of all of the federal requirements that govern the P&A systems.
As well as the ones of The Council and UCED.
Rewrote 11.4: “Familiarizes all new Board Directors (or Commission) members with the mission and goals of the DD Act, it’s role in the larger ___ rights movement, and the developmental disabilities –related goals of the P&A.

11.4 Includes Board of Directors (or Commission) members who attend public events on issues related to developmental disabilities such as community meetings, legislative hearings, or non-profit organizations’ events.

Comments
Not clear.
This is too restrictive. There may be Board members who attend public events that are not DD oriented such as; Economic development, Education Reform, Transportation, Housing etc. These people too might be very valuable to the mission of the P&A's.
What does this mean?
Makes board or commission members aware of public events and invites them to participate if interested and available.
No doubt this would happen, but I don't think it should be a requirement for board membership
This is not a sentence. Includes what? Where?
Not something for this doc. Something else perhaps.

11.5 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.

Comments
Contingent on funding
The staff infrastructure needs to successfully address the mission of the P&A. The wording of this standard is intrusive into magement and Board responsibilities.
Rewrote 11.6: “Maintains a staff infrastructure with well-defined but flexible roles and responsibilities. Torn as to whether these should be in this document rather than another—not sure this is the place.

11.6 Conducts an annual performance review of all staff members.

Comments
Could add: "including performance criteria 'relevant to each person is specific' job"
This is a management issue
Uses the performance review to drive staff development plans.

11.7 Receives an unqualified audit finding (i.e., clean audit with no findings, no notice of noncompliance) each year.

Comments
There are different kinds of findings, so this seems too broad. See revision. Rewrote line 11.8: Receives an unqualified audit finding each year.
Not all "findings" are especially important – reward.
This MUST be re-worded. The standard should be to have an Annual Independent Audit. The audit will identify if it is "qualified or unqualified" and it will expose its findings to the Board of Directors.
Audit should be required—don't know about unqualified findings.
I am not sure or clear about this standard.
Require an audit – can't specify no findings. The issue is how P&A responds to findings
or if it recieves an unqualified finding immediately addresses it.

11.8 Budgets for professional development for staff.

Comments
Too detailed: laudable but with scarce resources this may not be feasible every budget year.
Excellent recommendation but Management is responsible for assuring that the staff has the competencies to meet the needs of the clients.
Especially for staff to attend continuing education and self advocacy conferences and trainings.
Bases the budget on a written staff development plan.
Same for Dis Training/Devel. For Board

Standard 12: P&A governance adheres to the principles and goals of the DD Act.

Comments
Self evident
It's the law
May not have the requisite funds to send board members to trainings.
This may be a resource issue from year to year.

12.1 Maintains complete independence from the Governor and the developmental disabilities service system of the state or territory.

Comments
Define "independence"
Requires clarification. Some P&As receive state funding and/or have contacts with state government to do advocacy work. This should be allowed.
Define "complete independence" There will and needs to be relationship with the DD service system. This language needs clarification.

Comments
Yes/But "Complete independence" needs to be defined. Does this mean that a person with a disability of family member who recieves services from a DD Service provider can not serve on the Board?
Some P&As are within state agencies
Strongly agree – would be a conflict of interest if P&A had to do litigation against state.
Rewrote line 12.1 Drop the word "complete" and replace with "operational."
Delete 'complete' – doesn't add anything
Please remember this when looking at other standards. The DD council for example requires appointment by the governor and is tied to the state services system by its very nature. this does occassionaly impact our ability to speak with one voice - a standard for collaboration.

12.2 Provides supports needed to ensure meaningful participation by Board of Directors (or Commission) members.

Comments
This is a reasonable accomodation. None of us are any good at REALLY ensuring meaningful participation. We might be ale to enhance opportunitied for meaningful participation through accomodations — but ensuring — we'd never pass this standard.

12.3 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available to each member in accessible format.

Comments
To each member "who requires them"
ADA requirement.
Location should also be close by public transportation, buses, etc.
Accessible format as needed or do you mean universal design?
Not this document.

12.4 Funds at least one Board or Commission member's attendance at a developmental disabilities-related national meeting each year.

Comments
Too prescriptive particularly as funding decreasing. Not even clear NDRN conf would meet standards. Rewrote line 12.4: Funds at least one Board of Commission member's attendance at a disabilities-related conference each year.
Add "Pending the availability of funds"
Too rigid. In a tight budget year, this may not be feasible.
This is a management of resources issue. They may actually see more value in responding to a caller than sending a Board Member to a national meeting. The meeting materials may be available through different formats.
May not have funding
Good objective. Not sure if it should be required.
This may not be feasible each year, either due to budget concerns or due to unavailablity of board members to travel.
Rewrote 12.4: "Funds at least one Board or Commission member's attendance partnered with at least one staff member's developmental disabilities-related (why not staff?) national meeting each year. Staff should have 1st representation here.

12.5 Further comments or additional standards and criteria for governance and management

Comments
Missing Standard: a requirement that the Board or Commission actually governs, i.e., sets policy and long range goals for the P&A; and holds the E.O/CEO accountable for adhering to those policies and long range goals.
General Comment – how do sheltered workshops fit in with the standards – how can we monitor what they are doing? That employees are not being exploited or left day after day with nothing to do? Make sure staff are always recognized for their achievements – at Board meetings, in press, community, etc.
I think management and governance two separate standards.

Appendix V3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

UCEDDs
Draft Standards and Performance Criteria – Version 1

Panel Member Comments

A. 5-Year Planning

Standard 1: UCEDDs identify the key issues, needs, and priorities of people with developmental disabilities and family members in their state or territory.

Comments
The way this is worded is more appropriate to Council State plans. It should just say that the UCEDD has a 5 year plan, based on data from a variety of sources, and the plan reflects the goals and principles of the DD Act. NOTE: The DD Act does not include any reference to STATE/TERRITORY-based planning for UCEDDs.
This standard and its performance criteria make it sound like a UCEDD's Five Year Plan is to be very similar to the DDC's state plan. The UCEDD's Five Year plan should build on the DDC's work but not duplicate that planning process. Because this standard misses the mark, it is difficult to Comment on the performance criteria.
Suggest that UCEDDS have availability of interaction with the community and that instead of just identifying; they assist n identification of needs in partnership with local, state and regional groups. UCEDDs have a unique position and have a lot to offer in the way of leadership
Hard to disagree but the standard is so open ended that it can operationally mean anything
This should directly state the DD ACt expectation for UCEDDS that there be a 5 Year Plan(S 154 (a)(2) that is part of the Core grant application The language utilized here is more descriptive of the DD Council responsibility in planning; Comments on program criteria that follow reflect the respect for the 5year plan as outlined in the act as opposed to this phrasing Comments on
See specific Comments
Very important that UCEDDs be involved in identifying priorities that fit/specific to their state and capacity

1.1 Collects input for the 5-Year Plan from internal and external sources.

- Examples of internal sources include UCEDD faculty and staff, the Consumer Advisory Committee (CAC), students, and DD Network partners in the state or territory.

- Examples of external sources include people with developmental disabilities receiving services from the UCEDD, data from UCEDD activities (e.g., community services), research and other reports that contain valid and reliably collected data, and state and territory disability organizations and advocates.

Comments
This should focus on the concept of using data from a variety of sources, and could incorporate some concepts from 1.3-1.5 below. I don't think the internal/external sources distinction is relevant. If it is used, the definitions have to be changed. CAC and DD Network partners are external, not internal.
This is worded generically enough that it's hard to disagree. But it does NOT reflect the correct understanding of what is "internal" and what is "external." For example, UCEDDs have CAC's to get external input into their planning and operations as well as evalutation of their performance. CACs are not "internal."
Another addition to examples of external sources is the state DD agency
Exceeds the standard As written. Concern about examples throughout document as being viewed as absolutely predictive. Either make clear that programs are not required to do all or leave it out
Example could include national priorities based on policy area changes such as health care reform or new research findings which may not at the time be high priorities for state agencies or consumers
External also includes families, service providers and policy makers
Should also include policymakers and families. Assume age, gender, ethnic diversity
Doesn't address university context which is imperative
Internal to what? Unclear. However, CAC is NOT an internal body of the UCEDD. By definition they are 'community partners and stakeholders'.
First, there are too many performance criteria for this standard and they border on stipulating the obvious or micromanaging the process. With regard to this performance standard, there should be internal and external sources. The examples should be qualified to state "may include, though are not limited to" instead of just "include."

1.2 Collects input for the 5-Year Plan from geographic regions across the state or territory.

Comments
It seems to me that the focus on geographic representation is more appropriate for the DDC's state plan.
How is this different from internal and external sources? I think it could be a part but some states may have different way of interpreting this standard. Suggest adding this to the criteria 1.1 above as a possible way to categorize sources
There are only a few states where geography really plays a role in differentiating consumer needs. In most other states even the large Western states, the issue is type of community (e.g., urban/suburban/rural/isolated) not geography. I think this criterion should be dropped.
Interview
This may be a reasonable requirement for states with only one UCEDD - but for states with more than one there needs to be a regional contingency to avoid competition, gaps and overlaps.
Quantitative; qualitative
Planning requirement should reflect the scope of UCEDD functioning-saome are statewide; others mutliple UCEDDS in state
At least regions within UCEDD's catchment when state has more than one UCEDD
I don't disagree with the need to have data that represents the needs of stakeholder across the state or territory. Using the verb "Collect" though goes beyond the requirments and could be interpreted to require that the UCEDD can only use data that is directly collected by the UCEDD. There are multiple sources of data that should be used, much of which is not "collected" directly by the UCEDD.

1.3 Uses a variety of methods for collecting input for the 5-year Plan (e.g., focus groups, surveys, social media outlets, the UCEDD website, and review and analysis of reports and studies).

Comments
Again, this is generic enough that it's hard to disagree. But there needs to be a correct understanding of what the UCEDD Five Year Plan is supposed to be.

Comments
May suggest standardizing this to a specific # of methods i.e., at least two different methods of collecting input (e.g., focus groups…) Using a variety really doesn't suggest multiple methods unless that is NOT what you are after as a criterion?
Exceeds the standard as written. Same Comment as earlier. Make sure it is clear that examples do not all have to be done to meet the standards of take them out
Too prescriptive
Would be appropriate if not all were required - i.e., focus groups, surveys, social media should be listed with "or"
Include SES as distinct variable and group. Disability plus poverty is highly correlated and needs are very different by income level
Other disability [illegible] not just DD
Too prescriptive without being elucidating- suggest terms: "comprehensive planning which utilizes methodologies appropriate to university and state context"
The parenthetical e.g., could be interpreted to require all or most of these methods. Either delete the parenthetical examples or state that such methods "may include but are not limited to"…

1.4 Collects input for the 5-Year Plan from, or on behalf of, a broad population of people with developmental disabilities (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups) in the state or territory.

Comments
Again, this is generic enough that it's hard to disagree. But there needs to be a correct understanding of what the UCEDD Five Year Plan is supposed to be.
Again, how is this different from 1.1? People with disabilities are mentioned as external source in 1.1. Expand the definition for the criteria above and eliminate this one.
All disability types too broad a category
This criterion is problematic. There are an infinite number of ways the population can be segmented. Further, the more segmentation that is done to assure that data are gathered to represent each segment, the smaller the cell numbers become and the less useful the data are. I would suggest wording for 1.4: "Gathers input for its five year plan from a wide cross-section of the state or territory's disability population representing many different segments of the community". Don't enumerate the segments. This should be left to the UCEDD.
Would be quite expensive and beyond legislation to require all. If implemented would require a large number of subgroups. Useful though as examples indicating possible groups
How about intellectual barriers or communication barriers etc.?
The requirement should be to reach out – survey but cannot guarantee they will respond. 'Collects input' from all groups – across all regions. This could be difficult/impossible to do.
Again, the paranthetical e.g., requires actions that are neither required nor achievable. It would be impossible to get input from someone from every "type" of developmental disability. This would also require UCEDDs to become overly categorical in reporting, something many UCEDDs fight against. Further, many external data source do not provide detailed information on types of DD. Delete this.

1.5 Collects input for the 5-Year Plan using a variety of modes (e.g., in person, electronic, written, use of pictures, translations) to accommodate people with developmental disabilities or people facing geographic, language, or cultural barriers.

Comments
Again, this is generic enough that it's hard to disagree. But there needs to be a correct understanding of what the UCEDD Five Year Plan is supposed to be.
1.3 specifies using a variety of methods for collection of input – specify that methods and efforts are made for accommodation – doesn't really need to be a separate criteria on a checklist

Comments
This is duplicative. You've already established criteria specifying multimethod and multisource.
Again - UCEDDs as all network members are required to have meetings and materials accessible. To translate all materials for all possible significant populations would require more than available resources and would leave little for other functions other than needs assessment
This is a great idea but currently the UCEDD and the other network partners have different planning cycles
reference "comprehenisve"
I don't oppose this, it's just too prescriptive. There are too many performance standards, and this one is one that can be deleted. Further, most of these are process standards and really do little to ensure quality.

1.6 Leverages its own planning efforts with the planning efforts of DD Network programs in the state or territory and other developmental disabilities partners to increase planning efficiency.

Comments
This should be worded: The plan should be consistent with, and to the extent feasible, complement and further, the Council goals contained in the Council Plan and the P & A Plan.
The concept is OK, but the language is unclear. What does "leverages" mean? It would be better to more closely reflect the language is Sec 154 of the DD Act.
Yes, how to document this? Leveraging sometimes refers to dollars and/or personnel time. Clarification or examples of what this might look like for those states with weaker partnerships
Although not explicit in the standard, this is ***critical*** to make sure "other partners" includes the state agency
Although this may be desirable, it is often not feasible given that our network "sisters" may be on different planning cycles.
You've already specified a criterion to include data from the DD Network in the planning. I'm not sure what this one means?
This is an area where ADD technical assistance might be useful.
"leverage" is misused here; coordination or utilizes material is more apporpriate
'Must. But still DD Council and P&A have a very different focus and mission. So their needs assessments have different info – different questions. We may have different areas of emphasis
Delete "to increase planning efficiency" and just end it after "partners."

1.7 Gathers data for planning on an ongoing basis throughout the planning cycle.

Comments
This should be worded: The plan is reviewed and revised annually as necessary to address emerging trends and needs.
Too unclear. What is the "planning cycle?" How long is it?
I think this makes common sense, but is it something that will be measured by ADD in reporting? If not, don't see the need for a criteria in the performance standards
But a good idea
Although desirable, may not be measurable.
If the standard is a five year plan, then the data collection should be relevant to a five year plan. If the standard were 'ongoing planning processes then this one would be relevant.
unclear what this means; ok to reference the point about yearly review of goals & progress with CAC specified in DD Act
There needs to be a planning cycle and implementation cycle.
What's the planing cycle? Arguably, the most important data is the data closest in time to the submission of the plan. Delete this performance standard.

1.8 Has faculty and staff who serve on community and agency boards and committees to complement ongoing information collection about the needs of people with developmental disabilities and family members.

Comments
This is OK, but the primary purpose of faculty and staff seving on boards and committees is not for the UCEDD's Five Year Plan.
UCEDDs are unique organizations and faculty and staff serve in many capacities. This most definitely should be the criteria
Good idea and perhaps rather than a required activity be one of the examples of how to meet the standard
Make sure no conflicts of interest
May be desirable but not feasible or measurable.
This criterion does not specify that the boards are state or territory. They could be local or national in which case the data or information may not be relevant
Although could be a recommended practice and should not be a criteria as it is beyond performance standard
Serving on boards should not just be for UCEDD info collection but to improve community outcomes as well.
If faculty and staff do this on paid time or as a representative of the UCEDD, this is certainly desirable and can be required; however, what people do on their own time should not be a requirement.
Faculty & staff serve on boards to provide TA, disseminate info & increase community capacity- information learned is a by product not the purpose
Clearly exceeds requirements. This would just become a "check if done this" type of requirement. Delete it.

Standard 2: UCEDD 5-Year Plans reflect the needs of people with developmental disabilities and family members in the state or territory and are blueprints for UCEDD action.

Comments
I don't think this is necessary. All of the perf criteria related to the 5-year plan can be included under one standard.
It would be better to more closely reflect the purpose stated in Section 154 of the DD Act.
Again so broad it is hard to disagree – but the 'needs' of people with ID (esp. adults) and families may be at odds
This is a compound requirement. The first part duplicates the previous standard. It would be simpler if it were not two parts.
This is two separate tasks - reflects needs and serves as a blueprint.
Need to include university conext here; following criteria should lead with DD Act-reverse order of 2.2 & 2.1
This seems redundant or unnecessary. The first standard deals with anything of substance in this standard.

2.1 Reflects the internal and external input from the planning process.

Comments
This is ok, but I would recommend removing internal and external (see above).
Yes, but get the "internal" and "external" examples correct.
How would we document this?
synthesis of input would seem to be a more appropriate construct
Internal and external to what? Needs more clarity
This repeats what's required in Standard 1.

2.2 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (e.g., access, inclusion, choice, basic human rights, quality of life).

Comments
This is fine, but I would review the examples of principles and realign more closely with the DD Act.
Of course. But it would be more accurrately to use the language in Section 153 of the DD Act (e.g., exercise self-determination, be independent, be productive…)
Kind of obvious?
I believe that these are important issues, but UCEDDs are complex organizations and often have programs that do not directly support the DD Act
The examples are too limiting, expand the options or delete all together.
Drop '2000' to accent on reauthorization
BUT state goals & principles with more precision
This seems obvious and unnecessary to state. Perhaps just a preamble to Standard 1 to state this. I don't think the Standard is necessary, but if it stays in, this is the only unique item.

2.3 Drives the activities that the UCEDD conducts and supports.

Comments
OK, but would recommend Guides instead of Drives.
Five years is a very long time and state environment can change drastically due to political changes and economy. There is always the option to amend parts of the plan
Would help to operationalize with examples
I believe that there needs to be room for activities outside of the five year plan in order to respond to emergency needs and opportunities
How is this measured in the context of a 5-year plan? It's an annual report item, perhaps.

2.4 Contains priorities that balance the needs of people with developmental disabilities and family members with UCEDD resources, outside resources, and the potential impact of strategies that were considered.

Comments
Unclear.
What does "balance" mean? How would you measure this?
The word 'balance' is confusing – perhaps 'reflect'?
Include family members only for minors, do not give same preference to family members of adults
This standard is poorly written - I have no idea what it means.
Not sure how this would be measured - seems vague
I don't know how this would be documented
this feels like there is too sharp a division between the UCEDD & the community I'd prefer to see "reflect" rsather than balancing
Redundent to Standard 1.

2.5 Further comments, additional standards or criteria for planning

Comments
The 5 year plan section could easily be handled under one standard. At a minimum, the performance criteria should address the requirements of the DD Act. In addition to the criteria-specific Comments above, two additional key issues with regard to the 5 year plan should be addressed here, as additional performance criteria: 1) the plan includes goals and activities in each of the core function areas; and 2) the CAC consults with the UCEDD on the development of the 5 year plan, and annually review and comment on the progress of the UCEDD in meeting the goals in the plan, and recommend plan revisions as appropriate. NOTE: The DD Act does not include any reference to STATE/TERRITORY-based planning for UCEDDs. UCEDDs work closely with their Councils on developing the DD Council StatePlans, and then utilize the Council plans (and other plans) in UCEDD planning.
Although there is extensive effort to gather input from DD partner agencies there does not seem to be any effect to incorporate elements of all five year plans jointly. Since all the DDCs, UCEDDS, and P&As are working on this project with Westat it would seem an opportune time to see how the five year plan could be used to support the partnerships of these agencies within states. Even more significantly would be states with more than one UECDD
More emphasis is needed on working with the state agency partners – the state is the largest funder of ID/DD services and really drives the system – UCEDDs need to influence, support, and enhance those systems
These standards are not ones that are espoused for the UCEDDs in the DD Act and I find it troubling. Although a good planning process is critical in laying out our work plan for the next 5 years, the prescriptive nature of these standards is problematic. It seems as though we are being thrust into the same pot as the DD Councils who do have more specific planning responsibilities. In addition, many of these standards are not measurable.
Standards imposed for this area reflect only one of our many constituencies including families, university students, state service agencies, and others. The standards only address state/territory needs, nothing about national capacity or segmentation
Clearly a needs assessment is important one has to be careful that the processes do not throw out of balance the allocation of resources for this area versus other functions of the UCEDDs. Also I think it is important that some of the activities of the UCEDD are driven by the resources which they are able to leverage. Unlike the DD Councils who have much more flexibility on the areas to which they allocate their resources.
Need something about having UCEDD leverage other public and private ? and report to ADD/ Also need to break plan of action into three areas: -Research -Training-Technical Assistance -client services
NEED TO CLEAVE MORE TIGHTLY TO THE DD ACT & THE ROLE OF THE UCEDD-WHICH IS DIFFERENT THAN THE DDCOUNCILS- BOTH PLAN BUT IN DIFFERENT WAYS
Delete Standard 2, it's redundant and unnecessary. Reduce the number of performance criteria in Standard 1 to eliminate unnecessary microanalysis and paperwork standards.

B. Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3: UCEDDs prepare students to implement an interdisciplinary approach to serving people with developmental disabilities and family members.

An interdisciplinary approach requires interaction among multiple disciplines to resolve a common problem.

Comments
See detailed Comments on this standard and criteria below.
Poor definition of "interdisciplinary" as approach to resolving "common problem." Interdisciplinary training is much more than an approach delivering clinical services. Consult AUCD's Council on Interdisciplinary Services and National Training Directors' Council. As with Standard 1, when the standard misses the mark, it's hard to critique the performance criteria.
I think this is a good principle but reads more like a definition of interdisciplinary approach. It should be a standard of professional training to expose and educate students in the interdisciplinary approach – consider writing a stronger statement
Add 'family members of minors', then will agree
This is NOT consistent with the DD Act. This needs to be re-written
"common problem": don't like the idea that DD is a problem
The UCEDDs are preparing practitioners (even though they may be students during their work/studies with the UCEDD)
UCEDDs provide interdisicplinary training-services & supports are not necessarily interdisicplinary. This also has too much of an underlying assumption of clinical service delivery Resent the term "common problem"-in supporting individuals with DD & their families we do not think of that or them as "problems"
I have no problem with the first part of this, but the "definition" of an interdisciplinary approach, particularly the underlined "a common problem" bit, is out of left field. Delete that.

3.1 Offers developmental disabilities-related courses or trainings based on content from a variety of disciplines.

Comments
There is too much emphasis in the performance criteria for Standard 3 on didactic courses and trainings. Criteria that address clinical training must also reflect clinical experiences and mentoring.
Would add technical assistance after courses and trainings
. . a variety of disciplines relevant to the disabilities field.
And emerging research and ?
Assumption of "courses" doesn't reflect the structure of many disciplines, i.e in medicine or workshops. Clinical & leadership training as well as community traiing & practicum expoeriences are not captured by these terms
Having said that - I don't think this should 'require' UCEDDs to only offer trainings and classes that are 'interdisciplinary'. Single discipline courses and/trainings also have their place/value
Fine, but you could combine Performance Criteria 3.1, 3.2, and 3.3 into one performance criteria.

3.2 Offers developmental disabilities-related courses or trainings taught by faculty and staff from multiple disciplines.

Comments
There is too much emphasis in the performance criteria for Standard 3 on didactic courses and trainings. Criteria that address clinical training must also reflect clinical experiences and mentoring.
May want to operationalize to how many disciplines and/or which ones
This level of drill down is unnecessary
Must co-teach with people who are impacted. Add 'family members and/or PWDs' to 'faculty and staff from different disciplines'
Should include self-advocates and families
Multiple disciplines - vague
emphasis on "courses" misplaced

Comments
Again, should be offered but all courses can or should be taught by faculty from multiple disciplines
Fine, but you could combine Performance Criteria 3.1, 3.2, and 3.3 into one performance criteria.

3.3 Offers developmental disabilities-related courses or trainings to students from multiple disciplines.

Comments
There is too much emphasis in the performance criteria for Standard 3 on didactic courses and trainings. Criteria that address clinical training must also reflect clinical experiences and mentoring.
3.1 – 3.3 seem redundant. UCEDDS exist n different environments and different generations. Some have faculty with teaching responsibilities with course etc. and others are clinical based. There needs to be a standard that allows for the variety of teaching environments (person, online, synchronous and asynchronous) as well as the source of the education; grand rounds. Important standard criteria but one is needed here not three separate ones
Isn't this the same as above?
Fine, but you could combine Performance Criteria 3.1, 3.2, and 3.3 into one performance criteria.

3.4 Involves students in the conduct of research and reporting.

Comments
Suggest separating 'research' from 'reporting'. Students may engage in research but not be around to report on it. Otherwise, students should be encouraged to start research or investigate topics of interest pertaining to research. Criteria should be more specific as to activities that would meet this criteria that are beneficial to the students
Although laudable, some students may only be seeking training
Although admirable, again, not consistent with the DD Act.
Not sure what 'reporting' means
Doesn't directly relate to standard but would be an important item
Should this not be under Research? Or should be phrased as 'teaches research skills to students'
Although involvement in research is most likely a part of most students' training, this criteria exceeds the standard and would simply result in statements in the 5-year plan that this would be done. Delete it.

3.5 Assists students in finding work, career or educational options that benefit the quality of life of people with developmental disabilities.

Comments
Of course, UCEDDs want to facilitate trainees' career searches they are not placement services.
I think this would be very difficult for the UCEDDs to do successfully. I feel that while we certainly assist students with reference letters and resources such as AUCD trainee network, this is a difficult criteria for UCEDDs to be evaluated on
Nice idea but perhaps outside the scope of the UCEDD
Again, admirable but not consistent with the DD Act.
This activity though important is after training
May be informally done but does not rise to the level of a performance criteria
I don't think we can be held responsible /accountable to find jobs – too many factors beyond UCEDD's control
Same problem as above. It would only be a stock statement in the Plan and although I'm sure it happens in most UCEDDs, it exceeds any real requirement.

3.6 Infuses disability-related content into courses outside the department and school in which the UCEDD is housed.

Comments
This is of course ideal but again does not take into account the variety of settings a UCEDD might be housed. This could be an unfair burden for some programs to accomplish. Some programs are housed in hospital programs (clinical)
Laudable: but not sure how or if a UCEDD can/should be required to successfully do this as it takes other departments/schools within a university to succeed. UCEDD can't be held accountable for other department's failure to act
They may be able to offer input or influence this but the offers aren't accepted – perhaps 'demonstrates efforts to infuse"
Assume the UCEDD can work to do this they may not always be successful. Their success is sometimes out of their control
This is a swell idea but is often impossible to do given the complexities of curriculum approval at the university. "infusion" is only one of several strategies that might be used.
Again - a worthwhile activity but exceeds level of the standard Suggest: insert or "influence" and include trainings and materials
narrow view-"coursework
We don't have control over this. Plus funding in Universities (teaching credit hours) is often an institutional impediment
Performance criteria 3.6., 3.7, and 3.8 exceed ADD requirements and given the requirement for follow up with trainees, becomes a paperwork and resource burden to document. They could be combined into a single criteria that states that the standard "may be" be achieved, in part, by activities "such as"... Otherwise, delete these three.

3.7 Lists UCEDD-developed courses in more than one department in the university.

Comments
This is desirable but may not always be possible; therefore, it should not be a performance expectation.
Again see Comments re: concern about settings. Course lists could appear elsewhere such as ? And as non-credit offering on a UCEDD site. Limiting to just university may also not be up to the UCEDD to determine what is listed for departments
Again, this is one strategy, but is often against code or practice in many universities
some centers cannot give courses or have course numbers
Would be nice but this idea is highly ? And dependent on the specific rules of each partner university. Difficult to mandate and a UCEDD should not be measured against this standard when it may have no control over its implementation
Different institutions have different rules, while desirable cross listing may not be an option in some environments
narrow view-"coursework
Again, although we have this at [UCEDD], the UECDD has little authority over such matters
Performance criteria 3.6., 3.7, and 3.8 exceed ADD requirements and given the requirement for follow up with trainees, becomes a paperwork and resource burden to document. They could be combined into a single criteria that states that the standard "may be" be achieved, in part, by activities "such as"... Otherwise, delete these three.

3.8 Develops courses that are adopted by other universities.

Comments
Absolutely out of the question (and very worrisome that it would even be included in the draft). It is very naïve and indicates a lack of understanding of the academic environment in which UCEDDs operate.

Comments
Plus or the cherry on the top
Nice idea but again probably not enforceable
Again, not in their control what's accepted by other Universities
Not required by the DD Act.
Course exports are rare
Highly desirable but can we reasonable hold them responsible for something they don't have control over?
narrow view-"coursework
I can't begin to imagine how this might happen
Performance criteria 3.6., 3.7, and 3.8 exceed ADD requirements and given the requirement for follow up with trainees, becomes a paperwork and resource burden to document. They could be combined into single criteria that states that the standard "may be" be achieved, in part, by activities "such as"... Otherwise, delete these three.

3.9 Impacts the community by having former students enter a disability-focused field or line of work.

Comments
Purpose is to generate a professional workforce – should be an outcome of the program. However, trainees move – may not be the community of that particular UCEDD that benefits
How does the UCEDD have control over this? Again could be one possible target
UCEDDs have NO control over this - again, nice to measure but shouldn't be a standard in this way. This is a great measurable outcome but not a performance standard.
How would you ever be able to tell if the students that entered the field impacted the community?
This is ideal but the UCEDD cannot be held responsible for the decisions of its students once they leave the training environment
This, again, is two different tasks - impactingthe community and having trained practitioners enter disability-focused positions. Having trained practitioners eneter disability-related positions is reasonable - it would be a long stretch and many years to document impact on the community.
IWhat ius a disability focused field or line of work? People with disabilitties utilize a range of services & supports in the community. Too narrow a view
But this needs to be open: Question would getting a job as a university professor meet this requirement? Perhaps not...
The requirement of follow up questionnaires already deals with it. Delete it.

3.10 Prepares students to apply a multidisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.

Comments
OK. But why not "interdisciplinary?"
Use 'interdisciplinary' in place of 'multidisciplinary' for consistency. Consider rewriting – ultimate outcome of training but how do you hold a UCEDD accountable for this as a measure? # of trainees generated, # of people served by the trainees in the field, but how do you measure an 'increase in inclusion and choice for PWD'?
Absolutely
Need a standard that requires student involvement/practicing during school in a DD service ? In other words, to get experience and more than just in research
People don't "apply" a mutlidisicplinary approach-they can learn to function within an multidiciplinary/interdisicplinary context; appreciate the contributions of others et. Inconsistencey between interdisciplinary & mutlidisciplinary-DD Act: interdisciplinary training
Difficult to operationalize and measure

Comments
This is fine.

Standard 4: UCEDDs prepare students to reach a diverse population of people with developmental disabilities.

Comments
This could be a performance criterion - no need for a separate standard. See Comments below.
What does "reach" mean? Once again, when the standard is off the mark, it makes Commenting on the performance criteria difficult.
This is a duplicate question
what does "reach" mean students are trained to be culturally & linguistically competent in their approach
Could we not have training programs that specialize training in cerebral palsy or autism?
This is fine.

4.1 Recruits students from culturally and linguistically diverse backgrounds.

Comments
Recruiting is a process. We should focus on outcomes - actually including diverse trainees in our training activities.
Fine, but don't we want to do more than recruit? We need them to enroll.
How does this relate to preparing students to work with diverse cultures? I think it's important but in wrong place
Make the language understandable
substittues outreach for recuit
Don't disagree with this. But not sure how the two are related
This is fine.

4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities (e.g., serving as lead instructors, co-instructors, curriculum developers).

Comments
Yes – this is preparation of students' exposure.
Remove e.g., or make clear not held to standard
And practitioners
criteria is important-examples overreach "lead" instructor- what does this mean; need to appreciate university titles & requirements
Not convinced this should be a performance criterion for all trainings
Although many UCEDDs do this, it seems to me to add to the requirements. Most LENDS do this, and I'm not philosophically opposed to it, I just don't think it should be a "thou must" type of item.

4.3 Provides students with coursework that leads to an understanding of the daily lives of people with developmental disabilities and their families.

Comments
But this must be MUCH more than "coursework." There must be practicum experiences.
Yes
would insert "or trainings"

Comments
And experience. Seems like a better way to say this: e.g., experience, education
I like this – speaks to real-life relevance
This is fine.

4.4 Provides pre-service and graduate students with opportunities to interact with people with members.

Comments
Yes
what does "interact" mean?
Need to be more specific. This could just be a trip to a DD Center. [Rest of the Comment illegible.]
Good
Maybe this criteria could include a "may include" that reflects the intent of criteria 4.2 so that it's not viewed as mandated.

Standard 5: UCEDDs improve the knowledge, skills, and strategies of service providers and practitioners through a continuing education program.

Comments
See Comments below.
"a continuing education program?" It's unclear what the expected scope of continuing education should be.
Need to define continuing education for UCEDDs. This means different things to people i.e., credit for licensure OR continued education for one's knowledge
would suggest adding after ce - inservice or technical assistance
Need to specify the target audience and professionals
"A" contuinung ed program? Is that one offering Suggest provides continuing education & inservice training that imporves supports- increases capacity See definitions in DD ACT
I don't interpret the ADD Core Function for Interdisciplinary training to require contining education, but instead as a means to the end of achieving interdisciplinary training. Eliminate this standard.

5.1 Provides continuing education course work to a variety of professionals in the community.

Comments
5.2 says it better. Not all UCEDDs will offer courses of this type.
Again a definition of continuing education. Add 'conferences approved for CEUs, workshops' etc. to 'course work'
DD Act refers to this under Community Training and TA
again include "inservice"
When? Get specific. Is it CE or TA? Or do we need both?
language of coursework is problematic
MJST, to build capacity
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

5.2 Provides continuing education on topics of interest to service providers and practitioners.

Comments
How is this different from 'professional in the community' in 5.1?

Comments
Solicits topics of interest
DD Act refers to this under Community Training and TA
Duplicates other criteria
Tie back to five year plan needs assessment. This is a big problem in the UCEDD world. Topics of interest to whom? Must be relevant
"topics of interest"???
How do you measure this? By participation? Survey? How is it different from 5.3?
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

5.3 Bases continuing education course topics on documented needs in the state or territory.

Comments
Yes
DD Act refers to this under Community Training and TA
Five year plan
neglects importance of continuing ed & inservice as creating a vision
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

5.4 Develops continuing education programs (including courses) that are adopted by other states or internationally.

Comments
Once again, very naïve.
Ok, clarity on 'programs' and 'courses'. I think criteria should be more specific here yet still allow for flexibility and diversity of UCEDD training in the community
Adoption not in their control.
These are nice indicators of quality, but they rarely occur
Little control over this in many states
Again, the UCEDDs can't be held responsible for something they have no control over.
Five year plan
This is ridiculous- state needs vary
Needs might be state/region specific. If we are measured in courses that get only get picked up nationally or internationally, might reduce emphasis on state/region needs
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

5.5 Develops continuing education that becomes part of a state requirement or certification.

Comments
I can see this as a product of state contract that would meet the standard however may be difficult for every UCEDD to make it happen
Up to the state to decide
Again not in their control
Not consistent with the DD Act
The reverse is more often the case where the continuing education is developed to help people meet certification requirements
Again this is ideal but the UCEDD cannot be held responsible for the state's mechanisms for establishing state requirements for certification

Comments
States can have changes in command that might make this impossible for some programs
Over whom? What? As written this is just self promotion
Cannot make a UCEDD responsible for state requirements or certification which are beyond its control
Not sure we have a lot of control over this. This is great when it happens but VERY rare
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

5.6 Can document that participants in continuing education impact the developmental disabilities community.

Comments
How is this to be measured and documented?
"Impact": How would we determine this? With asynchronous or community training we may not be able identify participants for followup to determine outcomes/outputs from our community education
Unmeasurable standard!
While some kind of learner satisfaction and training evaluation is appropriate, you'd break the bank trying to document the impact of continuing education on the DD community
Expensive and extremely difficult to track longitudinally
Very difficult and costly to do
Can document that participants are well prepared to work in the disability field but documenting impact will take a long time and divert resources.
Documentation needs to be very carefully thought out.
(Illegible): ? an impact could be very difficult to document. ?
This in its present form is not measurable- How would you define impact?
But will be hard to capture
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

5.7 Further comments, additional standards and criteria for interdisciplinary preservice training and education:

Comments
This section is a very difficult section to rate for a number of reasons. It just seems to miss the mark in terms of this core function. It reflects only one (of many) approaches used by UCEDDs to conduct training. The focus on university courses and coursework is too limiting. Many UCEDDs also conduct extensive interdisciplinary preservice programs, as part of practica, field work, internship or fellowship training. These programs have organized curricula, but are not presented as university courses. Also, the point of interdisciplinary training is not to prepare students to implement and interdisciplinary approach. It is to advance practice, scholarship and policy that impacts the lives of people with DD and their families. That should be included in the standard. The performance criteria could include: Continued on attached document ..... Performance criteria could include: integrates knowledge and methods from two or more distinct disciplines; integrates direct contributions to the field made by people with disabilities and family members; advances the academic or professional credentials of participants; incorporates cultural and linguistic competence elements into training; addresses policy development, implementation and evaluation elements; includes trainees from underrepresented racial and ethnic groups, in proportion to the state or region; can document the percent of graduates who are engaged in work related to people with DD and their families 5 years after training; can document the percent of graduates in leadership positions related to DD; may offer training that leads to the award of an academic degree, professional certificate, or advanced academic credential. Continuing Ed: Should include performance Criteria such as: provides participants in Continuing Education activities with certificates of completion or CEUs; addresses topics that allow professionals to maintain professional credentials, expand their knowledge base, and stay up-to-date on new developments; provides continuing education training that promotes the principles of the DD Act.
Continuing education specifically adult education is a rapidly changing and UCEDDs are trying to catch up. All are good goals but how to capture these elements needs refining and defining of terms is critical to some semblance of consistency across programs
Again, working in partnership with states is critical as they set the training requirements for providers and the UCEDDs need to mesh with those requirements and if possible, influence the requirements.
Many of these standards are not consistent with the DD Act under interdisciplinary pre-service training. Equally as important, most of the standards would vbe difficult to near impossible to measure.
One has to be careful with only listing continuing education which is a term of art in many states. Would include; inservice training and technical assistance to cover the ground in which many UCEDDs are involved.
This standard is way too meager and will do nothing to improve the UCEDD. It is very self promotional. Needs a lot more thinking
UCEDDs are preparing practitioners (even though they are students at the time) and that should be reflected throughout. And requirements/standards must be something that the programs have control over despite the fact they they are highly desirable.

C. Basic and Applied Research

Standard 6: UCEDD faculty and staff conduct research that is relevant to improvements in the lives of people with developmental disabilities or family members.

Comments
definition of research will be important and will need to include evaluation efforts
“improvements”: Not sure this item is necessary. Reword as ‘relevant to the lives of…” +! Family members – not ‘or’ only

Comments
Need standards on: -presentation/publication/application of
Language of "improvement" seems unprecise & inapporpriate
Applied emphasis this will not relate to 'basic' research/science
This is fine.

6.1 Conducts basic research, evaluation, or policy analysis relevant to improvements in the lives of people with developmental disabilities or family members.

Comments
But, must add applied research to the criterion, as stated in the DD Act.
Use the language in Section 153 of the DD Act: "conduct of research, which may include basic or applied research, evaluation and analysis of public policy..."
How is 'relevancy' determined? What is that standard?
How is 'basic' defined? Basic in the DD field is often taken to mean medical, genetic, or causal research
UCEDDs can and should conduct research, evaluation and/or policy analysis but requiring laboratory-based "basic research" is an expensive proposition that UCEDD funding would not begin to make happen.
Emphasis on 'relevant'
improvement is not an apporpriate term
May be 'evaluation and policy analysis' but difficult to see how this reaches basic research. Not all centers do basic research or policy analysis.
This is fine except you need to delete the adjective "basic." If anything, UCEDDs do applied research, but don't qualify it either way, just leave as "conducts research ..."

6.2 Involves people with developmental disabilities in the development, design, or implementation of the research (e.g., identify research topics, assist with the design of data collection instruments, help to ensure that research materials are in accessible and understandable formats, recruit people with developmental disabilities and family members as study participants).

Comments
What others might be involved?
Same issue about examples
Uses participatory and empowerment research strategies
I understand the theory but do not feel it should be a requirement for research
I think there is a lot of research that is NOT PAR [participatory action research?] that can benefit persons with DD and their families
Some research can meet this criteria,but for some types of research, this is inappropriate. Combine 6.2 with 6.1 and add "and, when appropriate, invovles them in the development, design, or implementation of the research."

6.3 Can document that their research has had a direct impact on people with developmental disabilities in the past 5 years.

Comments
How would this be documented?
This may be beyond the scope of the UCEDD to affect change – certainly could and does happen but feel it could create a burden for UCEDDs to meet this criteria as a requirement measure.
Measurement criteria?

Comments
Evaluation of the impact of research on people with disabilities is important and relevant. But 'direct' impact is ill defined and placing a five year time limit is arbitrary
Not in control of the researcher
I would like to see this happen, but the reality is that it will take more than 5 years and lots of funding to document direct impact.
Add 'positive' to 'direct impact'
direct? why a 5 year time frame?
Not sure we could always measure this without violating confidentiality
This can be done in some cases, not in others. Five years is an arbitrary time. Even in my own research in self-determination, it was about a decade before you could point to direct impact from that research. I'd be inclined to delete it as a performance criteria.

Standard 7: UCEDD faculty members and staff are leaders in their field of research.

Comments
Not clear what this means.
We have the best people. Research is a core function. It should be a high standard of your faculty
How do you decide?
Why just research? Some are leaders in practice, policy, and advocacy or state collaborative efforts - should these not be included?
Leaders is an ideal. Some may be emerging leaders (e.g., post-docs; asst. profs.) This is an equally important role of UCEDDs to mentor these emerging leaders
Not sure how to define leaders, is anyone who publishes research a leader or are leaders perhaps only those who define a field.
How would you define leaders? # of grants; UCEDDS have a role in disseminating research even if they are not the ones generating it. Importance of evidence based preactice etc
UCEDDs differ as to the scope of their research mission. ADD requires that UCEDDs do research, not that they are "leaders in the field of research." Some UCEDDs could meet this standard easily, and others couldn't. I'd delete the standard and includes some of the criteria under Standard 6.

7.1 Publish research findings on developmental disabilities in peer-reviewed journals.

Comments
But should specify how many articles? 1, 10, 50?
Desirable but..... How often? How much?
There are now many other forms of publication and dissemination other that peer reviewed.
Need to specify 'relevant'
Move this as a criteria under Standard 6 and combine with 7.2.

7.2 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.

Comments
Again how often? Is one enough?
'relevant'
this assumes
Move this as a criteria under Standard 6 and combine with 7.1.

7.3 Are members of a peer-reviewed journal's editorial board.

Comments
This may not be possible on an on-going basis.
Being on a journal board really has nothing to do with conducting quality, socially valid research
Nice but not essential
Not every faculty member could or should do this though those who can should.
Editorial board-Too narrow conceptualization; some times consulting editors but ar enot on "Board"
Why just this? There are a lot of activities that could provide evidence of scholarly activities. It's impossible to list all of them, but perhaps reword to emphasize participation in scholarly activities, which might include but are not limited to serving as a journal editor, on an editorial board, or reviewing for journals; editing or writing scholarly texts; reviewing grants, and so forth.

Participate on a grant review panel (either for the University or for an outside organization).

Comments
This may not be possible on an on-going basis.
How often? How much? How measured
This criterion has nothing to do with conducting good research
This is inappropriate
Does everyone need to do this? Why?
Combine with 7.3 into broader creteria and move under Standard 6.

7.4 Further comments, additional standards or criteria for basic and applied research

Comments
The title of this section should be "Research"; remove the words "Basic & Applied". This core function also includes evaluation & policy analysis.
Research can be a collaborative activity and I think a boon to ADD network to have cross center research efforts. Impact on a region could incorporate research among multiple UCEDDs. Consider writing a criterion for this
Again, these standards exceed the requirements of the DD Act.
Need a standard for: -mentoring youths/students in field -document relevant research -document positive impact of research on field on local, state, national public ?
Suggest additional criteria: Faculty and staff who translate research to practice – thus improving the lives of PWDs and their families Faculty and staff are members of interdisciplinary research teams at their university Faculty and staff are numbers of interdisciplinary research teams in their communities

C. Community Services

Standard 8: UCEDDs provide or support community services through education, training, or technical assistance.

Comments
Remove the word education from this standard and just include training and ta - to make it consistent with DD Act.

Comments
But DD Act only says "training or technical assistance"
The wording on this standard is clumsy. I tried to fix it I'm not smart enough
People can do research but might not have some opportunities
Sree DD Act language "may provide"
This is fine.

8.1 Supports community services or at times provides direct services to people with developmental disabilities and family members.

Comments
See Comments below.
"At times" implies all UCEDDs must provide direct services. The DD Act says "may provide..."
"Provides" exceeds – the UCEDDs should support providers but perhaps should do assessment, training and technical assistance
UCEDDs sometimes in conflict of interest when providing services as well as their evaluating their impact
What does supports mean? Umnder what circumstances is the provision of direct services appropriate? What happen to exemplary services?
Supporting community services implies funding - a different word is needed to convey this thought since UCEDDs are not funders.
"supports" - vague
need for more precision
This is fine.

8.2 Provides training or technical assistance to service providers.

Comments
Again, use DD Act language for recipients of training/TA: individuals with DD, their families, professionals, paraprofessionals, policy-makers, students and othewr members of the community.
Change 'to service providers' to 'for service providers'
Separate into two: -training -TA Tie to five year plan
this feels too unconnected; DD Act refers to syste,s
Not sure UCEDDs should be held to this performance criteria. We cannot require service providers to take/come to these trainings
This is fine, but delete "to service providers and make it broader... e.g., to stakeholders in the DD community.

8.3 Implements community services that are endorsed or funded by state agencies.

Comments
Not sure what this means
I don't think UCEDDs should be paid providers except for very 'high tech' services such as behavioral treatments or genetic assessments
What does this mean?
In addition to earlier Comments about conflicts is this only way to fund services?
Although many do - this is beyond what should be required
Some UCEDDs do not implement community services directly either by philosophy (mission) or university charter

Comments
Again, UCEDDs have no control over this. Many do provide or assist others to provide state funded or endorsed services but the availability of funds dictates what they may ormay not do.
I don't think as written that this is the role of a UCEDD. If a UCEDD is in the client service business, say that
This standard may not be subject to the UCEDD's control
someitmes UCEDDS are the source of innovation
Why specify funding source? Could this performance criteria should read 'local, county, state, or private agencies'. In [State], agencies are country driven more than state
Goes beyond what's required. These could be privately funded, funded by federal sources, etc. Just deleting the "state agencies" portion makes it redundant to 8.1. Delete this.

8.4 Can demonstrate that the community services provided or supported by the UCEDD for people with developmental disabilities and family members were integrated into training and research activities of the UCEDD in the past 5 years.

Comments
Unclear. "Community services" integrated into (pre-service) training??
i.e., clinical services are a part of training for students and opportunities to collect data research?
????????????????????????????
It's nice but training and services are connected but sometimes this violates the contract or funding agency regulations under which some services are provided. It can also run afoul of some management guidelines
Would feel more comfortable with and AND/OR between training and research
I don't understand this one why?
what does it mean to "integrate services into training & research?"
Well beyond the requirements.

8.5 Can demonstrate that the training, technical assistance or other community services it provides has resulted in increased and improved services for people with developmental disabilities and their families in the past 5 years.

Comments
Unclear. DD Act defines "community services" as "training or technical assistance" so what are "other community services?" Also, improvements may be more than in services (e.g., policy changes).
How do we do this? Technical assistance by definition may not provide the opportunity to go back and find this out. Training perhaps and services, but not always. Great output if could be measured with consistency across all programs
How would they demonstrate this? Can this be operationalized?
How????????????????????????????
"people with developmental disabilities and their families": Change to 'or'
Who would measure this? State/country? NIRS?
Same concern as with the "impact of research in 5 years" criteria… difficult to determine causal effect, fie years is an arbitrary time.

8.6 Further comments, additional standards and criteria for community service

Comments
As part of the definition of the core function of community servives, the DD Act includes: may provide services, supports and other assistance through demonstration and model activities. There should be a Standard to address that core function. The performance crierion could include: If a UCEDD provides model or demonstration services, they are integrated with training, research, and/or dissemination functions (similar to 8.4 above).
Community Services again would need to be better aligned as well as evaluative measures developed to determine long term outcomes from this activity. Technical assistance is such a specific activity that crosses domains of service, training, and dissemination. Hard to measure impact of TA only. Here is where the UCEDD faculty serving on disability specific boards would be appropriate
Exceeds requirement of the DD Act, are not relevant or are not measurable.
Need something about how the activities attended? Students into fields -Community/family ratification? Standard needed -practice standard -policy standard
Community services should address identified needs as elaborated in the needs assessment and state plan Community services should foster the values of the Act (e.g., inclusion, etc.) Community services should address issues across all types of disabilities, needs, ages, economic and cultural groups

D. Dissemination

Standard 9: UCEDD dissemination activities address the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.

Comments
Switch order of Standards 9 & 10
This is only one of many important constituencies of most UCEDDs
Agree to an extent - however, the real focus of UCEDD dissemination activities should be to practitioners.
Reverse Standard 9 & 10 10 should logically be first
Need to extend this to other stakeholders beyond just people with DD and their families, including service providers and the general public. Need to extend this to other stakeholders beyond just people with DD and their families, including service providers and the general public.

9.1 Provides publications, material and other resources in accessible formats.

Comments
Materials (not material)?
Rewrite “easily accessible”
This is fine.

9.2 Provides accessible training and technical assistance activities.

Comments
Should this (or a variation of it) go under Standard 8?
This should be under community training and TA
needs more precision- is it training & ta are accessible to whom & HOW
Rewrite ‘easily accessible’
How do you define accessible?

Comments
This is fine, though it could be combined with 9.1.

9.3 Seeks input on materials and resources from people with developmental disabilities and family members (e.g., CAC members, advisory groups connected with research and community service activities).

Comments
Remove examples or indicate that it is not all required to meet standard
EXAMPLES IN PARANTHESES SHOULD BE OMMITTED
Sometimes this is appropropriate, other times its not. Delete it.

9.4 Provides materials and other resources in formats appropriate for people with cognitive impairments.

Comments
Please use more appropriate/image-enhancing terms - intellectual and developmental - please do not use impairments.
This duplicates criterion 9.1
"Cognitive impairments": Old terminology. Reference AUCDD for current language – intellectual disability
This is too hard to read. Make it clear. Make everyone understand it.
Some materials may not have people with cognitive impairments as the audience. Modify by saying "Provides consumer-oriented materials in..."
APPROPRIATE IS NOT THE TERM OF ART- "ACCESSIBLE" IS- APPROPRIATE IS IMPRECISE & CONDESCENDING
This should be limited to materials relevant/targeted to persons with ID
Redundant. Combine with 9.1.

9.5 Maintains and routinely updates a fully accessible website.

Comments
UCEDDs most often design their web sites within strict university branding and communication guidelines. Also, this criterion is vague...what does it mean to routinely update the web site?...what constitutes the web site as a project web site? We just don't want to go there.
Emphasis on 'fully'.
Too micro. Define "fully accessible"? You could include it as part of a revised 9.1.

9.6 Evaluates dissemination activities and results on an ongoing basis (e.g., monitors number of website hits, conducts targeted surveys, monitors the use of materials).

Comments
Be careful when talking about "results." ADD acknowledges that dissemination activities cannot be evaluated in terms of outcomes (either initial outcomes or intermediate outcomes). See the latest draft of the UCEDD logic model.
<e.g.> Comments
EXAMPLES BECOME NORMATIVE WITHOUT A BASIS
Not feasible for all such activities, however.

9.7 Makes its products, resources, and materials available to DD Network programs in its own state or territory.

Comments
Combine with 9.8
The majority of products developed at a UCEDD are targeted to a specific audience for a specific purpose – often funded by a specific non-ADD agency
Why just DD Network? Publish to the public
Product audiences vary. If a UCEDD is meeting 9.1 and 9.2, then this is redundant.

9.8 Makes its products, resources and materials available to UCEDDs, DD Councils, and P&As in other states and territories.

Comments
Combine with 9.7
And to the public in general including their state partners
While we may make some of our products available to other states, we don't do it with everything we do
This will just happen in this internet age – not a required criterion
Electronically?
Product audiences vary. If a UCEDD is meeting 9.1 and 9.2, then this is redundant.

Standard 10. UCEDD dissemination activities bridge the gap between research and practice.

Comments
Switch order of Standards 9 & 10
How to measure this?
Make more clear and readable
This standard is repetitive with all previous standards. If should be collapsed into them more efficiently: eliminate as a separate standard
What does this mean?
Not sure that DD Act talks about translational research
Exceeds requirements. Too micro. MOstly redundatn. Delete this standard. You could include some criteria from this under Standard 9.

10.1 Publishes on developmental disability-related issues in professional newsletters and other publications for providers and practitioners.

Comments
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.2 Uses a variety of distribution modes (e.g., electronic, in-person, and print) and strategies (mass mailings, YouTube videos, seminar series) to disseminate information and research findings to providers and practitioners.

Comments
Social media?
Seems obvious
Same Comment re e.g.
Include 'and families and PWDs, and researchers'.
dissemination not d"distribution"

Comments
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.3 Makes effective use of practitioner organization networks, listServs, and contact lists to expand its dissemination range.

Comments
Incorporate into 10.2
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.4 Disseminates the work of other UCEDDs to providers and practitioners.

Comments
When relevant
Not only UCEDDs – very self serving criterion. Should say 'disseminate the work of disability researchers, self advocates, and service practitioners'.
Not necessary given ? methods
the relevance of the work is the important issue not whether it was generated in a UCEDD
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.5 Uses the national developmental disabilities organizations to disseminate to other UCEDDs, P&As, and DD Councils.

- The national developmental disabilities organizations are the National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD).

Comments
incorporate into 10.2
There are many other disability organizations that have a much broader range than the usual gang
A great idea but goes beyond current law and regulations
How about professional associations such as AAIDD, TASH, CEC, IASSD etc. This seems to be a very limited criterion.
Same as above
Our respective national organizations?
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.6 Integrates UCEDD research findings into the preparation and continuing education of pre-service interdisciplinary trainees.

Comments
continuing education of pre-service trainees" does not make sense. Should this be addressed here or under Interdisciplinary Training and/or Research?
Often times, the research being done at a UCEDD is in a domain far removed from its training and continuing education
yes integrate research findings but THIS CONFUSES PRE_SERVICE & CONTINUING ED!
Must

Comments
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.7 Disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.

Comments
This is required in the DD Act, but it would be important to acknowledge that a UCEDD must do this within the protocol of its university for interacting with legislators.
This could be tricky – need specific guidelines on this
But a good idea!
The target audience is practitioners and prospective pratitioners. Let's not ask the UCEDDs to "be all things to all people" and do not of it well. It is better to be targeted and do it extremely well.
Our university
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.8 Makes materials, resources, and information on developmental disabilities available to the University community (e.g., publishes in the university newspaper, organizes and presents at a University-wide seminar).

Comments
Same e.g., Comment
Many do but again probably goes beyond current law and regulation.
the examples are too normative & limiting
I don't believe this standard should be included and believe the performance criteria exceed the UCEED requirements.

10.9 Further comments, additional standards and criteria for dissemination

Comments
Switch the order of # 9 & # 10
Include people with DD and families in dissemination activities

E. Governance and Management

Standard 11: UCEDDs leverage funding to support and maintain its programs.

Comments
Refocus this standard (see Comments below)
Completely arbitrary.
Agree under current law, but don't agree ultimately. It is a fact of life due to the funding structure but it is unfortunate – P&A and DDCs are hot held to this same standard. This should be addressed in the re-authorization and not be a standard, per se. It is an artificial standard
This needs work. -research transparency -use resources wisely and efficiently Leverages university resources
Given current economics this might be too high a standard for some.

Comments
need better phrasing
Must
This is fine.

11.1 Leverages funds that amount to at least three times the amount of the ADD grant.

Comments
I do not feel qualified to Comment – this seems to result in UCEDDs having to become providers to gin up revenue
Is this a number that holds true for all even now with the budget issues?
Is this reasonable for UCEDDs in very small population states? Perhaps it should be a tiered expectation.
I don't think it is appropriate to place a specification in the leveraging ratio. A better way to get at this would be something like "the UCEDD documents the degree to which it leverages ADD and university funds to support its programs"
Agree under current law, but don't agree ultimately. It is a fact of life due to the funding structure but it is unfortunate – P&A and DDCs are hot held to this same standard. This should be addressed in the re-authorization and not be a standard, per se. It is an artificial standard
Three times seems ? -public/private resources -transparency in leveraged funds
But all sources should be counted: foundation, gifts, county state and other federal dollars
Not sure where "3 times" came from. There is no such requirement, to my knowledge.

11.2 Leverages funds and in kind resources (e.g., space, use of University infrastructure) from the University in which it is housed.

Comments
Leveraging funds is important. I would keep the concept and reword as follows: Leverages funds and in-kind resources to support programs and achieve the goals of the 5-year plan.
OK with this edit: Leverages funds and/or in-kind resources
I am unsure about the standard
Prove it. Don't just write about it in an application
When U. accepts reduced F&A is this not a university in kind support? If so – this is a moot performance measure
This is fine.

Standard 12: UCEDDs maintain and support involvement from CACs.

Comments
This Standard is needed, of course, but it should not be placed under "Governance and Mangement." CACs are advisory only–they do not function like boards of directors.

12.1 Fills all vacancies on the CAC within 1 year.

Comments
This should be changed to "the majority of the CAC members are individuals with DD and family members."
Fill all vacancies on the CAC "as required by operating standards"
Three months! 1 year is too generous. 6 for new, 3 for existing

Comments
Too micro, there are often circumstances that intervene. You could rewrite to show evidence of effort to do so, but that seems too micromanaging as well.

12.2 Continuously maintains CAC membership that includes people who are knowledgeable about the full range of the developmental disabilities population in the state or territory (e.g., all disability types, age groups, living arrangements, and major ethnic and nationality groups in the state or territory).

Comments
This should be specific and include the composition of the CAC as required in the DD Act.
What about state partners?
Add geographic representation
Again – all disability groups too broad
Involvement of P&A and DD Council are also important and relevant
People who are knowledgeable about… implies professionals or DSPs not PWDs or family members
"Reflects" rather than knowledgeable
Some people may be knowledgeable in one or few DD pop but not the full range. What seems important is that CAC has diversity: age, disability, ethnicity, geography
This whole "full range" stuff is unnecessary. We want pepole who are knowledgeable about the needs of people with DD and their families, including people with DD and their families themselves. Reword this to reflect that.

12.3 Involve CAC members in the development and implementation of the 5-Year Plan.

Comments
Combine with 12.4 and include language from DD Act : "Consult regarding development of the 5 year plan, participate in an annual review of, and Comment on, the progress of the UCEDD in meeting the projected goals, and make recommendations regarding proposed revisions."
The DD Act also charges CACs to help UCEDDs evaluate their activities.
What does this mean - in terms of implementation?
"development, implementation, and evaluation of the five year plan"
Redundant with 12.1
This is fine.

12.4 Seeks and incorporates the input of the CAC into UCEDD activities throughout the planning cycle.

Comments
This should be combined with 12.3.
Duplicative with the previous criterion
Not sure what the planning cycle is. This seems redundant. Delete it.

12.5 Supports its CAC for a minimum of two meetings each year.

Comments
Should add: "or as often as necessary to carry out the role of the committee"
quarterly.
I'm not sure about 12.5 and 12.6. For one thing, they seem to contradict one another. Second, where did "two meetings" come from? Are these face-to-face or by phone, etc.? Seems arbitrary.

12.6 Supports its CAC for more than two meetings each year.

Comments
How about a criteria of no less than two meetings a year and leave it at that?
But perhaps could set a standard that establishes 'formal' input but no another meeting
Have one or the other
Is this a trick question?
Two or more times a year
quarterly
I'm not sure about 12.5 and 12.6. For one thing, they seem to contradict one another. Second, where did "two meetings" come from? Are these face-to-face or by phone, etc.? Seems arbitrary.

12.7 Provides CAC members with any supports that are needed to ensure meaningful participation.

Comments
Accommodation, travel, distance meeting
Would drop the word "any"
"Provides CAC members with disabilities and/or family members…"
Required by law
This is fine.

12.8 Further comments additional standards or criteria for governance and management

Comments
The first standard under governance should be something like: UCEDDs are interdisciplinary education, research and public service units of universities or public or not-for-profit entities associate with universities. Then one performance criterion should address a written agreement between the UCEDD and the university, and another performance criterion should address leveraging (see wording suggested under 11.2) The CAC section is very important. It should more closely reflect the requirements of the DD Act.
There needs to be a criterion here on UCEDD Mgmt structure, lines within the UCEDD What about a criterion for the UCEDD director? (Degree, university role, experience etc.)? Any criterion on reporting requirements
This standard is weak. It needs a lot more work. Either change the name or make it a real Governance and Management standard. Leveraging resources and having a? What about the following? ▪ Governance ▪ Relationship to the university ▪ Relationship to PWID/DD ▪ CAC ▪ Facilities/equipment ▪ Management ▪ Program management ▪ Student services ▪ Fiscal/resource management ▪ Staff management

Appendix V4. Collaboration

Collaboration
Draft Standards and Performance Criteria – Version 1

Panel Member Comments

Standard 1: All DD Network programs in the state or territory achieve common goals through collaboration.

Comments
I agree that this is the standard by which Councils and the DD Network should work. However, we have to acknowledge that this is difficult in some states. It will take leadership more than anything to make this happen.
Does this imply all goals?> One Goal, different members of the network have different priorities and roles. If "common" is being used in the broad sense, i.e., community inclusion, then it is fine.
May be difficult in some states
I have spent many, many years trying to "achieve common goals." FYI, there are also Projects of National Significance initiatives that come and go in a state. These grantees often do not see a need to involve the network on the front end of the endeavor or during [the endeavor].
These standards on collaboration should also embedded in the standards performance criteria – see 1.1, 1.6, 4.3, Standard 5, 5.1 and 6.4 (DDC Standards)
While all goals likely cannot be shared across the Network, the impact of all three program types is important. This is a critical standard, I think.
I am not so sure.
Need a federal law or federal regulation/rule citation regarding this whole standard
Clarify phrasing. Too rigid. There may be some overlap on some goals but there will probably be goals unique to each partner.
The P&A collaboration responsibilites include, but are not limited to the DD network.
Collaboration is useful but the missions of the programs are very different and there has been way too much emphasis on this in the past
DRC of [state] has a good working relationship with our DD Network Partners. However the network doesn't always agree on how to address specific issues. And not all DD partners around the country have the luxury of that type of relationship. DRC of [state] is the only DD partner in the [state] network which is directly federally funded.
Do not agree that there needs to be a standard on collaboration. There are some projects that the networks can collaborate on but there are matters that require different strategies. This standard should be eliminated because it doesn't clearly distinguish where our goals and priorities may diverge.
Each partner plays a different role within the system, although they should collaborate when appropriate and feasible.
This is fine.

1.1 Identify and acknowledge a common goal or goals.

Comments
One goal only
What does acknowledge mean? Also, some of the partners may need to take a "behind the scenes" approach so acknowledging may be counter- productive to the strategy.

Comments
All of the subs under 1 are really overlapping and are simply strategies to meet the standard. 1.3 and 1.4 are redundant.
Would prefer 'inform' not standard-like a best practice once again due to political issues that may exist in some situations
Often, 2/3 of the partners (e.g., the council and the UCEDD) will share a goal that the 3rd organization does not. The real issue is usually who will fund the collaboration? This is often put on Councils. Need further clarification in DD Act and concomitant planning cycles
Much appreciated! I think many states will need technical assistance to implement this
How would you do this?
Change the word 'acknowledge' to some other action word such as 'agree upon'
This is critical to productivity, communication and effective advocacy between DD Systems and programs
Nice to demonstrate but should not be a standard
There should also be much more understanding between programs about what each other does
Need to fix the Standard first. 1.1 then should read that each DD Network partner had gone through a process to identify common goal or goals through a public/Board/Advisory Council vetting process.
May not be appropriate or feasible
Add "for the DD network team and specific goals/priorities undertaken by the contributing parties individually"
At least 3-5 goals in the five year plan
This is fine.

1.2 Articulate dedicated activities or tasks for each DD Network program.

Comments
It is more than articulate - identify is probably a better word. Also, it needs to be based on a strategy that are within the scope of each programs resources and expertise and contribute collectively to the good.
This is strategy. There may be goals in which all 3 programs need specific tasks, there may be times when only 2 programs need to do something active. There needs to be flexibility in ensuring that the goal gets achieved. This is too specific and is a managerial issue. The focus should be on achievement of outcome not the specifics of how it is done.
. . . role, activities or tasks . .
I do not feel this should be a requirement
A creative, ? approach to collaboration 'dedicated activities'
With two different boards and one advisory, this is very difficult. Network EDs met regularly and collaborate by exchanging info and insights
Consider 'delineate' instead of 'articulate'.
I think this should say, "Articulates at least one activity for each Network member that connects to the common goal."
Change 'articulate' to 'identify' or some other word.
This will help partners clarify expectations and use each other's strengths and resources to maximum benefit
The language of the DD Act is the driving force here (values)
and should identify how each of the DD Network programs play a role in the stated outcomes
What does this mean? Not clear. Rewrite please. Each plan shall articulate activities on tasks for each DD network plan
This is with respect to achieving the common goal, correct? While agree, I am not sure that it should be included as a required component.
Again, the Standard has to be fixed first. After that, I think it is reasonable for each remaining DD Network partner to be able to articulate a task for a collaborative goal.
Unsure what this means or what it would look like in practice. Also potentially time and resource intensive. Perhaps a more realistic criterion would be for a partner agency to offer its unique perspective, expertise, or resources to the others when appropriate and feasible.

Comments
Different partners may take different…
Reword 'articulate' as 'specify'. Add "…member organizations in relation to the overall priorities
Articulate: how do we do this?
Is this in reference to identified 'common' goal?
This is fine.

1.3 Demonstrate a united front on key (identified) issues.

Comments
It may not be possible for this to happen Front should be united although each program needs to respect their parameters under the DD Act
There may be good reasons to take different aspects of an issue
Redundant with 1.4
While we are all working toward a common goal, we may all have differing perspectives and reasons for engaing in the activity, so, we need the latitude to present our differening perspetives and reasons wihout threatening our common goal.
I do not feel this should be a requirement
Agree if you take out the word 'identified'
On several key topics, our P&A has taken positions that significantly differ from that of the Council
Yes! We don't need our partners questioning key stands on issues like the use of institutions. We must work together
I think it's reasonable to ask the network to be united on their joint goal, but beyond that is asking too much preparation so insure that everyone is all the networks is on the same page.
Change 'united front' to a collaborative term. There are very different roles that are played – sometimes one part of the network takes the lead and has the 'out there' on the edge while others are working in the background.
This could be combined with the next indicator. Should not stand alone.
This is paramount to effective advocacy between all parties, the DD systems and programs have contact with either the general public, persons with DD or our legislators.
This exceeds only because Gov. appoints SCDD members and SCDD at various times has not supported DD Act values
The language of the DD Act is the driving force here (values)
Reword "on one or more key (identified) issues"
This needs more explanation
if there are differences they should be identified and stated. Concern that a required united front may freeze one or more partners.
A united front on key issues is not critical to collaboration
Demonstrate a united "perspective." It should be clear that this requirement does not apply to all issues but rather only on those that have been agreed upon by the three entities.
Not every DD Network partner will be in a political position to "demonstrate a united front." For example, the UCEDDS may agree with a policy advocacy position but because of advocacy restrictions within the University system, may not be able to testify at a Committee hearing.
Ideal goal. May be unrealistic.
The DD council for example requires appointment by the governor and is tied to the state services system by its very nature. this does occasionally impact our ability to speak with one voice - a standard for collaboration.
Not appropriate. DD Network programs share values and committed to DD Act. May have different viewpoints and different roles
This standard and the next (1.4) are not relevant. Each program in the DD Network has it's own unique context and role. It is inappropriate (and not relevant) to ask them to speak with one voice.

Comments
This is complicated. The DD Act wisely identifies different roles for the three "sisters" and it isn't always possible to demonstrate a united front. For example, the UCEDD may have a contractual partnership with the state DD authority to help implement Money Follows the Person but the P&A may be suing the state to increase the speed of deinstitutionalization. Therefore, there may have to be distance between these two sisters although there is a common goal.
How do we do this? Variety of ways to do this that may look good (superficial) but we need to hold each other accountable to fulfilling this partnership
Perhaps agreed upon identified issues
I'm not sure what this means
'United front' is subjective. It needs to be built of 11.1 , 11.2 ? input/implementation
Too ambiguous.

1.4 Talk with a common voice on key (identified) issues.

Comments
There are times where it is appropriate for us not to speak in one voice. At times the P&A is the bad cop and the other two sisters are the good cop. This is effective advocacy and collaboration.
Goes boyond the law and regulation to require consensus. One can collaborate while still having differences
Redundant with 1.3
While we are all working toward a common goal, we may all have differing perspectives and reasons for engaing in the activity, so, we need the latitude to present our differening perspetives and reasons wihout threatening our common goal.
Agree if you take out the word 'identified'
See 1.3 – this is dependent on what is identified by whom as 'key'
Again, at least one issue. It is too much to expect the network members to do this for several issues.
Replace 'talk' with 'communicate' to be more inclusive of communication channels. The communication should be in keeping with the DD Act principles. Add "…and in keeping with DD Act Principles'
Please consider combining this indicator with the previous one.
Again this is critical to effective advocacy efforts between stakeholders.
This exceeds only because Gov. appoints SCDD members and SCDD at various times has not supported DD Act values
The DD Act is the guide
DD Partners can work collaboratively by using parallel, complementary messages. A common voice i.e., formal joint position is not necessary
If they agree on Key issues there should be three distinct voices saying the same message.
meaning that they all understand to scope and intnnt and value of the issues
However need to address how "common voice" and "key issues" are decide. Without this clarification this could cause some serious problems for DD Partners.
Same as demonstrating a united front
Not every DD Network partner will be in a political position to "demonstrate a united front." For example, the UCEDDS may agree with some policy advocacy positions but because of advocacy restrictions within the University system, may not be able to testify at a Committee hearing.
Ideal goal. May be unrealistic.
The DD council for example requires appointment by the governor and is tied to the state services system by its very nature. this does occasionally impact our ability to speak with one voice - a standard for collaboration.
Ridiculous
Seems a bit redundant to 1.3

Comments
This is complicated. The DD Act wisely identifies different roles for the three "sisters" and it isn't always possible to demonstrate a united front. For example, the UCEDD may have a contractual partnership with the state DD authority to help implement Money Follows the Person but the P&A may be suing the state to increase the speed of deinstitutionalization. Therefore, there may have to be distance between these two sisters although there is a common goal.
I'm not sure what this means
'United front' is subjective. It needs to be built of 11.1 , 11.2 ? input/implementation
I think we each have our message/voice. As long as message is consistent, I don't think we want DD Council speaking for the UCEDDs or UCEDDs speaking for the DD Councils etc.
Same as previous criteria, too ambiguous.

1.5 Include staff from all three DD Network programs in collaborative planning meetings and implementation activities.

Comments
Who is involved in activiites, meetings, etc. is a management decision and should not be dictated. It is up to the EDs of each orgnaization to determine how and when staff should be utilized.
representatives of the three programs, not necessarily staff of those programs (though that is the most likely scenario).
This could be very costly – i.e., distances to get everyone in the same place etc. It happens but would rather this be 'informal' not required.
Delete 'planning' and 'implementation activities'. Reword as 'in collaborative meetings'. Not that the Act is not as strong on collaboration among the networks as it should be. We meet together regularly. Implementation occasionally includes all three programs on one initiative and two of the three on e.g., 2,3 others. We rarely have council-funded initiative in which all three are involved.
Since several states have several UCEDDs, I think this would be clearer to say, "all three DD Network program types". That way, all examples of each type would be required to collaborate.
Not sure this is totally necessary.
Some collaborations are planned by directors and/or delegated to vendors/grantees/consultants. 'Staff' may be a too narrow a term.
"involve' rather than 'include' Also, combine staff and volunteer board members into one indicator - more efficient , cleaner in my view.
This allows advocacy efforts to draw directly on the experiences of all stakeholders.
Not sure what planning meetings are referring to
Not sufficiently detailed to mean much in the way of guidance to the three network participants
Good idea, but the P&As may used their limited resources to respond to clients' needs. This standard is micro-managing very limited resources.
There are meetings that are appropriate for DD Network staff to attend to work through common objectives
Merge 1.5 with 1.6
Where appropriate and feasible
As appropriate
Fine, just don't predetermine how many meetings or the nature of these meetings.

1.6 Include members of the DD Council, Consumer Advisory Committee (CAC) and P&A Board of Directors (or Commission) in collaborative planning meetings and implementation activities.

Comments
Nice but difficult to make happen - perhaps we could aim toward this on occasion.

Comments
This needs to have a caveat for as appropraite. It is not always effective to involved large numbers of indiivduals in planning meetings and implementation activiites. The Councils and Board are the strategic voice. They set the expectations, goals and priorities and expect staff to carry them out. When appropriate council members are involved in meetings, testimony, legislative communication, etc., but whether or not that occurs will depend on the activity, the expertise of the individuals, etc. AGain this is an operational issue that should not be dictated. It is the outcome that counts.
Higly desirable but oftentimes not reasonable for our volunteer members and presents incredible difficulties working around very busy schedules (our members and our DD Network professional schedules).
This could be very costly – i.e., distances to get everyone in the same place etc. It happens but would rather this be 'informal' not required.
Could be combined with 1.5 and the word 'consumer' bothers me but maybe I'm the only person with DD who does not like it.
"members' vs. staff Costs... the council and the P&A usually have two or three shard members. The council ED is not allowed to sit on the P&A board other than ex officio. Old ADD ruling that Councils were service providers. P&A and UCEDD Directors both sit on Council as members so we probably meet the standard in this sense. There are rarely CAC members in our meeting
Consider a standard such as 'encourage the participation of' rather than 'include'. It is more important for Council members to participate on committees, task forces, etc. directly relating to the state plan objectives. We have more activities than members to fill them. This would result in pulling someone off something more important to meet an unnecessary standard.
Should also require the DD agency
Sometimes you can have too many people at meetings and hard to get anything done.
Why only one consumer advisory council? I think you want consumers from each Network program type, and my druthers would be at least two from each.
Not sure this is totally necessary
This may exceed any budget. In our state the P&A Board is really a Legal Aid Board and is not connected to the DD Network
Should be written with one above, combining staff and volunteer board members.
There should be flexibility with this standard because not all representatives from DD systems and programs will be available for all meetings and activities
Not sure what planning meetings are referring to
Too rigid. Should be more flexibility re: when to deploy staff or Board members
This tends to happen because many of the same people are involved in more than one agency. Setting this as a standard seems too perscriptive.
isn't this the same as 1.5
There could be conflicts of interest between these groups. DD partners are not always on the same page in term of how to achieve a goal.
This is not relevant and there is potential for a conflict of interest.
Merge 1.5 and 1.6
Not only is this not relevant, this creates conflicts of interest. For example, the Governor's Councils are appointees of the Governor. In [State], the Chair is the Director of the Arizona Department of Health Services. If our DD Network has a collaborative activity aimed at a policy change with DHS, it would be a conflict of interest for the Chair of the Council to appoint himself to the planning meeting. It could happen. Plus, these are voluntary Councils and Boards and it is too much to expect volunteers to be involved in planning and implementation activities at this level. This should be rejected for the conflict of interest it presents.
Already specified
This would be very difficult logistically and financially, and the return on investment would be limited. Also, members of these groups are volunteers and are already involved in so much. I don't think we could add to their work.
May want to encourage other partners
Combine with 1.5

Comments
I prefer limiting it to staff and not overburden our volunteer CAC members
redundant to above.

1.7 Can demonstrate that they have achieved common goals in the past 5 years through their collaborative efforts.

Comments
Again, how do you demonstrate this?
Worked on common goals - desinstitutionallization has bee a goal in many states which still has not been achieved in many.
We do this through our PPR on an annual basis.
goal – not goals – sometime things take a long time to come to fruition
This could be very costly – i.e., distances to get everyone in the same place etc. It happens but would rather this be 'informal' not required.
Demonstrating proof or causality is hard to find
We may 'set' common goals but not achieve them due to factors no within the network control
I don't think ADD should care if the network can demonstrate something, but rather that it DOES demonstrate it. So this should say, "Demonstrates", and as with the Council standards, I think examples here would go a long way toward clarity - how can demonstration be accomplished?
This is an absolute must given our economic and political climate
This could work, but what happens if two of the three partners play nice together and the third does not. Are all three partners held to the same stanndard as a whole, or are they evaluated individually?
This is a concern because the DD network is not required to develop collaborative efforts and doesn't refeclt the current DD network system.
The DD Network should keep records for the past 3 years, not 5. 5 is too burdensome.
Fine line here... achieves versus worked toward. We have activities that have been ongoing for more than 5 years that finally came to fruition.

1.8 Further comments; additional standards or criteria for collaboration

Comments
While collaboration among the DD Netowrk has worked very well in some states, it has not in others. This may be based on the kinds of organizations that partners are i.e., a UCEDD that is clinically based or a DD Council that is seen just as a source of funding. In addition, even when working collaboratively, it may mean that one of the partners has to take a behind the scenes approach. There will have to be leadership and technical assistance to help improve relations among the programs.
[I] Am concerned about requiring a common voice and consensus.. There are many instances where the 3 network partners take different perspectives to get something done.
This is an area that would benefit from better guidance and technical assistance from ADD.
Please see previous Comments about smaller councils with only one or two staff
I think the addition of targeted requirements for the 3 ADD partners to work on specific initiatives together is needed and overdue. I especially appreciated language about presenting a united front on key issues (e.g., in our state, sheltered employment, de-institutionalization)
I think examples for each standard, and maybe for the performance criteria would be helpful for the Network and for promoting inter-rater consistency.
It is clear that thought and effort went into the writing of these standards and criteria. They are fair and reasonable
Requirement for P&A to be on the Council creates a conflict of interest for funding P&A activities
The collaborative effort between the DD network programs do not need a separate standard but documentation of collaboration might be appropriate as part of the collaboration process generally in the individual program standards.

Comments
Each program should attend other programs meetings and share details and talk about each other's five year plan
Maybe include something about assessing these forms of collaboration between agencies Finding a way to include constituents/clients in at least a sub-objective when it comes to sharing forces
There should be an expectation that Collaboration must also include non-DD Act partners in order for a UCEDD to play its role effectively.
How about collaborative efforts written in the 5 year plan that show the activities or common efforts for collaboration? This could be an operational objective in the five year plan for that state's DD network programs. dependence on each other.
Collaboration needs to extend beyond the DD network – while collaboration among the members is essential, collaboration with the broader system is also essential – as an example, even when a P&A sues a state, they need to continue to collaborate and communicate with the state. The DD networks can become a closed universe that can be irrelevant to the larger systems…
Important to emphasize that collaboration is a process and that the outcomes of the process are what is important.
Collaboration is a lofty goal and it should be met. However, it is not stressed enough by ADD.

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Appendix W. Version 2 Rating Results

W1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

W2. PROTECTION AND ADVOCACY SYSTEMS

W3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

W4. COLLABORATION

Appendix W1. State Councils on Developmental Disabilities

Draft Standards and Performance Criteria – Version 2
State Councils on Developmental Disabilities

Rating Results*

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory to lead meaningful and productive lives.	18	0	1	2
1.1 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities in the state or territory.	17	3	0	1
1.2 Collects input for the State Plan from a variety of sources.	20	1	0	0
1.3 Collects input for the State Plan from the various geographic regions across the state or territory.	16	3	2	0
1.4 Uses a variety of methods for collecting input for the State Plan.	21	0	0	0
1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.	18	1	1	1
1.6 Uses information from the planning efforts of other organizations in the State or territory to increase planning efficiency.	17	4	0	0
1.7 Gathers input on needs on an ongoing basis.	12	9	0	0
Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and is a guide to DD Council action.	18	3	0	0
2.1 Is consistent with the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).	19	1	0	1
2.2 Is consistent with the input received from the planning process.	16	3	0	2
2.3 Drives activities that the DD Council conducts and supports.	21	0	0	0
2.4 Contains priorities that consider the needs of people with developmental disabilities and family members, DD Council resources, and what is already taking place in the state and local communities. .	20	1	0	0

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
Standard 3: DD Councils develop self-advocates and leaders among people with developmental disabilities and family members through the support of activities that provide exposure, education, training, and technical assistance.	17	4	0	0
3.1 Actively reaches out to people with developmental disabilities from the broad population of people with developmental disabilities in the state or territory to participate in education, training, and technical assistance activities.	17	3	1	0
3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities to inform the effectiveness of Council self-advocacy and leadership activities.	18	1	2	0
Standard 4: Participants in DD Council self-advocacy and leadership development activities exercise self-determination and provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.	15	3	3	0
4.1 Can document that participants in self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.	16	3	1	1
4.2 Supports and helps to grow at least one statewide organization led and staffed by people with developmental disabilities.	14	5	0	2
Standard 5. DD Councils improve the capacity of communities to include and support community members with developmental disabilities.	17	2	2	0
5.1 Supports information, training, and technical assistance to people and organizations in the community at large.	17	2	1	1
5.2 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.	15	5	0	1
5.3 Documents the outcomes of efforts.	19	2	0	0
Standard 6: DD Councils support, lead and participate in advocacy efforts that are expected to result in system changes that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life for people with developmental disabilities.	18	1	2	0
6.1 Uses a variety of strategies to meet systems change objectives.	19	2	0	0

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
6.2 In addition to partners and collaborators, includes both Council members and staff in implementing advocacy activities.	13	5	3	0
6.3 Makes sure policy makers personally know some Council members or staff.	11	6	4	0
6.4 Evaluates its advocacy efforts throughout the year, and makes adjustments as necessary.	16	2	3	0
6.5 Documents the outcome and effects of its advocacy efforts.	19	0	2	0
Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members.	16	2	3	0
7.1 Disseminates or promotes new or innovative practices demonstrated to be effective.	17	1	3	0
7.2 Documents that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.	11	6	2	2
Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.	16	2	3	0
8.1 Reflects the range of the population of people with developmental disabilities in the state or territory.	18	2	1	0
8.2 Actively works to fill Council vacancies in a timely manner and documents efforts to do so.	18	3	0	0
8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.	16	4	1	0
8.4 Documents attendance in DD Council meeting minutes.	20	0	1	0
8.5 Has members who play an active role in meeting DD Council objectives.	19	2	0	0
8.6 Provides an orientation to new DD Council members.	20	1	0	0
8.7 Mentors new DD Council members.	12	8	1	0
8.8 Provides supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.	19	2	0	0
8.9 Supports at least one DD Council member to attend a national meeting, conference, or training each year.	13	3	5	0
Standard 9. DD Councils are effective in fulfilling their governing responsibilities.	15	4	1	1
9.1 Reviews the performance of the Executive Director each year.	20	1	0	0

Draft standards/performance criteria (PC) – Version 2		Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
9.2	Reviews itself every 3-5 years.	15	3	2	1
9.3	Trains and supports Council members on the core functions of their roles and responsibilities.	19	2	0	0
9.4	Uses a fair, transparent, and effective process to select competent and experienced grantees.	20	0	1	0
9.5	Maintains a system to manage grants and measure grantee results.	21	0	0	0

*21 panel members rated the DD Council draft standards and performance criteria.

Appendix W2. Protection and Advocacy Systems

Draft Standards and Performance Criteria – Version 2
Protection and Advocacy System

Rating Results*

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities in the state or territory.	18	0	0	0
1.1 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities in the state or territory.	17	0	0	1
1.2 Collects input for the Statement of Goals and Priorities (SGP) from a variety of sources.	17	0	1	0
1.3 Collects input for the SGP from geographic regions across the state or territory.	16	1	1	0
1.4 Uses a variety of methods for collecting input for the SGP.	16	1	0	1
1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.	17	0	0	1
1.6 Uses information from the planning efforts of other organizations in the state or territory to increase planning efficiency.	13	5	0	0
1.7 Gathers information on the needs of people with developmental disabilities on an ongoing basis.	14	3	0	1
Standard 2: P&A SGPs reflect the needs of people with developmental disabilities in the state or territory and is a guide to P&A action.	18	0	0	0
2.1 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).	18	0	0	0
2.2 Reflects the input from the planning process.	16	0	2	0
2.3 Drives primary activities that the P&A conducts and supports.	18	0	0	0
2.4 Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statues, regulations, or priorities.	16	1	1	0
Standard 3: The P&A intake process is equitable, efficient, and effective.	10	4	4	0

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
3.1 Maintains written intake procedures that include but are not limited to: ▪ Procedures for documenting client information in a computerized database, and ▪ Procedures for priority case selection.	18	0	0	0
3.2 Provides training on the intake procedures to new intake staff.	18	0	0	0
3.3 Monitors staff adherence to intake procedures periodically.	16	2	0	0
3.4 Directs callers and others who seek assistance from the P&A to the appropriate level of assistance.	16	0	1	1
3.5 Applies a rigorous methodology to assess satisfaction with the P&A intake and assistance process every 3 to 5 years.	9	7	0	2
3.6 Provides intake staff with access to ongoing professional development.	16	2	0	0
Standard 4: P&A casework reflects the priorities set in the SGP.	14	4	0	0
4.1 Maintains written procedures to guide the selection and processing of individual advocacy cases.	17	1	0	0
4.2 Selects individual advocacy cases that are consistent with but not limited to the goals and priorities in the SGP.	15	1	2	0
Standard 5: P&A provides high quality representation.	15	3	0	0
5.1 Provides staff with individualized ways to discuss and review cases.	14	2	2	0
5.2 Provides and encourages use of easily accessible resources.	13	2	2	1
Standard 6: Individual advocacy meets client objectives.	15	3	0	0
6.1 Ascertains accommodation and necessary support services at intake.	16	2	0	0
6.2 Commits resources to support all clients being served so that individual advocacy staff is able to communicate with any client whose case is taken.	16	2	0	0
6.3 Except in the case of an emergency or time-limited circumstances, provides and updates a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.	16	2	0	0
6.4 Sends or gives clients a closing letter in simple language documenting actions taken, results, and notification that the case is closed.	17	1	0	0
6.5 Informs the following individuals about the grievance process in writing:	17	1	0	0
6.6 Resolves a majority of issues in favor of P&A clients.	9	7	1	1
6.7 Has a mechanism for gathering and assessing client feedback and satisfaction with P&A services.	18	0	0	0
Standard 7: P&A strictly adheres to confidentiality.	18	0	0	0

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
7.1 Has a written confidentiality policy – covering onsite staff, staff working at home, students, volunteers, and contracted staff – with well-delineated requirements.	18	0	0	0
7.2 Has structures in place to maintain confidentiality.	18	0	0	0
7.3 Requires demonstrable compliance with the P&As written confidentiality policies and procedures by anyone who is privy to client information.	16	1	1	0
7.4 Reviews confidentiality requirements in orientations to new staff, students, contracted staff, volunteers, and Board of Directors or Commissioners.	17	0	0	1
Standard 8: P&A systemic advocacy improves access to State systems and community practice and reduces abuse and neglect.	15	2	0	1
8.1 Uses a variety of strategies to meet systemic advocacy objectives.	18	0	0	0
8.2 Provides documentation that illustrates outcomes within the past 5 years that are associated with its systemic advocacy efforts.	16	0	0	2
8.3 Conducts ongoing review to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.	17	0	1	0
Standard 9: P&As engage in effective outreach activities to identify unserved and underserved populations.	18	0	0	0
9.1 Conducts ongoing outreach activities.	18	0	0	0
9.2 Targets populations that are underrepresented or unserved.	17	0	0	1
9.3 Maintains a budget for outreach activities.	13	3	1	1
9.4 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.	17	0	0	1
9.5 Reports on measureable targets and outreach activities.	13	3	1	1
9.6 Periodically reviews outreach activities so that outreach plans and strategies can be revised as needed.	17	0	0	1
Standard 10: P&As have an impact on access to services and community participation for people with developmental disabilities through the provision of education training, and technical assistance.	17	0	1	0
10.1 Provides culturally appropriate and targeted education, training, and technical assistance activities to people with developmental disabilities and family members. .	17	0	0	1
10.2 Maintains a budget for education, training, and technical assistance activities.	12	4	1	1
10.3 Measures recipient satisfaction with education activities.	18	0	0	0

Draft standards/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
Standard 11: P&A Board of Directors or Commission sets policy and long range goals for the P&A and holds the Executive Director accountable for adhering to the policies and goals.	17	1	0	0
11.1 Conducts an annual performance review of the Executive Director.	18	0	0	0
11.2 Actively works to fill Board of Directors (Commission) vacancies in a timely manner and documents efforts to do so.	18	0	0	0
11.3 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues, and who are knowledgeable about the developmental disabilities population and issues.	16	2	0	0
11.4 Familiarizes all new Board of Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.	18	0	0	0
11.5 Provides supports needed to facilitate meaningful participation by Board of Directors (or Commission) members.	17	1	0	0
11.6 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available in accessible format for each member who requires them.	16	1	1	0
Standard 12: P&As maintain an infrastructure that enables them to conduct key functions efficiently and effectively.	17	1	0	0
12.1 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.	17	0	0	1
12.2 Conducts an annual performance review of all staff members.	17	0	0	1
12.3 Receives an independent audit each year, and immediately addresses qualified findings.	18	0	0	0
12.4 Budgets for professional development for staff.	17	1	0	0
Standard 13: P&A maintain operational independence from the Governor and the developmental disabilities service system of the state or territory.	18	0	0	0

*18 panel members rated the P&A draft standards and performance criteria.

Appendix W3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

Draft Standards and Performance Criteria – Version 2
University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)

Rating Results

Draft standard/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
Standard 1: UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and the goals contained in the DD Council State Plan.	11	3	1	0
1.1 Collects input for the 5-Year Plan from a variety of sources.	15	0	0	0
1.2 Obtains input for the 5-Year Plan that covers various geographic regions across the state or territory.	10	3	2	0
1.3 Uses a variety of methods for collecting input for the 5-year Plan.	13	2	0	0
1.4 Gathers input for the 5-year plan from or about a wide cross-section of the state or territory's disability population representing many different segments of the community.	8	4	3	0
1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.	12	3	0	0
1.6 Uses information from the planning efforts of other organizations to increase planning efficiency.	12	3	0	0
Standard 2: UCEDD 5-Year Plans are a guide for UCEDD action	12	1	2	0
2.1 Reflects the input from the planning process.	14	1	0	0
2.2 Reflects the goals and principles in the DD Act.	13	1	1	0
2.3 Guides the activities that the UCEDD conducts and supports, while including provisions for responding to emergency needs and opportunities	11	2	2	0
Standard 3: UCEDDs advance practice, scholarship and policy that impacts the lives of people with developmental disabilities and their families.	14	0	1	0
3.1 May offer training that leads to the award of an academic degree, professional certificate, or advanced academic credential.	11	4	0	0
3.2 Advances the academic or professional credentials of trainees.	11	3	1	0

Draft standard/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
3.3 Offers developmental disabilities-related courses, clinical experiences, mentorings, or trainings based on content from a variety of disciplines.	14	0	1	0
3.4 Offers developmental disabilities-related courses, clinical experiences, mentoring, or trainings taught by faculty and staff from multiple disciplines.	10	2	0	3
3.5 Offers developmental disabilities-related courses, clinical experiences, mentoring, or trainings to students from multiple disciplines.	10	0	2	3
3.6 Teaches students about the conduct and interpretation of research.	11	4	0	0
3.7 Integrates UCEDD research findings into interdisciplinary pre-service preparation and continuing education activities.	11	4	0	0
3.8 Can document the percentage of graduates who are engaged in work related to people with developmental disabilities and their families 5 years after training.	12	3	0	0
3.9 Can document the percentage of graduates in leadership positions related to developmental disabilities.	9	6	0	0
3.10 Prepares students to apply an interdisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.	11	3	1	0
Standard 4: UCEDDs prepare students to work on behalf of a diverse population of people with developmental disabilities.	13	1	1	0
4.1 Enrolls students from culturally and linguistically diverse backgrounds.	11	4	0	0
4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities.	12	2	0	1
4.3 Provides students with experiences that lead to an understanding of the daily lives of people with developmental disabilities and their families.	12	1	1	1
Standard 5: UCEDDs improve the knowledge and skills of service providers and practitioners through continuing education, inservice training, and technical assistance.	12	0	2	1
5.1 Provides continuing education to a variety of professionals in the community.	12	2	0	1
5.2 Bases continuing education on documented needs in the state or territory, as identified in the 5-year plan.	11	3	0	1
Standard 6: UCEDD faculty and staff conduct research that is relevant to the lives of people with developmental disabilities and family members	13	1	0	1
6.1 Conduct basic or applied research, evaluation, or policy analysis relevant to the lives of people with developmental disabilities or family members.	13	0	1	1

Draft standard/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
6.2 Involve people with developmental disabilities in the development, design, or implementation of the research.	10	4	0	1
6.3 Publish research findings on developmental disabilities in peer-reviewed journals and other venues.	13	1	0	1
6.4 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.	13	1	0	1
Standard 7: UCEDDs provide community services through training or technical assistance for people with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community. And may provide services, supports, and assistance through demonstration and model activities	11	3	0	1
7.1 Addresses topics that allow professionals to maintain professional credentials, expand their knowledge base, and stay up-to-date on new developments	8	5	1	1
7.2 Provides community services that address issues across the range of the population of people with developmental disabilities in the state or territory.	10	4	0	1
7.3 Provides continuing education training and technical assistance that promote the principles of the DD Act.	13	1	0	1
7.4 Integrates community services with training, research and/or dissemination functions.	6	7	1	1
7.5 Provides participants in continuing education activities with certificates of completion or continuing education units (CEUs).	8	6	0	1
7.6 Can document that recipients of training and technical assistance use the knowledge and skills they obtained from these activities.	7	6	1	1
Standard 8. UCEDD dissemination bridges the gap between research and practice.	12	2	0	1
8.1 Uses a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners.	13	1	0	1
8.2 Within university guidelines, disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.	8	6	0	1
Standard 9: UCEDD dissemination addresses the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.	12	1	1	1
9.1 Provides publications, materials and other resources in accessible formats.	13	1	0	1
9.2 Provides easily accessible training and technical assistance activities.	11	1	2	1

Draft standard/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
9.3 Seeks input on materials and resources from people with developmental disabilities and family members.	11	3	0	1
9.4 Evaluates dissemination activities and results on an ongoing basis.	12	2	0	1
9.5 Makes its products, resources, and materials available to other DD Network programs.	12	2	0	1
Standard 10: UCEDDs leverage ADD funding and in-kind resources to achieve the goals of the 5-year plan	13	1	0	1
10.1 Documents the degree to which the UCEDD leverages ADD and university funds.	12	1	1	1
Standard 11: UCEDDs maintain and support involvement from CACs.	14	0	0	1
11.1 Actively works to fill CAC vacancies in a timely manner and documents efforts to do so.	11	1	2	1
11.2 Maintains a diverse CAC membership.	13	1	0	1
11.3 Involves CAC members in the development and implementation of the 5-year plan.	14	0	0	1
11.4 Supports its CAC for a minimum of two meetings each year.	12	2	0	1
11.5 Provides CAC members with supports that are needed to ensure meaningful participation.	13	1	0	1

Appendix W4. Collaboration

Draft Standards and Performance Criteria – Version 2
Collaboration

Rating Results*

Draft standard/performance criteria (PC) – Version 2	Agree/ PC required	Unsure/ exceeds the standards	Disagree/ not relevant	Missing
Standard 1: All DD Network programs in the state or territory achieve common goals through collaboration.	41	3	3	0
1.1 Identify and acknowledge a common goal or goals.	44	3	0	0
1.2 Identify roles, activities and tasks for each DD Network program supporting the common goal or goals that are identified.	40	5	1	1
1.3 Demonstrate a united perspective on key issues related to common goals.	32	9	6	0
1.4 Involve representatives from all three DD Network programs in collaborative meetings.	39	3	2	3
1.5 Document the outcomes of collaborative efforts.	44	1	2	0

*47 panel members rated the draft standards and performance criteria for collaboration among the three DD network programs.

Appendix X. Cover Letters – Version 3 Materials

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1650 Research Boulevard
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July 25, 2011

Dear Panel Member:

I'd like to thank you for your participation as a member of the Draft Standards Panels on the State Council on Developmental Disabilities and collaboration.

Based on panel ratings, comments, and suggestions, we have revised Version 2 and present you with Version 3 of the Draft Standards and Performance Criteria for the State Councils on Developmental Disabilities. I am also including draft standards and performance criteria for collaboration.

Version 3 of the draft standards and performance criteria will be submitted to the Administration on Developmental Disabilities (ADD) as part of our final report on the National Independent Study of the Administration on Developmental Disabilities Programs. These are still considered draft standards and performance criteria, but they will provide ADD with a starting point that has received the benefit of careful review and comment by experts on the Developmental Disabilities (DD) Network programs like yourself.

I am attaching the following files to this email:

1. Rating Results of Version 2 of Draft Standards and Performance Criteria for the State Councils on Developmental Disabilities,
2. Version 3 of Draft Standards and Performance Criteria for the State Councils on Developmental Disabilities (no tracking),
3. Version 3 of Draft Standards and Performance Criteria for the State Councils on Developmental Disabilities (in tracking),
4. Panel member comments on Version 2 of the Draft Standards and Performance Criteria for State Councils on Developmental Disabilities (no one is identified),
5. Rating Results of Version 2 of Draft Standards and Performance Criteria on Collaboration,
6. Version 3 of Draft Standards and Performance Criteria on Collaboration (no tracking),
7. Version 3 of Draft Standards and Performance Criteria on Collaboration (in tracking), and
8. Panel member comments on Collaboration (no one is identified).

These files are contained in a zip file. **If you have trouble opening the file or would like to receive these files in hard copy, please let me know**.

Our approach to making changes to Version 2 was similar to the one we used previously. In general, we tried not to change those standards and performance criteria with a high percentage of agreement from panel members. We also eliminated those with a low percentage and tried to follow

the suggestions for combining standards and performance criteria, simplifying, and rewording based on suggestions from panel members. Unfortunately, we were unable to incorporate every single suggestion since sometimes panel members held differing viewpoints.

For the draft standards and performance criteria for the State Councils on Developmental Disabilities, we took out the category headings (we agree that the categories of Council functions are not straightforward and often overlapping), combined a number of the performance criteria in the planning section and elsewhere, added many of the examples suggested by panel members, split one of the standards into two separate standards, and made some of the performance criteria into examples. We also tried not to limit the systems change section to advocacy efforts alone. A suggestion that came up often was to put all examples in a separate section. Although there were many suggestions for improved examples (and we tried to honor those), we felt that the draft standards and performance criteria would be best understood with the examples in close proximity to the appropriate section.

Again, I would like to thank you for your invaluable assistance, dedication, and hard work on this project.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies

Attachments

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Rockville, MD 20850-3195
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July 25, 2011

Dear Panel Member:

I'd like to thank you for your participation as a member of the Draft Standards Panels for the Protection and Advocacy (P&A) System and collaboration.

Based on panel ratings, comments, and suggestions, we have revised Version 2 and present you with Version 3 of the Draft Standards and Performance Criteria for the Protection and Advocacy System. I am also including draft standards and performance criteria for collaboration.

Version 3 of the draft standards and performance criteria will be submitted to the Administration on Developmental Disabilities (ADD) as part of our final report on the National Independent Study of the Administration on Developmental Disabilities Programs. These are still considered draft standards and performance criteria, but they will provide ADD with a starting point that has received the benefit of careful review and comment by experts on the Developmental Disabilities (DD) Network programs like yourself.

I am attaching the following files to this email:

1. Rating Results of Version 2 of Draft Standards and Performance Criteria for the Protection and Advocacy System,
2. Version 3 of Draft Standards and Performance Criteria for the Protection and Advocacy System (no tracking),
3. Version 3 of Draft Standards and Performance Criteria for the Protection and Advocacy System (in tracking),
4. Panel member comments on Version 2 of the Draft Standards and Performance Criteria for the Protection and Advocacy System (no one is identified),
5. Rating Results of Version 2 of Draft Standards and Performance Criteria on Collaboration,
6. Version 3 of Draft Standards and Performance Criteria on Collaboration (no tracking),
7. Version 3 of Draft Standards and Performance Criteria on Collaboration (in tracking), and
8. Panel member comments on Collaboration (no one is identified).

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Our approach to making changes to Version 2 was similar to the one we used previously. In general, we tried not to change those standards and performance criteria with a high percentage of agreement from panel members. We also eliminated those with a low percentage and tried to follow the suggestions for combining standards and performance criteria, simplifying, and rewording as much as possible. Unfortunately, we were unable to incorporate every single suggestion since sometimes panel members held differing viewpoints.

Again, I would like to thank you for your invaluable assistance, dedication, and hard work on this project.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies

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July 25, 2011

Dear Panel Member:

I'd like to thank you for your participation as a member of the Draft Standards Panel for University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) and Collaboration.

Based on panel ratings, comments, and suggestions, we have revised Version 2 and present you with Version 3 of the Draft Standards and Performance Criteria for the State Councils on Developmental Disabilities. I am also including draft standards and performance criteria for collaboration. Version 3 of the draft standards and performance criteria will be submitted to the Administration on Developmental Disabilities (ADD) as part of our final report on the National Independent Study of the Administration on Developmental Disabilities Programs. These are still considered draft standards and performance criteria, but they will provide ADD with a starting point that has received the benefit of careful review and comment by experts on the Developmental Disabilities (DD) Network programs like yourself.

I am attaching the following files to this email:

1. Rating Results of Version 2 of Draft Standards and Performance Criteria for the UCEDDs,
2. Version 3 of Draft Standards and Performance Criteria for the UCEDDs (no tracking),
3. Version 3 of Draft Standards and Performance Criteria for the UCEDDs (in tracking),
4. Panel member comments on Version 2 of the Draft Standards and Performance Criteria for UCEDDs (no one is identified),
5. Rating Results of Version 2 of Draft Standards and Performance Criteria on Collaboration,
6. Version 3 of Draft Standards and Performance Criteria on Collaboration (no tracking),
7. Version 3 of Draft Standards and Performance Criteria on Collaboration (in tracking), and
8. Panel member comments on Collaboration (no one is identified).

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In this version, we continued to use the core functions found in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) to organize the UCEDD draft standards and performance criteria, attempted to make the sections on continuing education and community services more consistent with the DD Act. A suggestion that came up often was to put all examples in a separate section. Although there were many suggestions for improved examples (and we tried to honor those), we felt that the document would be best understood with the examples in close proximity to the appropriate section.

Again, I would like to thank you for your invaluable assistance in this project and appreciate your dedication and hard work.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies

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July 25, 2011

Dear Panel Members:

I'd like to thank you for your participation as a member of the Draft Standards Panels for Protection and Advocacy (P&A), University Centers for Excellence in Developmental Disabilities Education, research, and Service (UCEDD), and collaboration.

Based on panel ratings, comments, and suggestions, we have revised Version 2 and present you with Version 3 of the Draft Standards and Performance Criteria for these two DD Network Programs and collaboration. Version 3 of the draft standards and performance criteria will be submitted to the Administration on Developmental Disabilities (ADD) as part of our final report on the National Independent Study of the Administration on Developmental Disabilities Programs. These are still considered draft standards and performance criteria, but they will provide ADD with a starting point that has received the benefit of careful review and comment by experts on the DD Network programs like yourself.

I am attaching the following files to this email:

1. Rating Results of Version 2 of Draft Standards and Performance Criteria for P&As, UCEDDs and collaboration,
2. Version 3 of Draft Standards and Performance Criteria for P&As, UCEDDs and collaboration (no tracking),
3. Version 3 of Draft Standards and Performance Criteria for P&As, UCEDDs, and collaboration (in tracking), and
4. Panel member comments on Version 2 of the Draft Standards and Performance Criteria (no one is identified).

These files are contained in zip files – a separate zip file for the P&A, UCEDDs, and collaboration. **If you have trouble opening any of these files or would like to receive these files in hard copy, please let me know**.

Our approach to making changes to Version 2 was similar to the one we used previously. In general, we tried not to change those standards and performance criteria with a high percentage of agreement from panel members. We also eliminated those with a low percentage and tried to follow the suggestions for combining standards and performance criteria, simplifying, and rewording based on suggestions from panel members. Unfortunately, we were unable to incorporate every single suggestion since sometimes panel members held differing viewpoints.

For the P&A draft standards and performance criteria, we also took out the category headings. For UCEDDs, we continued to use the core functions found in the DD Act to organize the UCEDD draft standards and performance criteria, attempted to make the sections on continuing education and community services more consistent with the DD Act. A suggestion that came up often was to put all examples in a separate section. Although there were many suggestions for improved examples (and we tried to honor those), we felt that the document would be best understood with the examples in close proximity to the appropriate section.

Again, I would like to thank you for your invaluable assistance, dedication, and hard work on this project.

Sincerely,

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July 25, 2011

Dear Panel Members:

I'd like to thank you for your participation as a member of the three Developmental Disabilities (DD) Network program and collaboration Draft Standards Panels.

Based on panel ratings, comments, and suggestions, we have revised Version 2 and present you with Version 3 of the Draft Standards and Performance Criteria for all three DD Network Programs and collaboration. Version 3 of the draft standards and performance criteria will be submitted to the Administration on Developmental Disabilities (ADD) as part of our final report on the National Independent Study of the Administration on Developmental Disabilities Programs. These are still considered draft standards and performance criteria, but they will provide ADD with a starting point that has received the benefit of careful review and comment by experts on the DD Network programs like yourself.

I am attaching the following files to this email:

1. Rating Results of Version 2 of Draft Standards and Performance Criteria for State Councils on Developmental Disabilities, P&As, UCEDDs and collaboration,
2. Version 3 of Draft Standards and Performance Criteria for State Councils on Developmental Disabilities, P&As, UCEDDs and collaboration (no tracking),
3. Version 3 of Draft Standards and Performance Criteria for State Councils on Developmental Disabilities, P&As, UCEDDs, and collaboration (in tracking), and
4. Panel member comments on Version 2 of the Draft Standards and Performance Criteria (no one is identified).

These files are contained in zip files – a separate zip file for the Council, P&A, UCEDDs, and collaboration. **If you have trouble opening any of these files or would like to receive these files in hard copy, please let me know**.

Our approach to making changes to Version 2 was similar to the one we used previously. In general, we tried not to change those standards and performance criteria with a high percentage of agreement from panel members. We also eliminated those with a low percentage and tried to follow the suggestions for combining standards and performance criteria, simplifying, and rewording based on suggestions from panel members. Unfortunately, we were unable to incorporate every single suggestion since sometimes panel members held differing viewpoints.

For the draft standards and performance criteria for the State Councils on Developmental Disabilities and P&As, we took out the category headings (we agree that the categories of Council functions are not straightforward and often overlapping), combined a number of the performance criteria in the planning section and elsewhere, added many of the examples suggested by panel members, split one of the standards into two separate standards, and made some of the performance criteria into examples. We also tried not to limit the systems change section to advocacy efforts alone. A suggestion that came up often was to put all examples in a separate section. Although there were many suggestions for improved examples (and we tried to honor those), we felt that the draft standards and performance criteria would be best understood with the examples in close proximity to the appropriate section.

For the P&A draft standards and performance criteria, we also took out the category headings. For UCEDDs, we continued to use the core functions found in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) to organize the UCEDD draft standards and performance criteria and attempted to make the sections on continuing education and community services more consistent with the DD Act.

Again, I would like to thank you for your invaluable assistance, dedication, and hard work on this project.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies

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July 25, 2011

Dear Panel Members:

I'd like to thank you for your participation as a member of the Draft Standards Panels for State Councils on Developmental Disabilities, National Network of University Centers for Excellence in Developmental Disabilities in Education, Research, and Service (UCEDD), and Collaboration.

Based on panel ratings, comments, and suggestions, we have revised Version 2 and present you with Version 3 of the Draft Standards and Performance Criteria for these two DD Network Programs and collaboration. Version 3 of the draft standards and performance criteria will be submitted to the Administration on Developmental Disabilities (ADD) as part of our final report on the National Independent Study of the Administration on Developmental Disabilities Programs. These are still considered draft standards and performance criteria, but they will provide the Administration on Developmental Disabilities (ADD) with a starting point that has received the benefit of careful review and comment by experts on the DD Network programs like yourself.

I am attaching the following files to this email:

1. Rating Results of Version 2 of Draft Standards and Performance Criteria for State Councils on Developmental Disabilities, UCEDDs, and collaboration,
2. Version 3 of Draft Standards and Performance Criteria for State Councils on Developmental Disabilities, UCEDDs, and collaboration (no tracking),
3. Version 3 of Draft Standards and Performance Criteria for State Councils on Developmental Disabilities, UCEDDs, and collaboration (in tracking), and
4. Panel member comments on Version 2 of the Draft Standards and Performance Criteria (no one is identified).

These files are contained in zip files – a separate zip file for the Council, P&A, UCEDDs, and collaboration. **If you have trouble opening any of these files or would like to receive these files in hard copy, please let me know**.

Our approach to making changes to Version 2 was similar to the one we used previously. In general, we tried not to change those standards and performance criteria with a high percentage of agreement from panel members. We also eliminated those with a low percentage and tried to follow the suggestions for combining standards and performance criteria, simplifying, and rewording based on suggestions from panel members. Unfortunately, we were unable to incorporate every single suggestion since sometimes panel members held differing viewpoints.

For the draft standards and performance criteria for the State Councils on Developmental Disabilities, we took out the category headings (we agree that the categories of Council functions are not straightforward and often overlapping), combined a number of the performance criteria in the planning section and elsewhere, added many of the examples suggested by panel members, split one of the standards into two separate standards, and made some of the performance criteria into examples. We also tried not to limit the systems change section to advocacy efforts alone. A suggestion that came up often was to put all examples in a separate section. Although there were many suggestions for improved examples (and we tried to honor those), we felt that the draft standards and performance criteria would be best understood with the examples in close proximity to the appropriate section.

For UCEDDs, we continued to use the core functions found in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) to organize the UCEDD draft standards and performance criteria, attempted to make the sections on continuing education and community services more consistent with the DD Act. A suggestion that came up often was to put all examples in a separate section.

Again, I would like to thank you for your invaluable assistance, dedication, and hard work on this project.

Sincerely,

Lynn Elinson, Ph.D.
Associate Director, Health Studies

Attachments

Appendix Y. Draft Standards and Performance Criteria – Version 3

Y1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

Y2. PROTECTION AND ADVOCACY SYSTEMS

Y3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

Y4. COLLABORATION

Appendix Y1. State Councils on Developmental Disabilities

State Councils on Developmental Disabilities (Councils)

Draft Standards and Performance Criteria – Version 3

Standard 1: State Councils on Developmental Disabilities identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory.

A Council that meets this standard:

1.1 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities in the state or territory, from a variety of sources, and across the state or territory.

- Examples of members of a broad population of people with developmental disabilities include a variety of developmental disability types, age groups, living arrangements, geographic locations, socio-economic status, and ethnic and racial groups.*
- Examples of sources of input include people with developmental disabilities, family members, Council staff and members, DD Network partners in the state or territory (i.e., P&A and UCEDD[s]), results from the previous 5-year plan, focus group results from other agency needs assessments, the public, State agency staff, participants in Council supported activities, and disability organizations and advocates.*

1.2 Uses a variety of methods for collecting input for the State Plan, including accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of methods include focus groups, surveys (telephone, electronic and written), social media outlets, the Council website, collection of formal testimony through Council organized summits, information gathered from serving on boards and committees, the review and analysis of reports and studies, in person discussions, use of pictures, translations, webinars, chat rooms, and other electronic options.*

*Note: These are examples. Not all are required. Others may be used.

1.3 Uses information from the planning efforts of other organizations in the State or territory to increase planning efficiency.

- Examples of other organizations may include P&A, UCEDD(s), developmental disabilities partners, disability specific state agencies, Centers for Independent Living and statewide Independent Living Councils, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

1.4 Shows evidence that the Council received and considered the input it received.

Standard 2: State plans guide Council action.

A State Plan that meets this standard:

2.1 Drives activities that the State Council on Developmental Disabilities conducts and supports.

Standard 3: State Councils on Developmental Disabilities support the development of self-advocates and leaders among people with developmental disabilities and family members.

A Council that meets this standard:

3.1 Actively reaches out to people with developmental disabilities from the broad population of people with developmental disabilities in the state or territory to participate in self-advocacy and leadership activities.

- Examples of members of a broad population of people with developmental disabilities include a variety of developmental disability types, age groups, living arrangements, geographic locations, socio-economic status, ethnic and racial groups, and both men and women.*

  *Note: These are examples. Not all are required. Others may be used.

3.2 Work with state and territorial self-advocacy groups in the development and support of self-advocacy and leadership among people with developmental disabilities.

3.3 Establishes or strengthens a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities.

3.4 Supports and expands participation of people with developmental disabilities in cross-disability and culturally diverse leadership coalitions.

3.5 Seeks feedback (either directly or through their grantees) from participants in Council self-advocacy and leadership activities to examine and improve these activities.

Standard 4: Participants in Council self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.

A Council that meets this standard:

4.1 Promotes participation of trained self-advocates on advisory boards, boards of directors, and councils and committees where their voice can affect services and supports relevant to the needs of people with developmental disabilities and their families.

4.2 Can document that participants in self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.

- Examples of the use of such knowledge and skills include:*
  - Activity on one's own behalf,
  - Serving on the board of a disability-related organization,
  - Advocating policymakers to change or maintain services or access for people with developmental disabilities,
  - Participating in training other people with a developmental disability in self-advocacy and/or leadership, and
  - Participating on a board of a generic community organization, such as a church or disability specific state agency.

  *Note: These are examples. Not all are required. Others may be used.

Standard 5. State Councils on Developmental Disabilities improve the capacity of communities to include and support community members with developmental disabilities.

- Examples of improving the capacity of communities include increasing community awareness, knowledge, skills, and abilities; improving access to supports and services; and improving the infrastructure for service delivery throughout the State or territory.*

  *Note: These are examples. Not all are required. Others may be used.

A Council that meets this standard:

5.1 Supports information, training, and technical assistance to people and organizations in the community at large.

5.2 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.

- Examples of target audiences include health care providers, emergency response personnel, community recreation staff, building managers, teachers, daycare workers, faith-based organizations, service system providers, and employers.*

  *Note: These are examples. Not all are required. Others may be used.

5.3 Documents the outcomes of efforts to improve the capacity of the community.

Standard 6: State Councils on Developmental Disabilities support, lead and participate in efforts that result in system changes that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life for people with developmental disabilities.

A Council that meets this standard:

6.1 Uses a variety of strategies to meet its systems change objectives.

- Examples include writing position papers or other reports; obtaining press coverage; educating policy makers; giving public testimony; developing partnerships with self-advocacy groups; community capacity building activities, and promoting changes in law, policy, and practice.*

  *Note: These are examples. Not all are required. Others may be used.

6.2 Engages actively with partners, collaborators, and Council members and staff in implementing system change activities.

6.3 Evaluates its system change efforts, and makes adjustments as necessary.

6.4 Documents the outcomes of its system change efforts.

6.5 Identifies, tries out, and promotes new or innovative practices to improve services and supports for people with developmental disabilities and family members.

- Examples of how Councils do this include issuing requests for proposals, securing external funding to identify or test new or innovative practices, assisting community organizations in obtaining funding to identify or test promising practices, partnering

with other agencies or organizations in the state promoting new or innovative practices demonstrated to be effective, and supporting the replication of innovative projects found successful by other Councils in their home states.*

*Note: These are examples. Not all are required. Others may be used.

Standard 7. State Councils on Developmental Disabilities effectively fulfill their roles and meet their responsibilities.

A Council that meets this standard:

7.1 Meets the stipulations of the DD Act in the composition of Council membership.

7.2 Reflects the range of the population of people with developmental disabilities in the state or territory.

- Examples include a variety of developmental disability types, age groups, living arrangements, socio-economic status, the state's or territory's geographic areas, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

7.3 Actively works to expedite or facilitate filling Council vacancies in a timely manner and documents efforts to do so.

7.4 Communicates a written attendance policy, and documents attendance in Council meeting minutes.

7.5 Has members who play an active role in meeting Council objectives.

- An active role includes membership or chairmanship of a sub-committee, acting as representative with other committees and work groups, participation in public policy activities, participation in demonstration project oversight, and participation in Council and committee/task force activities.*

  *Note: These are examples. Not all are required. Others may be used.

7.6 Provides an orientation to new Council members.

- The orientation includes the principles and goals of the DD Act, background on the Council, Council goals and objectives, and the current State Plan, and, if necessary, should be provided in more than one format to meet Council member needs.

7.7 Provides supports and ongoing education and training to Council members to ensure meaningful participation.

- Examples of supports and ongoing education and training include mentorship of new Council members, one-on-one assistance for Council members as necessary; training on the core functions of Council member roles and responsibilities, and provision of resources for Council members to attend meetings and events that broaden their knowledge and skills to effectively serve on the Council.*

  *Note: These are examples. Not all are required. Others may be used.

7.8 Reviews the performance of the Executive Director each year.

7.9 Uses a fair, transparent, and effective process to select competent and experienced grantees.

- Evidence of a fair, transparent and effective process includes adherence to procedures for selecting grantees; adherence to procedures for handling unsolicited proposals; the inclusion of outside expertise during the proposal review process, as necessary; and the selection of grantee projects that reflect the goals and priorities stipulated in the State Plan.*

  *Note: These are examples. Not all are required. Others may be used.

7.10 Maintains a system to manage grants and measure grantee results.

Appendix Y2. Protection and Advocacy Systems

Protection and Advocacy Systems (P&As)

Draft Standards and Performance Criteria – Version 3

Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities in the state or territory.

A P&A that meets this standard:

1.1 Collects input for the Statement of Goals and Priorities (SGP) from, or on behalf of, a broad population of people with developmental disabilities in the state or territory, from a variety of sources, and across the state or territory.

- Examples of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, geographic locations, and ethnic and racial groups.*
- Examples of sources include people with developmental disabilities, family members, P&A staff, Board of Directors or Commission members, DD Network partners in the state or territory, data from P&A activities (e.g., intake and referral, outreach and education), research and other reports that contain valid and reliably collected data, community gatherings, church affiliated events, state developmental disability agency, examples of first-hand accounts through state and territory disability organizations, advocates, and self-advocacy groups.*
- *Note: These are examples. Not all are required. Others may be used.

1.2 Uses a variety of methods for collecting input for the SGP, including accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of methods include focus groups, surveys (written and electronic), social media outlets, the P&A website, review and analysis of reports and studies, use of spoken/conversational in person discussions, simple language test, use of pictures, translations, webinars, chat rooms, and other electronic options.*

  *Note: These are examples. Not all are required. Others may be used.

1.3 Uses information from the planning efforts of other organizations in the state or territory to increase planning efficiency.

- Examples of other organizations may include the DD Council, UCEDD(s), developmental disabilities partners, developmental disability state agency, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

1.4 Shows evidence that the P&A received and considered the input it received.

1.5 Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statues, regulations, or priorities.

Standard 2: P&A SGPs are a guide to P&A action.

A P&A SGP that meets this standard:

2.1 Drives primary activities that the P&A conducts and supports.

Standard 3: The P&A intake process is fair, efficient, and effective.

A P&A that meets this standard:

3.1. Maintains written intake procedures that include but are not limited to procedures for documenting client information in a computerized database.

3.2 Ascertains accommodation and necessary support services at intake.

3.3 Provides training on the intake procedures to new intake staff.

3.4 Monitors intake staff adherence to intake procedures periodically.

3.5 Directs individuals who seek assistance from the P&A to the appropriate level of assistance.

- Examples of the different levels of assistance include referral, provision of information and resources, possible individual advocacy.*

  *Note: These are examples. Not all are required. Others may be used.

3.6 Provides intake staff with access to ongoing professional development.

Standard 4: P&A caseload reflects the priorities set in the SGP.

A P&A that meets this standard:

4.1 Maintains written procedures to guide the selection and processing of individual advocacy cases.

4.2 Selects individual advocacy cases that are consistent with but not limited to the goals and priorities in the SGP.

Standard 5: P&As provide high quality representation.

A P&A that meets this standard:

5.1 Has infrastructures for the review and discussion of individual advocacy cases.

- Examples of such infrastructures include weekly staff meetings to discuss ongoing cases or one-on-one meetings between advocates and lawyers to discuss cases.*

  *Note: These are examples. Not all are required. Others may be used.

Standard 6: Individual advocacy meets client objectives.

A P&A that meets this standard:

6.1 Has available resources to ensure staff is able to communicate with any client whose case is taken.

- Examples include availability of a language line and/or interpreters, staff that speaks a language other than English, a policy for including a support person for clients with cognitive disabilities if needed.*

- *Note: These are examples. Not all are required. Others may be used.

6.2 Except in the case of an emergency or time-limited circumstances, provides and updates a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.

6.3 Sends or gives clients a closing letter in understandable language documenting actions taken, results, and notification that the case is closed.

6.4 Informs the following individuals about the grievance process in writing:

- People with developmental disabilities whose case is turned down for individual advocacy, and
- Clients whose case is closed.

6.5 Has a mechanism for gathering and assessing client feedback and satisfaction with P&A services.

Standard 7: P&As strictly adhere to confidentiality.

A P&A that meets this standard:

7.1 Has a written confidentiality policy -- covering onsite or offsite staff, students, volunteers, and contracted staff -- with well-delineated requirements.

- Examples of confidentiality requirements include checking with clients about whether phone messages can be left, turning off the computer at the end of the day, and storing files in a cabinet or drawer so they are not left in view of someone walking through the office .*

  *Note: These are examples. Not all are required. Others may be used.

7.2 Has structures in place to maintain confidentiality.

- Examples of structures include shredding capability, private offices, email encryption, ongoing staff training on confidentiality, locking file cabinets.*

7.3 Requires compliance with the P&As written confidentiality policies and procedures by anyone who has access to client information.

7.4 Reviews confidentiality requirements to new staff, students, contracted staff, volunteers, and Board of Directors or Commissioners.

Standard 8: P&A systemic advocacy improves access to supports and services and reduces abuse and neglect.

A P&A that meets this standard:

8.1 Uses a variety of strategies to meet systemic advocacy objectives.

- Examples of strategies to effect systems change include writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation, filing amicus briefs, monitoring residential facilities, monitoring

existing databases, collaborating with developmental disabilities partners, and following up on identified patterns of abuse and neglect).*

*Note: These are examples. Not all are required. Others may be used.

8.2 Is able to document outcomes associated with its systemic advocacy efforts.

8.3 Conducts ongoing review of new or improved external policies to ensure appropriate implementation and assess potentially negative unintended consequences.

Standard 9: P&As engage in effective outreach activities to identify unserved and underserved populations.

A P&A that meets this standard:

9.1 Conducts ongoing outreach activities.

- Examples of outreach activities include use of the P&A website, distribution of brochures, presentations at community events on the P&A and P&A services, and Board of Director (or Commissioner) networking.*

9.2 Targets populations that are underrepresented or unserved.

9.3 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.

9.4 Periodically reviews outreach activities so that outreach plans and strategies can be revised as needed.

Standard 10: P&As have an impact on access to services and community participation for people with developmental disabilities through the provision of education, training, and technical assistance.

A P&A that meets this standard:

10.1 Provides culturally appropriate and targeted education, training, and technical assistance activities to people with developmental disabilities, family members, providers, and community members.

10.2 Measures recipient satisfaction with education activities.

Standard 11: P&A Board of Directors or Commission sets policy and long range goals for the P&A and holds the Executive Director accountable for adhering to the policies and goals.

A P&A that meets this standard:

11.1 Conducts an annual performance review of the Executive Director.

11.2 Actively works to fill Board of Directors (Commission) vacancies in a timely manner and documents efforts to do so.

11.3 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues, and who are knowledgeable about the developmental disabilities population and issues.

11.4 Familiarizes all new Board of Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.

11.5 Provides supports needed to facilitate meaningful participation by Board of Directors (or Commission) members.

- Examples include a physically accessible facility for all Board of Directors (or Commission) meetings, availability of accessible format print materials for each member who requires them.*

  *Note: These are examples. Not all are required. Others may be used.

Standard 12: P&As maintain an infrastructure that enables them to conduct key functions efficiently and effectively.

- Examples of key functions include intake and referral, individual advocacy, systemic advocacy, outreach, and community education.*

  *Note: These are examples. Not all are required. Others may be used.

A P&A that meets this standard:

12.1 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.

12.2 Conducts an annual performance review of all staff members.

12.3 Receives an independent audit each year, and immediately addresses qualified findings.

12.4 Budgets for professional development for staff.

Standard 13: P&As maintain operational independence from the Governor and the developmental disabilities service system of the state or territory.

Appendix Y3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)

Draft Standards and Performance Criteria – Version 3

A. 5-Year Planning

Standard 1: UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

A UCEDD that meets this standard:

1.1 Obtains input for the 5-Year Plan from a variety of sources.

- Examples of sources include people with developmental disabilities, family members, UCEDD faculty and staff, the Consumer Advisory Committee (CAC), students, DD Network partners in the state or territory, data from UCEDD activities (e.g., community services), research and other reports that contain valid and reliably collected data, state developmental disability agency and other policy makers, service providers, public meetings and hearings, and state and territory disability organizations and advocates.*

  *Note: These are examples. Not all are required. Others may be used.

1.2 Obtains input for the 5-year plan from or about a wide cross-section of the state or territory's developmental disability population representing many different segments of the community.

1.3 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

1.4 Uses information from the planning efforts of other organizations to increase planning efficiency.

- Examples of other organizations may include the DD Council, P&A, and other UCEDDs in the state, developmental disabilities partners, disability specific state

agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

*Note: These are examples. Not all are required. Others may be used.

1.5 Includes provisions for revising goals and priorities during the year to reflect new or changing conditions or priorities.

Standard 2: UCEDD 5-Year Plans are a guide for UCEDD action.

A 5-Year Plan that meets this standard:

2.1 Reflects the input from the planning process, and are consistent with, and to the extent feasible complement and further the goals of the State Plan of the State Council on Developmental Disabilities.

2.2 Guides the activities that the UCEDD conducts and supports, while including provisions for responding to emerging needs and opportunities.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

B. Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3: UCEDDs advance practice, scholarship and policy that impacts the lives of people with developmental disabilities and their families through pre-service training.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

A UCEDD that meets this standard:

3.1 Offers training that contributes to the award of an academic degree, professional certificate, or advanced academic credential.

3.2 Offers developmental disabilities-related courses, clinical experiences, mentorings, or trainings based on content from a variety of disciplines, taught by faculty and staff from multiple disciplines, to students from multiple disciplines.

3.3 Teaches students about the conduct and interpretation of research.

3.4 Integrates research findings into interdisciplinary pre-service preparation and continuing education activities.

3.5 Can document the percentage of graduates who are engaged in work related to people with developmental disabilities or their families 5 years after training.

3.6 Prepares students to apply an interdisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.

Standard 4: UCEDDs prepare students to work on behalf of a diverse population of people with developmental disabilities.

A UCEDD that meets this standard:

4.1 Enrolls students from culturally and linguistically diverse backgrounds.

4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities.

4.3 Provides students with experiences (beyond formal training) that lead to an understanding of the daily lives of people with developmental disabilities and their families.

- Examples include the provision of opportunities to interact with people with developmental disabilities and family members.*

  *Note: These are examples. Not all are required. Others may be used.

C. Basic and Applied Research

Standard 5: UCEDD faculty and staff conduct research, evaluation and/or policy analysis that is relevant to the lives of people with developmental disabilities and family members.

A UCEDD that meets this standard has research faculty and staff who:

5.1 Involves people with developmental disabilities in the development, design, or implementation of the research.

- Examples of involvement include identifying research topics, assisting with the design of data collection instruments, helping to ensure that research materials are in accessible and understandable formats, recruiting people with developmental disabilities and family members as study participants.*

*Note: These are examples. Not all are required. Others may be used.

5.2 Publishes research findings on developmental disabilities in peer-reviewed journals and other venues.

- Examples of other venues include public awareness documents, popular journals, websites, newsletters, guidebooks, and policy briefs.*

  *Note: These are examples. Not all are required. Others may be used.

5.3 Presents research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.

5.4 Facilitates student research on developmental disabilities.

- Examples of ways to facilitate student research include becoming a thesis supervisor or dissertation committee member, or supervising a student research project.*

  *Note: These are examples. Not all are required. Others may be used.

D. Community Services

Standard 6: UCEDDs provide training or technical assistance for people with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community.

And may provide services, supports, and assistance through demonstration and model activities.

A UCEDD that meets this standard:

6.1 Provides community services that address issues across the range of the population of people with developmental disabilities in the state or territory.

- Examples include a variety of developmental disability types, age groups, living arrangements, geographic locations, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

E. Dissemination

Standard 7. UCEDD dissemination bridges the gap between research and practice and reaches people with developmental disabilities and their families.

A UCEDD that meets this standard:

7.1 Uses a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners.

- Examples include electronic, in-person, and print; mass mailings, YouTube videos, and seminar series; use of practitioner organization networks, listServs, contact lists to expand its dissemination range; and publication on developmental disability-related issues in professional newsletters and other publications for providers and practitioners.*

  *Note: These are examples. Not all are required. Others may be used.

7.2 Provides publications, materials and other resources in accessible formats.

7.3 Provides accommodations for people with developmental disabilities to make training and technical assistance accessible.

7.4 Seeks input on materials and resources from people with developmental disabilities and family members.

7.5 Evaluates dissemination activities and results on an ongoing basis.

- Examples include monitoring number of website hits, conducting targeted surveys, following up the use of materials.*

  *Note: These are examples. Not all are required. Others may be used.

7.6 Makes its products, resources, and materials available to other DD Network programs.

F. Governance and Management

Standard 8: UCEDDs leverage ADD funding and in-kind resources to achieve the goals of the 5-year plan.

A UCEDD that meets this standard:

8.1 Documents the degree to which the UCEDD leverages ADD and university funds.

Standard 9: UCEDDs maintain and support involvement from CACs.

A UCEDD that meets this standard:

9.1 Maintains a diverse CAC membership.

9.2 Involves CAC members in the development and implementation of the 5-year plan.

9.3 Supports its CAC for a minimum of two meetings each year.

9.4 Provides CAC members with supports that are needed to ensure meaningful participation.

Appendix Y4. Collaboration

Draft Standards and Performance Criteria – Version 3

Collaboration

Standard 1: All DD Network programs in the state or territory achieve one or more common goals through collaboration.

DD Network programs in a state or territory are the State Council on Developmental Disabilities (DD Council), the Protection and Advocacy (P&A) System, and one or more University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).

DD Network programs in a state or territory that meet this standard:

1.1 Identify a common goal or goals.

1.2 Identify roles, activities and tasks for each DD Network program supporting the common goal or goals that are identified.

1.3 Maintain a united perspective on key issues related to common goals.

1.4 Include participation from all three types of DD Network programs in collaborative efforts.

1.5 Document the outcomes of collaborative efforts.

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Appendix Z. Version 2 Comments

Z1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

Z2. PROTECTION AND ADVOCACY SYSTEMS

Z3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE

Z4. COLLABORATION

Appendix Z1. State Councils on Developmental Disabilities

State Councils on Developmental Disabilities (Councils)
Draft Standards and Performance Criteria
Version 2
Panel Member Comments

A. Planning

Standard 1: DD Councils identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory to lead meaningful and productive lives.

Comments
I agree; but my experience after serving out my terms on the DD Council is that it is difficult to get input from people for the state plan
But adding 'to lead meaningful and productive lives' could imply the exclusion of other values, e.g. integrated lives or independent lives. Could say 'to live lives consistent with the values of the DD Act'.
I think this is one of the essential reasons for Councils to exist.
Do not like the additional phrase ' to lead meaningful & productive lives'. It doesn't make sense in this sentence. The sentence is clear the way it read in Version 1. The addition produces a sentence that is not worded well.
DD Councils should be working with people with DD to identify needs, priorities.

A Council that meets this standard:

1.1 Collects input for the State Plan from, or on behalf of, a broad population of people with developmental disabilities in the state or territory.

- Examples of members of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
We get very little input on the state plan. We get most of our input from listening sessions.
"on behalf of" – What does this mean?
This PC would be acceptable if it is re-stated as "solicits" input - as noted in prior comment from this group, collecting is something that we have no real control over but we can certainly solicit input widely.
I continue to believe that "solicits input" or "requests" is better than "collects." We can ask for input, but cannot control what we receive in return. Were the wording changed, I would agree to "required to meet standard."
Add this to the list "…and geographic locations'
I like the examples because I think it helps Councils be clear about the scope of the input.

1.2 Collects input for the State Plan from a variety of sources.

- Examples of sources include DD Council staff, DD Council members, DD Network partners in the state or territory (i.e., P&A and UCEDD[s]), results from the previous 5-year plan, focus group results from other agency needs assessments, the public, State agency staff, participants in DD Council supported activities, and disability organizations and advocates.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
This has worked well for [STATE] that we can gather input from many sources
Can't we combine 1.1, 1.2, 1.3 and 1.4 to say "collects input for the state plane from people with developmental disabilities and from geographic regions?
I continue to believe that "solicits input" or "requests" is better than "collects." We can ask for input, but cannot control what we receive in return. Were the wording changed, I would agree to "required to meet standard."
This should also include relevant data from reports and studies. That is covered in 1.4 (methods) and should be referenced here (sources) as well.
This doesn't specifically call for input from individuals w/disabilities – that needs to be explicit. "Disability orgs and advocates' may be groups with no actual representation from people with DD
The state DD agency should be explicitly required and prioritized

1.3 Collects input for the State Plan from the various geographic regions across the state or territory.

Comments
This PC would be acceptable if it is re-stated as "solicits" input - as noted in prior comments from this group, collecting is something that we have no real control over but we can certainly solicit input widely.
I continue to believe that "solicits input" or "requests" is better than "collects." We can ask for input, but cannot control what we receive in return. Were the wording changed, I would agree to "required to meet standard."
Is this needed? How would we measure this?
This is unnecessary if you add it to the list of 1.1
This standard is appropriate. Data should be obtained from rural services, areas especially metropolitan areas should not dominate data collection.

1.4 Uses a variety of methods for collecting input for the State Plan.

- Examples of methods include focus groups, surveys, social media outlets, serving on Boards and committees in the state or local community, the DD Council website, collection of formal testimony through DD Council organized summits, and the review and analysis of reports and studies.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Remains a target for ADD technical Assistance
I'd drop the word 'formal'.

Comments
Again no specific requirement for gathering input directly from people with DD
This should require more purposeful exchange of info with the state DD agency
A variety of public forums should be used.
I think these examples are important and comprehensive. Much better than the i.e. in the earlier version. However, I think the phrase "serving on basoards and committees in the state of local community" does not make sense with "methods for collecting input". So, I suggests instead, "using information gathered from serving on boards and committees..."

1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include in person discussions, electronic surveys, written surveys, use of pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Remains a target for expert technical assistance from ADD - more than peer-to-peer assistance is needed.
I would add "accommodations required by the Americans with Disabilities Act" to specify what you mean by "accommodations."
Again, the examples are important and I think ought to include "telephones, webinars, chat rooms and other electronic options" rather than voice (i.e. telephone, chatrooms). A two layer example could easily confuse people.
This is extremely important. Standard may want to include documentation of efforts.

1.6 Uses information from the planning efforts of other organizations in the State or territory to increase planning efficiency.

- Examples of other organizations may include P&A, UCEDD(s), developmental disabilities partners, disability specific state agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Centers for Independent Living and Statewide Independent Living Councils
Don't think it's efficient to try to expand the plan with relevant generic agencies.
Still remains a target for ADD technical assistance
While this seems like a good idea, it is not one that should be required. Seems prescriptive.
This could be covered in 1.2 and 1.4.
This language should be changed to say "coordinates planning efforts with the plans of other orgs.' This sounds like Councils just pull info off other agencies' plans
Also should use information from providers
This is an imiportant standard as well, but i think it should read "efficiency and effectiveness."

1.7 Gathers input on needs on an ongoing basis.

Comments
How?
Not necessary
It depends on what is meant by ongoing. We are required to do a comprehensive assessment every 5 years (In [STATE] we do it every 3) and annual environmental updates. IF that is what is meant, it is fine. We also gather input as a result of policy and liaison activities, and receive public comment etc. If what is meant is a requirement for an annual needs assessment that would exceed the capacity and resources of most DD Councils.
Requires staffing capacity and dilutes sense of urgency.
Too vague as written. Is this really about gathering input more often, or is it about using input received during efforts to refine and improve State activities?
Important but too vague. It should include "needs of people with DD and their families" alaong with some examples of "ongoing". The word on-going could mean continuous, and no Council should be doing this.
Sometimes input gathered closer to the plan development is best, most current. A standard requiring when/how often ("ongoing") a Council gathers data goes beyond the standard and beyond what is intended in the Act. I don't see this as useful or reasonable.
This standard is necessary because the culture in which DD services are being provided is changing.

Standard 2: State plans reflect the needs of people with developmental disabilities and family members in the state or territory and is a guide to DD Council action.

Comments
Should be combined with Standard 1
Clearly the state plan needs to reflect assessed needs but it cannot be reflect of all needs. The Councils gather input and look at the Assessment and must prioritize based on important issues and resources. A reference to prioritization should be included in the standard.
This statement would be appropriate only if " within available financial resources" is added. There must be realistic boundaries - DDCs receive a small amount of funding and prioritization of what can be done within that boundary is essential.
I said it before and I guess others didn't agree, but this is two standards, not one. One is whether or not the plan actually reflects the needs that were identified in all the data gathering, which is imporotant. But equally important is that the plan ACTUALLY GUIDES what the Council does. I think these should be separate since the activities are distinct.

A State Plan that meets this standard:

2.1 Is consistent with the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

- Examples include self-determination, independence, productivity, integration, and inclusion in all facets of community life.*

*Note: These are examples. Not all are required. Others may be used.

Comments
This is redundant and unnecessary. Clearly state plans must meet the tenets of the DD Act.
The plan should comply with the requirements of the DD Act. What being "consistent with its goals and principles" means is subjective.
Don't believe the examples are needed. The Act says what it says. Ultimately ADD will determine whether this criteria is met.
The value of this standard is obvious. Inclusion and quality of life are reasons why we advocate for and provide services to persons with DD in the first place.

2.2 Is consistent with the input received from the planning process.

Comments
See Standard 1
It depends on what is being referred to as "input" The state plan must clearly address key issues found in the comprehensive assessment and be as responsive as possible to public inputs. However, the Council must still make determinations and prioritize this input. Suppose for example the Council received 100 letters of public comment from an organization that supported activity that is inconsistent with the DD Act (i.e., support of institutions). In that case the state plan developed would not be consistent with that input. Resources, (financial and staffing) make a difference here too. A Council can receive input that could address 10s of issues but cannot within current allocations address them all. This would lead some constituents to feel that the Council was not responding to public input. If this is kept the wording should be refined.
Again boundaries and priorities come into play - our plans must be based on public input but realities of what actually can be done and getting the "biggest bang for the buck" must also figure into the decision making.
Some input may not be appropriate to reflect: e.g., "People should remain in institutions where they are safe." Reword: evidence is present that input was received and considered by the Council" or something along those lines.
Unsure – some things might change during the planning process

2.3 Drives activities that the DD Council conducts and supports.

Comments
Absolutely
Seems redundant. This is required by law.
Drives 'all' activities?
Yes, and this one goes to the standard about the plan directing COuncil activites.

2.4 Contains priorities that consider the needs of people with developmental disabilities and family members, DD Council resources, and what is already taking place in the state and local communities.

Comments
This is crucial consideration but it is not adequate, alone, to address the comments included in Standard 2.
Great wording for this standard – we used this in our planning this past year.
Reword: "Contains priorities that show evidence that consideration has been given to the needs..."
I would use 'reflect' rather than 'consider'. Also, I suggest the effective use of Council resources should be a separate criteria. Not replicating what is taking place elsewhere is a measure of that.
"Consider" could also be 'connect' to be stronger
Yes, this is a good description of the context for planning.

Additional comments; additional standards or performance criteria for Planning

Comments
I think there should be a standard to any priorities should be consistent with the data collected (as opposed to the strong wishes of Council members and stakeholder groups)
Should combine 1 and 2
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion.
DD Councils need guidance in how to reconcile the standard e.g. the goals of the DD act and the expressed needs of people
As stated above, I think that standard #2 should be two different standards. In one part of this standard, the Council is reponsible for insuring that the plan is well tied to the findings of the Council's various info. gathering strategies. The plan must connect well to this since it is intended in inform subsequent Council activity. But the second part of the existing standard, "is a guide...", is a separate activity. It's about whther the Council USES its plan to direct what it does. They are separate behaviors and I think should be seen as separate standards.

B. Self-Advocacy and Leadership

Standard 3: DD Councils develop self-advocates and leaders among people with developmental disabilities and family members through the support of activities that provide exposure, education, training, and technical assistance.

Comments
But I would drop the word 'self-advocate'
Can't self advocates be leaders? But families cannot be self-advocates. This needs to be clear.
Last line should be changed to and/or technical assistance as a Council may not conduct all of these activities.
Agree in concept if the statement ends without the extender so that it says –> "DD Councils develop self-advocates and leaders among people with developmental disabilities and family members." The additional verbiage is not consistent in format with the other standard statements.
'Family Members' not required by the Act
I am unclear what "provide exposure" means. Perhaps you might use "raise public awareness."

Comments
I'm still not sure that family members should be included. The Act specifically delineates leadership of PWDD, and family members are not noted in any of the criteria below.
Replaced 'develop' with 'support', deleted 'the support of activities that provide'; Replaced exposure with 'expanded opportunities'. Instead of develop, use 'support'.
But should work with self advocacy groups in the state to do this.
Another essential Council activity.
Delete the word 'exposure'. I don't know what this means and it may be difficult to assess if not clear.
DD Councils can and should invest in the development of their self-advocates and leaders.

A Council that meets this standard:

3.1 Actively reaches out to people with developmental disabilities from the broad population of people with developmental disabilities in the state or territory to participate in education, training, and technical assistance activities.

- Examples of members of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups, and both men and women.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Should be clarified. If this refers to solicitng individuals to participate in the Council's self advocacy and training programs, then it is fine as there should be broad solicitation for these programs.. If it goes beyond that to generally reach out to all people with DD to solicit participating in training, education, and TA, that is beyond the resources of most Councils. A lot of these issues noted in comments could be addressed by tweaks in wording that would make it clear that the expectation is not to do "all."
If the Council's initiative is budgeted to include pwdd, it's great to reach out; however, the budget may limit the capacity of the Council or its grantee to do this.
Rewrote 'disabilities' as 'developmental disabilities'
Good as far as this goes, but I think it would be useful to describe technical assistance activites in an example as well
Practicing this standard will provide the richest and broadest base of information regarding the needs of people with DD.

3.2 Seeks feedback from participants in DD Council self-advocacy and leadership activities to inform the effectiveness of Council self-advocacy and leadership activities.

- Examples of ways to seek feedback include surveys and interviews.*

*Note: These are examples. Not all are required. Others may be used.

Comments
Listening sessions, for example at continuing education at Partners in Policymaking graduation session is a valuable tool to gain feedback as well as getting feedback from other DD sponsored activities.
In some of these standards, it is difficult to distinguish what the Council is being asked to do vs. what the grantees may be asked to do on behalf of the Council. Are these participants in formal activities that are directly funded by the Council (in our case, Partners); in on-going activities of the Council's grantees; or people attending a one-time event such as a conference, not held by the Council itself, but for which the Council funded the keynote speaker?
As stated before, this needs to go beyond current participants in DD Council self-advocacy activities to ensure a broad range of self advocate perspectives.
Well, I think this is a little confusing. If the standard is about whether the Council helped to prepare them to be self advocates and leaders, then the standard should be "seeks feedback about the PREPARATION OF SELF ADVOCATES for acvocacy and leadership". If the standard is about the EFFECTIVENESS (outcomes) of the activities, then it should say, " ...and leadership activities to allow the Council to examine the effectivenss of self advocacy and leadership efforts".

Standard 4: Participants in DD Council self-advocacy and leadership development activities exercise self-determination and provide effective leadership and advocacy in the state or territory around issues that improve the lives of people with developmental disabilities.

Comments
Focus should be on what the Council can document as an outcome. The Council can provide training and educate self advocates and can track activities of those who are responsive to queries. The Council cannot ensure that these participates exercise effective leadership and advocacy that improves lives.
Agree in concept but there is still an artifical distinction between standards #3 & #4. Furthermore the phrase " exercise self-determination and" is an add-on that changes the intent of the standard (i.e. leadership development to provide effective leadership & advocacy).
This standard is not suspectible to any objective measure. "Exercise self-determination;" "effective leadership" and "issues that improve the lives of people" are very subjective and applied, presumably, to all participants.
Consider dropping 'self-determination" as this is not directly related to leadership and is hard to measure. Either that or sepatate the two. Taking a leadership role in advocacy around issues is different than exercizing self-determination, which is more a reflection of self-advocacy. Upon further reflection, maybe the standard should be the first part of criteria 4.1 (Participants in...activities use the knowledge and skills they obtain.)
I like this one, except for the word "effective". While I agree that leadership is about effectiveness, I think the word is not helpful here and so i would leave it out.

A Council that meets this standard:

4.1 Can document that participants in self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.

- Examples of the use of such knowledge and skills include:*
  - Serving on the board of a disability-related organization (within the past 3 years),
  - Advocating policymakers to change or maintain services or access for people with developmental disabilities (within the past 3 years),
  - Participating in training other people with a developmental disability in self-advocacy and/or leadership (within the past 3 years),
  - Demonstrating the use of self-advocacy/leadership skills developed (within the past 3 years), and
  - Participating on a board of a generic community organization, such as a church or disability specific state agency.

*Note: These are examples. Not all are required. Others may be used.

Comments
Self advocates for change is a good example.
This will take lots of resources and follow up that have proved difficult in the past
The council can request this information but cannot guarantee that it will be submitted.
The bullet on legislative advocacy is far too limiting to cover all direct advocacy efforts. Some DDCs do not do legislative advocacy but do have a full advocacy agenda with a variety of different policy makers, including State Executive staff, state agency leaders, service provider agency leadership, and leadership of statewide organization and provider associations, etc. where they have more success and better outcomes than legislative advocacy.
I like the expansion of the examples to include participation in generic community organizations.
There are not enough examples of the use of such knowledge – personal, individual action ie., Activity on one's own behalf
I said this before, but this standard should NOT be about whether a Council CAN do this but whether they DO do this. I think the standard should be "Documents that participants in self advocacy...".
Add the following as an indicator: supports and expands participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions
This standard is a good expectation for leaders and self-advocates – DD Council should expect a return on their investment of training, education, and technical assistance.

4.2 Supports and helps to grow at least one statewide organization led and staffed by people with developmental disabilities.

Comments
Restate using the DD Act language - - 1) support - not support and help grow; 2) the statewide organization should be led "by and for" people with DD - being staffed by people w/DD, while certainly desirable, is not essential. Also, need to define support more broadly than provision of funds..
'Helps to grow' not essential to the Act
The DD Act does not require that Councils provide funding to a statewide organization. The definition of "supports" and "helps to grow" is not clear here. "Support" may include the assistance of Council staff or members. How much "support" is enough? Reword: "Council can document that it has offered support in the form of (list examples" to at least one statewide organization. " There is no requirement that the statewide organization accept that support, hence the use of the word "offered" or "made available."
Consider using language consistent with what is in the DD Act. "establish or strengthen a program for the direct funding".
I agree with other statements that there are multiple ways to support groups that may not be statewide. This is an improvement over the previous wording; but some examples of helping grow/support groups also would be helpful to get an idea of the range of things Councils can do to support and expand self-advocates
consider change to read: "establishes or strengthens a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities" This is directly from the Act and a clearer indicator.
This standard needs further exploration. Some examples might be helpful.

Further comments, Additional standards or performance criteria for Self-Advocacy and Leadership Development

Comments
It depends on if one is needed or nessasary.
This needs to be consistent with the DD Act. This suggests we have to fund leadership training for everyone – not sure this meets the intent of the Act.
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. The DD Act directs 3 things related to self-advocacy - support of a statewide organization, leadership development, and involvement in cross-disability coalitions - the later was not addressed in any fashion. This section has artificial distinctions - which were brought up previously - the section should be labeled "advocacy" and include standards on general disability advocacy and self-advocacy which would more appropriately depict our advocacy and self-advocacy responsibilities under the law.
I thik an additional perfomance criterion would be good and it should be something like: Promotes particpation of trained self advocates on advisory boards boards of directors, councils and committees where their voices can affect services and supports relevant to the needs of people with DD and their families. I think this ties in nicely to the next standard about community capacity as well, so it would be fine with me if the performance criterion were there.
The above standard is a wonderful benchmark. It should be kept in mind that many organizations may philosophically support leadership opportunities for people with disabilities but are unwilling to practice it. Also many people with DD would need significant supports to function in a leadership role or capacity.

C. Community Capacity Development

Standard 5. DD Councils improve the capacity of communities to include and support community members with developmental disabilities.

- Examples of improving the capacity of communities include increasing community awareness, knowledge, skills, and abilities and improving the infrastructure for service delivery throughout the State or territory.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Councils support capacity building activities. Ultimately it is the community that improves capacity not the Council. We can fund demonstration programs; we can educate; we can make recommendations. We cannot guarantee that these programs will improve capacity. This is too high a standard. The examples are fine but the standard itself needs to be more nuanced.
The law directs DDCs to build capacity of the service delivery system - not to do community capacity development (which is only a part of capacity building). We are told to focus on the access to, availability of, and delivery of services, supports and assistance (for which we can be held accountable) while changing communities is a very slow and evolutionary process which is next to impossible to measure and for which we should not be held accountable.
Added 'accessibility' to examples
The example includes 2 very different domains 1. The community 2. The service system – drop #2 from the example.
This standard is necessary if DD Councils are to meet and exceed their goals of full community inclusion for persons with disabilities.

A Council that meets this standard:

5.1 Supports information, training, and technical assistance to people and organizations in the community at large.

Comments
See comments under Standard #5. I could support the concept of "Supports information, training, and technical assistance to people and organizations" for buidling capacity but focused on the community at large is unacceptable.
With assistance from self-advocacy groups
I don't know what "supports information" means, so I suggest insstead "provides information, training and technical assistance..."
Not sure they have time to do this
Reword: .... increases capacity of public or private organizations so that they are more accessible to individuals with developmental disabilities and increase the individuals' independence, productivity and inclusuion in the community.

5.2 Targets community capacity development efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities.

- Examples of target audiences include health care providers, real estate agents, emergency response personnel, community recreation staff, building managers, teachers, daycare workers, social service providers, and employers.

  *Note: These are examples. Not all are required. Others may be used.

Comments
Councils are about systems change. This generally means targeted policymakers and leaders. Whle some of the examples like employers make sense, it is unlikely that targeting building managers, daycare workers, etc. will result in increased community capacity. Funding of demonstration projects may help the community at large to advocate for increased/changed services but the ultimate target must be those who and effect change on a broad basis. In addition, reaching localities, particularly with limited resources and staff is much more difficult. To reach the type of audiences listed above, Councils would need more funding.
We are responsible for building the capacity of the service delivery system - it is real nice if that can extend into the community but impossible to measure and more than we can be held responsible for. The PC should be restated as "Builds service system capacity to increase and improve services, choice and inclusion for people with developmental disabilities."
Do these first two standards assume that Councils will fund initiatives in these areas each year or instead assume that when the Council does so that the initiative will meet the standard?
Added 'faith-based organizations' to the examples.
Replaced 'social service providers' with 'service system.'
With assistance from self-advocacy groups.
Again, I have a verb problem in that I think "targets" is too vague. How would a reviewer know if a council targetted its efforts? I'd like to see a verb that is more visible - such as "works with the community at large to increase its capacity to serve and support people with DD and their families, increase and improve services, choice, and inclusion for people with DD."

5.3 Documents the outcomes of efforts.

Comments
I agree with statement conceptually and could accept the statement if it was refocused to the service delivery system but it is unacceptable when the focus is on the community.
If required (efforts)

Further comments, additional standards and performance criteria for Community Capacity Development

Comments
Do we need a standard "Supporting and educating people with disabilities/families to know and effectively utilize the services and resources local communities offer." Seems this is the partner standard to 5.2
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. I am incredibly disappointed that the comments you received on round 1 were not used to redefine this section to focus on capacity building. The focus on community capacity development exceeds what we can do with the small amount of financial resources provided under the DD Act. I will restate my concerns once again –> DDCs are directed to do capacity building - not specifically Community Capacity Development. The entire focus of Standard 5 needs to reflect that point and the terminology changed. We should be building capacity in all aspects of the service delivery and community-based service systems - not limiting it to a single aspect.
This standard should be more clearly stated. Generic community with examples Service system with examples DO NOT mix the two
Mostly these work; my focus in on what it would be like to be a reviewer trying to figure out if a council actually did this - how would I know? How would a council know what evidence to bring forward?
DD Councils should continue to fund projects that bring public awareness to the issues facing those with I/DD. If permanent funding is not possible, then a train the trainer model should be used to continue education efforts at the local level.

D. Systems Change through Advocacy

Standard 6: DD Councils support, lead and participate in advocacy efforts that are expected to result in system changes that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life for people with developmental disabilities.

Comments
Absolutely
Standard 6 STILL does not reflect our systems change mission - it focuses almost entirely on advocacy. They are NOT the same. This standard and all the performance criteria needs to be re-worked to make that distinction. Advocacy and systems change are two separate and distinct functions which sometime (maybe frequently) are needed to work "hand in glove" to achieve a desired end.
I don't like the term 'expected". Maybe 'targeted' or 'implemented'.
I made this omment before, but i think it's important so I'm making it again. In order to do what this standard calls for, COuncil have to have sort of system change framework to use. There are many out there, but I really think that one of the performance criteria here has to be: "has selected and uses a system change framework/model to guide all its systems change efforts."
Change "D" to read "Systems Change". Advocacy is one way to accomplish systems change. This heading seems too narrow.

A Council that meets this standard:

6.1 Uses a variety of strategies to meet systems change objectives.

- Examples include provision of funding to support systems change efforts; writing position papers or other reports; obtaining press coverage; educating policy makers; giving public testimony; and promoting changes in law, policy, and practice).*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Should just provide support to those entities that are the system changers. In [STATE] for example: We only have one full time staff person. We can't expect our only staff person to wear all hats
This PC is appropriate ONLY if the Standard is refocused and restated on systems change - not advocacy. Use of a variety of strategies, including but not limited to advocacy, is very appropriate to effective promote systems change.
I like this as it shows how Councils can define system change efforts
Can you clarify the wording? Does this mean a variety of strategies for each system change objective? Or that the Council simultaneously conducts a variety of system change initiatives?
Example should include funding, research
With assistance from self advocacy groups
These are all examples from a system change framework, and so it reinforces for me the need for a standard that speaks to the framework.

6.2 In addition to partners and collaborators, includes both Council members and staff in implementing advocacy activities.

Comments
This PC would certainly be acceptable and appropriate should you refocus the Self-Advocacy and Leadership standard to Advocacy and Leadership (with self-advocacy as one element) and move it under such a standard. However, Standard 6 is inappropriately focused on advocacy. This standard needs to be refocused and re-stated before any of the PC will be acceptable. Advocacy and systems change are two separate and distinct functions.
Without a definition of systems change, advocacy, or capacity building, the shift here from "systems change" (6.1) to "advocacy" is confusing. The use of "members" (vs. Council) further adds to that confusion. Is the "advocacy" here that associated with the initiatives the Council is funding? Or is it going into the legislature to advocate more generally? "Implementing" implies that Council members have an active role in grant-funded initiatives once they are on the ground, for example, making site visits. I would prefer verbs like "developing" or "providing oversight." Involving members in implementation can get costly. I would prefer "The Council's members and its staff are actively engaged with partners and collaborators in systems change initiatives." That would meet the standard.
The participation of Council members is important. Do we need 'in addition to'?
Unclear as to why this level of detail in implementation is necessary. Not sure what you're getting at as written: that Councils should work in partnership with others and within their own Council and staff to implement? Councils should be the facilitators/leaders of this larger group?

6.3 Makes sure policy makers personally know some Council members or staff.

Comments
Too prescriptive. Also hard to define what equals 'know'
Some Councils may be prohibited from this kind of activity
Would be better to reverse the direction and state that Council members and staff develop relationships or contact policy makers directly.
Nice but not necesary and certainly not mandatory.
Policymakers are required members of the Council. Why should we have to make sure people who are at the same meeting "personally get to know" each other? Policymakers outside the membership exceeds the standard."Personally know" is not susceptible to measurement.
"Implements efforts to make personal connecions between policynmakers and Council members or staff" should be the criteria. I'm not sure how to measure 'makes sure'.
Rewrote 'policy makers personally' as 'know'
Council should hold a variety of functions to make this happen
I think this is critical, but I think the criterion is too limited. It should say something more about which policy makers, so I suggest: "Makes sure policy makers, including those in a wide range of state agencies, personally know some Council members or staff." Too often, I think, Councils focus on the traditional DD agencies and don't look to state departments of Labor or housing, which should be a focus if inclusion is a goal.
This statement feels like a 'low ball' to me - if there are councils underperforming in this area, whose Council members are not involved in the Council's activities, I feel that we should deal with those instances directly. This doesn't seem like a quality standard for ADD to have for state councils. I think that we describe the level of involvement expected for Council members in another standard.

6.4 Evaluates its advocacy efforts throughout the year, and makes adjustments as necessary.

Comments
Part of the state plan
Would suggest replacing throughout with annually.
The concept of evaluation and course changes is certainly appropriate but not if focused solely on advocacy rather than encompasssing advocacy as one systems change strategy. The concept is appropriate (having evidence) but the statement as located is mis-guided.
What is meant by "evaluate" or by "advocacy efforts?" "Throughout the year" may create staff burdens. We informally evaluate and course correct throughout the year.
Continuous improvement - yes
With assistance from the self-advocacy groups
There should be one standard that relates to evaluation of all Council actvities, and looks for ways that Councils respond to evaluation information, how they use the evaluation information.
Flexibility is key. New opportunities usually come up and need action.

6.5 Documents the outcome and effects of its advocacy efforts.

Comments
Drop 'and effects'
The concept of documentation is certainly appropriate but not if focused solely on advocacy rather than encompasssing advocacy as one systems change strategy. The concept is appropriate (having documentation) but the statement as located is mis-guided.
If any
Again, is everything we do "advocacy" and "systems change?" We use "advocacy" to mean the direct involvement in funded or non-funded activities of families/self-advocates on the Council and those not on it in making systems change. Not sure how you are defining it. Do not think you can use these words interchangeably without defininining them. We document the outcome and effect of funded initiatives whether we label them "advocacy," "capacity building" or "systems change." This meets the standard if it applies to anything the Council funds or conducts directly.
Examples will be helpful
But it should say "outputs, outcomes and effects" since often outcomes are difficult to tie directly to Council efforts alone.
I think this should read " documents outcomes of systems change efforts"

Further comments, additional standards or Performance criteria for Systems Change Through Advocacy:

Comments
But all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. I am incredibly disappointed and frustrated that the comments you received on round 1 were not used to redefine this section to fully account for the major work of the DDCs - over half of the comments indicated that the standards and related PC were inappropriately focused - please read them again and take heed. I remind you once again - SYSTEMS CHANGE IS WHAT WE DO (and what we are directed to do under the DD Act) - advocacy and demonstration projects are only two of many strategies for effecting systems change. If you remain rigid to your original framework (which the data, your site visits, and reviewer comments do not support) and can't get this standard right then this entire set of standards and performance criterion is absolutely useless. I will again re-state my orginal points –> You are "mixing apples and oranges." Standard 6 does not reflect our systems change mission - it focuses almost entirely on advocacy. They are NOT the same. And advocacy - like demonstration of new approaches - is only one of many systems change strategies. It is not better nor more used than any other stategy and should not be singled out inappropriately as such. This standard and all the performance criteria needs to be re-worked to make that distinction. Advocacy and systems change are two separate and distinct functions which sometime (maybe frequently) are needed to work "hand in glove" to achieve a desired end.
don't agree with limiting the area of systems change, a core function of Councils, to advocacy.

E. Demonstration of New Approaches to Services and Supports

Standard 7: DD Councils identify, try out, and promote new or innovative practices to improve services and supports for people with developmental disabilities and family members.

- Examples of how DD Councils do this include issuing requests for proposals, securing external funding to identify or test new or innovative practices, assisting community organizations in obtaining funding to identify or test promising practices, and partnering with other agencies or organizations in the state.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Can partner with CIL's or SILC
Practices can be new and/or innovative and not be effective. The focus should be on effective practices. It is unclear as to what is meant by assisting community orgajnizations to obtain funding. If it is agreeing to serve as advisors when a project is funded or writing a letter of support, that is fine. If it is an expectation that the Council would assist with grant writing, etc. this is unrealistic in light of council resources.
This standard is a performance criterion - it is not an appropriate standard. Demonstration of new approaches is a strategy used to effect systems change. This entire section should be subsumed under a standard specific to systems change.
Systems change is not necessarily about 'services and supports'
This may yield new approaches but unsure if it should be a standard – should there be a separate list of 'recommended practices' that are beyond the standards?
With assistance from self-advocacy groups
Another critical role for Councils.
I don't agree that issuing an RFP is an example of how Councils demonstrate new or innovative practices.

A Council that meets this standard:

7.1 Disseminates or promotes new or innovative practices demonstrated to be effective.

Comments
See above, the original focus should be on effective practices or perhaps demonstration programs, but not necessarily new or innovative.
An appropriate concept which should be included under a standard on systems change Demonstration of new approaches is a strategy used to effect systems change. This entire section should be subsumed under a standard specific to systems change.
I don't know what "promote" means so I suggest taking that word out. If there are other verbs that can substitute - funds, celebrates - then they would be clearer and would allow reviewers to evaluate against this standard.

7.2 Documents that new and innovative practices found to be effective by the DD Council were integrated into community practice within the past 5 years.

- Examples of documentation include journal articles, newspaper and magazine articles, websites, and reports from state agencies and organizations.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
An appropriate concept which should be included under a standard on systems change Demonstration of new approaches is a strategy used to effect systems change. This entire section should be subsumed under a standard specific to systems change.
'Community Practice' makes sense. 'Services and supports' does not.
If a state has progressive state leadership and an effective Council, this will occur. Minus progressive state leadership, no amount of Council work will result in sustainability of Council's work. Also "found to be effective" by the Council implies that Councils have the resources and expertise to determine that a policy/practice has an evidence base.
This should be 'documents efforts to promote integration of ...into community practice'. Councils do not have the power to insure implementation, though I wish we did!
No guarantee that implementing a new or promising practice will yield results or that integration will occur.
This standard is a great visionary measure, but change in practice is very slow and may take much longer than five years to see benefit.

Further comments; Additional Standards and Performance Criteria for Demonstration of New Approaches to Services and supports

Comments
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. I am incredibly disappointed and frustrated that the comments you received on round 1 were not used to redefine this section to fully account for the major work of the DDCs - over half of the comments indicated that the standards and related PC were inappropriately focused - please read them again and take heed. I remind you once again - SYSTEMS CHANGE IS WHAT WE DO (and what we are directed to do under the DD Act) - advocacy and demonstration projects are only two of many strategies for effecting systems change. If you remain rigid to your original framework (which the data, your site visits, and reviewer comments do not support) and can't get this standard right then this set of standards and performance criterion are absolutely useless. The fact that you could only identify 2 PC for this standard should have led you to re- think its appropriateness as a standard and considered reframing it under s systems change standard. I again repeat my original contention –> Demonstration of new approaches is one of many systems change strategies. It is not better or more used that any other strategy and should not be singled out inappropriately as such. This needs to be reflected in a systems change standard and related performance criterion not as a stand alone standard.
Throughout the entire document, you refer to us as DD Councils. I think many of us prefer Councils on DD. It is a bit of "people first" language applied to the body itself. Of course, anything beats "State Planning Councils."
There are criteria for promoting successful innovation but no criteria for trying them out. There should be at least one for showing the effort, whether it is successful or not. It should be acknowledged that sometimes we try but fail.

Comments
7.3 Supports the replication of innovative projects found successful by other DD Councils in their home states. This speaks to using the netowrk of Councils to improve practice nation-wide, and I think it is incumbent upon Councils to look outside their own states.

F. Governance and Management

Standard 8. DD Council members have the capacity to effectively fulfill their roles and meet their responsibilities.

Comments
Continued use of "have the capacity to" is troublesome (and politically incorrect) as was explained in reviewer comments on round 1. This standard is unacceptable until that is changed.
This one is hard because it could be used to eliminate participation or people with more involved disabilities. I guess I would recommend eliminating this.
Better stated as the capacity of the Council than as the members
Since the word "capacity" was not changed, I have to disagree. Standard should be that members are provided the training and support to meet expectations of their roles." Capacity is an internal state. "Effectively fulfill" is too subjective. If the governor appoints the wrong people, all you can do is provide the training and support they need... no guarantees.
Again, I don't know how you meaure this. So I would suggest taking out "have the capacity to" and leaving it "as fulfill their roles and meet their responsibilities."
Reword: Councils include members that effectively fulfill the role and respnsibilities of the Council. As written, the statement is awkward.

A Council that meets this standard:

8.1 Reflects the range of the population of people with developmental disabilities in the state or territory.

- Examples include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Since Governors appoint may be difficult to ensure
Shouldn't this be the place where we look at the stipulations in the DD Act on composition of membership and focus on that since it is nowhere else in this piece of work? Should be reflects " the diversity of people w/DD" Please add to this statement..."within reason and wherever possible." The political nature of Gubernatorial appointments is a major inhibitor - so unless structural changes to the DD Act occur surrounding DDC membership, in reality, we may be in a position of choosing one over the other.

Comments
The Council cannot control who is appointed. We nominate to the governor a slate of applicants that reflect the range of the population. "The Council can document its advocacy for the appointment of a membership that reflects..."
Replaced 'disability types' with 'developmental disabilities'.
This is a place where the example is very helpful.
add 'the state's geographical areas"

8.2 Actively works to fill Council vacancies in a timely manner and documents efforts to do so.

Comments
Governors control this, not Councils
Not all Councils have control over appointments. We can work to expedite or facilitate appointments but we cannot guarantee they will be filled in a timely manner.
Documenting efforts is the key.
just right. It puts the responsibility where it belongs and identifies where the control for this lies.

8.3 Communicates a written attendance policy that requires attendance for a minimum number of meetings.

Comments
In our state, a written attendance policy was determined unenforceable
Judgement is essential on this point, We definitely need to have our members attending meetings and making decisions - and we "move mountains" to help them do so. But, they are volunteers and as persons with disabilities they have personal situations, health issues and crises to take into account. There is no reason to "release" a perfectly good and active member because a temporary situation does not allow making a requisite number of meetings - that is a necessary ACCOMMODATION.
Such standards in practice discriminate against young parents
Only the Governor can remove a member; so, we can communicate a policy that "requires" attendance, but there is no real consequence (particularly for agency members) of non-attendance. Federal law requires that the agency members be there and be represented at the policymaking level. It is unlikely that agency staff or family/self-advocates are going to be removed from the Council for non-attendance. Generally, you can train people to provide an excused absence; but, it doesn't do a thing to help make quorum.
May want to add 'and delineates actions for non-attendance'.

8.4 Documents attendance in DD Council meeting minutes.

Comments
This doesn't seem to be a quality standard to me. Council's should follow their attendance policy, but specifying content of minutes seems too instructive.

8.5 Has members who play an active role in meeting DD Council objectives.

- An active role includes membership or chairmanship of a sub-committee and participation in DD Council activities throughout the year.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Should be people with disabilities in leadership roles
This seems a bit vague unless a definition or rubric is developed for what an “active” role means.
The PC is acceptable but the definition is not acceptable. A member is able to participate and be active without taking on a leadership role or extra responsibilities.
A broader range of examples would be useful – acting as representative with other committees, work groups; writing letters to policymakers, testifying, telling their story to policymakers etc.
I think this should say "Example: an active role...." and I suggest including in the example "...particpation in DD Cuncil and committee/task force activities throughout the year." I think "active" should be more than attends meetings, so the exmaples can help promote that concept.
This is where we should capture members involved in public policy actvities, particpation in demonstration oversight, etc..

8.6 Provides an orientation to new DD Council members.

- The orientation includes the principles and goals of the DD Act, background on the DD Council, DD Council goals and objectives, and the current State Plan.
- If necessary, the orientation should be provided in more than one format to meet Council member needs.

Comments
The goals and objectives are part of the State Plan. Switch to "goals and objectives included in the current State Plan."
Should include range of roles individual board members can take.
I don't like the "if nesessary"...it should ALWAYS be available in a VARIETY of formats, and Councils should have to show that they do this.
should add "and ongoing educational activities"

8.7 Mentors new DD Council members.

Comments
As noted in many prior comments, mentoring is only on approach to supporting, orienting, acculturating and assimilating our new members. This PC needs to be broadened to include the variety of potential approaches to assisting new members to understand and full participate which can be tailored and based on individual needs and desires.
Ok if mentoring is a collective rather than individual activity.
Not susceptible to measurement.
Not all new members want or feel the need to be mentored. Maybe this could be 'offers mentoring and documents efforts'. This could also be covered in 8.8 by adding 'mentoring' to the criteria or as an example.
Include examples of ways to effectively mentor.
Here is a place where examples would be helpful. The example could be something like. Examples of mentoring could include individual meetings with council staff or more experienced council members to review process, anser questions, etc. ; pairing new members with senior members throughout the first year of membership; sending materials out in a variety of formats and follwing up beofr meetings happen to insure that members are prepared.
I think this is too instrusive.

8.8 Provides supports that are needed to ensure meaningful participation by DD Council members, including one-on-one assistance for DD Council members as necessary.

Comments
But instead of 'including one to one…" I would say "including making reasonable accommodations to meet individual needs'.
As noted in many prior comments, there are a variety of ways to provide supports to DDC Members that may not rely on one-to-one assistance. The statement should read "Provides suports that are needed to ensure meaningful participation of DD Council members."
Who should determine it is "necessary?" Reword: Provides supports…including appropriate accommodations under the ADA." "Necessary assistance" is too speculative. Do be aware that the provision of cognitive accommodations under the ADA is not well understood and requires, e.g., strategies to make the meaning of information contained in Council-produced documents accessible to people with intellectual disabilities. Reword: "Supports meaningful participation of Council members, by complying with the ADA, employing strategies to encourage active involvement of members, and presenting information in a user-friendly manner."
And here the example would help and it could replicate what I suggested for 8.7.

8.9 Supports at least one DD Council member to attend a national meeting, conference, or training each year.

Comments
Time for a reality check here - - - not financially feasible, within state travel guidelines, nor necessary or necessarily desireable to the membership. This absolutely must be at state discretion not a requirement.
Travel restrictions.
DSAs well known to freeze travel.
I may have changed my thinking on this one. I think that I understand the intent, but I'm not sure 'national' meetings insures member development. I suggest a criteria to support member participation in events that broaden their knowledge and skills to effectively serve the Council.
Seems minimal.
It's not fair to require this as some can't afford this.
It is the 21st century. All information, education, and training should be available 24/7/365 and not dependent upon face to face training events. What I more important is learning and application of knowledge rather than attendance.
This should come under ongoing education/training.

Standard 9. DD Councils are effective in fulfilling their governing responsibilities.

Comments
They don't govern. Drop 'governing'
What are the "governing responsibilities?" What constitutes "effective?"
This standard may need examples.

A Council that meets this standard:

9.1 Reviews the performance of the Executive Director each year.

Comments
Annual is nice but periodic is more reasonable. If everything gets done on an annual basis, there is no time for new work. These people are volunteers and have a life outside the DDC.
This one is hard because I have been reviewed but volunteer chair, never produced written document. It is hard to badger someone about this ☺

9.2 Reviews itself every 3-5 years.

Comments
This is what the state plan does
What does this mean? The Council should be judged according to its effectivenes in meeting the goals of the state plan and should be reviewing its work on an ongoing basis to ensure that it is governing effectively. Ongoing informal evaluations are more effective than an every 3-5 year formal evaluation. Suggest that this be changed to periodic assessment of performance and modification as necessary.
Too vague.
Something more specific about what we are reviewing would be better. Organizational plan or structure? Effectiveness?
Annually to every 3 years – more often than every 5
Should review every year.
Here's a place where an example would be helpful - what does "reviews itself" mean?

9.3 Trains and supports Council members on the core functions of their roles and responsibilities.

Comments
Actually should go in previous standard.
...as long as both formal and informal approaches are deemed acceptable.
This should be 'governing' responsibilities to distinguish it from the criteria in Standard 8.
Yes, but this should be true for Council staff as well.
combine this with orientation and ongoing education/training. I think we lose emphasis on items when they are scattered over severakl indicators.

9.4 Uses a fair, transparent, and effective process to select competent and experienced grantees.

- Evidence of a fair, transparent and effective process includes adherence to procedures for selecting grantees; adherence to procedures for handling unsolicited proposals; the inclusion of outside expertise during the proposal review process, as necessary; and the selection of grantee projects that reflect the goals and priorities stipulated in the State Plan.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
"experienced" – eliminate new grantees?
Most, if not all, states have rigorous procurement systems that DDCs must comply with in addition to federal guidelines.
Why is experience necessary? The we'd always have the same grantees.
I think the evidence list is helpful here.

9.5 Maintains a system to manage grants and measure grantee results.

Comments
Most , if not all, states have rigorous grant monitoring systems that DDCs must comply with in addition to federal guidelines.
Should also be sure to inform grantees when things change that might affect their grants

Further Comments, Additional Standards or Performance Criteria for Governance and Management

Comments
I would add a standard "Council members actively engage in setting policy direction for the Council and makes clear delegations to the Executive Director to implement the policy direction'
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. There should be a performance criterion in this section about meeting the stipulations of the DD Act in the composition of the DDC membership (i.e. individuals, family membes, provider, statutory agencies - and percent consumer vs. agency). This is one of the most directive sections of the law and there is no mention of it in the performance criterion. This was also mentioned in round 1 - maybe its time to give it some credence.
I think governing is about more than grantee management and evaluating the director. I think there should be a criteria that addresses personnel policies and annual staff evalutions at a minimum to make this standard complete. I also think that a performance criterion should be developed that looks at the internal structure of the Council - its committees, task forces, work groups, whatever - and confirms existing structures or makes changes that better rreflect both council mission and the context of activity in the state.

Additional comments by email:

Comments
I know that I should follow the official process for feedback, but I wonder if I can offer a minor point of clarification to you and this minor point might inform the work in setting standards for ADD itself. We have had a hard travel ban for years and we are also facing some very dire weeks ahead if there is no budget in place by July 1st in our state. In reading through the ADD standards for Councils, there is one standard about attendance at a national conference for at least one person at least once a year. Our Department has a hard and fast rule: It is the 21st Century, any content available at a face to face conference should be available in multiple other formats including online training/courses. I understand the desire for face to face conferences, but when we have surveyed individuals and families, there is far greater use of the Internet than ever before to gain information, education, training, etc. Yes, I know that face to face events offer a great wealth of personal connections, but is it possible for ADD and others to update their thinking (even a little bit).
I have reviewed the revisions made to the State Councils on DD draft standards and performance criteria and found real improvement as a result of your edits. Attached is the Version 2 rating form with my comments. In addition to the comments and recommendations that I have included in the Rating Form – Version 2, I would like to provide the following general comments: The criteria are a combination of what would probably be considered basic conditions for receipt of the DD Act funds and evaluative criteria (or how well councils have implemented the conditions required for the funds). Performance standards and criteria really should focus on the latter – how well councils are implementing the requirements of the grant. While performance standards should incorporate requirements of the DD Act, it should be from the perspective of how well the councils have implemented these requirements. Also, if the standards and criteria are going to include some of the requirements, then they should include all the requirements, or at least all of the major requirements. The standards and criteria as presented include some of the requirements of the DD Act, but not all, nor all of the major requirements. The recommendations I have made in version 2 includes several additions to capture at least the major elements of what we are required to do (or how well we are doing what we are required to do). I am concerned about the lack of attention to requirements that are not included in these standards and criteria. There are many instances where there really is not a connection between a criterion and the standard. The criterion may be related to the topic of the standard but not the focus of the standard. Recommendations have been included relative to this. Our new State Plan Template includes many new requirements that are significantly impacting the key elements for the state plan and shifting the focus of the council's work. Some recommendations have been included relative to this, but more attention to this may be needed. Some of the criteria require "documenting" of the work. All the criteria will need documentation that they are achieved. The criteria that include or focus on the documentation should be revised to remove the "document" term and focus on what it is that needed to be documented. As defined, the performance standards are missing critical elements of the work of the council, including but not limited to collaboration/partnership building, barrier elimination, and system redesign. These are major gaps that need to be addressed. Council will look at these performance standards and criteria as how they will be evaluated, if there is not some recognition of the importance of these elements, they may not be continued. Systems change is not just advocacy. This is a misinterpretation of the work of the council. The comments from the workgroup clearly conveyed that message.

Appendix Z2. Protection and Advocacy Systems

P&A Draft Standards and Performance Criteria
Version 2
Panel Member Comments

A. Planning and Priority Setting

Standard 1: P&As identify the key issues, needs, and priorities of people with developmental disabilities in the state or territory.

Comments
None

A P&A that meets this standard:

1.1 Collects input for the SGP from, or on behalf of, a broad population of people with developmental disabilities in the state or territory.

- Examples of a broad population of people with developmental disabilities include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Thanks for separating the examples from the standards
Spell out SGP
"Collects ongoing input" What type of documentation will be required to demonstrate this – i.e. do we need to collect demographics on people responding to surveys etc.

1.2 Collects input for the Statement of Goals and Priorities (SGP) from a variety of sources.

- Examples of sources include people with developmental disabilities, family members, P&A staff, Board of Directors or Commission members, DD Network partners in the state or territory, data from P&A activities (e.g., intake and assistance, outreach and education), research and other reports that contain valid and reliably collected data, community gatherings, church affiliated events, and examples of first-hand accounts through state and territory disability organizations, advocates, and self-advocacy groups.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Added 'may' to "Examples for sources" I would add 'may' see above as not every source would be used.
Add to the examples the state developmental disabilities agency. It is important for the P&A to learn to understand the state DD agency's priorities and goals.
Example is redundant. BOD approves. 1.1 hits on potential clients.

1.3 Collects input for the SGP from geographic regions across the state or territory.

Comments
None
Already in 1.1

1.4 Uses a variety of methods for collecting input for the SGP.

- Examples of methods include focus groups, surveys, social media outlets, the P&A website, and review and analysis of reports and studies.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Add 'may' to examples
The data collection tools should also be available in alternate formats to accomodate disabilities and different languages.
How is this different from 1.2?

1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

Comments
"Provides accommodation when needed…" replaced 'people' with 'others providing input who may have…" See suggestions. Should not assume all people need accommodations.
Should have some limiting term - such as practical - for example if you had individuals from 10 different language groups - it would be very challenging to provide interpretive services for such a range.

1.6 Uses information from the planning efforts of other organizations in the state or territory to increase planning efficiency.

- Examples of other organizations may include the DD Council, UCEDD(s), developmental disabilities partners, disability specific state agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Using 'may' is Nice and what I am suggesting for others. While 'generic' is clear to me, may not be understood by all; therefore may not be necessary
this is a good concept but how will planning efficiency be measured?
Add 'state DD Agency' to the examples. Agree as amended.
In general, I think this will happen; but I would hate to have to seek out such sources just to meet the standard, when they would not always be needed.
"...of other organizations in the state or territory..." exceeds the standard

1.7 Gathers information on the needs of people with developmental disabilities on an ongoing basis.

Comments
Not sure the standard should be ongoing.
i.e. self advocacy groups, ARCs etc., service providers, parent groups
Does "on going" mean annually or continous? This could lead to a continous shift in priorities and uncertainty in identifying the priorities.
Not sure a separate requirement for this is necessary.
Redundant

Standard 2: P&A SGPs reflect the needs of people with developmental disabilities in the state or territory and is a guide to P&A action.

Comments
Replaced 'is a guide to' with 'guides' Just wordsmithing for clarity above.

A P&A SGP that meets this standard:

2.1 Reflects the goals and principles in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

- Examples of some of the goals and principles in the DD Act include self-determination, independence, productivity, integration, and inclusion in all facets of community life.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Agree as amended. Rewrote as "Reflects the one or more goals.." your examples give examples of some goals but standard seems to require SGP reflect all goals. For example, in a given year we might choose an SGP that reflects inclusion in one area of life but not all.

2.2 Reflects the input from the planning process.

Comments
Yes… but…. be careful on this. If community input dictates the need to promote the development of congragrated sites, how does this match the ADD Values and standards.
"Reflects some of the input…" If one person has an idea, it does not have to be included
Unnecessary

2.3 Drives primary activities that the P&A conducts and supports.

Comments
Does 'and supports' add something?
Not sure how this is different

2.4 Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statues, regulations, or priorities.

Comments
I don't think the SGP has to specifically include a provision to revise. Should just be able to do this.
Flexibility or the ability to respond to "wild cards" should be a part of the standard but the priorities are set up to prevent trying to be all things to all people – not doing either well.

Further comments; additional standards and performance criteria for Planning

Comments
Much clearer, thank you!
Please read the comments. Some of these standards are well intended but may have unintended consequences. Constantly changing priorities would not be helpful, but the flexibility to remain agile and respond to the unexpected would be a quality of the P&A.

A. Intake and Assistance

Standard 3: The P&A intake process is equitable, efficient, and effective.

By equitable we mean that anyone contacting the P&A will be able to be served.

Comments
Equitable to me means equal access on issues handled by the P&As from diverse ethnic, geographic regions. Given limited financial resources, we cannot say anyone contacting P&A will be served. For example, we do not serve parents whose interests conflict with adult children's. State bar would prohibit this. We also do not serve individuals who want to obtain a conservatorship.
Vague
This is misleading. It implies that non-disabled people will get service. That would violate federal law
Not everyone who contacts the P&A necessarily should be served…also, budget cuts may prevent deserving contactors to be served

Comments
The measurment of this standard will still be problematic. those who are served will find the process equitable,efficient and effective, others will not.
Should it say all eligible people contacting the P&A. Is equitable with a certain timeframe like within a week?
Their issue must fit priorities or involve abuse or neglect to serve them. We do not serve everyone who contacts us. This explanation is not helpful
Disagree with the explanation of "equitable" because it actually may be more confusing. It could be interpreted to mean there is a right to be served. Standard 3 is more agreeable without the explanation of equitable.
Should reflect/focus on persons with developmental disabilities
I don't like the word 'equitable' or your definition of it. I would rather: "The P&A Intake process is fair, efficient, and effective"

A P&A that meets this standard:

3.1 Maintains written intake procedures that include but are not limited to:

- Procedures for documenting client information in a computerized database, and
- Procedures for priority case selection.

Comments
With the addition: "Procedures for case evaluation"

3.2 Provides training on the intake procedures to new intake staff.

Comments
This should be a given.
It should be to <u>all</u> staff.
I would change 3.2 to read "Provides ongoing training on intake procedures'

3.3 Monitors staff adherence to intake procedures periodically.

Comments
Excellent management criteria but it exceeds the standard. A better standard might be management training.
Reword – Quality control process is in place to periodically monitor staff adherence to intake procedures
f only the intake staff are trained on the intake procedures, it would exceed the standard if the P & A were to monitor all"staff" adherence to intake procedures." Criterion should be qualified to state: Monitors intake staff adherence to intake procedures periodically.

3.4 Directs callers and others who seek assistance from the P&A to the appropriate level of assistance.

- Examples of the different levels of assistance include referral, provision of information and resources, possible individual advocacy.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Replaced callers with 'individuals'. However, sometimes appropriate response is no assistance so example is not entirely accurate.

3.5 Applies a rigorous methodology to assess satisfaction with the P&A intake and assistance process every 3 to 5 years.

- Examples of such rigorous methodologies (i.e., those that achieve high response rate and obtain representative data) include a survey of every caller for a period of 2 weeks or a followup telephone call to a random selection of callers.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
I don't think rigorous should be included, obtaining a high response rate is quite challenging and undefined, what is high? I do agree we should attempt to assess satisfaction. Plus, satisfaction should not be limited to intake and assistance.
Unsure
This depends on scarce and dwindling resources
Again a management issue
It would exceed the standard to assess for satisfaction when the standard requires the process to be "equitable, efficient and effective." A methodology would be acceptable if it measured the efficiency of the intake process but there are too many variables that influence satisfaction with the intake process, for example, the result of the assistance provided, declining representation etc.
Even though I understand why you put this in, it seems odd. Why single out intake? We don't mandate a similar rigorous methodology to assess satisfaction with any of our other services.
"Rigorous" – how is this different from input

3.6 Provides intake staff with access to ongoing professional development.

Comments
Should be provided to all advocates, attorneys and management.
This would meet the standard if it simply said: Provides intake staff with appropriate training. As written, it seem to impose a higher standard for intake staff development and removes the P & As discretion to determine what staff development is appropriate for which intake function.

B. Individual Advocacy

Standard 4: P&A casework reflects the priorities set in the SGP.

Comments
Do you mean 'case load'?
This may not be under the P&As control.
As long as there is a mechanism in which those may change throughout a year if a major systemic issue arises.
Some in need may require assistance with issues that do not specifically align with the SGP priorities

A P&A that meets this standard:

4.1 Maintains written procedures to guide the selection and processing of individual advocacy cases.

Comments
Again with flexibility to respond to the unexpected.

4.2 Selects individual advocacy cases that are consistent with but not limited to the goals and priorities in the SGP.

Comments
This appears to conflict with the standard. It sounds like a big loophole to allow the P&As to choose any cases they want that don't fit the goals and priorities of the SGP
Not sure what "consistent with but not limited to" means.
Or provide rationale why others were selected
The individuals selected should be consistent with the goals.

Standard 5: P&A provides high quality representation.

Comments
What does that mean? To whom? Subjective - reword
Agree - but how will this be measured. Tough challenge in the P&A context. e.g. parent who did not win case maybe be unhappy with P&A advocacy and yet they could have done all that is possible.
It is still unclear what activities would distinguish "high quality" from "quality" representation. The "high" sounds very good until compared to "low quality" or "poor quality" both of which would be unacceptable. Unless there are specific measures the standard shouldn't describe levels of quality - either the P & A is providing "quality" representation or it isn't meeting the standard.
High quality representation should be defined.

A P&A that meets this standard:

5.1 Provides staff with individualized ways to discuss and review cases.

Comments
Agree but do not use 'individualized'
Vague "individualized ways"
Management issue
What does this mean? This is not an outcome. Do you mean – staff discuss and review cases in a professional, respectful, and individualized manner?
Not sure what this one means. Could be interpreted that "everyone does what they want".
The P & A shouldn't be required to provide "individualized" ways. For example, group staffings may be appropriate in some cases and not others. Suggest the requirement should be: Provides staff with effective ways to discuss and review cases.
Not sure what this means. Does it mean: "Provides supervision of case-handling staff in accordance with their individual needs"? If so, I think it should be required.

5.2 Provides and encourages use of easily accessible resources.

Comments
management issue
seems like a weak performance measure -
The only reason this exceeds is because of the use of "easily." Some resources might be more difficult to access but readily available with a little effort Suggest the requirement be: Provides and encourages the use of available resources.
Provides to whom? To clients? To staff?
Seems as though this is a mare minimum and should be expected?

Standard 6: Individual advocacy meets client objectives.

Comments
This implies that every case is a win i.e. it meets the client objective (of getting out of institutions, getting off the waiting list) - Unrealistic
P&A's must be held to the standard of well representing the clients (legal) wishes and not what they believe to be in the client's "best interest". Obviously the case must have merit.
...if we are lucky. How about Individual Advocacy strategies meet client objectives.
This standard ignores the fact that the client's objectives might lack merit and that needs to be explained to the client. The standard would be acceptable if it stated: Individual advocacy addresses client objectives.

A P&A that meets this standard:

6.1 Ascertains accommodation and necessary support services at intake.

Comments
Should not be limited to intake.
ADA requirement
Rewrite "Accommodations and necessary support services are available at intake"
I do think this is important just not sure that it should be in this section. There was a previous section involving intake that this might have fit better into.
This should be part of an internal procedure. However, I'm not sure what value it has as a performance measure.

6.2 Commits resources to support all clients being served so that individual advocacy staff is able to communicate with any client whose case is taken.

- Examples include availability of a language line and/or interpreters, staff that speaks a language other than English, a policy for including a support person for clients with cognitive disabilities if needed.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Rewrote as "Commits resources that individual advocacy staff is able to effectively communicate with all clients whose case is taken."
management issue
This does not clearly relate to the standard - not sure if it exceeds or isn't relevant. The P & A has to communicate with a client whether it takes the case or declines representation. Perhaps it would be clearer to state: Resources are available to insure staff is able to communicate with all persons seeking service.

6.3 Except in the case of an emergency or time-limited circumstances, provides and updates a written representation agreement so both the client and P&A staff member have the same understanding of the issues, approach, and tentative timing of the individual advocacy case.

Comments
Added 'scope of the representation". Not all of this would go in a written representation agreement
Clarify that it should be signed by advocate and client
Management issue

6.4 Sends or gives clients a closing letter in simple language documenting actions taken, results, and notification that the case is closed.

Comments
Rewrote as 'sends or gives clients a closing letter in language appropriate to their disability or primary language needs..." Should not assume 'simple' or change simple to 'understandable'
Good advice but this too may be a management issue
And right to appeal?
The addition of "in simple language" exceesds the standard. Suggest: Provides a letter to the client at the conclusion of representation that documents the actions taken, the results obtained and clearly communicates that representation is concluded.
Very important
Replace 'simple' with 'accessible'

6.5 Informs the following individuals about the grievance process in writing:

- Those who contact the P&A and whose case is turned down for individual advocacy, and
- Clients whose case is closed.

Comments
Do you intend the first bullet to include non-disabled people?
Cases not resolved in the client's favor should also be reviewed to better manage case selection criteria and skill levels of the staff and the process by which the case merits are evaluated. This is a management issue
Put with 6.4
verbally and/or in writing

6.6 Resolves a majority of issues in favor of P&A clients.

Comments
Should also be specified. Must be fair.
The success rate for individualized advocacy cases should be at least 80%
While this is generally the case, there are many factors related to 'winning' and we do not 'fail' if matters are not resolved in client's favor. We help assure access to the legal system. It's difficult to check a box
Believe this would exceed statutue and regulations
It is the P & As hope that this will be the case but sometimes if you are litigating a case/issue, you cannot guarantee the outcome. So this could become an issue under 6.6.
This would meet the standard if "in favor of" was replaced with 'to the satisfaction of.' As written it suggests the client won, when in fact, many matters are resolved successfully because the client better understands the options available.
So, if this is a requirement is the P&A defunded if it fails to achieve this standard?
Too dependent on issues or circumstances out of the P&A's control.
Too many variables in litigation

6.7 Has a mechanism for gathering and assessing client feedback and satisfaction with P&A services.

Comments
This is fine, make intake standard for satisfaction like this.
This is reasonable
It's a bit loose. I suggest "has an effective mechanism for…with P&A services onanongoingbasis"

Standard 7: P&A strictly adheres to confidentiality.

Comments
None.

A P&A that meets this standard:

7.1 Has a written confidentiality policy -- covering onsite staff, staff working at home, students, volunteers, and contracted staff -- with well-delineated requirements.

- Examples of confidentiality requirements include checking with clients about whether phone messages can be left, turning off the computer at the end of the day, and storing files in a cabinet or drawer so they are not left in view of someone walking through the office.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Added 'may' to 'include'. Staff can work a variety of locations on and off site e.g. a state hospital. So don't think you want to just mention those two work locations. Also, students are likely to be either staff (paid) or volunteers so I would not separately identify them
Files should be locked

7.2 Has structures in place to maintain confidentiality.

- Examples of structures include shredding capability, private offices, email encryption, locking file cabinets.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Add 'ongoing staff training'

7.3 Requires demonstrable compliance with the P&As written confidentiality policies and procedures by anyone who is privy to client information.

Comments
Rewrote as "Requires compliance with the P&A's written confidentiality policies and procedures". Not sure why 'demonstrable' here, seems like we should demonstrate compliance with all standards; I think wrong to limit to just client info.
This should be required to meet the standard if reworded to state: Demonstrates compliance with…
How is compliance demonstrated and/or documented?

7.4 Reviews confidentiality requirements in orientations to new staff, students, contracted staff, volunteers, and Board of Directors or Commissioners.

Comments
Rewrote as 'Reviews confidentiality requirements with new staff, contractors, volunteers, and Board of Directors or Commissioner". I agree this applies to Board etc. but this is the first time you mention. Does not have to be in orientation.

Further comments; additional standards and performance criteria for Individual Advocacy

Comments
A standard for ongoing Management training might better address some of my concerns in this section.

C. Systemic Advocacy

Standard 8: P&A systemic advocacy improves access to State systems and community practice and reduces abuse and neglect.

Comments
Rewrote as "P&A systemic advocacy improves access to service systems and helps reduce abuse and neglect". I have no idea what 'community practice' means and 'state systems' implies only state agencies. Also we can't really demonstrate abuse reduction, may be can help reduce.
"Community Practice"? How about "community services and supports"?
Replaced 'community practice' with 'community programs'. 'Community practice' is not clear. I liked the previous wording better.
Not quite sure how this would be measured as it has two metrics - access to State systems and reduction of abuse and neglect. Should this be seperated into individual perfomance criteria?
Again the concern is guaranteeing an outcome. I think the language could be more along the lines of P & A systemic advocacy is aimed at improving access to State Systems and community practice and reduce abuse and neglect.
"Community practice" is vague and unclear.
Don't like the wording "State systems and community practice'. Why not: "…improves access to services and supports"
Don't like the wording "State systems and community practice'. Why not: "…improves access to services and supports"

A P&A that meets this standard:

8.1 Uses a variety of strategies to meet systemic advocacy objectives.

- Examples of strategies to effect systems change include writing position papers or other reports, obtaining press coverage, educating policy makers, giving public testimony, drafting legislation, securing pro bono assistance in class action suits from legal firms, filing amicus briefs, monitoring residential facilities, monitoring existing databases, collaborating with developmental disabilities partners, and following up on identified patterns of abuse and neglect). *

  *Note: These are examples. Not all are required. Others may be used.

Comments
Deleted "securing pro bono assistance' and 'from law firms'. An example is bringing class actions with or without pro bono assistance, Not getting the pro bono assistance and from 'legal firms' is redundant.

8.2 Provides documentation that illustrates outcomes within the past 5 years that are associated with its systemic advocacy efforts.

Comments
Rewrote as "Demonstrates outcomes within the past 5 years that are associated with the systemic advocacy efforts'.
Provides this information to whom?
Rewrote: "Provides annual documentation that illustrates outcomes every year that are associated with its systemic advocacy efforts"
Not sure what this means

8.3 Conducts ongoing review to ensure appropriate implementation of new policies and to assess potentially negative unintended consequences.

Comments
This is completely unclear. Review of policies by whom? Why ongoing? Wouldn't it be better to say "positively impacts policy to ensure consistency with the rules of the DD Act?"
Conducts ongoing review of what? 'Implementation of new policies' by whom? Language is unclear.
Should specifywhat kind of policies - state agencies, providers????
Clarify that this refers to new or improvements in existing external policies.

Further Comments; Additional standards and performance criteria for Systemic Advocacy

Comments
Documentatiuon of systemic impact is important but it is unclear for what purpose. If it is to build the P&A image or credibility in order to influence further systemic change then its a good idea.

D. Outreach and Education

Standard 9: P&As engage in effective outreach activities to identify unserved and underserved populations.

A P&A that meets this standard:

9.1 Conducts ongoing outreach activities.

- Examples of outreach activities include use of the P&A website, distribution of brochures, presentations at community events on the P&A and P&A services, and Board of Director (or Commissioner) networking.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
But should not list Board as an example. This is one of few places Board is mentioned; there are many things Boards could do.
define "ongoing"
'Board of Director (or Commissioner) networking': I don't know what this means. Staff networking with Board? Board networking with community members in their roles of ambassadors to the organization? Maybe leave out 'Board of Director or Commissioner' and just say 'networking'. It's still a pretty amorphous term (networking).

9.2 Targets populations that are underrepresented or unserved.

Comments
The needs of the underserved and unserved populations might not match the input recieved from the priority setting process. Either the underrepresented populations are not responding to surveys or the survey results are honestly reflecting needs of a broader population.
this will need to be balanced with available resources to meet the needs of those already seeking P&A services

9.3 Maintains a budget for outreach activities.

Comments
Outreach can be built into other parts of the budget i.e. travel, Board Meetings, conferences, website
Management issue
The important thing is that outreach is done, not which pot the money comes from.
Again, odd. Why talk about a budget here, but not for any other P&A function like Intake, Systems, and Individual Advocacy?
We have an integrated budget – i.e. staff travel includes all travel - this could be burdensome

9.4 Adjusts outreach activities to reflect cultural appropriateness and other needed accommodations for the target audience.

Comments
Rewrote as "Adjusts outreach activities to reflect cultural/and language competence and other needed accommodations for the target audience?

9.5 Reports on measureable targets and outreach activities.

Comments
Why report this but no reporting of other items.
Report to whom? It's hard to measure
If this standard is included then targets need to be measurable.
...and outcomes of..."

9.6 Periodically reviews outreach activities so that outreach plans and strategies can be revised as needed.

Comments
management issue

Standard 10: P&As have an impact on access to services and community participation for people with developmental disabilities through the provision of education training, and technical assistance.

Comments
Rewrote as "P&As inform PwDD and others about how to access services and enhance community participation through the provision of education, training, and technical assistance". Cannot demonstrate impact on access to services; can demonstrate that you tell people about how to do this.
Another possible impact = "improving service quality"
Add a comma between education, training

A P&A that meets this standard:

10.1 Provides culturally appropriate and targeted education, training, and technical assistance activities to people with developmental disabilities and family members.

Comments
Replaced 'culturally appropriate' with 'culturally and language competent'
should clarify whether activities should be directed toward access of community based services in education, community living, employments, etc
Add providers and community members.

10.2 Maintains a budget for education, training, and technical assistance activities.

Comments
management issue
Budget allocations seem beyound statute and regulations. Could be put in recommended practices if such a category is created.
This would be a problem for finance and administration because so often education, training and outreach take place at one event. Perhaps this criterion could reference back to 9.3 by stating: Education, training and technical assistance activities are accounted for in developing a general outreach budget.
Again, the important thing is that the activities are accvomplished, not which pot the money comes from.
Again, odd. Why talk about a budget here, but not for any other P&A function like Intake, Systems, and Individual Advocacy?
This could be burdensome i.e. staff travel includes all -

10.3 Measures recipient satisfaction with education activities.

Comments
None

Further comments; additional standards and performance criteria for Outreach and Education

Comments
I think you could continue to fold outreach and education together. For example, satisfaction with education but not outreach? Why a separate outreach budget; separate training budget?
Again, a few good management training might be a more valuable standard.

E. Governance and Management

Standard 11: P&A Board of Directors or Commission sets policy and long range goals for the P&A and holds the Executive Director accountable for adhering to the policies and goals.

Comments
None

A P&A that meets this standard:

11.1 Conducts an annual performance review of the Executive Director.

Comments
And the Board

11.2 Actively works to fill Board of Directors (Commission) vacancies in a timely manner and documents efforts to do so.

Comments
I think the DD Act requires vacancies filled within 60 days (Unless I have this confused with PAIMI)
"...and documents efforts to do so" exceeds the standard

11.3 Maintains a Board of Directors (or Commission) with expertise in fiscal, policy, and legal issues, and who are knowledgeable about the developmental disabilities population and issues.

Comments
Dislike 'populations'. Add: Board which reflects the geographic, ethnic diversity of the state
Great practice
This should also require that the board consist of family members and/or members with developmental disabilities.
The P & A does not have direct control over the nominating or appointment process so it does not maintain the Board or control its decisions. There is no question that the Board should reflect these qualities but the P & A cannot be held responsible for meeting this criterion.

11.4 Familiarizes all new Board of Directors (or Commission) members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A.

Comments
None

11.5 Provides supports needed to facilitate meaningful participation by Board of Directors (or Commission) members.

Comments
None

11.6 Ensures that its facility for Board of Directors (or Commission) meetings is physically accessible and that all print materials are available in accessible format for each member who requires them.

Comments
Implies one facility. Out Board rotates meeting locations to accessible hotels around the state
The facility may not be under P & A control but the criterion could be reworded to state: Ensures Board of Directors (or Commission) meetings are held in places that are physically accessible and...)
Assumed in 11.5.

Standard 12: P&As maintain an infrastructure that enables them to conduct key functions efficiently and effectively.

Comments
Examples of key functions would be helpful
Measurment of "efficient and effectively" will be hard to quantify.
Seems vague and difficult to measure

A P&A that meets this standard:

12.1 Maintains a staff infrastructure with well-defined supervisory roles and responsibilities.

Comments
Management issue
Again, the important thing is that professional development occurs, not which pot the money comes from.

12.2 Conducts an annual performance review of all staff members.

Comments
Management issue

12.3 Receives an independent audit each year, and immediately addresses qualified findings.

Comments
Possible add-on: “With full report to the Board or Commission”
This is required by others, not only ADD

12.4 Budgets for professional development for staff.

Comments
Since you have this here do not need to separately ask about budget for intake; assessment
Some of these seem repetitive

Standard 13: P&A maintain operational independence from the Governor and the developmental disabilities service system of the state or territory.

Comments
None

Further Comments; Additional standards or performance criteria for Governance and Management:

Comments
"There should be mechanisms in place to inform the Board more often and in more detail about specific cases staff/front line workers are working on and to encourage the Board to praise staff more often for a job well done. Board should recognize staff/front line workers more often for working hard and resolving cases, such as getting clients out of sheltered workshops or other group situations, etc. There should also be mechanisms in place to allow staff/front line workers to be able to communicate with the board about their cases, when needed, to obtain advice, input and feedback. Finally, there should be more opportunities/mechanisms in place for staff/front line workers to receive pay raises (such as perhaps performance reviews, etc.)."

General Comments:

- Would like the P&As to work more with clients and staff in sheltered employment group home-type settings – are currently being overlooked. Also do more work with day programs or adult day care programs.

Appendix Z3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)
Draft Standards and Performance Criteria – Version 2

Panel Member Comments

A. 5-Year Planning

Standard 1: UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and the goals contained in the DD Council State Plan.

Comments
Should be "consistent with the DD Council State Plan, to the extent feasible", as in the DD Act.
Sounds good but doesn't really say anything. Old wording is better. "Data driven" – where or what in the expectation here for UCEDDs to secure, create, conduct data in order to complete a five year state plan. Sounds like everything should flow from this data w/o a definition of what this data is exactly. Liked the Version 1 wording better. Simpler and easy to understand where we were going next.
While these plans might be required – it seems a lot of resources are directed to the planning – is there some way to do this that is less resource intensive?
This still needs work. The language in the Act clarifies the relationship between UCEDD goals and DD Council goals. This wording could be interpreted to mean that the UCEDD's goals should address the Council's goals, which is NOT consistent with the Act or good strategy re. planning.
Should also include the "needs of the state."
Developing a 5 year plan based on any data is immaterial if the data is not firmly founded in consumer based needs. The assumption that this is through data gathering. Unfortunately, data gathering is frequently a ploy for validating a predetermined agenda that may have little if any relationship to real needs of real people.
I disagree with the last part: "and the goals contained in a DD Council State Plan." That should not be a required of the standard for UCEDDs. "UCEDDs use data driven strategic planning to develop a 5-year plan that is consistent with the objectives of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)."

A UCEDD that meets this standard:

1.1 Collects input for the 5-Year Plan from a variety of sources.

- Examples of sources include people with developmental disabilities, family members, UCEDD faculty and staff, the Consumer Advisory Committee (CAC), students, DD Network partners in the state or territory, data from UCEDD activities (e.g., community services), research and other reports that contain valid and reliably collected data, state developmental disability agency and other policy makers, service providers, and state and territory disability organizations and advocates.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
OK – data here is defined better but clearly 'input' may not be data but surveys, feedback, focus groups etc could be. This leaves room for UCEDDs go gather info necessary to draft a relevant five year plan for their State/territory.
This is a nice way to handle the examples so they don't become prescriptive. Also, this allows for gathering National or multistate data.
The examples are numerically in favor of professional entitites which gets to my point above.
The objective is fine, the examples list should not be included lest it be interpreted as mandatory.

1.2 Obtains input for the 5-Year Plan that covers various geographic regions across the state or territory.

Comments
If it stays in, Combine with 1.4.
Change to 'obtain' from 'collect' lessens the burden on the UCEDD to conduct their own data collections and would encourage collaboration with other DD agencies to obtain information they might have.
This is troublesome if there is more than one UCEDD is a given state - use "defined service area" rather than various geographic regions across the state. Could be combined with 1.4 or deleted
I read that as meaning collecting input from people across the state.
The intent is good, but it can't be "mandated" given the difficulty in collecting data in rural areas.

1.3 Uses a variety of methods for collecting input for the 5-year Plan.

- Examples include focus groups, surveys, social media outlets, the UCEDD website, serving on Boards and committees in the state or local community, and review and analysis of reports and studies.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
"serving on Boards and committees in the state or local community" excellent addition to the measure to show the diversity of UCEDD staff and activities.
Should also include public meetings and hearings as part of the examples.
More emphasis should be placed on involving parents and persons with disabilities on UCEDD boards and mentoring them in leadership roles

Comments
Not too much paperwork.
Yes, if the point is that information should be obtained though mutliple sources/mediums.

1.4 Gathers input for the 5-year plan from or about a wide cross-section of the state or territory's disability population representing many different segments of the community.

Comments
If this stays in, combine with 1.2.
It isn't clear whether the standard relates to the entire disability population in the state or the population of people with developmental disabilities.
Yes important. Question whether w e need 3 measures here? Suggest rewriting. How is this different from 1.2 and 1.3? Can we not make one measure that encompasses diversity of audience, variety of methods and inclusion of geographic areas and community? Is there a reason why these should be separated out into three different measures?
Also a bit vague – different can mean many things – age, degree of impairment; or type of disability.
Not 'or' but 'and'
Could be combined with 1.2 or deleted
Duplicate question.
Why would UCEDDs be required to survey persons with non-DD conditions to serve persons with DD?

1.5 Provides accommodations for people with developmental disabilities or people facing geographic, language, or cultural barriers so they are able to provide input.

- Examples of ways to accommodate include use of spoken/conversational in person discussions, electronic surveys, written surveys, simple language text, pictures, translations, voice (e.g., telephone, chatrooms).*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Yes, I can see this being a separate measure because it addresses accessibility of the UCEDD not a criteria for when to obtain information (1.2, 1.3, 1.4 all pertain to collection of data)
This duplicates 1.4
Great idea and one that should be pursued but can we require given the standard? Also isn't this already covered in 1.1?
UDL should play a significant role here
This would be difficult to govern.
This as a requirement is micromanaging the process. We should give UCEDD Directors credit for knowing they need to do this.

1.5 Uses information from the planning efforts of other organizations to increase planning efficiency.

- Examples of other organizations may include the DD Council, P&A, and other UCEDDs in the state, developmental disabilities partners, disability specific state agencies, and relevant generic agencies, such as housing, transportation, labor, and education.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Back to 'obtaining information' again (1.2). How is this different from 1.1? Is this about planning or finding collaborative topics? (planning efficiency?) I agree that this collaborative effort should be here but this measure should be rewritten to reflect what you are looking for here?
Why don't UCEDDs plan in conjunction with other organizations – some type of coordinated plan
This duplicates 1.3. Using planning efforts from other agencies is one of the varieties o methods that could be used.
The examples are so far removed from what's going on in disability communities outside of the UCEDD that its almost embarrassing to read this. There are numerous advocacy and disability leadership groups that should be sources of information.
Only in-so-far as the other DD network/state agency/etc partner information relates to the UCEDD's mission.
This as a requirement is micromanaging the process. We should give UCEDD Directors credit for knowing they need to do this.

Standard 2: UCEDD 5-Year Plans are a guide for UCEDD action.

Comments
Of course. But the DD Act calls for the Five Year Plan to include goals in one or more areas of emphasis for each of the core functions. Should the Standard be elaborated?
As long a option to revise plan still exists.
Pretty wishy-washy but does take into acount availability of external funding - or lack thereof. Standards #1 and 2 should be combined.
This is self-evident. This as a standard is micromanaging the process. We should give UCEDD Directors credit for knowing they need to do this.

A 5-Year Plan that meets this standard:

2.1 Reflects the input from the planning process.

Comments
What about highlighting the necessity of incorporating the input from the CAC?
If the planning process is flawed because the standards are not complete then logically the actions taken by the UCEDD will relevance and efficacy if they are based on plans governed by these standards.
Seems redundant.
This as a requirement is micromanaging the process. We should give UCEDD Directors credit for knowing they need to do this.

2.2 Reflects the goals and principles in the DD Act.

- Examples include self-determination, independence, productivity, integration, and inclusion in all facets of community life.*

*Note: These are examples. Not all are required. Others may be used.

Comments
In this case, delete the asterisk. The goals and principles of the DD Act are NOT examples. We must address them.
Added "…and complements the goals of the state DD Council"
This is redundant - the concept is already in Standard #1
Must.
This as a requirement is micromanaging the process. We should give UCEDD Directors credit for knowing they need to do this.

2.3 Guides the activities that the UCEDD conducts and supports, while including provisions for responding to emergency needs and opportunities.

Comments
It is "emerging needs and opportunities" not "emergency"
I like the change from 'drive' to 'guide' – leaves room for revision and addressing emerging issues. I would suggest a difference between emerging issues and emergency issues. Eg. Restraint and seclusion legislation issues versus Hurricane Katrina or earthquake. How a UCEDD responds is different with these situations.
Emerging needs, emergency needs and opportunities
Would suggest including the word "emerging" along with emergency.
Not sure but do agree that some latitutde is needed to be able to resond to needs of the state that might not have been anticipated in the current DD Act.
Not even sure what "responding to emergency needs and opportunities" refers to… UCEDDs do all sorts of things that are not in the 5 year plan.

Further Comments, Additional Standards and Performance Criteria for 5-Year Planning:

Comments
Still feel that theses two standards could be combined into one.
See comments re: emergency and emerging issues. Several UCEDDs in several states have encountered natural disasters where in the UCEDD was directly affected as well as the UCEDDs in neighboring states. Emerging issues may not need an immediate response or have an immediate impact, <u>but</u> should still be included as part of the UCEDD planning piece.
This is a nice improvement over Version 1.0. It still has a few problems. First of all, there is no place in the plan for a. building capacity (fo the UCEDD, disability community, or service systems) or B. participation in the National Network. Both of these are important and unique elements outlined in the Act. Second, the relationship between the UCEDD planning process and its ultimate five year plan and the state DDC goals is still awkward. Language in the Act clarifies this relationship by saying that the UCEDD goals are 'consistent with and to the extent feasible complement and further" the goals of the Council. It might simplify this if Standard 1 was about the data gathering and planning process (leave out the stuff about the plane – the PCs don't address that anyway) and have Standard 2 about the plan and add a PC – the UCEDD's five year plan is consistent with and complements and furthers the state DD Council plan. See suggested edits earlier in this section.
Language in this section is clear. Input for planning is comprehensive and data driven. Planning process guides and informs the UCEDD's work

Comments
Suggest adding this one taken from the P&A set: "2.4 Includes provisions for revising goals and priorities during the year to reflect new or changing conditions, statues, regulations, or priorities."
The standards are weak at best. Each UCEDD can establish its own agenda based on its interpretation of the DD Act with no specific outcome-based focus. The final measure of impact should be the effects of UCEDD activities on families and persons with DD, not whether or not they meet organizational or governance standards.
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. Standards #1 & #2 could easily be combined - there are artificial distinctions being made that really are unnecessary - as was noted in Round #1 comments.
These are obvious.

A. Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3: UCEDDs advance practice, scholarship and policy that impacts the lives of people with developmental disabilities and their families.

Comments
This is too generic. The statement is fine but add "through pre-service training" at the end to reinforce the standard relates to this aspect of the core function.
Yes – broader statement but very good.

A UCEDD that meets this standard:

3.1 May offer training that leads to the award of an academic degree, professional certificate, or advanced academic credential.

Comments
We should be able to combine # 3.1 & 3.2
Delete "May" and substitute "contributes to" for "leads to." Every UCEDD provides training that does this.
Includes our short term and long term trainees
Replaced 'May offer with 'Offers' and "advanced academic" with "other". Wording is equivocal. If It is a performance criterion, it shouldn't start with 'May'
Academic degrees, professional certificates and credentials are great. Direct experience should be validated in this context. There are epistemic elements of the disability experience that persons without disabilities who have not lived the disability experience are simply unqualified to address.
If this is a PC, the word "may" should not be used. Despite that, I agree that training should/could lead to credentials.
The wording is odd since how can something "required" state with "may offer"? I'm not sure that it should be REQUIRED but certainly should be strongly encouraged.
A standard that begins with"May" isn't very helpful. Many UCEDDs do not award degrees, certificates or credentials, yet still fulfill the obligations of UCEDDs, so there's no reason to list this as an objective.

3.2 Advances the academic or professional credentials of trainees.

Comments
Not sure that UCEDDs should be held responsible for trainees completing an academic program. Too many variables for a UCEDD to be responsible for this.
If credentials is all you are about, then you will continue to distance yourself from those of us who are authentic members of the disability community. Unfortunately, I have to answer that it should be required to meet the standard because of how the standards are constructed, with the assumption that UCEDDs have such a limited focus based on these standards.
Rather vague standard. I'm not sure what this means or how it would be measured.
See above. How would one meet this if one doesn't award degrees or credentials?

3.3 Offers developmental disabilities-related courses, clinical experiences, mentorings, or trainings based on content from a variety of disciplines.

Comments
Rewrote as "UCEDD faculty offer…to students from multiple disciplines". YES!!
Combine 3.3, 3.4.& 3.5
The training should include people with disabilities as the trainers.

3.4 Offers developmental disabilities-related courses, clinical experiences, mentoring, or trainings taught by faculty and staff from multiple disciplines.

Comments
Combine 3.3, 3.4, and 3.5.
If we offer it, who else would teach it? Seems duplicative again! Measure 3.3 – 3.5
Redundant with 3.3
Once again, the failure to recognized the experience of persons with disabilities who do not have a credential as a valid experience. So, how do I answer this…I would have to answer in favor only because it's partially meets at least my professional expectation.
Combine 3.3, 3.4.& 3.5
I prefer this over 3.3 - much easier to measure and a better assurance of covering interdisciplinary content.

3.5 Offers developmental disabilities-related courses, clinical experiences, mentoring, or trainings to students from multiple disciplines.

Comments
"Students from multiple disciplines" – If we offer it who else would teach it to? Seems duplicative again! Measure 3.3 – 3.5
Agree conceptually but this really is redundant. Combine 3.3, 3.4.& 3.5
Seems redundant to the previous two.

3.6 Teaches students about the conduct and interpretation of research.

Comments
Must to meet the research portion of the Mission.
Most of our trainees have this expertise already when they come into the program, we don't teach it specifically.

3.7 Integrates UCEDD research findings into interdisciplinary pre-service preparation and continuing education activities.

Comments
We should remove UCEDD from this criterion. It is research findings in general, not just the UCEDD's research.
Delete continuing education activities. The other PCs under this standard don't address continuing education. Integrating research findings into continuing ed activities is important but doesn't it belong under Standard 5?
Would drop UCEDD here in that the research findings will not only be from the UCEDD.
Not all activities have findings
Nothing in the Act requires this. Why "UCEDD research findings"? Training should be research-based, but even that exceeds the requirements of the Act. UCEDDs know that training should be evidence/research based, so establishing a standard/requirment is just micromanaging.

3.8 Can document the percentage of graduates who are engaged in work related to people with developmental disabilities and their families 5 years after training.

Comments
That's a follow up survey. How is this percentage calculated? Based off total number of trainees who completed program or number of trainees responding to the follow up survey? The first measure could be seen as punitive towards the UCEDD
Why five years? I think two years is a better threshold, given today's economy and job market.
change to "...OR their families...". If trainees work with adults with DD - they might not necessarily also (AND) work with their families as well.

3.9 Can document the percentage of graduates in leadership positions related to developmental disabilities.

Comments
That's a follow up survey. How is this percentage calculated? Based off total number of trainees who completed program or number of trainees responding to the follow up survey? The first measure could be seen as punitive towards the UCEDD
Define leadership Better to combine with 3.8
This would be swell, but it would break the bank to try to document
Should be able to document the number of persons with DD recruited into UCEDD programs who complete the programs and are graduates in leadership positions.
This requires some time frame - it is not realistic for any UCEDD to keep track of its graduates forever - even in the age of technology.
Practically speaking, this is difficult if not impossible and is redundant to the previous requirement.

3.10 Prepares students to apply an interdisciplinary approach in a field in which they can increase inclusion and choice for people with developmental disabilities.

Comments
Not sure if we can measure the 'field in which they can increase inclusion and choice". How do we measure this? We have a percentage in the earlier measure why not here as well?
I have no idea how this could ever be documented.
This will be difficult to measure and demonstrate.
How would one even measure this?

Standard 4: UCEDDs prepare students to work on behalf of a diverse population of people with developmental disabilities.

Comments
Absolutely
The wording on this has become so politically correct that it really has no meaning

A UCEDD that meets this standard:

4.1 Enrolls students from culturally and linguistically diverse backgrounds.

Comments
Added 'when available' to the PC. There are regions of this country that are ethnically 'poor' as to student populations. Historically black colleges have few or any graduate programs. I think a network discussion should take place regarding the unique needs of states to open up the pool of students but fear putting too great a measure on states that have little choice in the student makeup.
Depends on UCEDD's location. A UCEDD in [STATE] will not likely be as culturally/linguistically diverse as a UCEDD in California, for example
I still think this standard has no focus. These PCs could be added to Standard 3 instead.
Enrolls students with developmental disabilities…come on what you are really about here??????

4.2 Includes people with developmental disabilities and family members in the planning and delivery of interdisciplinary pre-service education activities.

Comments
Again a great practice and should be encouraged but seems to exceed the standard. Do we have a section for not required but recommended practices or strategies?
How about recruitment and mentoring for training so they may graduate into leadership roles. On the one hand, at least one of your UCEDDs is federally funded to promote access to college for persons with DD. The question, is how much to UCEDDs promote access to their training by persons with DD. And if you can claim that you do this, why doesn't this standard reflect this?
Definitely! Don't leave them out.
Is this not an automatic with consumer participation on CAC?

4.3 Provides students with experiences that lead to an understanding of the daily lives of people with developmental disabilities and their families.

- Examples include the provision of opportunities to interact with people with developmental disabilities and family members.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Delete asterisk. Interaction with people with developmental disabilities and their families should be required.
Rewrote as "Provides students with experiences beyond formal training sessions..." This is beyond or in addition to the formal training structure in 4.2 measure.
Redundant with 4.2
absolutely
Once again, the example is so pathetic its embarrassing. The disability studies literature comes to mind. ? What exactly are your criteria, standards and benchmarks for"understanding of the daily lives of people with DD and their families? As a person with a DD this is so offensive that I will use it as an example in classes I teach on campus.
Would be helpful.
How would you measure this? Ask students what their "understanding" is? This is just micromanaging.

Standard 5: UCEDDs improve the knowledge and skills of service providers and practitioners through continuing education, inservice training, and technical assistance.

Comments
Delete inservice training and technical assistance. They belong under Community Servcies.
At this point I have elected to terminate responding to the ratings and only offer comments. I do so because I know longer am in agreement with the assumptions and presumptiosn that underlie the standards. Therefore, I logically cannot offer any further defensible ratings.
I don't disagree with the sentiment, I just believe that making this a standard will be impracticable. I know of no way to "measure" improvement in knowledge and skills from many of the types of trainings UCEDDs do that would not require substantial resource allocation to accomplish.

A UCEDD that meets this standard:

5.1 Provides continuing education to a variety of professionals in the community.

Comments
Is this expected to be conferring of CEUs or contact hours for professional?
Continuing education alone can be interpreted as a term of art signifying education experiences that produce CEU's or CME's. Would suggest inserting after education, in-service, seminars, trainings and workshops including webinars.
Focus should be on educating UCEDDs on the needs of the disability community and perspectives of disability. The assumption is that UCEDDs have something to offer.
Many UCEDDs do not provide continuing Ed, but meet the training requirements in other ways.

5.2 Bases continuing education on documented needs in the state or territory, as identified in the 5-year plan.

Comments
No provision for addressing national or regional needs
Continuing education needs are difficult to predict in a five year plan for the entire period of the grant. Centers need the flexibility to respond to emerging needs, changes in state and national policy. For example, had the Restraints and Seclusion bill been passed UCEDDs would have had to gear up major efforts in the training and continuing education around positive behavioral supports.
..."or designated serice area" for states with more than one UCEDD
We may not want UCEDDs to limit themselves only to planning done 3-5 years ago. Needs for training might change in between and UCEDDs should have the latitude to adapt and respond to changing CE needs in the community - even if they are NOT contained in their 5-year plan.
Many UCEDDs do not provide continuing ed, but meet the training requirements in other ways.

Further comments; additional Standards or Performance Criteria for Interdisciplinary Pre-Service Preparation and Continuing Education

Comments
Define continuing education in measure 5.1 for professionals.
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. I agree with the concepts presented for the most part but feel that Standards 4 & 5 & the related PC really could really be subsumed or moved under Standard 3. You have made some very artifical distinctions between practitioners, pre-service students and continuing education. This really could be re-strucured and presented in a far more streamlined fashion.

B. Basic and Applied Research

Standard 6: UCEDD faculty and staff conduct research that is relevant to the lives of people with developmental disabilities and family members.

Comments
Would like to see included after research, "evaluation and/or policy analysis."
How can it be relevant when your standards provide no meaningful focus on the recruitment and involvement of persons with disabilities in training and research…when you provide lip service to understanding our lives?
Who decides what is relevant research?? This could be a slippery slope.

A UCEDD that meets this standard has research faculty and staff who:

6.1 Conduct basic or applied research, evaluation, or policy analysis relevant to the lives of people with developmental disabilities or family members.

Comments
How is this different than standard 6 wording?
Who decides what is relevant research?? This could be a slippery slope.
How is this requirement any different from the standard itself?

6.2 Involve people with developmental disabilities in the development, design, or implementation of the research.

- Examples of involvement include identifying research topics, assisting with the design of data collection instruments, helping to ensure that research materials are in accessible and understandable formats, recruiting people with developmental disabilities and family members as study participants.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
Substitute "and" for "or"
Nothing about us without us – SABE
A practice to be encouraged clearly but not really stated or implied in statute or regulations.
At some point this will go full cycle. People without disabilities and specifically professionals will be the targeted research subjects to investigate how limited the understanding is of the disability experience. This is already the case in DS.
Yes- Don't leave us out.
I don't think this is essential to conducting good science.
Not all research is appropriate for PAR type of activities.

6.3 Publish research findings on developmental disabilities in peer-reviewed journals and other venues.

Comments
Suggest including other venue examples, to include public awareness documents, popular journals, websites, newsletters, ,guidebooks and policy briefs.
If they want to be published.

6.4 Present research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.

Comments
HAS RESEARCH FACULTY AND STAFF WITH DD
It would help the field.

Further comments, additional standards and performance criteria for Basic and Applied Research:

Comments
What about faculty involvement in research with other entities (collaborative efforts of UCEDD to advance research in other fields?) We took out measures of journal editorial board, but we have faculty who assist students in dissertation committees, master's theses, administrative responsibilities, and student supervision in research. All of this is missing
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion.

C. Community Services

Standard 7: UCEDDs provide community services through training or technical assistance for people with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community.

And may provide services, supports, and assistance through demonstration and model activities.

Comments
Training is covered under Section B to professionals in the community. Confusing to have it here again.
Don't agree about services unless they are clinical supports
The wording on this has become so inclusive and politically correct that I can't make sense out of it.
Confusing - I just don't know what is being said - the UCEDD is providing community service - OR – the UCEDD is providing training & TA. lean toward the latter and would remove the words "community service through."

A UCEDD that meets this standard:

7.1 Addresses topics that allow professionals to maintain professional credentials, expand their knowledge base, and stay up-to-date on new developments.

Comments
This is confusing. It seems like this could go under Continuing Ed.
"maintain professional credentials" is more appropriate for Continuing Education than Community Services.
Not sure that this should be required.
This may happen, but should not be "required".

7.2 Provides community services that address issues across the range of the population of people with developmental disabilities in the state or territory.

- Examples include a variety of disability types, age groups, living arrangements, socio-economic status, and ethnic and racial groups.*

  *Note: These are examples. Not all are required. Others may be used.

Comments
This is ok, but not limited to States. Take out "State or territorry."
Often the UCEDD is providing services based on a service agency contract (e.g. Part C or MCH/CSHCN clinic) and has few degree of freedom to add to or shift focus of service to other disability group
Should say "Provides community services that address issues faced by people with developmental disabilities. "across the range of the population" is just too confusing and the problems are universal not limited to a state/territory/service area.

7.3 Provides continuing education training and technical assistance that promote the principles of the DD Act.

Comments
Ok, but take out Continuing Ed and replace with community training.
Why is continuing education included here?
Agree, but not here. In Section B Interdisciplinary Training
Shouldn't there be commas between education, training, and technical assistance?
Redundant - if the 5 year plan must do this - then it applies to the community service done under that plan.

7.4 Integrates community services with training, research and/or dissemination functions.

Comments
What does "integrate community services with training" mean?
Agree, but not here. In Section B Interdisciplinary Training
"...when/wherever possible" - this is not always a good thing to do but should definitely be encouraged.
Community services should be evidence-based, but don't know how, practically, one would prove one meets this requirement.

7.5 Provides participants in continuing education activities with certificates of completion or continuing education units (CEUs).

Comments
Ok, but this goes under the section on ID training and Cont ed.
This PC seems more appropriate for Continuing Education then Community Services.
Agree, but not here. In Section B Interdisciplinary Training
No mention in either statute or regulations. This should be a may and not a shall or will.
By definition/regulation, this is governed by CE granting agencies.
Many UCEDDs do not provide Continuing Education.

7.6 Can document that recipients of training and technical assistance use the knowledge and skills they obtained from these activities.

Comments
Agree, but not here. In Section B Interdisciplinary Training
This is very difficult to do, too many factors are involved in whether a concept, policy, or practice is implemented or not.
One of the touchiest things to do is to document that training results in changes in practice – doable but would require additional resources.
It is reasonable to ask the UCEDDs to document improved skills but not "use of skills and knowledge."
This would be difficult to assess on the spot. This would require some sort of follow-up survey post-training.
The documentation of this would require more resources than currently allotted.

Further comments additional standards and performance criteria for community services

Comments
Including Continuing Ed under this section is confusing. The Community training referred to in this core function is different from Continuing Ed. (See NIRS definitions).
There is still very minimal mention of technical assistance. The DD Act charges UCEDDs to help build state and community capacity and one way of achieving this important outcome is through technical assistance that helps improve services systems through policy change and other means.
B. Pre-service Prep/Interdisciplinary training seems to include credentials for professionals in community. These measures are addressing the same thing but do not mention the outputs for TA or demonstration services! Where are those? Need to be very clear here just where training for professionals should be found. Only one core function can be selected for an activity. It is duplicative both in effort and reporting to enter a professional training twice.
The wording on the standard is terrible. It reflects our own mixed up thinking. I suggest something like "UCEDDs do stuff for everybody". Or, we need segment out activities for different parts of the communities we serve. Something like services for PWD and their families, tech asst. for agencies and programs, education and training for students enrolled in degree/certificate/credential programs, and continuing Ed for post degree or non degree people – and just get used to the idea that folks can end up in one or more categories
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. This could be streamlined considerably - too many artifical delineations.

D. Dissemination

Standard 8. UCEDD dissemination bridges the gap between research and practice.

Comments
But suggest changing this one to read "UCEDD dissemination efforts translate research findings into practice and service and support strategies. Think we need something a little more concrete than "bridging the gap."
Don't understand this

A UCEDD that meets this standard:

8.1 Uses a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners.

Comments
Would add to other researchers and professionals.
Would help a great deal!

8.2 Within university guidelines, disseminates information on developmental disabilities to members of the State legislature, members of Congress, or other policymakers.

Comments
This needs to be kept to explicitly sanction our efforts with legislators.
This is nice if it can be done. But, the focus should remain on providers and practitioners. The impact is diluted when we are trying to be "all things to all people."

Standard 9: UCEDD dissemination addresses the principles and purpose of the DD Act by reaching people with developmental disabilities and family members.

Comments
Include them as contributors to dissemination programs
This is a real nice things where it can be done but not essential. The UCEDDs need to maintain a clear focus on improving the knowledge and skills of providers and practitioners. That is the piece of the DD Act "pie" that they are intended to focus on.
Too broadly written… and micromanaging.

A UCEDD that meets this standard:

9.1 Provides publications, materials and other resources in accessible formats.

Comments
Changed 'format' to 'formats' [the 's' accidentally dropped from the rating form distributed to panel members]
We do this, we don't need a requirement to document that we do this.

9.2 Provides easily accessible training and technical assistance activities.

Comments
Why is this under dissemination? Shoulds be under community services.
Changed 'easily accessible' to 'accommodations for people with disabilities to make' training and technical assistance activities accessible'. Without these edits this PC could mean time of day, city, day of month, whatever.
Why only to activities? Suggest – conducts a training and technical assistance efforts such they are accessible to and accommodate the needs of participants with disabilities.
All trainings should be accessible to the target audience of the said training.
We do this, we don't need a requirement to document that we do this.

9.3 Seeks input on materials and resources from people with developmental disabilities and family members.

Comments
Again – a great idea but seems beyond statute and regulations.
We do this, we don't need a requirement to document that we do this.

9.4 Evaluates dissemination activities and results on an ongoing basis.

- Examples include monitoring number of website hits, conducting targeted surveys, following up the use of materials.*

*Note: These are examples. Not all are required. Others may be used.

Comments
Measuring "results" when it comes to information dissemination is very problematic. ADD recognized this in supporting the new UCEDD Annual Report Logic Model.
It all depends.
We do this, we don't need a requirement to document that we do this.

9.5 Makes its products, resources, and materials available to other DD Network programs.

Comments
And the state and provider community
We do this, we don't need a requirement to document that we do this.

Further comments, additional standards and performance criteria for Dissemination

Comments
Wonder whether we should not create a section for recommended but not required standards which could be optional for centers to use. A number of the performance criteria should be encouraged but there is not a strong base for requiring them in the list.
Put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the presentation of the standards and performance criterion. The PC are all reasonable for all UCEDD dissemination activities and should not be limited to people with DD and their families. The standard is mis-focused but the PC should be applied to all materials development and dissemination activities. All dissemination activities can be combined into a single standard and set of PC - too many artifical delineations.

E. Governance and Management

Standard 10: UCEDDs leverage ADD funding and in-kind resources to achieve the goals of the 5-year plan.

Comments
None

A UCEDD that meets this standard:

10.1 Documents the degree to which the UCEDD leverages ADD and university funds.

Comments
How is this different from the standard?

Standard 11: UCEDDs maintain and support involvement from CACs.

Comments
Absolutely!

A UCEDD that meets this standard:

11.1 Actively works to fill CAC vacancies in a timely manner and documents efforts to do so.

Comments
What is a vacancy? There is no set number of members required, so what is a vacancy? It might be better to say that the composition meets the rerquirtements of the DD Act (and summarize them here.).
As I understand it, CAC membership composition is important - but, there is not set of "required members" so the term vacancy is inappropriate. The CAC should be reflective of the composition outlined in the DD Act.

11.2 Maintains a diverse CAC membership.

Comments
Diverse is too broad a term. UCEDDs do this, requiring it is micromanaging.

11.3 Involves CAC members in the development and implementation of the 5-year plan.

Comments
CACs are also to be involved in evaluating the success of the UCEDD in implementing the 5-Year Plan.

11.4 Supports its CAC for a minimum of two meetings each year.

Comments
DD Act doesn't require anything like this. A requirement is micromanaging.

11.5 Provides CAC members with supports that are needed to ensure meaningful participation.

Comments
We do this already, requiring it is micromanaging.

Further comments; additional standards and performance criteria for Governance and Management:

Comments
I guess I don't understand why all the ADD organizations don't plan in concert with specific activities that related to overarching goals within their specific mission. ADD would have more impact if these organization – UCEDD, DDC, and P&A worked together more fully.
I did not answer the first document due to my frustration the logical assumptions and the implied conclusions based on these assumptions. My recommendation is that these standards simply maintain the existing threshold of employment predominately for persons without disabilities and an industry that founded on maintaining the perception of incompetence and need of persons with developmental disabilities. To this end, I am submitting this and terminating my involvement in this project. I do not want and nor will I accept reimbursement for this. I would strongly urge the designers of the standards to reexamine the logical assumptions and the conclusions that are clearly implied by the standards. If this is not clear, then a course in basic logic may be warranted.
This set of 11 standards and their PC is bulky and unwieldy. It really needs to be streamlined for implementation. There are too many artifical delineations and too many discrete steps - implementation and use for program improvement will be next to impossible. There are a lot of things that would be "nice" but really are far above what is/should be required. Finally, reviewer comments indicated need for lotsm ore definition and examples which did not get translated into Round 2. This definitely needs to be done. Then, put all the examples and definitions throughout this document in a separate set of guidelines. They need a lot of improvement and detract from the focus on the standards and performance criterion when integrated.

Additional comments by email

Comments
I thought your team did a really good job of responding to the feedback from Round 1. I think there are a few more items to refine, but Version 2 was much improved.
I have to tell you that I reviewed the first draft of the standards and pretty much was so frustrated and upset that I gave up. On this one I got about halfway through, put in ratings, and then finally gave up. This whole thing is nonsense. When you folks really want to get around to talking about improving the quality of lives of people with developmental disabilities by actually directly involving them in the recruitment, employment, leadership by UCEDDs, contact me. [COMMENTS THAT MIGHT ENABLE IDENTIFICATION.] In the meantime, for whatever its worth, my comments on the second draft are attached. What is proposed is a total embarrassment in my opinion. As indicated in my response, do not send me any reimbursement for this. I will not accept it. I want no part of this. And quite frankly, you gave me a lot of fodder for a class I teach on understanding the disability experience. So, thank you for that. I wish you the best on this despite my feelings about these so called “standards”.

Appendix Z4. Collaboration

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)
Draft Standards and Performance Criteria – Version 2

Panel Member Comments

Standard 1: All DD Network programs in the state or territory achieve common goals through collaboration.

DD Network programs in a state or territory are the State Council on Developmental Disabilities (DD Council), the Protection and Advocacy (P&A) System, and one or more University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).

Comments
Absolutely
I agree as long as it is clear that some and not all goals are necessarily achieved through collaboration.
Suggest changing standard to say one or more common goals.
The standard is sentence one ONLY. The remainder is an explanation or definition and should be placed in a separate guidance document.
As I said before, I have spent 21 years trying to get my Network partners to set "common goals." Until this is mandated in the Act, it is not going to happen. Again, PNS grantees often do not engage the ADD Network partners in the state in which they are funded.
The edits make this clearer
I think it's quite reasonable to expect the three DD entities (Councils, P&A and UCEDDs) to be able to identify at least one specific measurable goal on which to collaborate.
Rewrote as "All DD Network programs in the state or territory work to achieve…"
I would suggest that they arrive or identify common goals through collaboration. The large goal might be the same or similar but how they choose to achieve it could be very different and even have different timeframes. Identifying areas of common need can occur through collaboration but achieving goals may occur independently.
The DD Network should not be required to collaborate as organization goals may not lead to this. However, there should be a value to collaborating when appropriate.
When the networks work together their impact is outstanding and significant – this does not mean they should not do individual projects, but should collaborate on the big issues. A stellar example is [STATE] where in concert with the state P&A sued, the DD Council did advocacy, the UCEDD provided training and all the institutions were closed

DD Network programs in a state or territory that meet this standard:

1.1 Identify and acknowledge a common goal or goals.

Comments
Must work together; yet independently
In a good year, 2 of the 3 partners may identify a common goal.
Should also network with family groups and statewide self-advocacy groups, parent-to-parent network and others like [local advocacy group]
While there might be a common goal, it must be understood that because of the different activities/roles of the DD Network, that the activities will NOT be the same. So there must be room for different objectives.
How these programs arrive at common goals should be a measure (output) of collaboration
'Acknowledge' is a vague term. Suggest rephrasing: "DD Network programs develop common goal or goals"

1.2 Identify roles, activities and tasks for each DD Network program supporting the common goal or goals that are identified.

Comments
Obviously joint planning will be needed but this seems too prescriptive.
"Identify roles, activities OR tasks..." - not necessary to do all three.
With 2 diffferent boards (Council and P&A) and one advisory (UCEDD), this is very difficult. Network EDs meet regularly and collaborate by exchanging information and insights.
A procedure for recognizing 'extenuating circumstances' should be drafted between collaborating DD network constituents if a network constituent is unable or chooses not to participate in pursuing a common goal.
It is very important that all DD network programs talk to each other and work together; this currently does not happen in all states
While there might be a common goal, it must be understood that because of the different activities/roles of the DD Network, that the activities will NOT be the same. so there must be room for different objectives.
Beautiful
Deleted 'or goals that are identified'. See edits to standard criteria. Yes, this meets my comments on the entire standard on previous page. This is more behind the scenes.
Clear deliverables and roles for partners is a good operational expectation.
Each member should identify their own contribution
Don't see why the programs need to be mandated(?) on the issue. While probably an important step to accomplish a goal, don't think it needs to be [illegible]

1.3 Demonstrate a united perspective on key issues related to common goals.

Comments
No mention in statute or regulations - often perspectives will be different even though the goal will be the same. To organize advocates, sue an organization or system and train its leadership - are coming from different perspectives but could be supporting a common goal of inclusion or community living.
The word "demonstrate" just doesn't work - "maintain" (or something synonymous) might be a better alternative - We need to work together toward shared or common goals; we don't need to make a show of it for the benefit of outside parties.
I don't know what to look for as evidence of "a united perspective" so I think this would be difficult for a reviewer. Perhaps you could craft some examples here. These might include joint advocacy efforts, co-authoring white papers or policy memos, co-hosting a conference, etc.
Don't know how you measure this, or how you do the first two indicators without this is place.
Agree but A procedure for recognizing 'extenuating circumstances' should be drafted between collaborating DD network constituents if a network constituent is unable or chooses not to participate in pursuing a common goal.
This has not always been possible - since the P&A's position are driven by our case work - what is actually happening to people with ID/DD - which might contradict theory.
Perhaps including 'identify' here as well. On one hand, it may seem redundant but, on the other, it supports/prompts communication about these issues prior to the act of 'demonstrating'. These simple assumptions could create challenges, so at least suggesting preliminary chat may help
This is more public. Ok – demonstrating (public acknowledgement or joint activity) common goals should be an output of collaboration.
Not sure what 'united perspective' gets at the heart of this criteria – believe that the standard should mandate alignment with the DD principles stated in the DD Act. Suggest "Demonstrate full alignment with self determination principles in the DD Act"
Perhaps not key but selected, agreed upon issues – the common goals they agreed upon from 1.1
Even though P&As always do not align when in litigation
Again, may or may not be necessary to accomplishing goals
One partner may take a lead on an issue and may feel stronger or have to have a harder stance on the issue to effectively advocate.

1.4 Involve representatives from all three DD Network programs in collaborative meetings.

Comments
I think this would be an excellent requirement
Not all collaborative activities involve all three partners; some involve two. Even when all three are involved, it may not be necessary for all 3 to always attend meetings depending on the activity that is taking place or the discussion being held.
I made this comment before and I think it's important. In many states there are more than three programs (several UCEDDs for example), so I think this would be clearer if the criterion referenced "all three DD Network program types (UCEDDs, Council, P&A) in collaboarative meetings."
When it's appropriate
Ad hoc basis to attend when reasonable to do so. Standing invitations should be issued to participants. Directors should be required to meet at least twice yearly. Their representatives, at other times to be determined by need/circumstances.
Some projects may include only 2 members however (after collective decision). Would it be helpful to include a specific here? Such as "…collaboration meetings at least twice a year"? Knowing that other meetings throughout may not require all three.
How else would you have collaboration? Seems elementary to just have representatives. Isn't the meeting or communications the important issue? Suggest rewriting this to show that the true measure is the communication and participation is the emphasis – not the representation.

Comments
How can you collaborate without this?
Agree as long as meetings can be understood to take on many formats, phone, email etc.

1.5 Document the outcomes of collaborative efforts.

Comments
As noted in the comments for the DD Council version 2, documentation that the criterion is met will be needed for all criteria. The need to document should not be identified for any one criterion. Recommend rewording as follows: Evaluation the outcomes of the collaborative efforts.
HOWEVER, there is a caveat - there needs to be technical assistance and a reasonable structure for doing this. The current PPR structure (for DDCs & P&As) really only allows one very limited perspective (and doesn't even require the knowledge or concurrence of the other partners) - not a balanced and well rounded picture.
Assuming there are collaborative efforts, I support that outcomes are documented.
I love this detail. Should there be further specifics about the form of documentation, however, so comparisons can be made among states and national averages/details could also be obtained?
Obviously collaboration will be part of any report to ADD. However, what is it ADD really wants here? Is there a product, activity or effort to be captured? Just not a strong criterion.
Outcomes must be evaluated prior to documentation. Suggest that DD Network programs be required to implement a good evaluation methodology in addition to documenting outcomes.

Further comments; additional standards and performance criteria for collaboration:

Comments
I think it's imperative that all DD Network programs work together
The only way that having a standard and performance criterion for network collaboration to be effective or reasonable means a commitment by ADD to take a strong role with technical assistance and performance management in this area - and that includes reasonable structures for "documenting the outcomes." Unless that happens, this was a wasted exercise.
Collaboration is a reasonable expectation. However, at times, network DD members should have the ability to take opposing viewpoints, provided that it is justified and fully explained.
Should also seek outside DD network for additional collaboration; so that important programs can be supported like programs for families and programs for self advocates. These movements are not always supported in all states and they should be. Don't just support short term tasks, such as grants and scholarships. No money right now for family and self advocacy programs and there should be. We all have common interests and seem to be short on funding. Unfortunately, sometimes people are brought in from outside the state to do self-advocacy trainings and family trainings. There are already trainers in the state who could do it. Why not use them?
I believe in collaboration but is sometimes is difficult to achieve because of personalities, etc. Successful collaboration can not be mandated.
This was amazing! Seeing the ideas come together as they did was fascinating. Thanks for including such diverse voices/perspectives. I'm honored to have participated
The big issue for me is documenting through data the sustained and significant impact of DD Network activities – too many 'nice' but small projects that do not have a lasting impact – but there are many examples of collaboration that do lead to sustained positive change and the DD Network needs to study these and develop a strategic approach that has long-lasting impact on the DD systems – and unless you can measure the impact, it's all lovely stories.
Emphasis should be placed upon outcomes, articulating what the outcomes are, barriers encountered, but process variables do not need to be mentioned

Further Comments by email:

Comments
I have only had time to open one of the sections for DD councils and it was entitled “collaboration.” I was so relieved to see that your team was open to suggestions and recommendations. I think this set of standards reads so much better. I cannot wait to see the rest of them.

Appendix AA. ADD Assessment Interview Guides

AA1. ADD COMMISSIONER

AA2. ADD STAFF

AA3. FEDERAL AGENCIES

AA4. NATIONAL DISABILITY ORGANIZATIONS

AA5. PROJECTS OF NATIONAL SIGNIFICANCE

Appendix AA1. ADD Commissioner

A NATIONAL INDEPENDENT STUDY OF THE STATE DEVELOPMENTAL DISABILITIES PROGRAMS

ADD ASSESSMENT

INTERVIEW WITH COMMISSIONER OF ADD

Introductory Remarks

- Purpose of this interview: To determine Commissioner's views on a variety of high level issues that set off a cascade of events and processes—ADD roles, goals, balancing of roles, major activities (key functions), Projects of National Significance, expectations for DD Network programs, plans for the future, proposed use of the National Independent Study findings.

- Permission to record

Confirmation of What Commissioner Would Like to Achieve

1. Full National Independent Study

   The Commissioner noted that there has not been an independent evaluation of the DD network in at least 20 years and maybe never. She believes that it provide a perspective on the programs that will be important to share with Congress, the programs themselves, and shareholders. She believes it is important for the ADD to share the strengths and weaknesses of the programs.

   She said that there is an inherent difficulty in evaluating these programs in that they are all locally driven and state based. They all have a singular focus on system change. Given that all are dependent on the state environment in which they operate it is difficult to impossible to quantify the progress they make. She hopes the qualitative aspects, and the report narrative will help tell the story that needs to be told about the work of these agencies.

   She hopes that she will be able to use some part of the evaluation in developing the strategic plan for ADD. Timing is working against this as she needs to have a plan developed by March in order to get it operational before the end of this administration.

   She hopes the evaluation will help inform the reauthorization process for the DD Act. Given that quantifiable performance measures are so difficult under these circumstances will the evaluation provide some tangible qualitative measures to illustrate what the DD network is doing.

2. ADD Assessment

Vision for Developmental Disabilities Population

3. Commissioner's vision for the developmental disabilities population/broader community.

The Commissioner envisions that the DD Act will remain the foundation for the DD network mission. She wants to ensure that the ID/DD community and their families direct the systems that provide services. She would like to see a direct relationship at the state and national level between the DD agencies including the DD network and state DD agencies and the CMS. She would like the DD network to have a direct relationship including activities such as reviewing Medicaid waivers and perhaps a fiduciary responsibility between DD agencies and CMS.

She said that currently the DD system is on the defense. States are moving more to less specialized waivers. DD systems are being included under the same umbrella and aging and physical disability. DD services are losing out as the aging and physical disability agendas prevail. She would like the values of the DD system , including community based services, self determination inform the system. She would like the DD services system to gain some of the service supports available in aging services such as having services available on a sliding scale or fee for service basis so that disability services could be available to all who need them in the way that aging services already are. The Commissioner would like an alignment of strategic goals among disability, CMS, and services for aging. The Secretary of HHS current priority for Community Living provides an opportunity for that to happen.

A DD's R oles

4. What do you see as ADD's major roles for helping to achieve that vision?

   Probe:

   - Oversight of DD Act – monitoring, making sure that grant awards are made; primary, important; ensuring work of Programs of National Significance (PNS) grants completed
   - Federal agency role: Influencing and informing what occurs at the Federal level related to the developmental disabilities community and to non-disability communities (e.g., how housing, TANF, and child care policies will have an impact on people with developmental disabilities).
   - Leadership role: To provide leadership and direction to the DD Network programs, PNS grantees
   - To provide a mechanism to expand the impact of local success of DD Network programs to national scene
   - Other

5. Do you think your perception of the key ADD roles was the case 5 years ago?

6. When you began as Commissioner, how did you see ADD balancing these roles?

7. How would you like to see the roles balanced in the future?

8. What do you see as the goals of ADD? How do you see these goals dovetailing with ADD roles?

9. What role do you see the National Study and the ADD Assessment playing in achieving these goals?

ADD Activities

We will be getting some of the specifics on ADD activities from ADD staff. What we're more interested in from you is what you see as the major activities (we often refer to them as "key functions") ADD staff carry out.

10. What do you see as ADD's key functions currently?

    Probe:

    - Monitoring DD Network programs and Programs of National Significance for compliance and quality
    - Advocacy on behalf of DD Network programs
    - Policy making at the Federal level
    - Provision of technical assistance
    - Provision of means for knowledge sharing among programs
    - Setting an agenda for the developmental disabilities field
    - Other

11. Are there additional key functions you'd like to see for ADD? Please describe.

12. When you started as Commissioner, on what types of activities did you see staff spending most of their time?

13. How would you like to see staff time allocated?

Projects of National Significance

We've been told that the Projects of National Significance are a way for ADD to provide leadership and direction to the developmental disabilities field.

14. Is that how you see their role? Please explain.

15. In the past, how has ADD determined the major direction for Projects of National Significance?

16. What are your plans for the future?

17. Do you have any initial thoughts on what direction the Projects of National Significance should take—that is, where you would like to direct ADD's discretionary funding?

A DD's E xpectations

One of the original goals of the National Independent Study (when it was called the Developmental Disabilities Program Independent Evaluation or DDPIE) was to develop performance standards for the three DD Network programs. We still have that as a goal, as you know, but the intent is to arrive at something more qualitative.

18. With that in mind, what do you expect from the DD Network programs? Do you have any preliminary thoughts on the kinds of "standards" to which you want to hold them accountable?

    Probe:

    - Compliance with the DD Act
    - Efficient systems and processes
    - Participation of people with developmental disabilities in activities
    - Attention to unserved and underserved populations
    - Collaboration among the three DD Network programs
    - Leadership and collaboration with the disability community in each state
    - Specific outcomes related to enhancing the lives of people with developmental disabilities and their families
    - Other

19. What's your idea of a high quality program?

    a. For the DD Councils?

    b. For the P&As?

    c. For the UCEDDs?

20. What are your expectations for the Projects of National Significance?

Technical Assistance

21. Given what you expect from the DD Network programs, what type of technical assistance would you like ADD to be providing or sponsoring to help the DD Network programs meet these expectations?

22. What are the major elements of the technical assistance the DD Network programs are currently receiving?

23. Would you like to see any changes put in place? Please describe.

24. Given what you expect from the Projects of National Significance, what type of technical assistance would you like to be providing to these grantees?

Barriers and Facilitators

25. Given the goals you have in mind for ADD, what do you see are the major facilitators to achieving those goals?

26. What do you think are the barriers to achieving those goals?

27. Given your expectations for the DD Network programs, what do you see are the greatest barriers to the programs meeting those expectations? For DD Councils? For P&As? For UCEDDs?

    Probe:

    - Sections of the DD Act
    - Lack of ADD staff time
    - Current reporting requirements
    - State level funding
    - Lack of authority to hire or fire staff
    - Other

28. Given your expectations for the DD Network programs, what do you see could be the greatest facilitators for the programs meeting those expectations? For DD Councils? For P&As? For UCEDDs?

    Probe:

    - Changes to the DD Act
    - Greater/different technical assistance
    - Dissemination of DD Network program successes and "best practices"
    - ADD staff
    - Different types of reporting (e.g., more streamlined, qualitative)
    - Other

29. We are finished with our questions. Is there anything else you'd like to tell us about your future plans for ADD and the DD Network programs?

Appendix AA2. ADD Staff

A NATIONAL INDEPENDENT STUDY OF THE STATE DEVELOPMENTAL DISABILITIES PROGRAMS

ADD ASSESSMENT INTERVIEW

GUIDE FOR ADD STAFF

Introductory Remarks

- Background and purpose of National Independent Study and ADD Assessment
  - Phase 1 and Phase 2
  - Purpose of National Study – to conduct an independent study of the three national DD Network programs to assess program effectiveness and achievements.
  - ADD Assessment part of National Independent Study
  - Purpose of ADD Assessment - to examine the efficiency and effectiveness of ADD in accomplishing its mission as described in the DD Act.
- Purpose of this interview - To obtain information on what you do as an ADD staff member, how you do it, and changes you think should be made to improve ADD efficiency and effectiveness
- Permission to record

Staff Background

- How long have you been at ADD?
- What is your current position at ADD?
- How long have you been in this position?

A DD's R oles

We recently met with Commissioner Lewis, as well as Jennifer Johnson and Ophelia McClain, who told us about the major roles played by ADD:

- Oversight of DD Act
  - Awarding and announcing grants
  - Monitoring the DD Network programs (DD Councils, P&As, UCEDDs)
  - Ensuring work of the DD Network programs and Projects of National Significance (PNS) is efficient and effective.
- Federal agency role:

Influencing and informing what occurs at the Federal level related to the developmental disabilities community and to non-disability communities [e.g., how housing, Temporary Assistance to Needy Families (TANF), and child care policies will have an impact on people with developmental disabilities].

- Leadership role:

Providing leadership and direction to the DD Network programs and the PNS grantees.

- Do you see any other roles for ADD?

Your Activities

Now we'd like to talk about **your** responsibilities and activities to carry out some of these roles.

A. Monitoring DD Network Programs

- Are you involved in monitoring DD Network programs? (If yes, proceed to next question. If no, proceed to Section B.)
- Which programs?
- What tasks or activities do you do to support monitoring the DD Network programs?

  Probe:

  - ☐ Prepare allotment and grant announcements
  - ☐ Review or monitor budgets
  - ☐ Review annual program reports
  - ☐ Review other program reports
  - ☐ Other

- Please take us through each activity to help us understand exactly what you do to monitor DD Network programs.

  Probe:

  - Description of activity
  - ADD staff involved
  - Interaction with programs
  - Followup
  - Report write-up
  - Other

- Overall, about what percentage of your time do you spend on monitoring DD Network programs?
- Is there anything you feel could be changed with regard to monitoring DD Network programs to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

B. Assessing DD Network Programs for Performance/Quality

- Are you involved in assessing DD network program performance/quality? (If yes, proceed to next question. If no, proceed to Section C.)
- Which programs?
- What tasks or activities do you do that are related to monitoring DD Network programs for performance/quality?

  Probe:

  - ☐ Select programs to visit
  - ☐ Prepare for or participate in MTARS visits
  - ☐ Participate in other types of visits to programs
  - ☐ Review program products
  - ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved in assessing DD Network programs for performance/quality.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with programs
  - Follow up
  - Report write-up
  - Other

- What do you consider to be a "high quality" DD Network program?
- Overall, about what percentage of your time do you spend on assessing DD Network programs for performance/quality?
- Is there anything you feel could be changed with regard to monitoring DD Network programs for performance/quality to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all

- Do something differently

C. Providing or supporting technical assistance to DD Network programs

- Are you involved in providing or supporting technical assistance to DD Network programs? (If yes, proceed to next question. If no, proceed to Section D)
- To which programs do you help provide or support technical assistance?
- What do you do related to providing or supporting technical support for the DD Network programs?

  Probe:

  - ☐ Set up and/or administer technical assistance contracts
  - ☐ Identify technical assistance needs (for national DD Network programs and individual state/territorial programs)
  - ☐ Participate in development of agendas for technical assistance meetings
  - ☐ Provide logistical support
  - ☐ Provide a means for knowledge sharing among DD Network programs
  - ☐ Provide and/or arrange direct technical assistance to selected state/territorial programs
  - ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with programs
  - Followup
  - Report write up
  - Other

- Overall, about what percentage of your time do you spend on technical assistance for DD Network programs?

- Is there anything you feel could be changed with regard to provision or support of technical assistance to the DD Network programs to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

D. Advocating on Behalf of DD Network Programs

- How does ADD advocate on behalf of DD Network programs?
- Are any of your tasks or activities at ADD related to advocating on behalf of the DD Network programs? (If yes, proceed to next question. If no, proceed to Section E.)
- For which programs do you help ADD advocate?
- Please take us through each task and activity to help us understand exactly what you do.

  Probe:

  - Develop and make recommendations on budgets
  - Speak for the developmental disabilities community at Federal meetings with other agencies
  - Speak for the developmental disabilities community at ACF meetings
  - Write or contribute to reports, white papers
  - Other
- Overall, about what percentage of your time do you spend on advocating for DD Network programs?
- Is there anything you feel could be changed with regard to advocating for DD Network programs to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

E. Projects of National Significance (PNS)

We'd like to move into some questions on the Projects of National Significance. Our questions relate to setting a direction for the PNS, selecting grantees, and administering the grants.

- Do you currently or have you in the past worked with the PNS? (If yes, proceed to the next questions. If no, proceed to Section F.)

Setting the Direction

- In the past (e.g., 5 years ago), how did ADD determine the major direction for the PNS?
- How does ADD currently determine the major direction for the PNS?
- Are you involved in determining the major direction for the PNS? Please describe.
- Are there other types of PNS categories you think ADD should support that it currently does not support? Please describe.

Selecting Grantees

- Are you currently involved in the selection of PNS grantees? (If yes, proceed to next question. If no, proceed to question 39.)
- What tasks or activities do you do to support the selection of the PNS grantees?

  Probe:

  - ☐ Develop selection criteria
  - ☐ Establish selection committees
  - ☐ Provide logistical support for project selection
  - ☐ Review proposals and make recommendations
  - ☐ Select grantees
  - ☐ Prepare announcements
  - ☐ Other

- Please take us through each task or activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with grantees
  - Followup
  - Report write-up
  - Other

- Is there anything you feel could be changed with regard to selection of PNS grantees to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

Administering the PNS Grants

- Are you currently involved in administering the PNS grants? (If yes, proceed to next question. If no, proceed to Section F)
- What tasks or activities do you do to support the administration of PNS projects?

  Probe:

  - ☐ Prepare grant announcements
  - ☐ Review reports (monthly, quarterly, annual)
  - ☐ Provide logistical support
  - ☐ Review other types of reports
  - ☐ Other

- Please take us through each activity to help us understand exactly what you do to administer the PNS grants.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with grantees
  - Followup
  - Report write-up
  - Other

- Overall, about what percentage of your time do you spend on activities related to Projects of National Significance?

- Is there anything you feel could be changed with regard to selection of PNS grantees to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

F. Providing and Supporting Technical Assistance to the PNS

- What kind of technical assistance does ADD provide or support for the PNS grantees?

- Are you involved in providing or supporting technical assistance to the PNS grantees? (If yes, proceed to next question. If no, proceed to Section G)

- What do you do related to providing or supporting technical assistance for the PNS grantees?

  Probe:

  - ☐ Set up or administer technical assistance contracts
  - ☐ Identify technical assistance needs
  - ☐ Develop agendas for technical assistance meetings
  - ☐ Provide logistical support
  - ☐ Provide a means for knowledge sharing among PNS grantees

- ☐ Provide or support direct technical assistance to selected projects
- ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with grantees
  - Followup
  - Report write-up
  - Other

- Overall, about what percentage of your time do you spend on technical assistance for Projects of National Significance?

- Is there anything you feel could be changed with regard to provision or support of technical assistance to PNS grantees to make it more efficient or effective? Please explain

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

G. Supporting Policymaking at the Federal Level

- What kind of policy making does ADD support at the Federal level?

- Are you involved in providing or supporting Federal level policy making? (If yes, proceed to next question. If no, proceed to Section H)

- What activities do you perform with regard to Federal level policy making?

  Probe:

  - ☐ Keep up to date on DD issues
  - ☐ Prepare or contribute to reports, white papers
  - ☐ Attend Federal agency meetings
  - ☐ Host Federal agency meetings
  - ☐ Inform other Federal agencies about DD issues
  - ☐ Prepare drafts of legislative language
  - ☐ Comment on drafts of legislative language
  - ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with other Federal agencies
  - Interaction with national disability organizations
  - Interaction with DD Network programs
  - Interaction with people with developmental disabilities and family members
  - Follow up
  - Report write-up
  - Other

- Overall, about what percentage of your time do you spend on the support of policymaking at the Federal level?

- Is there anything you feel could be changed with regard to the support of Federal policy making to make it more efficient or effective? Please explain.

  Probe:

  - Do something more

- Do something less or not at all
- Do something differently

H. Establishing a National Direction and Setting an Agenda for the Developmental Disabilities Field

- In the past (e.g., 5 years ago), was ADD involved in establishing a national direction and setting an agenda for the developmental disabilities field?
- Is ADD currently establishing a national direction and setting an agenda for the developmental disabilities field?

  Probe:

  - Process
  - National direction/agenda
- Are you involved in this function? (If yes, proceed to next question. If no, proceed to next section.)
- What tasks or activities do you do that are related to ADD efforts to establish a national direction and set an agenda for the developmental disabilities field?

  Probe:

  - ☐ Collaborate with other Federal agencies
  - ☐ Seek input from national disability organizations
  - ☐ Seek input from DD Network programs
  - ☐ Seek input from people with development disabilities or their families
  - ☐ Other
- Please take us through each task and activity to help us understand exactly what you do.

  Probe:

  - Description of process
  - ADD staff involved
  - Follow up
  - Report write-up
  - Other

- Overall, about what percentage of your time do you spend on the establishment of a national direction or agenda?

- Is there anything you feel could be changed with regard to the establishment of a national direction or agenda to make it more efficient or effective? Please explain.

  Probe:

  - Do something more
  - Do something less or not at all
  - Do something differently

Facilitators and Barriers

Now we would like to ask some questions specifically about the things that might facilitate or provide barriers to ADD staff in carrying out their responsibilities.

- What do you see are the major facilitators that help you carry out your responsibilities to and for the DD Network programs? Please describe.
- What do you see as the major barriers you face in carrying out your responsibilities to and for the DD Network programs? Please describe.
- What do you see are the major facilitators that help you carry out your responsibilities for the PNS? Please describe.
- What do you see are the major barriers you face in carrying out your responsibilities for the PNS? Please describe.

Closing Remarks

- Are there additional tasks or activities you do that we haven't discussed? Please describe.
- We are finished with our questions. Is there anything else you'd like to tell us about your work at ADD, ADD's activities and future plans, or the DD Network programs and the Projects of National Significance?

Thank you for your assistance.

Appendix AA3. Federal Agencies

A NATIONAL INDEPENDENT STUDY OF THE STATE DEVELOPMENTAL DISABILITIES PROGRAMS

ADD ASSESSMENT

INTERVIEW GUIDE FOR ADD'S FEDERAL PARTNERS

Introductory Remarks

- Background and purpose of National Independent Study and ADD Assessment
  - Phase 1 and Phase 2
  - Purpose of National Study – to conduct an independent study of the three national DD Network programs to assess program effectiveness and achievements.
  - ADD Assessment part of National Independent Study
  - Purpose of ADD Assessment - to examine the efficiency and effectiveness of ADD in accomplishing its mission as described in the DD Act.
- Purpose of this interview - To understand ADD's place in the Federal disability community
- Permission to record

Agency/Program Mission

- To start out, would you please describe the mission of your agency/program and what it does?

  Probe:

  - In general
  - Specifically on behalf of people with developmental disabilities
- How does your specific role relate to people with developmental disabilities? Please describe.

Perception of ADD's Roles

- What roles do you see ADD playing within the developmental disabilities arena?

  Probe:

- Supporting policy making at the Federal level
- Supporting policy making at the state level
- Providing leadership and direction to Federal agencies/departments on developmental disabilities
- Contributing to setting a national direction or agenda on developmental disabilities
- Administration of the Developmental Disabilities Act
    1. Awarding and announcing grants
    2. Monitoring the DD Network programs (DD Councils, P&As, UCEDDs)
    3. Ensuring work of the DD Network programs and Projects of National Significance (PNS) is efficient and effective.
- Other

Interactions with ADD

Now we'd like to talk about how your agency/program interacts with ADD.

A. Policymaking at the Federal Level

- Are you and your agency/program involved in any way in development of Federal policy that would have an impact on people with developmental disabilities? Please describe.

  Probe:

  - Type of policy (e.g., disability-related; other)
  - How agency/program is involved
  - Other

- From your agency's perspective, what has been ADD's role with respect to development of Federal policy on behalf of people with developmental disabilities? Please describe.

  Probe:

  - ☐ Prepare or contribute to reports, white papers
  - ☐ Attend Federal agency meetings
  - ☐ Host Federal agency meetings
  - ☐ Inform other Federal agencies about DD issues
  - ☐ Prepare drafts of legislative/policy language
  - ☐ Comment on drafts of legislative/policy language
  - ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with other Federal agencies
  - Interaction with national disability organizations
  - Interaction with DD Network programs
  - Interaction with people with developmental disabilities and family members
  - Follow up
  - Report write-up
  - Other

B. Policymaking at the State Level

- Are you and your agency/program involved in any way in development of policy at the state level that would have an impact on people with developmental disabilities? Please describe.

  Probe:

  - Type of policy (e.g., disability-related; other)

- How agency/program is involved
- Other

- From your agency's perspective, what has been ADD's role with respect to development of policy at the state level on behalf of people with developmental disabilities? Please describe.

  Probe:

  - ☐ Prepare or contribute to reports, white papers
  - ☐ Attend state agency meetings
  - ☐ Host meetings with state agencies and other stakeholders
  - ☐ Inform other state agencies about DD issues
  - ☐ Prepare drafts of legislative/policy language
  - ☐ Comment on drafts of legislative/policy language
  - ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with other Federal agencies
  - Interaction with national disability organizations
  - Interaction with DD Network programs
  - Interaction with people with developmental disabilities and family members
  - Follow up
  - Report write-up
  - Other

C. Establishing a National Direction and Setting an Agenda for the Developmental Disabilities Field

- In the past (e.g., 5 years ago), was ADD involved in establishing a national direction and setting an agenda for the developmental disabilities field? Please describe.

- Is ADD currently establishing a national direction and setting an agenda for the developmental disabilities field? Please describe.

  Probe:

  - Process
  - National direction/agenda

- Is your organization/program involved in this function? Please describe.

- From your agency's/program's perspective, what does ADD do to establish a national direction and set an agenda for the developmental disabilities field?

  Probe:

  - ☐ Collaborate with other Federal agencies
  - ☐ Seek input from national disability organizations
  - ☐ Seek input from DD Network programs
  - ☐ Seek input from people with development disabilities or their families
  - ☐ Other

- Please take us through each activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Follow up
  - Report write-up
  - Other

D. Federal (Interagency) Committees

- Has anyone from your agency/program sat on any committees with ADD in the past 5 years? Please describe.

  Probe:

  - Name/type of committee
  - Role played by Federal partner
  - Role played by ADD and others on committee

- Committee products and outcomes
- ADD contributions
- Other

E. Joint Projects

- Have you or anyone from your agency/program been involved in any joint projects with ADD in the past 5 years? Please describe.

  Probe:

  - Nature of project
  - Role played by Federal partner
  - Role played by ADD and others
  - Products and outcomes
  - ADD contributions
  - Other

F. Other Interactions

- What other types of interactions have you had with ADD? Please describe.

  Probe:

  - Nature of interaction
  - Role played by Federal partner
  - Role played by ADD and others
  - Products and outcomes
  - ADD contributions
  - Other

Gaps in Policies, Supports and Services for People with Developmental Disabilities

Now we would like to ask some questions about what you think are the gaps in policies, supports and services for people with developmental disabilities and how ADD might be involved in addressing those gaps.

- What do you see as the major gaps in policies, supports, and services for people with developmental disabilities? Please describe.
- How do you see those gaps being addressed?
- What is your agency's/program's role in addressing those gaps?
- What role do you see ADD playing in addressing those gaps?

Closing Remarks

- Are there additional roles or activities you see for ADD? Please describe.
- We are finished with our questions. Is there anything else you'd like to tell us about your work for the developmental disability community and with ADD?

Thank you for your assistance.

Appendix AA4. National Disability Organizations

A NATIONAL INDEPENDENT STUDY OF THE STATE DEVELOPMENTAL DISABILITIES PROGRAMS

ADD ASSESSMENT

INTERVIEW GUIDE FOR NATIONAL DISABILITY ORGANIZATIONS

Introductory Remarks

- Background and purpose of National Independent Study and ADD Assessment
  - Phase 1 and Phase 2
  - Purpose of National Study – to conduct an independent study of the three national DD Network programs to assess program effectiveness and achievements.
  - ADD Assessment part of National Independent Study
  - Purpose of ADD Assessment - to examine the efficiency and effectiveness of ADD in accomplishing its mission as described in the DD Act.
- Purpose of this interview - To understand ADD's role in meeting the principles and goals of the DD Act
- Permission to record

Organization Mission

- To start out, would you please describe the mission of your organization and what it does?

  Probe:

  - Mission
  - Organizational structure – national/state/local
  - Description of membership
  - Other
- How does your specific role relate to people with developmental disabilities? Please describe.

Perception of ADD's Roles

- What roles do you see ADD playing within the developmental disabilities arena?

  Probe:

  - Supporting policy making at the Federal level
  - Providing leadership and direction to Federal agencies/departments on developmental disabilities
  - Contributing to setting a national direction or agenda on developmental disabilities
  - Administration of the Developmental Disabilities Act
    1. Awarding and announcing grants
    2. Monitoring the DD Network programs (DD Councils, P&As, UCEDDs)
    3. Ensuring work of the DD Network programs and Projects of National Significance (PNS) is efficient and effective.
  - Other

Interactions with ADD

Now we'd like to talk about how your organization interacts with ADD.

A. Policymaking at the Federal Level

- Are you or your organization involved in any way in development of Federal policy that would have an impact on people with developmental disabilities? Please describe.
- Probe:
  - Type of policy (e.g., disability-related; other)
  - How agency/program is involved
  - Other

- From your perspective, what has been ADD's role with respect to development of Federal policy on behalf of people with developmental disabilities? Please describe.

  Probe:

  - ☐ Keep up to date on DD issues
  - ☐ Prepare or contribute to reports, white papers
  - ☐ Attend Federal agency meetings
  - ☐ Host Federal agency meetings
  - ☐ Inform other Federal agencies about DD issues
  - ☐ Prepare drafts of legislative language
  - ☐ Comment on drafts of legislative language
  - ☐ Other

- Please take us through each task and activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Interaction with other Federal agencies
  - Interaction with national disability organizations
  - Interaction with DD Network programs
  - Interaction with people with developmental disabilities and family members
  - Follow up
  - Report write-up
  - Other

B. Establishing a National Direction and Setting an Agenda for the Developmental Disabilities Field

- In the past (e.g., 5 years ago), was ADD involved in any way in the establishment of a national direction and setting an agenda for the developmental disabilities field? Please describe.

- Is ADD currently involved in the establishment of a national direction and setting an agenda for the developmental disabilities field? Please describe.

  Probe:

  - Process
  - National direction/agenda

- Is your organization involved in this function? Please describe.

- From your perspective, what does ADD do to establish a national direction and set an agenda for the developmental disabilities field?

  Probe:

  - ☐ Collaborate with other Federal agencies
  - ☐ Seek input from national disability organizations
  - ☐ Seek input from DD Network programs
  - ☐ Seek input from people with development disabilities or their families
  - ☐ Other

- Please take us through each activity to help us understand exactly what is involved.

  Probe:

  - Description of process
  - ADD staff involved
  - Follow up
  - Report write-up
  - Other

C. Disability-Related Committees

- Has anyone from your organization sat on any committees with ADD in the past 5 years? Please describe.

  Probe:

  - Name/type of committee
  - Role played by national disability organization
  - Role played by ADD and others on committee

- Committee products and outcomes
- ADD contributions
- Other

D. Joint Projects

- Have you or anyone from your organization been involved in any joint projects with ADD in the past 5 years? Please describe.

  Probe:

  - Nature of project
  - Role played by national disability organization
  - Role played by ADD and others
  - Products and outcomes
  - ADD contributions
  - Other

E. Other Interactions

- What other types of interactions have you had with ADD? Please describe.

  Probe:

  - Nature of interaction
  - Role played by national disability organization
  - Role played by ADD and others
  - Products and outcomes
  - ADD contributions
  - Other

Gaps in Policies, Supports and Services for People with Developmental Disabilities

Now we would like to ask some questions about what you think are the gaps in policies, supports and services for people with developmental disabilities and how ADD might be involved in addressing those gaps.

- What do you see as the major gaps in policies, supports, and services for people with developmental disabilities? Please describe.
- How do you see those gaps being addressed?
- What is your organization's role in addressing those gaps?
- What role do you see ADD playing in addressing those gaps?

Closing Remarks

- Are there additional roles or activities you see for ADD? Please describe.
- We are finished with our questions. Is there anything else you'd like to tell us about your work for the developmental disability community and with ADD?

Thank you for your assistance.

Appendix AA5. Projects of National Significance

A NATIONAL INDEPENDENT STUDY OF THE STATE DEVELOPMENTAL DISABILITIES PROGRAMS

ADD ASSESSMENT

INTERVIEW GUIDE FOR PROJECTS OF NATIONAL SIGNIFICANCE

Introductory Remarks

- Name of Interviewee:
- Background and purpose of National Independent Study and ADD Assessment
  - Phase 1 and Phase 2
  - Original purpose of National Study – to conduct an independent study of the three national DD Network programs to assess program effectiveness and achievements.
  - Addition of ADD Assessment to the National Independent Study
  - Purpose of ADD Assessment - to examine the efficiency and effectiveness of ADD in accomplishing its mission as described in the DD Act.
- Purpose of this interview

  To understand:
  - Role of projects of national significance play in meeting the goals of the DD Act and
  - What ADD does to facilitate that role.
- Confidentiality statement
- Permission to record

Description of the PNS

Note to interviewer: Prior to interview, interviewer must read background documents on the project.

1. Confirm name of project
2. Confirm category in which project belongs
   - ☐ Family Support Initiatives
     - ☐ Emergency Preparedness Special Initiation
     - ☐ Family Support and Community Access Demonstrations
   - ☐ National Autism Resource and Information Center
   - ☐ Voting Project
   - ☐ PNS Family Support 360
     - ☐ Non-Military
     - ☐ Military
   - ☐ Youth Information, Training, and Resource Center Grants
   - ☐ Medicaid Reference Desk
   - ☐ Ongoing Data Collection and Information Dissemination
3. Please describe your project.

   Probe:

   - Purpose of project
   - Target population
   - Objectives
   - Procedures
   - Status
   - Findings to date (if appropriate)

4. Please describe what you believe is the role of the Projects of National Significance in helping ADD meet the goals and objectives of the DD Act.

   Probe:

   - Role of all projects of national significance
   - This project

5. Please describe the selection process for your PNS.

   Probe:

   - ADD process
   - Previous (or concurrent) experience with PNS applications and projects
   - Distinguishing factors in your application
   - Discussions with ADD regarding your application
   - Other

A. Interactions with ADD: Monitoring and Evaluation of the PNS

6. We would like to discuss specific types of interactions you have with ADD. We'll start with **ADD monitoring and evaluation**. Please describe how ADD monitors your project.

   Probe:

   - Type of ADD monitoring (e.g., in person on site; written communications; telephone, email, and other electronic communications; monthly/quarterly reports)
   - Purpose of the monitoring interactions
   - Frequency of the monitoring interactions
   - Process you follow
   - ADD Follow up

7. Which type(s) of interactions for purposes of monitoring would you say are the most beneficial in helping you meet the goals and objectives of your project? Please explain.

   Probe:

   - Examples
   - What works

8. Which interactions would you say are the least beneficial? Please explain.

   Probe:

   - Examples
   - What doesn't work

9. What changes would you like to see in your monitoring interactions with ADD? Please describe.

   Probe:

   - Structures that need to be in place
   - New/different/revised processes
   - ADD followup
   - Other

10. How would you describe the level of effort you expend in monitoring interactions with ADD? Please explain.

    ☐ Expend the right amount of effort, no change needed

    ☐ Need to spend more time interacting with ADD

    ☐ Need to spend less time interacting with ADD

B. Interactions with ADD: Technical Assistance

11. Please describe how ADD provides or supports technical assistance for your project.

    Probe:

    - Content
    - Format (e.g., in person, on-site; webinars; telephone, email)
    - Purpose of the technical assistance
    - Frequency of the technical assistance
    - ADD follow up

12. Which type(s) of technical assistance would you say are the most beneficial in helping you meet the goals and objectives of your PNS? Please explain.

    Probe:

    - Examples
    - What works

13. Which type(s) of technical assistance would you say are the least beneficial? Please explain.

    Probe:

    - Examples
    - What doesn't work

14. How would you rate the quality of the technical assistance ADD supports or provides for the PNS? Please explain.

    ☐ All technical assistance is of high quality

    ☐ Most technical assistance is of high quality

    ☐ Only some of the technical assistance is of high quality

    ☐ None of the technical assistance is of high quality

15. What changes would you like ADD to make in the technical assistance it supports or provides for your project? Please describe.

    Probe:

    - Structures that need to be in place
    - New/different/revised processes in identifying technical assistance that needs to be provided
    - Format
    - Contractors used (if appropriate)
    - Other

16. How would you describe the level of effort you expend in technical assistance activities supported or provided by ADD.? Please explain.

    ☐ Expend the right amount of effort, no change needed

    ☐ Need to spend more time on technical assistance activities

    ☐ Need to spend less time on technical assistance activities

C. Other ADD Initiatives and Programs

17. How familiar are you with other ADD initiatives and programs?

    ☐ Very familiar

    ☐ Somewhat familiar

    ☐ Not familiar at all

18. As a Project of National Significance, please describe what kind of interactions you have had with other ADD initiatives and programs?

    Probe:

    - Focus of interactions including other initiatives and programs involved in the interactions
    - Purpose of the interactions
    - Frequency of the interactions
    - Process you follow
    - Outcomes of the interactions
    - Not applicable; no interactions

19. How would you rate the value of the interactions with other ADD initiatives and programs in terms of helping you meet the goals and objectives of your project? Please explain.

    ☐ Very valuable

    ☐ Somewhat valuable

    ☐ Not valuable at all

    ☐ Not applicable; no interactions

20. How would you describe the level of effort you expend in interacting with other ADD initiative and programs? Please explain.

    ☐ Expend the right amount of effort, no change needed

    ☐ Need to spend more time interacting with other ADD initiatives and programs

    ☐ Need to spend less time interacting with other ADD initiatives and programs

E. ADD Roles and Responsibilities

21. What do you see as the roles and responsibilities of ADD with regard to your project?

22. How would you describe your satisfaction with how well ADD is meeting its responsibilities to those roles? Please explain.

    ☐ Satisfied with how well ADD is meeting all of its responsibilities

    ☐ Satisfied with how well ADD is meeting some of its responsibilities

    ☐ Not at all satisfied with how ADD is meeting its responsibilities

    ☐ Cannot answer; not familiar enough with ADD roles or its responsibilities in those roles

    ☐ Cannot answer; not familiar enough with how ADD is meeting its responsibilities in the roles it has

23. What do you see as the barriers that impede the efficiency and effectives of interactions between ADD and your project? Please describe.

24. What do you see as the factors that facilitate the efficiency and effectiveness of interactions between ADD and your project? Please describe.

25. What would you like ADD to do to help your project meet its goals and objectives? Please describe.

Closing Remarks

26. Do you have any suggestions to offer to ADD to make Projects of National Significance more relevant and useful to meeting the goals of the DD Act?

    Probe:

    - Identification of PNS categories
    - Application process
    - Selection process
    - Monitoring PNS projects
    - Technical Assistance
    - Involvement of the PNS with other ADD initiatives and programs
    - Other

27. We are finished with our questions. Is there anything else you'd like to tell us about your work with ADD?

Thank you for taking the time to answer our question

Appendix BB. Email to Stakeholders Requesting Participation

Email to ADD staff

Dear ...

As you may know, the Administration on Developmental Disabilities is conducting a National Independent Study of the Administration on Developmental Disabilities Programs. Begun as the Developmental Disabilities Program Independent Evaluation (DDPIE) to measure DD Network program impact, the project has been re-conceptualized by Commissioner Lewis to demonstrate program achievements and effectiveness and expanded to include an assessment of the Administration on Developmental Disabilities (ADD). ADD has engaged Westat, a private research company, to conduct the National Independent Study and the ADD Assessment.

Part of the process of the ADD Assessment is to seek feedback from ADD staff on what you do as a staff member, how you do it, and changes you think should be made to improve ADD efficiency and effectiveness. The purpose of this email is to arrange a telephone interview with you.
I would appreciate it if you would let me know your availability over the next two weeks [GIVE DATES] so we can arrange an interview. The interview will last about 30 – 45 minutes. Please be assured that all information will be confidential, and no one will be identified in any reporting that takes place for this study.

If you have any questions about the National Independent Study or the interview, please feel free to contact me or Dr. Lynn Elinson, who is the study project director (lynnelinson@westat.com or 412 421-8610). I look forward to speaking with you and learning about the important work that you do.

Sincerely,

Gerri Kochan

Cc: Lynn Elinson
Linda Lynch
Ophelia McClain or Jennifer Johnson

Email to national disability organizations

Dear ...

The Administration on Developmental Disabilities (ADD) is conducting a National Independent Study of the ADD Programs. The study includes an assessment of the ADD itself. ADD has engaged Westat, a private research company, to conduct the National Independent Study and the ADD Assessment. The purpose of this email is to tell you about the study and to seek your organization's participation.

The ADD Assessment includes the collection of data from representatives from a variety of stakeholders and partners, including national disability organizations like yours. I would like to invite you, or someone you designate in your organization, to provide us with feedback on ADD's role in meeting the goals of the Developmental Disabilities Act by participating in a short 15-20 minute telephone interview. Participation is voluntary. All information will remain confidential, and you and your organization will not be named in any reports to ADD.

I am attaching a brief summary of the National Independent Study. If you have any questions about the study, please feel free to contact me (CONTACT INFORMATION) or Dr. Lynn Elinson, Project Director (1-800-937-8281, ext. 5844, or lynnelinson@westat.com).

Your organization's perspective will be very important to this study, and we welcome your participation. If you agree to participate, please let me know who to contact to arrange a convenient time to talk with you. If you think that there is another person at your organization that would be more appropriate to speak with, please forward this person's contact information to me.

We look forward to learning more about your organization.

Sincerely,

Gerri and Lareissa

cc: Lynn Elinson, Ph.D.

Attachment

DRAFT

Email to National network disability organizations

Dear ...

As you know, the Administration on Developmental Disabilities (ADD) is conducting a National Independent Study of the ADD programs. In addition to the study of DD Network programs, the study now also includes an assessment of the ADD itself. The purpose of this email is to tell you a little more about the ADD assessment and to seek your participation in the ADD assessment component.

The ADD Assessment includes the collection of data from representatives from a variety of stakeholders and partners, including ADD staff, Federal partner agencies and programs, national disability organizations, and program executive directors. I would like to invite you to participate in a 30-minute telephone interview in order to provide us with feedback on your organization's interaction with ADD, ADD's role in the developmental disability community, and specifically on issues related to technical assistance. Participation is voluntary. All information will remain confidential, and you and your organization will not be named in any reports to ADD.

I am attaching a brief summary of the National Independent Study. If you have any questions about the study, please feel free to contact me (CONTACT INFORMATION) or Dr. Lynn Elinson, Project Director (1-800-937-8281, ext. 5844, or lynnelinson@westat.com).

Your perspective will be very important to this study, and we welcome your participation. If you agree to participate, please let me know who to contact to arrange a convenient time to talk with you.

I look forward to our discussion.

Sincerely,

Karen Stewart

cc: Lynn Elinson, Ph.D.

Attachment

Email to Projects of National Significance

Dear ...

The Administration on Developmental Disabilities (ADD) is conducting a National Independent Study of the ADD Programs. The study includes an assessment of the ADD itself. ADD has engaged Westat, a private research company, to conduct the National Independent Study and the ADD Assessment. The purpose of this email is to tell you about the study and to seek your participation.

The ADD Assessment includes the collection of data from representatives from a variety of stakeholders and partners, including Projects of National Significance grantees. I would like to invite you, or someone you designate from this project, to provide us with feedback on the role of Projects of National Significance in meeting the goals of the Developmental Disabilities Act and what ADD does to support you in conducting your project. We would like to conduct a short 20-30 minute telephone interview. Participation is voluntary. All information will remain confidential, and you and your project will not be named in any reports to ADD.

I am attaching a brief summary of the National Independent Study. If you have any questions about the study, please feel free to contact me (CONTACT INFORMATION) or Dr. Lynn Elinson, Project Director (1-800-937-8281, ext. 5844, or lynnelinson@westat.com).

Information about your project will be very important to this study, and we welcome your participation. If you agree to participate, please let me know whom to contact to arrange a convenient time to talk with you. If you think that there is another person on your project with whom it would be more appropriate to speak, please forward this person's contact information to me.

We look forward to learning more about your Project of National Significance.

Sincerely,

[name of Interviewer]

cc: Lynn Elinson, Ph.D.

Attachment

Email to Federal agencies/programs

Dear ...

The Administration on Developmental Disabilities (ADD) is conducting a National Independent Study of the ADD Programs. The study includes an assessment of the ADD itself. ADD has engaged Westat, a private research company, to conduct the National Independent Study and the ADD Assessment. The purpose of this email is to tell you about the study and to seek your agency's/program's participation.

The ADD Assessment includes the collection of data from representatives from a variety of stakeholders and partners, including Federal partners. I would like to invite you, or someone you designate in your agency/program, to provide us with feedback on ADD's role in meeting the goals of the Developmental Disabilities Act by participating in a short 15-20 minute telephone interview.

I am attaching a brief summary of the National Independent Study. If you have any questions about the study, please feel free to contact me (CONTACT INFORMATION) or Dr. Lynn Elinson, Project Director (1-800-937-8281, ext. 5844, or lynnelinson@westat.com).

Information about your agency/program will be very important to this study, and we welcome your participation. If you agree to participate, please let me know who to contact to arrange a convenient time to talk with you. If you think that there is another person in your agency/program that would be more appropriate to speak with, please forward this person's contact information to me.

We look forward to learning more about your agency/program and its interaction with ADD.

Sincerely,

[name of Interviewer]

cc: Lynn Elinson, Ph.D.

Attachment

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Appendix CC. Web Survey Findings – National Independent Study Participants Only

Roles

	Study participants							All EDs						
Question/program	N	Yes	No	DK	Total	% yes	% DK	N	Yes	No	DK	Total	% yes	% DK
Q1a														
SCDD	16	12	3	1	16	75.0	6.2	44	38	4	2	44	86.4	4.5
P&A	13	11	2	0	13	84.6	0.0	40	36	2	2	40	90.0	5.0
UCEDD	17	15	1	1	17	88.2	5.9	45	40	2	3	45	88.9	6.7
Total	46	38	6	2	46	82.6	4.3	129	114	8	7	129	88.4	5.4
Q2a - Impose enforcement measures - a role?														
SCDD	16	4	5	7	16	25.0	43.8	44	19	8	17	44	43.2	38.6
P&A	13	5	4	4	13	38.5	30.8	40	22	5	13	40	55.0	32.5
UCEDD	17	8	1	8	17	47.1	47.1	45	24	4	17	45	53.3	37.8
Total	46	17	10	19	46			129	65	17	47	129		
q3a - Assess impact of National DD Network on PWDD														
SCDD	16	10	3	3	16	62.5	18.8	44	32	6	6	44	72.7	13.6
P&A	13	8	4	1	13	61.5	7.7	40	29	5	6	40	72.5	12.5
UCEDD	17	16	1	0	17	94.1	0.0	45	42	2	1	45	93.3	4.4
Total	46	34	8	4	46	73.9	8.7	129	103	13	13	129	79.8	10.1
q4a - Assess impact of each state/territorial pgm on the state/territory														
SCDD	16	8	5	3	16	50.0	18.8	44	22	13	9	44	50.0	20.5
P&A	13	7	5	1	13	53.8	7.7	40	23	13	4	40	57.5	10.0
UCEDD	17	12	3	2	17	70.6	11.8	45	28	7	10	45	62.2	22.2
Total	46	27	13	6	46	58.7	13.0	129	73	33	23	129	56.6	17.8
q5a - Assess collective impact of network on state/territory in which located														
SCDD	16	8	5	3	16	50.0	18.8	44	21	15	8	44	47.7	18.2
P&A	13	8	5	0	13	61.5	0.0	40	24	11	5	40	60.0	12.5
UCEDD	17	15	0	2	17	88.2	11.8	45	30	6	9	45	66.7	20.0
Total	46	31	10	5	46	67.4	10.9	129	75	32	22	129	58.1	17.1
q6a - Articulate vision														
SCDD	16	9	4	3	16	56.3	18.8	44	29	11	4	44	65.9	9.1
P&A	13	8	3	2	13	61.5	15.4	40	30	7	3	40	75.0	7.5
UCEDD	17	13	3	1	17	76.5	5.9	45	37	4	4	45	82.2	8.9
Total	46	30	10	6	46	65.2	13.0	129	96	22	11	129	74.4	8.5
q7a - Set performance goals for three national programs														
SCDD	16	8	3	5	16	50.0	31.3	44	22	15	7	44	50.0	15.9
P&A	13	4	7	2	13	30.8	15.4	40	17	19	4	40	42.5	10.0
UCEDD	17	10	5	2	17	58.8	11.8	45	25	13	7	45	55.6	15.6
Total	46	22	15	9	46	47.8	19.6	129	64	47	18	129	49.6	14.0

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Appendix DD. Web Survey Questionnaire

A NATIONAL INDEPENDENT STUDY OF STATE DEVELOPMENTAL DISABILITIES PROGRAMS

(FORMERLY THE DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION OR DDPIE)

ADD ASSESSMENT EXECUTIVE DIRECTOR

QUESTIONNAIRE

June 6, 2010

Public reporting burden for this collection of information is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Completion of this questionnaire is voluntary. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: Administration on Developmental Disabilities, Administration for Children and Families, US Department of Health and Human Services, 370 L'Enfant Promenade, S.W., MAIL STOP: Humphrey Building, 405D, Washington, D.C. 20447 ATTN: PRA (0970-0372). Do not return the completed form to this address.

As an Executive Director of a state or territorial Developmental Disabilities (DD) program, you are an important source of information and advice for the Administration on Developmental Disabilities (ADD). We are asking for your opinions on ADD's roles, ADD activities, and interaction between your program and ADD. Questions on the Projects of National Significance are not included.

Please remember that completion of this questionnaire is voluntary and all your responses will remain confidential to the extent provided by law.

Definitions:

State level

- **State/territorial program: a single** DD Council, or P&A, or UCEDD program.
- **State/territorial network**: the DD Council, P&A, and UCEDD(s) collectively in a single state/territory.

National Level*

- **National DD Program**: there are 3 National DD programs: 1) all DD Councils, 2) all P&A's, and 3) all UCEDDs,
- **National DD Network**: all programs in all states and territories collectively.

* The Projects of National Significance and the national associations (NDRN, NACDD, AUCD) are NOT included in these definitions.

A. Section A: ADD's Roles

This first set of questions deals with ADD roles. Please tell us (a) whether each item below has been one of ADD's roles in the past 3 years and (b) how important you think that role is. **PLEASE CIRCLE 1 RESPONSE FOR QUESTION (a) AND (b).**

Role	(a) Has this been ADD's role in the past 3 years?	(b) How important do you think this role is?
1. Ensure state/territorial programs' compliance with the DD Act.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
2. Impose enforcement measures when a state/territorial program is out of compliance with the DD Act.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
3. Assess the impact of the National DD Network on people with developmental disabilities and their families.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
4. Assess the impact of each state/territorial program on the state/territory in which the program is located.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
5. Assess the collective impact of the state/territorial network on the state/territory in which the network is located.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
6. Articulate a vision for implementing the principles in the DD Act.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
7. Set performance goals for the three National DD programs.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4

Role	(a) Has this been ADD's role in the past 3 years?	(b) How important do you think this role is?
8. Assess the performance of each state/territorial program.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
9. Assess the performance of each of the National DD Programs.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
10. Advocate for the National DD Network.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
11. Participate with federal partners in national policy making on behalf of people with developmental disabilities and their families.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
12. Assist and/or intervene on behalf of a state/territorial program when needed.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
13. Represent the interests of state/territorial programs at national forums (e.g., federal task forces, interagency work groups, national meetings).	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
14. Enter into collegial relationships with a state/territorial program to work toward state, regional, and national improvements to services for people with developmental disabilities.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
15. Provide or support technical assistance to a state/territorial program. For example:	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4

Role	(a) Has this been ADD's role in the past 3 years?	(b) How important do you think this role is?
16. Conduct on-site technical assistance visits.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
17. Provide training on reporting requirements.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
18. Identify best practices.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
19. Monitor contracts with technical assistance providers.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
20. Generate opportunities for knowledge sharing among state/territorial programs.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
21. Fund the national organizations (NACDD, NDRN, AUCD) to provide technical assistance to state/territorial programs.	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
Other _____	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4
Other _____	Yes No Don't Know	Extremely important.....1 Important.....2 Somewhat important.....3 Not important.....4

22. Please provide any additional comments you have on ADD's role in the box below.

B. Section B: ADD Activities

You have given your opinion on ADD's roles. Now we would like you to consider ADD activities related to some of those roles. Please tell us:

(a) What is <u>your impression</u> of how important ADD considers each activity?

(b) How important do you consider each activity?

PLEASE CIRCLE 1 RESPONSE FOR QUESTION (a) AND (b).

Activities	(a) Importance to ADD (your impression)	(b) Importance to You
23. Establishes and implements reporting processes to monitor compliance with the DD Act.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4
24. Develops goals and expected outcomes for each National DD Program.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4
25. Assesses state/territorial program performance.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4

Activities	(a) Importance to ADD (your impression)	(b) Importance to You
26. Assesses performance of each National DD program.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4
27. Develops technical assistance plans to improve compliance with the DD Act.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4
28. Develops technical assistance plans to improve state/territorial program performance on achieving goals.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4
29. Learns about the details of your program.	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4
30. Organizes regional and national meetings to share knowledge and experience on specific issues (e.g., best practices).	Extremely important ..... 1 Important ..... 2 Somewhat important ..... 3 Not important 4	Extremely important .....1 Important .....2 Somewhat important .....3 Not important 4

31. Please provide any additional comments you have on ADD activities in the box below.

Section C: Interaction Between ADD and State/Territorial Programs

Please consider the interactions of the ADD with **YOUR** program. For each type of interaction, please tell us:

(a) Whether each interaction has occurred between **YOUR** program and ADD at least once in the past 3 years (yes or no); and

(b) How valuable this interaction is (or would be) to your program.

PLEASE CIRCLE 1 RESPONSE FOR QUESTION (a) AND (b).

Type of interaction	(a) Has occurred in past 3 years		(b) How valuable is or would this interaction be to your program ...
32. ADD provided feedback on your program's annual report.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
33. ADD provided technical assistance directly to your program.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
34. At least 1 of your staff, per year, participated in a technical assistance activity provided or supported by ADD.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
35. At least 1 person per year from your DD Council, Board, or Consumer Advisory Committee participated in a technical assistance meeting provided or supported by ADD.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
36. ADD participated in an MTARS visit to your program. (For this item only, consider the last 10 years.)	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
37. Your program contacted ADD for advice or information on a technical issue.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4

38. ADD sent at least one email bulletin on a national issue to your program.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
39. ADD provided feedback on the performance of your program.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4
40. ADD solicited and obtained input from your program on a developmental disabilities issue.	Yes	No	Extremely valuable.....1 Valuable.....2 Somewhat valuable .....3 Not valuable.....4

41. Please provide any additional comments you have on your program's interaction with ADD in the box below.

Section D. Additional Comments

42. What else would you like to see ADD do, or do more?

43. What would like to see ADD do less, or not at all?

Section E. Final Questions

44. Which DD Network program do you represent? **CHECK ONE BOX.**

- ☐ State Developmental Disabilities Council
- ☐ Protection and Advocacy System
- ☐ National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)

45. Was your program part of the sample of 19 states and 1 territory for the National Independent Study of the State Developmental Disabilities Programs (formerly known as the Developmental Disabilities Program Independent Evaluation or DDPIE)? **CHECK ONE BOX.**

☐ Yes

☐ No

Thank you for completing this questionnaire.
Please return the questionnaire to Westat in the return envelope.

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Appendix EE. Letter From ADD Commissioner to Executive Directors

Letter from Sharon Lewis about web-based survey

July XX, 2011

Dear Colleagues,

Many of you are aware of the National Independent Study of the Administration on Developmental Disabilities Programs. Begun as the Developmental Disabilities Program Independent Evaluation (DDPIE) to measure DD Network program impact, the project has been re-conceptualized to demonstrate program achievements and effectiveness and expanded to include an assessment of the Administration on Developmental Disabilities (ADD). Part of the process of the ADD Assessment is to seek feedback from DD Network Executive Directors on ADD's current and future roles in the developmental disabilities community and obtain recommendations on how ADD can better meet its goals under the Developmental Disabilities Act (DD Act).

The purpose of this letter is to let you know that you will soon be contacted by Westat to complete a web-based questionnaire as part of the ADD Assessment. The questionnaire was developed with assistance from three of your Executive Director colleagues and received a public review as part of the Office of Management and Budget (OMB) clearance process. The questionnaire and data collection effort were approved by OMB on _____ (OMB #_____). The questionnaire is expected to take no more than 1 hour to complete. All information will be confidential, and no one will be identified in any reporting that takes place.

Westat will be asking all Executive Directors to complete this questionnaire on a voluntary basis. Data will be incorporated into some sections of the National Study findings. In addition, the questionnaire will be analyzed on its own. This analysis will be particularly useful to ADD in helping to set the direction of the agency in working with the DD Network programs to meet all of our goals under the DD Act.

I want to again thank the DD Network programs for participating in the National Study and look forward to further information on the ways ADD can assist all programs into the future. Please do not hesitate to contact me with any questions or concerns on this study or any other matter.

Sincerely,

Sharon Lewis
Commissioner
Administration on Developmental Disabilities

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Appendix FF. Email to Executive Directors

Dear Mr./Ms./Dr. _____:

As followup to an email recently sent to you by Commissioner Sharon Lewis, I would like to invite you to complete a questionnaire on ADD's current and future roles in the developmental disabilities community and obtain recommendations on how ADD can better meet its goals under the Developmental Disabilities Act (DD Act).

The questionnaire was developed with assistance from three of your Executive Director colleagues and received a public review as part of the Office of Management and Budget (OMB) clearance process. The questionnaire and data collection effort were approved by OMB on 06/27/2011 (OMB # 0970-0372). The questionnaire is expected to take 60 minutes or less to complete. All information will be confidential, and no one will be identified in any reporting that takes place.

Completion of this questionnaire is voluntary. Data will be incorporated into some sections of the A National Independent Study of the State/Territorial Developmental Disabilities Programs findings. In addition, the questionnaire will be analyzed on its own. This analysis will be particularly useful to ADD in helping to set the direction of the agency in working with the DD Network programs to meet its goals under the DD Act.

Below you will find your username and a link to the questionnaire. To complete the questionnaire, please click on the following link: add final link here. We ask that you complete the questionnaire **by 08/05/2011**.

Login page: https://www.addsurvey.org/

PIN:

If you have any problems with this link or the PIN, or if you have any problems with the online questionnaire, please contact Amir Hassani ((AmirHassani@Westat.com or 240-453-2716).

If you have any questions regarding the content of the survey, please contact Lynn Elinson (lynnelinson@westat.com or 412 421-8610) or Martha Palan (marthapalan@westat.com or 401-289-0285) from Westat. IF YOU WOULD PREFER TO COMPLETE THIS QUESTIONNAIRE BY HAND, PLEASE LET US KNOW.

We appreciate you taking the time to complete this questionnaire.

The instructions for accessing and completing the survey are listed below.

Sincerely,

Lynn Elinson, Ph.D.
Instructions for ADD Web-based Survey

This questionnaire is web-based and should be completed electronically. However, if you prefer to complete it by hand, we will send you a hard copy of the survey. The questionnaire contains 38 questions and should take 60 minutes or less to complete. Some questions require brief, open-ended responses. For others, you will need to click the drop-down menu that corresponds to the question and select the desired response. Please be sure to provide a response for every question.

1. Go to this website to access the questionnaire: https://www.ADDSurvey.org (press CTRL and click on the link).

2. Click 'OK' on the Security Alert if you receive one.

3. Enter your Survey PIN and click Continue.

4. The first page contains a general introduction to the survey as well as definitions of key terms. After reading the screen, click Continue.

5. As you complete the questions on a page, click Continue to go to the next page of questions.

6. If you have completed some of the questions and want to stop and return at another time to finish, click Save and Continue Later. This will save your work.

7. If you want to go back a page on the survey, click Previous Page.

8. If you want to go back to the first page with the introduction and definitions, click Home.

9. Once you have completed all of the questions, click Submit Survey and your responses will be saved and sent to Westat. You will not be able to access the survey again after you submit the survey.

10. If you have not responded to all questions, the system will not let you submit the survey. You will be told which questions are incomplete.