National Independent Study of the Administration on Developmental Disabilities Programs

Final Report – Volume I

Contract No. HHSP23320095655WC
Task Order No. SP3337005T

Authors

Lynn Elinson
Martha B. Palan
Linda Lynch
Kathryn R. Caperna
Karen R. Stewart
Bibi V. Gollapudi
William D. Frey

December 2011

Prepared for:
Administration on Developmental Disabilities
200 Independent Avenue, SW
Washington, DC 20201

Prepared by:
Westat
1600 Research Boulevard
Rockville, Maryland 20850-3129
(301) 251-1500

Westat®

This page left blank intentionally.

Table of Contents

Chapter **Page**

Table

Figure

Exhibit

Part 1 – Appendices A through P

Appendix

Volume II. Part 2 – Appendices Q through FF

Appendix

This page left blank intentionally.

Executive Summary

1. Introduction

The National Independent Study of the Administration on Developmental Disabilities Programs[1] is a review of the three principal programs funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and administered by the Administration on Developmental Disabilities (ADD). The programs are State Developmental Disabilities Councils (SCDDs or Councils), the state Protection and Advocacy Systems (P&As), and the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs).[2] Each program includes at least one funded entity in each state and Federal territory. The study addressed three fundamental goals, mandated by the ADD: (1) development of standards and performance criteria for each program and collaboration among them, (2) a description of Developmental Disabilities (DD) Network program achievements viewed against the standards and performance criteria, and (3) an assessment of ADD effectiveness in assisting the programs in meeting their responsibilities under the DD Act.

The study was implemented in two phases. The goal of Phase 1 was to develop and pilot test data collection instruments and a methodology for data collection. Phase 1 also consisted of the development of working standards that were used to prepare the data collection instruments for Phase 2. Phase 2 consisted of an assessment of the three DD Network programs and collaboration among them. A sample of 19 states and one territory was selected (i.e., 60 programs) for participation in data collection. Findings were then used to return to the process of standards development. With the assistance of Draft Standards Panels, draft standards and performance criteria were developed and are submitted to ADD in this report.

The ADD assessment (Goal 3 above) was both qualitative and quantitative, consisting primarily of telephone interviews with ADD staff and stakeholders and a web-survey administered to executive directors of DD Network programs.

This report describes the study, achievements of the DD Network programs, findings from the ADD assessment, and Draft Standards and Performance Criteria. The report contains six chapters. Chapter 2 summarizes Phase 1 of the study and the development of a working version of standards

---

[1] The National Independent Study or National Study

[2] Projects of National Significance were not originally included in this study but were later added as part of the assessment of ADD.

and data collection instruments. Chapter 3 describes the program assessment activities in Phase 2 of the study—the methodology for data collection and the findings. Based on findings from program visits and interviews with key informants, as well as analysis of data from a self-administered questionnaire and review of program materials, an additional step took place to refine the working version of standards developed in Phase 1. The process for this further refinement, including the work of a Draft Standards Panel for each program and collaboration, is described in Chapter 4, along with the draft standards and performance criteria that were developed. Chapter 5 describes the methodology and findings of the ADD assessment.

Chapter 6 is a synthesis of all study findings. The synthesis is presented in four sections: (1) Achievements and effectiveness of the national DD Network programs; (2) Issues and challenges in developing final standards and performance criteria; (3) Effectiveness and Efficiency of the Administration on Developmental Disabilities; and (4) Recommendations.

2. Phase 1: Working Version of Standards and Performance Criteria

Phase 1 of this comprehensive study began with the review of background information on programs and consisted of numerous opportunities to obtain information and feedback from DD Network program executive directors, program staff, and other ADD stakeholders. Phase 1 activities included development of a framework for standards and a pilot study to test data collection materials and the methodology for assessing DD Network programs in Phase 2. Following the pilot study, Validation Panels met to review and confirm a working version of the standards that contained benchmarks, indicators, and performance standards. The benchmarks, indicators, and performance standards that were developed as a result of Validation Panel feedback were the basis for the data collection materials used in Phase 2.

3. Assessment of Programs and Collaboration Against Working Standards

Random Selection of States and Programs. Westat selected a systematic random sample of 19 states and one territory to participate in data collection. Among those states with more than one UCEDD, a single UCEDD was randomly selected. The selection process captured the expected variability among all programs; there was no intention to weight up to the general population of programs.

Data collection. Data collection consisted of program visits to each of the three programs in the randomly selected states and one territory, administration of tools developed in Phase 1, as well as the administration of an additional data collection instrument—a self-administered questionnaire (SAQ) to capture mostly quantitative data from DD Network programs. Westat also collected background materials on each program for review.

Westat conducted key informant interviews in person and by telephone. Executive directors and key staff were interviewed in person at all programs. State Council executive directors arranged interviews with the Chair and members of the Council, recipients of self-advocacy and leadership training; recipients of education and training intended to foster inclusion of people with developmental disabilities into the community; and a group of policy makers, stakeholders, and contractors (as appropriate) who collaborated with the State Council to meet a particular systems change goal. Westat also interviewed P&A governing board members, recipients of P&A community education, clients, and policymakers and collaborators who participated with the P&A in meeting a systemic advocacy goal. UCEDD directors arranged for Westat to interview Consumer Advisory Committee (CAC) members, current and former students, researchers and colleagues, and recipients of community services. All executive directors were interviewed on collaboration.

DD Network Program Achievements. The accomplishments and achievements of DD Network programs and collaboration among them are extensive and are described in detail in Section 3.4 of this report Across all sampled states, all programs have been able to set up structures and processes to reach program objectives (e.g., qualified and trained Council members, P&A governing board members who understand the issues surrounding developmental disabilities, and supports for Council and CAC members to be able to contribute at their maximum). Processes at all three programs consist of planning and priority setting and governance and management. Councils also provide self-advocacy and leadership training to people with developmental disabilities and family members and engage in a variety of activities in support of systems change (including the provision of testimony to legislators and other forms of legislator education). Councils reported a variety of systems change outcomes, achieved in collaboration with partners and collaborators, and were also able to show that individuals who participated in their self-advocacy and leadership activities went on to become Council members themselves and members of groups whose mission was to improve the quality of life of people with developmental disabilities.

All P&As conduct individual and systemic advocacy activities, intake and assistance to those who contact the P&A, and outreach and community education for people with developmental disabilities, family members, and the community at large (for the purposes of fostering self-advocacy and inclusion of people with developmental disabilities into the community). Across all P&As studied, the success rate in meeting client objectives among individual advocacy clients was 85.7 percent. P&As and their collaborators were also successful in achieving systemic advocacy outcomes.

All UCEDDs focus their efforts on the four core functions required in the DD Act—interdisciplinary pre-service preparation of students and fellows and continuing education; community services, basic and applied research, and dissemination. All produce research products, including research projects relevant to the developmental disabilities population, publications in peer-reviewed journals, presentations at meetings and conferences, and provision of public testimony. UCEDD outcomes consist of students who obtain positions that are expected to improve the quality of life for people with developmental disabilities or go on to further their education in a disability-related field.

All DD Network programs collaborate across the state with their sister agencies and were able to report common goals among the three DD Network programs. They also reported on a variety of collaborative efforts (e.g., brochures, workshops, conferences), as well as systems change outcomes that were typically achieved not only with collaboration among the three DD Network programs but also with a broad range of partners and other community collaborators.

4. A Refined Set of Standards and Performance Criteria

Phase 1 of this study consisted of the development of a working version of standards (see Chapter 2). Having had the opportunity to understand the extent to which the working standards were being met in the programs, Phase 2 consisted of further development of standards and performance criteria with panels of stakeholders using a consensual validation process.

Validation Process. The validation process consisted of the following steps: (1) establish panels; (2) develop Version 1 of the draft standards based on data collection findings; (3) panel member review, rating, and comment on Version 1 of the draft standards; (4) develop Version 2 based on panel ratings, comments, and suggestions; (5) panel member review, rating, and comment on Version 2 of the Draft Standards; and (6) develop Version 3 based on panel ratings, comments, and suggestions.

Westat established specific rules for developing new versions of standards and performance criteria. For example, in the case of the SCDD standards, if 65 percent or more (17+) of panel members agreed with a standard, the standard remained.

Result of Validation Process. Version 3 of draft standards and performance criteria is provided in Appendix Y. Version 3 for SCDDs addresses the functions of planning, self-advocacy and leadership development, development of community capacity, systems change, and governance and management. Four out of seven of the standards can be characterized as outcome standards (standards that apply to the achievement of goals).

Version 3 of the draft standards and performance criteria for P&As contains 13 draft standards and 42 performance criteria. Throughout this study, the P&As have been particularly vocal about the importance of standards that address outcomes and much less interested in standards related to process. The majority of draft standards focus on an outcome. Many of the performance criteria required to meet the standards, agreed upon by the P&A Draft Standards Panel, are structures, processes, or outputs.

Version 3 of the UCEDD Draft Standards and Performance Criteria contains nine standards, reduced from the original 12 draft standards in Version 1. Version 1 also contained 69 performance criteria. The number was cut by 60 percent in Version 3 to 30. Three out of the nine draft standards are outcome standards.

There is one draft standard and five performance criteria for collaboration in Version 3. The draft standard states “All DD Network programs in the state or territory achieve one or more common goals through collaboration.”

5. ADD Assessment

The purpose of the ADD assessment was to better understand “how ADD supports the grantees in achieving the purposes of the Act,” as well as to examine ADD’s efficiency and effectiveness in supporting the DD Network programs (Appendix J).

The assessment of ADD was both qualitative and quantitative. The ADD Commissioner and ADD staff were interviewed and asked about the roles ADD currently play and the roles it played in the past, as well as the structures and processes ADD currently undertakes to implement those roles. Stakeholders (Federal disability partners, national developmental disability organizations, the national associations for the DD Network programs) were asked about ADD's place in the Federal disability community and the community at large. Information was also gathered on ADD selection and monitoring of Projects of National Significance (PNS). Using a web survey methodology, Westat also collected quantitative data from DD Network program executive directors to examine issues related to ADD's roles, activities, and performance.

There appeared to be agreement among ADD staff and stakeholders (including DD Network program directors) that ADD in the past focused primarily on its monitoring and compliance role with regard to DD Network programs. Whether for reasons of staff size and complement, staff knowledge, or basic infrastructure impediments, the leadership and Federal agency role, policy development, and promotion of a vision for meeting the principles and goals of the DD Act were all reported to have taken a backseat to monitoring compliance with the requirements of the DD Act. This appears to be changing, at least according to feedback we received from ADD stakeholders and DD Network program directors. There also appears to be strong agreement that new leadership at ADD is moving in the direction of Federal policy making and leadership for the DD Network programs and the developmental disabilities community in general, as well as an open approach to communication with stakeholders.

Programs appeared to be looking to ADD to meet its accountability and oversight obligations. However, they were not satisfied with the methods that have been used in the past (e.g., yearly reports and feedback on those reports, MTARS visits, and the National Independent Study). DD Network programs see the importance of ADD's monitoring role and the usefulness of the development of performance standards. They appear open to receiving assistance from ADD in measuring such standards. Moreover, they were open to ADD taking on roles it had not been filling in the past—particularly, Federal policy making and the articulation of a vision for the system.

6. Implications of Study Findings and Recommendations

The description of program achievements within the context of the draft standards and performance criteria provide a general framework for national DD Network program functioning. For the most part, DD Network programs are meeting most of the standards laid out in Version 3. However, as a performance-based accountability tool, we believe that more work is needed to make these draft standards more useful to ADD and the programs themselves. Several issues will need to be addressed, including:

Formatting and characterizing standards. Throughout this study, Westat tested different standards-related terminologies and hierarchies. We started with the development of "benchmarks, indicators, and performance standards," and ended with "draft standards and performance criteria." We have no preference for one format approach over another, although the second appears to be more compact. Whatever format is used, however, we think it is critical that the final standards and performance criteria that are developed contain language that will call for specific expectations to be met at specific levels.

Qualitative versus quantitative standards. The goal of this study was to develop qualitative performance standards based on narrative descriptions. Such standards seem entirely appropriate given the nature of the programs, which are given considerable latitude in how each one meets the principles and goals of the DD Act. However, because the draft standards with their accompanying criteria do not provide the specific expectations that must be met to be appraised at a particular level of performance, they fall short of providing ADD with information to know whether the achievements of the programs are adequate.

Only ADD can set the criteria to decide whether the achievements of the DD network programs are good enough (reach a specific standard). In their current qualitative form, the standards and criteria do not do that.

Process of criteria development. ADD should not expect or even attempt to obtain complete agreement among all executive directors and other stakeholders on specifications for performance criteria. All have different perspectives, and if all were able to come to an agreement on the level at which standards should be met, one can only assume that the standards would be very low indeed and not likely very useful for program improvement purposes. Finally, it will never be possible to obtain perfect standards and performance criteria. ADD should be prepared to set standards and performance criteria quickly and change them if they do not appear to be as useful as hoped.

Process versus outcome standards. During the development of standards for each of the national DD Network programs, there was considerable discussion about the type of standards that should be developed. The statement of work for this study required a framework of structural, process, output, and outcome indicators for measurement of standards. However, feedback from program staff and other stakeholders was that national standards should primarily consist of outcome standards. Stakeholders were less interested in the structures and processes set up to achieve goals or the number of outputs (products) along the way. Their primary interest was the nature and extent to which program goals were achieved and the outcome standards that applied to the achievement of goals.

We are in general agreement with these stakeholders and believe that many national standards and performance criteria should be focusing on outcomes. Measuring outcomes, however, requires a rigorous approach to data collection which can be burdensome to programs with small staff and little expertise in evaluation or measurement. Therefore, we also believe there is a place for processes and outputs in national DD Network program standards (see below).

National standards. It was always the intent of this project to develop national DD Network program standards and performance criteria (also referred to as "system-wide standards") and not standards and performance criteria for individual programs in each state. The expectation was that we would develop national standards and performance criteria that would address expectations for the national SCDD network, the national P&A system, and the national network of UCEDDs. Although individual programs might want to use these standards to assess their own work, it was never ADD's plan to measure or report on the individual programs against these standards.

As they appear now, the national draft standards in Appendix Y consist of a separate set of standards for Councils, P&As, UCEDDs, and collaboration among the three programs. As ADD works with programs and other stakeholders to finalize these standards and performance criteria, we recommend that ADD focus on the key functions and type of standard presented in Table 1. The rationale for this approach is discussed in Section 6.2.5 for each DD Network program. Corresponding recommendations are provided in Section 6.4.

Table 1. Key function and type of national standards and performance recommended criteria for each DD Network Program

DD Councils	P&As	UCEDDs
▪ State Plan Development* ▪ Self-advocacy and Leadership** ▪ Systems Change**	▪ Planning and Priority Setting* ▪ Individual Advocacy** ▪ Systemic Advocacy** ▪ Outreach and Public Education*** ▪ Information and Referral*	▪ 5-year planning* ▪ Interdisciplinary pre-service preparation and continuing education** ▪ Basic and/or applied research*** ▪ Community services*** ▪ Dissemination of information*

*Process standards

**Outcome standards

***Outputs

Measurement of individual programs. The purpose of examining individual DD Network programs is to monitor compliance with DD Act requirements and measure the efficiency and effectiveness of each program. ADD currently uses the Performance Progress Report (PPR), annual report, and the Monitoring and Technical Assistance Review System (MTARS) as monitoring tools for individual programs. These tools examine compliance and all functions of DD Network programs. MTARS is also used to identify areas in which technical assistance may be needed by individual programs. The measurement of individual programs was not the focus of the National Independent Study. Nevertheless, our observations over the years and feedback from a variety of stakeholders form the underpinning of the following comments on individual program measurement.

- It is just as important to assess the quality and effectiveness of individual programs according to pre-defined standards as it is for the national DD Network programs as a whole.
- Unlike the national standards described above, it may be more appropriate to address individual program achievement with structural, process, and output standards instead of outcome standards.
- Structural, process, and output standards could be measured yearly (e.g., through yearly reports).
- If quantitative performance criteria are developed, then performance of all programs can be more easily rolled up to the national level.
- ADD needs to re-vamp the annual report so that programs can be assessed in a way that is useful to ADD and less burdensome for the programs.

- To reduce the burden placed on all programs, we recommend that ADD restrict its yearly progress reports to measures that can be easily and quickly captured by programs (see Section 6.2.6 and Table 6-2).
- The process for the assessment of yearly progress also needs to have a followup component. This followup component needs to include careful assessment by ADD staff of DD Network program annual reports, provision of feedback to programs, and the planning of technical assistance with the program, as appropriate.
- If individual program standards are developed and measured yearly, and appropriate followup is maintained, then the purpose of MTARS as a monitoring tool is partially being met. Thus, we do not think the expensive and time-consuming MTARS process needs to be continued as it currently exists.

Attribution. One of the cornerstones of DD Network activity, particularly as it relates to systems change efforts, is collaboration with partners who share the same basic goals of independence, inclusion and access to services for people with disabilities. Whereas collaboration is a powerful tool for meeting systems change objectives, such collaboration makes it difficult, without a rigorous research design (such as a randomized controlled trial) to attribute successes in systems change to a particular organization. Such a design would be inappropriate for ADD to undertake for a variety of reasons, and we do not recommend it. However, we do recommend that ADD require the reporting of systems change outcomes to include clear descriptions of the partners that participate in systems change efforts and the role each one plays.

7. Recommendations to ADD

We offer six types of recommendations to ADD—recommendations on: (1) the process for producing final standards; (2) national SCDD standards; (3) national P&A standards; (4) national UCEDD standards; (5) measurement of individual programs; and (6) ADD's future role.

7.1 Process for Producing Final National Standards

1. Move forward immediately to finalize the specific standards for each program that will provide ADD with the performance-based data it needs for good management and accountability.
2. As part of the process for finalizing standards and performance criteria, ADD should take advantage of earlier versions of draft standards that may prove to be useful.

3. Set standards that give clear and specific expectations that can be measured to determine the extent to which those expectations are reached or exceeded.

4. Just set some levels and see how it goes.

5. Finalize separate national standards for each of the three DD Network programs with the understanding that:

    a. The standards focus primarily on outcomes, with some process and output standards, as appropriate;

    b. Measurement of the achievement of national standards is conducted approximately every 5 years (i.e., not yearly) using a rigorous measurement methodology;

    c. Structural, process, and output indicators are reserved primarily for individual program performance that should be measured more frequently than national standards; and

    d. Programs will receive resources and technical assistance from ADD to conduct data collection for measuring the extent to which national standards are achieved.

7.2 Recommendations for State Councils on Developmental Disabilities

6. Finalize national standards for State Councils on Developmental Disabilities on three functions: (1) development of a 5-year State Plan; (2) the conduct of systems change activities for achieving changes to systems and community practice; and (3) the conduct of self-advocacy and leadership activities for people with developmental disabilities and family members.

7. Finalize process standards for Council development of a 5-year State plan.

    The following are examples of process standard performance criteria for the SCDD 5-year State Plan:

    – Collection of 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.

    – Use of 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.

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

8. Finalize outcome standards for self-advocacy and leadership.

Outcomes for self-advocacy and leadership appear particularly critical to understanding the effectiveness of Councils. Thus, we recommend that ADD use outcome standards for this function. Examples of outcome standards for self-advocacy and leadership are:

- Promotion of 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.

- Documentation that participants in self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities (e.g., 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).

9. Conduct a system-wide evaluation of Partners in Policymaking to determine whether such a program should become part of a national self-advocacy and leadership standard.

10. In measuring outcomes for systems change, use a multi-method measurement approach that puts as much responsibility on ADD as the program.

    - Prior to a site visit, obtain written information on the specific systems change issues being addressed (issue; short-term and long-term goals; strategies; summary of activities since last visit; summary of activities in past year; staffing, partners and collaborators and each one's role; short-term; interim; and long-term outcomes (if any).

    - Organize individual and group meetings with those with key roles in SCDD systems change activities. Individual meetings will take place with key staff members to ascertain their role, responsibilities, and activities that have taken place and to clarify issues that come up in reading background material. The group meeting will consist of key staff and partners to understand the roles and responsibilities of all players and the short-term, interim, and long-term goals that have been met.

    - After the site visit, summarize findings and conclusions. The result of this process should be able to ascertain:

        a. Clear and well-defined systems change goals,

        b. Clear and well-defined responsibilities among staff and partner collaborators,

        c. Achievement of stated goals (short-term, interim, and long-term, if appropriate), and

d. Plans for meeting future goals.

7.3 Recommendations for the Protection and Advocacy System

11. Focus national standards for the Protection and Advocacy System on three functions: (1) intake and provision of assistance to those who contact the P&A; (2) individual advocacy; and (3) systemic advocacy.

12. Finalize process standards for the P&A intake and assistance function that underscore the assurance that no one gets turned away due to language, cultural or disability barriers.

    We recommend that ADD establish structural, process, and output standards and performance criteria for P&As that require:

    – Availability of resources to ensure staff is able to communicate with any person who contacts the P&A and any client whose case is taken,

    – Provision of information on the grievance process in writing or other appropriate forms of communication to people with developmental disabilities whose case is turned down for individual advocacy, and clients whose case is closed, and

    – Use of a valid mechanism for gathering and assessing client feedback and satisfaction with P&A services.

13. Use a multi-method qualitative approach for measuring P&A systemic advocacy outcomes.

14. Produce a quantitative standard and performance criteria for individual advocacy that takes advantage of the measurement system in place at all P&As to record the outcome of each individual advocacy case (i.e., whether or not each issue addressed for a client has been resolved).

7.4 Recommendations for University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs)

15. Produce national standards for all four UCEDD core functions.

16. Establish and use process standards for UCEDD dissemination activities.

    Examples of process and output standards for dissemination are:

- Use of a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners,
- Provision of publications, materials and other resources in accessible formats, and
- Seeking input on materials and resources from people with developmental disabilities and family members.

17. With assistance from the UCEDDs and AUCD, finalize a clear definition of UCEDD-affiliated faculty and staff member and a UCEDD-affiliated student.

18. Finalize outcome standards and a process for measuring quantifiable outcomes of pre-service preparation and continuing education.

    The establishment of outcome standards for pre-service preparation and continuing education are expected to follow quickly once clear definitions of a UCEDD student and the outcomes of interest can be established. Examples of such standards are:

    - Interdisciplinary pre-service students who completed their course of study work to benefit and affect the quality of life of people with developmental disabilities.
    - Among those students who participated in a UCEDD-related program, disability is an important component of further education, career or their daily lives.

19. Finalize quantifiable output standards for UCEDD research activities.

20. Establish and measure structural and process standards for UCEDD community services.

7.5 Measurement of Individual Programs

21. Restrict yearly progress reports to the measurement of easily captured data that provide ADD with a quick snapshot of program status each year.

22. Examine individual program statistics within the context of individual program standards and follow up with programs to ascertain reasons for not meeting standards and technical assistance that may be required.

23. Revise or eliminate the MTARS process.

7.6 ADD's Future Role

24. Establish and maintain the ADD infrastructure required to expand ADD's role.

25. Coordinate and support the development, evaluation and dissemination of best practices for use by the DD Network programs and the developmental disabilities field.

This page left blank intentionally.

Introduction 1

The National Independent Study of the Administration on Developmental Disabilities Programs (The National Independent Study or National Study) is a review of the three principal programs funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and administered by the Administration on Developmental Disabilities (ADD). The programs include State Developmental Disabilities Councils (SCDDs or Councils), the state Protection and Advocacy Systems (P & As), and the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs). Each program includes at least one funded entity in each state and Federal territory. The study addressed three fundamental activities, mandated by the ADD: (1) development of standards and performance criteria for each program and collaboration among them, (2) a description of DD Network program achievements viewed against the standards and performance criteria, and (3) an assessment of ADD effectiveness in assisting the programs in meeting their responsibilities under the DD Act.

The study was implemented in two phases. The goal of Phase 1 was to develop and pilot test data collection instruments and a methodology for data collection. Phase 1 also consisted of the development of working standards that were used to prepare data collection instruments for Phase 2. Phase 2 consisted of an assessment of the three DD Network programs and collaboration among them. A sample of 19 states and one territory was selected (i.e., 60 programs) for participation in data collection. Findings were then used to return to the process of standards development. With the assistance of Draft Standards Panels, draft standards and performance criteria were developed and are submitted to ADD in this report.

The study was initiated in 2005. At that time, performance-based management and program accountability were becoming important accountability tools for all Federal agencies. As we complete this study in 2011, the desire for accountability and performance-based management is now even stronger. Government agencies are being asked not only to reduce their budgets by at least 5 percent below the 2011 enacted discretionary appropriation, but also to explain how they will "acquire, analyze, evaluate, and use data to improve policy and operationalize decisions" (Appendix

A).[3] Additionally, government agencies must reallocate and strengthen their "analytic and evaluation capacity to set outcome-focused priorities, identify the most effective and cost-effective practices and programs, and speed their adoption." Thus, the findings, conclusions, and recommendations in this Final Report will contribute to a path forward for ADD in performance-based management and accountability to its stakeholders.

ADD stakeholders are first and foremost comprised of people with developmental disabilities—the very people for whom the DD Act is intended to serve. It is the responsibility of ADD to ensure that the principles and goals in the Act are being met through the programs established in the DD Act—the Councils, P&As, and UCEDDs. Moreover, in addition to showing stakeholders that these principles and goals are being met, ADD also has a responsibility to assist these three programs (collectively referred to in this report as DD Network programs) in achieving these goals through technical assistance and other means.

ADD's original support for this study stems from accountability requirements set forth in the DD Act, the Government Performance and Results Act (GPRA) of 1993, and the Program Assessment Rating Tool (PART). The DD Act requires the DD Network to demonstrate that its work has resulted in self-determination, independence, productivity, integration, and inclusion in all facets of community life with increased choice, control, participation, access, and satisfaction among people with developmental disabilities and their families.

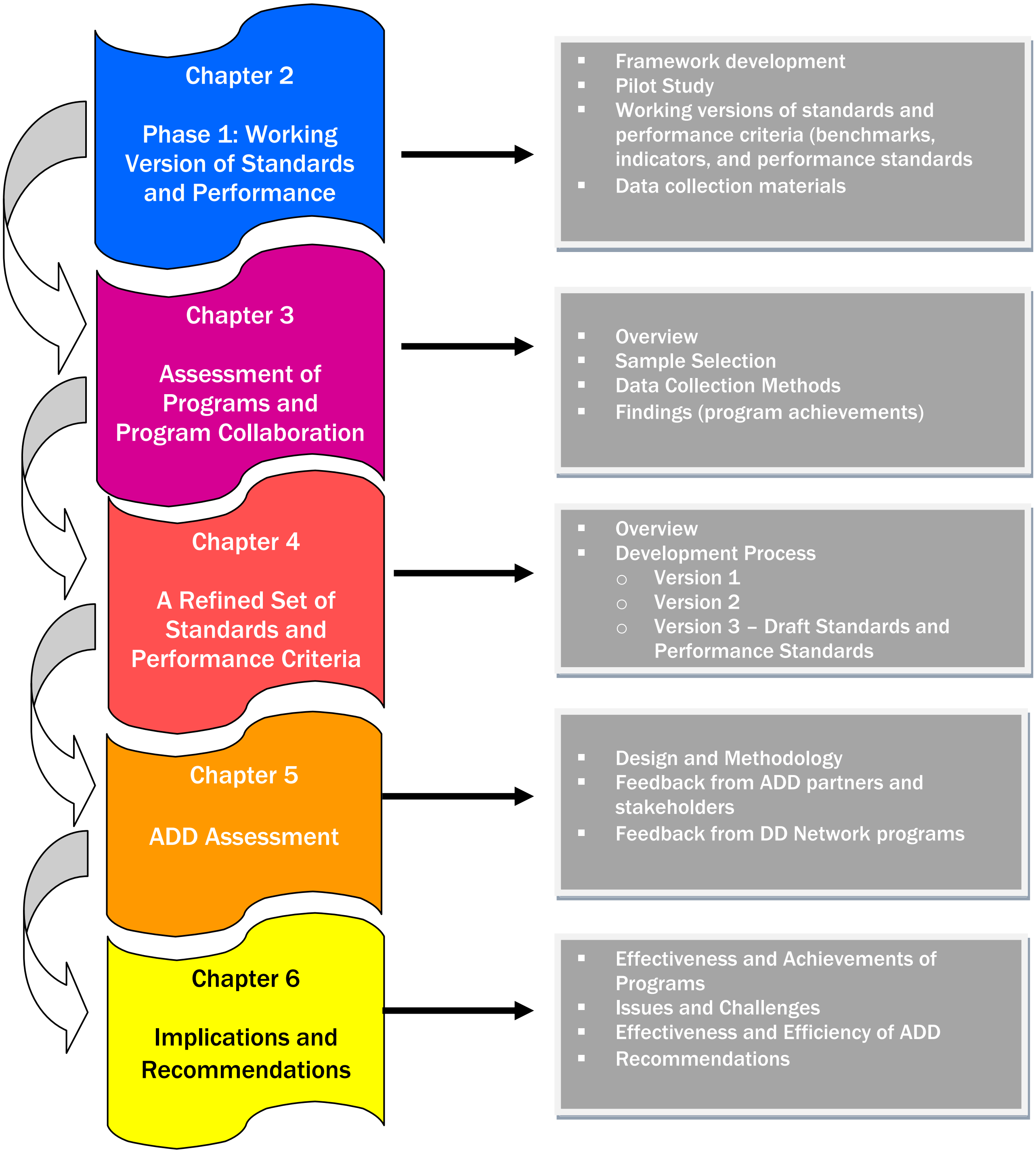
This report describes the study, achievements of the DD Network programs, findings from the ADD assessment, and Draft Standards and Performance Criteria. The report contains six chapters (Figure 1-1). Chapter 2 summarizes Phase 1 of the study and the development of a working version of standards. Chapter 3 describes the program assessment activities in Phase 2 of the study—the methodology for data collection and the findings. Based on findings from program visits and interviews with key informants, as well as analysis of data from a self-administered questionnaire and review of program materials, an additional step took place to refine the working version of standards developed in Phase 1. The process for this further refinement, including the work of a Draft Standards Panel for each program and collaboration, is described in Chapter 4, along with the draft standards and performance criteria that were developed. Chapter 5 describes the methodology and findings of the ADD assessment.

---

[3] Memorandum from Jacob J. Lew, Director of the Office of Management and Budget, to the Heads of Departments and Agencies, dated August 17, 2011 (Appendix A).

Chapter 6 is a synthesis of all study findings. The synthesis is presented in four sections: (1) Achievements and effectiveness and achievements of the national DD Network programs; (2) Issues and challenges in developing final standards and performance criteria; (3) Effectiveness and Efficiency of the Administration on Developmental Disabilities; and (4) Recommendations.

Figure 1-1. Report Overview



Chapter 2

Phase 1: Working Version of Standards and Performance

- Framework development
- Pilot Study
- Working versions of standards and performance criteria (benchmarks, indicators, and performance standards
- Data collection materials

Chapter 3

Assessment of Programs and Program Collaboration

- Overview
- Sample Selection
- Data Collection Methods
- Findings (program achievements)

Chapter 4

A Refined Set of Standards and Performance Criteria

- Overview
- Development Process
  - ○ Version 1
  - ○ Version 2
  - ○ Version 3 – Draft Standards and Performance Standards

Chapter 5

ADD Assessment

- Design and Methodology
- Feedback from ADD partners and stakeholders
- Feedback from DD Network programs

Chapter 6

Implications and Recommendations

- Effectiveness and Achievements of Programs
- Issues and Challenges
- Effectiveness and Efficiency of ADD
- Recommendations

Phase 1: Working Version of Standards and Performance Criteria

2

2.1 Overview

This chapter summarizes the work conducted in Phase 1 of the National Independent Study of the Administration on Developmental Disabilities Programs (the National Independent Study), which is fully described in the Phase 1 report to the Administration on Developmental Disabilities (ADD) (Elinson et al., 2008).

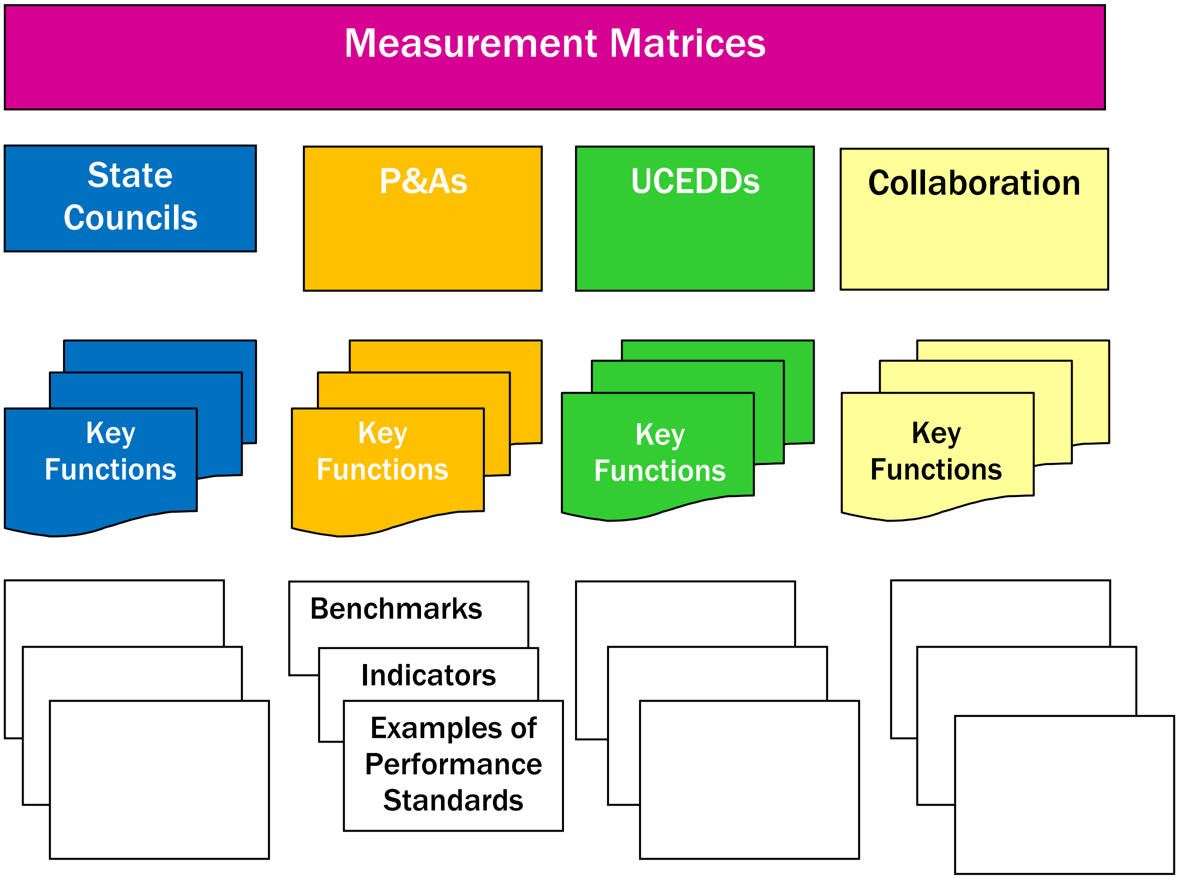
Phase 1 of this comprehensive study began with the review of background information on programs and consisted of numerous opportunities to obtain information and feedback from DD Network program executive directors, program staff, and other ADD stakeholders. Phase 1 activities included development of a framework for standards and a pilot study to test data collection materials and the methodology for assessing DD Network programs in Phase 2. Following the pilot study, Validation Panels met to review and confirm a working version of the standards that contained benchmarks, indicators, and performance standards. The benchmarks, indicators, and performance standards that were developed as a result of Validation Panel feedback were the basis for the data collection materials used in Phase 2.

2.2 Framework Development

To begin the study, Westat project staff accumulated and reviewed background documents on the ADD programs and related materials and conducted information-gathering interviews with key informants (the ADD commissioner, ADD staff and contractors, executive directors of national organizations, and DD Network program staff and stakeholders in one state). We also established an Advisory Panel that included people with developmental disabilities, family members, advocates, researchers, representatives from the DD Network programs and policy specialists. As a way of incorporating more program input into the process, ADD identified individuals working in DD Network programs. Westat organized and conducted P&A, Council, UCEDD and Collaboration Working Group meetings in person and by telephone and web cast throughout the spring, summer, and fall of 2006.

By the end of Year 1, Westat, with assistance from the Advisory Panel and Working Groups, had developed a framework for measurement (Figure 2-1). The framework was organized into matrices for each program and key functions[4] for each DD Network program. Within each key function, the framework consisted of benchmarks, indicators, and performance standards. Benchmarks were considered to be general standards or key expectations for each key function. Performance standards, more objectively defined than benchmarks, were statements of the expectations that DD Network programs should be achieving, doing, or having at a national level. Indicators were what would be measured to determine whether the benchmarks and performance standards were being met. Within this framework and these definitions, Westat developed draft measurement matrices to present to the three DD Network programs in person when they attended their annual meeting.

Figure 2-1. Framework for Standards and Performance Criteria: Benchmarks, Indicators, and Performance Standards Within Each Key Function Within Each DD Network Program



---

[4] Groups of activities that are implemented to achieve expected outcomes. All activities of DD Network programs should fall under one of the key functions.

2.3 Pilot Study

Based on comments and suggestions received from DD Network programs and the project's Advisory Panel, Westat developed pilot study questionnaires for assessing the three DD Network programs and collaboration among them. Data collection, which took place between January and April 2008, consisted primarily of semi-structured in-person individual and group key informant interviews and individual telephone interviews. In-person interviews were conducted during a 2-day program visit. Telephone interviews were scheduled in most cases after each program site visit. Questionnaires were administered by trained Westat staff to program personnel and members of program target audiences. Permission was requested from respondents to audio record all interviews. Recordings were transcribed after the site visit. In addition to data collection by interview, Westat also obtained a variety of materials from each of the programs participating in the pilot study for review.

2.4 Working Versions of Standards and Performance Criteria

Based on pilot study findings, project staff developed a working version of standards and performance criteria. We then convened three panels of experts (known as Validation Panels) to validate the performance standards that had been developed to date.

Advisory Panel members made recommendations to Westat on the membership of Validation Panels within three categories: (1) was a person with a developmental disability or family member; (2) was an advocate; and (3) had a familiarity with research and policy. In addition, panel members needed to have an understanding of the needs of people with developmental disabilities, an understanding of the purpose of the programs, an appreciation for outcomes, some involvement in the DD Network system, and a proven track record of self-advocacy (e.g., Council members; self-advocates outside the programs). Westat also obtained a mix of urban and rural representation, geographic representation, and senior and junior DD Network program staff. Each person that participated filled more than one category and criterion, and among the 25 Validation Panel members who participated, eight were self-advocates and two were family members. There were five executive directors of DD Network programs, a deputy director and three other program staff, as well as a P&A board member and six individuals representing outside organizations with policy or advocacy interest in developmental disability.

Validation Panel members met for two days in July, 2008. The meeting was devoted to commenting on benchmarks, indicators, and examples of performance standards and rating the importance of each indicator. Overall, the ratings demonstrated widespread agreement on the importance of a large number of indicators, with or without changes to wording. Based on these ratings, Westat revised the documents that had been given to the panel members (Appendix B).

The framework for the revised document was based on ADD's requirement to include structural, process, output, and outcome indicators. In this framework (Figure 2-2), **structures** (or inputs) are those resources that are needed to set processes in motion and keep them running (Katz, 1978; Miles, 1980; French & Bell, 1984). The structures in the system laid out by the DD Act consist of ADD, the three DD Network programs, Projects of National Significance,[5] and collaboration among the three programs. Each of these structures contains its own infrastructure (e.g., a governing board for P&As, a Consumer Advisory Committee for UCEDDs, funding, staff). Indicators were developed to measure DD Network programs, collaboration, and ADD structures.

Processes are those event sequences and arrangements of staff, services, and resources needed to achieve intended result(s) (e.g., processes that are set up to implement the activities of each DD Network component and their collaboration—for example, planning and priority setting, systemic advocacy, provision of training and technical assistance, dissemination of information) (Katz, 1978; Miles, 1980; French & Bell, 1984). When inputs are in place and processes are functioning as intended, then outputs and outcomes are produced. **Outputs**, often referred to as "products," are the "units" produced by processes supported by given inputs (Katz, 1978; Miles, 1980; French & Bell, 1984). Examples of outputs or products in this framework are informed decision makers, individual advocacy caseloads, education and training materials, and the common goals set jointly by the three DD Network programs for collaborative efforts.

Outcomes are the intended results of creating certain outputs or products. **Outcomes** represent the overarching goals of the DD Act. If the proposed pathway is correct, then the outputs become the inputs needed to produce the outcomes expected by the ADD-funded grant programs. There are two types of outcomes—short-term and intermediate/long-term. Examples of short-term outcomes for Councils are the results of systems change efforts (e.g., new/revised legislation) or self-advocates who participated in Council-supported self-advocacy and leadership activities participating in system

---

[5] Projects of National Significance were not originally included in the original study but were later added as part of the assessment of ADD.

Figure 2-2. Application of a structural, process, output and outcome model to the Developmental Disabilities Assistance and Bill of Rights Act of 2000

Structures (Inputs)	Processes	Outputs (Products)	Short-term Outcomes (target audience)	Long-term Outcomes (population)
1. Administrative office (ADD)	▪ Policy development ▪ Funding	▪ Programs ▪ Grantees ▪ Policies ▪ Leadership	▪ Effective programs ▪ Effective collaboration	• Access • Participation • Control • Informed choices • Employment • Improved housing • Transportation • Integrated community living • Freedom from abuse, neglect, financial and sexual exploitation, and violations of legal and human rights which result in: • Independence • Productivity • Self-determination • Integration • Inclusion
2. State DD Councils	▪ State Plan development ▪ Self-advocacy and leadership development ▪ Community capacity development ▪ Systems change activities ▪ Governance and management	▪ State Plan ▪ Programs to improve community capacity ▪ Participants in Council-supported self-advocacy and leadership activities	▪ New/revised legislation and policies ▪ Halting of legislation and policies ▪ Changes in community practice ▪ Self-advocate participation in advocacy efforts	
3. P&A	▪ Planning and priority setting ▪ Intake and assistance ▪ Individual advocacy ▪ Systemic advocacy ▪ Community outreach and education ▪ Governance and management	▪ Statement of Goals and Objectives ▪ Individual advocacy caseloads ▪ Referrals, disability information ▪ Education and training and materials	▪ Resolution of individual cases ▪ New/revised legislation, policies, practices ▪ Improved access to services and supports	
4. UCEDDs	▪ 5-year planning ▪ Interdisciplinary pre-service training and continuing education ▪ Basic and/or applied research ▪ Community services ▪ Dissemination ▪ Governance and management	▪ 5-year plan ▪ Best practices ▪ New information on providing services to people with developmental disabilities ▪ Publications in peer reviewed journals and other venues	▪ Leaders in disability education, research, policy development ▪ Improved community services for people with developmental disabilities	
5. Collaboration	▪ Collaboration	▪ Common goals ▪ Blended funding and other resources for collaborative project implementation	▪ Achievement of common goals resulting from collaboration	

change efforts. An example of a short-term P&A short-term outcome is the resolution of individual advocacy cases. UCEDD outcomes consist of leaders in disability education, research, and policy development. Outcomes for ADD consist of effective programs and effective collaboration.

Intermediate or long-term outcomes include changes in economic or policy conditions overall for people with developmental disabilities and are consistent with the purpose of the DD Act, such that people with developmental disabilities have access to services and supports that promote their independence, productivity, self-determination, integration and inclusion. The National Independent Study primarily examined the short-term outcomes that accrued to DD Network program target audiences because those are the ones that can be more directly linked to the efforts of the DD Network programs and ADD. The longer-term outcomes (e.g., increased independence, productivity, self-determination, integration and inclusion at the population level) are more difficult to ascertain and attribute directly to the work of ADD and the DD network programs.

Benchmarks, indicators, and examples of performance standards were developed for each key function within each DD Network program and for collaboration among the three DD Network programs (Table 2-1).

Table 2-1. Key Functions of DD Network Programs

Councils	P&As	UCEDDs
▪ 5-year State Plan Development ▪ Self-advocacy and Leadership Development ▪ Community Capacity Development ▪ Systems Change Through Advocacy ▪ Identification of Promising and Effective practices ▪ Governance and Management	▪ Annual Planning and Priority Setting ▪ Intake and Assistance ▪ Individual Advocacy ▪ Systemic Advocacy ▪ Community Outreach and Education ▪ Governance and Management	▪ 5-year Planning ▪ Interdisciplinary Pre-Service Preparation and Continuing Education ▪ Basic and/or Applied Research ▪ Community Services ▪ Dissemination of Information ▪ Governance and Management
Collaboration		

All programs contained a planning key function and a governance and management key function. Although key functions are specific to the particular mission of each program, all three programs had at least one key function in which efforts are made to increase the capacity of the community to better include people with developmental disabilities and provide them with independence and choice (Community Capacity Development for the Councils, Community Outreach and Education for the P&As and Community Services for the UCEDDs). Systems change efforts were also covered in each program, although for the UCEDDs, systems change efforts were mostly addressed within the research and community services key function. Key functions for the UCEDDs were consistent with the core functions described in the DD Act.

2.5 Data Collection Materials

The data collection materials developed for the full-scale evaluation in Phase 2 (Appendix C) were developed to determine whether each program could meet the working version of the draft standards. Chapter 3 describes the data collection methodology for administering these materials and the achievements of DD Network programs and collaboration among them.

This page left blank intentionally.

Assessment of Programs and Collaboration Against Working Standards

3

3.1 Overview

The validation process described in Chapter 2 consisted of broad representation from people both inside and outside the Developmental Disabilities (DD) Network programs and substantial participation of self-advocates and family members. The process resulted in relatively strong agreement on many of the benchmarks and indicators panel members were called upon to rate.

Once a subsequent version of the benchmarks, indicators, and examples of performance standards were developed (considered to be "working standards" still not final), based on feedback from Validation Panels, the next step was to assess programs against these benchmarks and example standards. To do this, Westat created data collection instruments that would measure the extent to which the benchmarks and example performance standards were being met. The plan was to use the data collected from key informants to refine and finalize performance standards for the Administration on Developmental Disabilities (ADD) (Chapter 4).

This chapter describes the assessment of DD Network programs and collaboration among them. The first step was to select a sample of programs on which to collect data. Next, Westat collected data using the data collection instruments that had been developed and then summarized the data. Findings were mapped to the benchmarks, indicators, and examples of performance standards in documents that came to be known as "Findings Forms."

This chapter describes each of these steps and the result of each step—the sample selection methodology and results, data collection methods, and findings for each DD Network program and collaboration.

3.2 Sample Selection

Programs vary in the ways in which they carry out the principles and goals in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), as well as in the barriers and facilitators that may impact on their ability to do so. Because visiting all programs in all states and territories would be cost-prohibitive, Westat selected a systematic random sample of 20 states/territories. The selection process captured the expected variability among all programs. There was no intention to weight up to the general population of programs.

Westat made the assumption that stratification by region would account for most of the variability among programs. Other factors (e.g., allotment size) were expected to be evenly distributed among programs that were selected, so we did not think it was necessary to stratify by other factors. Moreover, despite certain characteristics of programs (e.g., to a University Center for Excellence in Developmental Disabilities, Research, and Service [UCEDDs] holding a Leadership Education in Neurodevelopmental and Related Disabilities [LEND] grant; P&As functioning within the state government), it was ADD's expectation that the benchmarks and performance standards (as measured by the indicators addressed in the questionnaires) needed to be met by all programs.

The number of states Westat selected was a function of balancing cost with an attempt to account for variability. Given the amount of funds expected to be available, this was the greatest number of states/territories we felt we would be able to adequately assess to determine the influence of the DD Network programs on people with developmental disabilities and their families.

Sampling Strategy. Sampling was conducted by a Westat statistician. Geographic region (according to the regions designated by the U.S. Census) was used as a stratification variable. In addition to all 50 states, three territories were also included in the sampling frame—District of Columbia, Puerto Rico, and Guam—because they each contain three fully-functioning and fully-funded DD Network programs. District of Columbia and Puerto Rico were included in the sampling frame for Region 3 (South). Guam was included in Region 4 (West).

To conduct the sampling, the Westat statistician used an overall sampling rate of 37.7 percent (20/53). The observed and expected for each region appear in the table below (Table 3-1).

Table 3-1. Observed and expected number of states/territories in each U.S. census region

Region	Number observed (i.e., number of states/territories selected)	Number of states/territories expected
1: Northeast	3	3.39
2: Midwest	4	3.39
3: South	7	6.79
4: West	6	5.28

Once the sampling process was complete, it was noted that some of the states have more than one UCEDD. Thus, it was necessary to randomly select one UCEDD program within each state.

Description of Sample. Nineteen states and one territory were randomly selected for the National Independent Study of the Administration on Developmental Disabilities Programs (the National Independent Study)—three in the Northeast, four in the Midwest, seven in the south, and 6 in the west (including one territory) (Table 3-2). Five of the State Councils on Developmental Disabilities (SCDDs) received a minimum allotment in 2010 ($478,797). Seven Protection and Advocacy (P&A) System programs were minimum allotment programs, receiving $384,693 in 2010. The allotment for the Territorial SCDD was $249,344 and for the territorial P&A was $205,808.

Table 3-2. Characteristics of sampled states and territory

Characteristic	Number of states/ territory selected
Region	
Northeast	3
Midwest	4
South	7
West	6*
State Councils on Developmental Disabilities (SCDD)	
Minimum allotment	5
Independent state agency (501[3][c])	6
Non-profit (501[3][c])	3
Protection and Advocacy System (P&As)	
Minimum allotment	7
State agency	4**
Non-profit (501[3][C])	16
UCEDDs	
Medical school	7
Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program	11
Intellectual and Developmental Disabilities Research Center (IDDRC)	4

*includes territory

** One P&A resides within a state university

Among those states/territory sampled, six SCDDs were an independent state agency acting as its own Designated State Agency (DSA), and three were non-profit organizations (i.e., a 501[3][c]). Sixteen of the sampled P&As were non-profit organizations, three were a state agency, and one was located within a university.

Among the UCEDDs, seven were part of a medical school, and one was in a children's hospital. In addition to receiving ADD funding as a UCEDD, some UCEDDs also received funding through the LEND program, funded and administered by the Health Resources and Service's Administration's (HRSA) Maternal and Child Health Bureau (MCHB) in the US Department of Health and Human Services. LEND training programs prepare trainees from multiple professional disciplines to become leaders in their respective field in order to improve the health of infants, children, and adolescents with disabilities. LEND grants range in size from $450,000 to $850,000. Eleven of the UCEDDs included in the National Independent Study were also a LEND program.

Among the 11 LEND programs, four were also housed in a university with an Intellectual and Developmental Disabilities Research Center (IDDRC). IDDRCs are funded by the National Institute of Child Health and Human Development (NICHD). They are centers of excellence that conduct biomedical and behavioral research in mental retardation and developmental disabilities. IDDRCs receive up to $750,000 per year over a five year period.

3.3 Data Collection Methods

Data collection consisted of the administration of tools developed in Phase 1 as well as an additional data collection instrument—a self-administered questionnaire (SAQ) to capture mostly quantitative data from DD Network programs. This section describes the tools that were used to collect data and the method and results of testing the reliability of summarizing findings (Section 3.3.1 and 3.3.2).

3.3.1 Program Visits and Key Informant Interviews

After ADD notified programs about their selection for the independent evaluation (Appendix D), Westat sent an email to each program executive director to begin the process of arranging a visit and setting up the agenda (Appendix E). Westat worked with the executive director and staff in each program in each selected state/territory to schedule dates and times for the visit, identify key informants for interviews, and develop an agenda. A followup letter (Appendix F) was then sent to each program to confirm the dates of the visit, describe the visit further, and provide a copy of all questionnaires and consent forms (Appendix C and G, respectively).

As they were for the pilot study, the majority of key informants were identified by the executive director of each program, using the method and criteria for selection described in Table 3-3a – 3-3c.

Table 3-3a. Overview of data collection in program visits – State Councils on Developmental Disabilities

Key informant	Type of interview	Number of interviewed per site	Duration of interview	Criteria/method of selection
Executive director (ED) with staff, as appropriate	Individual, in person	1+	3-4 hours*	▪ Additional staff at discretion of ED (e.g., Associate Director)
DD Council members**	Individual, in person	3	½ hour – 45 minutes	▪ Chair ▪ 2 other members ▪ All have at least 1 year on DD Council ▪ At least one has gone through at least one State Plan development process
Mixed group to talk about systems design—policy makers, collaborators, contractors for systems design projects (as appropriate)**	Group, in person	Up to 8	1 ½ - 2 hours	Select a specific example with the ED and ask ED to select individuals from among the following categories: ▪ State directors ▪ Governor's liaison ▪ Committee staff ▪ City Council members ▪ Tribal and other community leaders ▪ Parents groups ▪ Other appropriate partners/collaborators ▪ Contractors that implemented project on behalf of DD Council
Recipients of advocacy/ leadership training**	Individual, in person	3	½ hour – 45 minutes	▪ People with developmental disabilities ▪ Family members ▪ Received training within past 3 years ▪ Range of disabilities
Recipients of education and training to improve community capacity	Individual, telephone	3	½ hour – 45 minutes	Ask ED to identify people in the following categories: ▪ Service providers to people with developmental disabilities ▪ People who interact with people with developmental disabilities as part of the general public (e.g., employers, dentists, city officials)

*Full interview will not take place all at once; staff may be interviewed separately, as appropriate.

**Signed consent form required.

Table 3-3b. Overview of data collection in program visits – State Protection and Advocacy (P&A) Systems

Key informant	Type of interview	Number of interviewed per site	Duration of interview	Criteria/method of selection
Executive director (ED)	Individual, in person	1+	3-4 hours*	▪ Additional senior staff at discretion of ED (e.g., Legal Director)
P&A staff	Individual, in person	3	½ hour - 45 minutes	▪ Intake ▪ Advocacy/legal ▪ Public education
Board of Directors	Individual, telephone	3	½ hour – 45 minutes	▪ Chair and two members ▪ At least one with 1 year on governing board ▪ At least one with 3+ years on governing board ▪ Mix of background and expertise ▪ At least one person has a relationship with developmental disabilities (self, family member)
Policymakers/ collaborators to talk about systemic advocacy activities**	Group, in person	Up to 8	1 ½ - 2 hours	Select a specific example with the ED and ask ED to select individuals from among the following categories: ▪ State directors ▪ Governor's liaison ▪ Committee staff ▪ City Council members ▪ Tribal and other community leaders ▪ Parents groups ▪ Other appropriate partners/collaborators
Recipients of community education	Individual, telephone	3	½ hour – 45 minutes	▪ Work with ED to randomly select 25 individuals ▪ ED purposefully selects from 25 contacts ▪ ED selects from among following categories: – employers – city officials – providers of services to people with developmental disabilities
P&A clients*	Individual, in person	3	½ hour - 45 minutes	▪ Work with ED to randomly select 25 clients using case file number within a specified time period as a sampling frame. ▪ Ask ED to purposefully select 25 individuals from among the 25. ▪ Select at least one client whose objective was not met. ▪ Personal assistant/family member may be present if client requests.

*Full interview will not take place all at once; staff may be interviewed separately, as appropriate.

**Signed consent form required.

Table 3-3c. Overview of data collection in program visits – National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service

Key informant	Type of interview	Number of interviewed per site	Duration of interview	Criteria/method of selection
Executive director (ED) with staff, as appropriate	Individual, in-person	1+	3-4 hours*	▪ Additional staff at discretion of ED (e.g., Associate Director)
Consumer Advisory Committee (CAC) members**	Individual, in-person	3	1/2 hour – 45 minutes	▪ Chair (if there is one) ▪ All have at least 1 year on CAC ▪ At least one has gone through at least one 5-year plan development process
Current/former students	Individual, telephone	3	1/2 hour - 45 minutes	▪ Could include: - Students who graduated from core disability program - Students who were exposed to disability content—could be current students - Participants in continuing education classes ▪ Timeframe: within past 3 years
Researchers/colleagues	Individual, telephone	3	1/2 hour – 45 minutes	▪ External colleagues: – not a member of a UCEDD or UCEDD's university faculty – collaborated on project or publication with a UCEDD faculty member or served on a professional committee with UCEDD faculty member ▪ University colleagues—not a member of the UCEDD
Recipients of community services (or those trained to provide community services)*	Individual, in person	3	½ hour to 45 minutes	Could include: ▪ People with developmental disabilities ▪ Family members ▪ Service providers to people with developmental disabilities ▪ People who interact with people with developmental disabilities as part of the general public (e.g., employers, dentists, city officials, fitness instructors)

*Full interview will not take place all at once; staff may be interviewed separately, as appropriate.

**Signed consent form required..

Westat staff provided selection criteria to the executive director who was asked to purposefully select individuals to participate in the interviews. The executive director was asked to contact all potential participants to ask their permission for Westat to interview them. Westat again obtained consent (written or verbal) at the time of the interview.

Interview data collection took place over a period of approximately seven months, beginning in March, 2010. It consisted primarily of semi-structured in-person individual and group key informant interviews and individual telephone interviews. Telephone interviews were conducted with those who worked or resided at a distance from the program or could not easily be available for an in-person interview on site (e.g., colleagues of UCEDD-affiliated faculty and staff; members of the P&A board of directors; students who graduated from a university program in which a UCEDD was housed). In-person interviews were conducted during the program visit, which lasted approximately a day and a half per program. Telephone interviews were scheduled after each program visit.

Two-person teams were deployed to each program. Team members collected and summarized data from each interview and group discussion for each program within each state or territory. These teams conducted program visits in all three programs in each state, followed up the collection of data using other methodologies (e.g., the SAQs; receipt of program materials), and summarized findings. Program visits to collect data lasted approximately 5 days to cover all three programs and collaboration among the programs in each state.

Interviewers obtained written consent from all individuals who were interviewed in person and were not considered program staff. In the pilot study, these individuals were paid a nominal amount to reimburse them for their time in assisting in the pilot study. In the full-scale evaluation study, there was no payment. However, all expenses (e.g., travel, payment for personal assistants) were covered. Respondents were also asked for permission to audio record all interviews. Recordings were transcribed and used for analysis.

Within three days of each program visit, data collection staff produced a summary report of the visit ("First Impressions"). Once transcripts were completed, the program visit team then summarized findings using a Findings Form (described below) (Appendix H). Study staff incorporated the findings on each benchmark and indicator into the Findings Form for each program.

3.3.2 Self-Administered Questionnaires

Description. During the pilot study in Phase 1 of this study, it became apparent that some questions (e.g., those that required quantitative data) were better answered with a structured questionnaire instead of as part of a semi-structured in-person interview. Thus, Westat developed a self-administered questionnaire (SAQ) for each of the three DD Network programs with questions that corresponded to a subset of indicator measurements (Appendix I). Because the questionnaires were not tested as part of the pilot study, it was necessary to test them prior to their administration, and revise accordingly.

The SAQ could be administered as a web-based questionnaire or on paper. Programs were given a choice of which method they would like to use. In addition, programs could choose to have more than one person complete the questionnaire. These questionnaires contained a specific reporting period that was designated by Westat. Those completing the questionnaire were asked only to consider data that applied to the reporting period. In that way, data from all states and programs could be aggregated.

Testing the Self-Administered Questionnaires. The questionnaires were tested by executive directors from DD Network programs that were was not included in the evaluation sample. ADD contacted three executive directors by email, and all agreed to test the questionnaires. There was a separate questionnaire for Councils, P&As, and UCEDDs. Testers were provided with a paper copy of the questionnaire and asked to enter a production web site to test the web-based questionnaire. They were asked to go through the whole process, including gaining access to the web site, compiling information on each question, entering data on each question as if they were completing the questionnaire for their own program, and saving their questionnaire. Westat staff then obtained feedback on their experiences.

Westat obtained feedback from testers by telephone on all components of the questionnaire—the web-based computer function, understandability of the questions, and time it took to compile information. The following questions were asked:

1. Did you experience any difficulties accessing (logging on to) the questionnaire? If so, what were those difficulties?
2. Once you were logged on, did you experience any difficulties navigating the questionnaire? Probe: moving from section to section, entering and saving data, using the different answer fields (text box, drop-down menu, check boxes).

3. Approximately how much time did it take to gather the necessary information for completing the questionnaire? Probe for each section. Once you had the necessary information gathered, how much time did it take to complete the questionnaire?

4. In terms of the content, were there questions that did not make sense to you? If so, which ones?

5. Were there any questions that you were unable to answer? If so, which ones and why?

6. Would you have preferred to complete the questionnaire on paper instead of in a web-based format?

7. Do you have any additional comments or suggestions to improve the questionnaire?

Based on responses to these questions, Westat revised the questionnaires and web site.

3.3.3 Review of Program Materials

In addition to the information collected by interview, programs were asked to provide materials to document and augment other data collection efforts (Table 3-4). These materials were highlighted throughout the interview guide and noted specifically in the SAQ.

Westat staff reviewed these materials and extracted details that provided examples of ways in which performance standards were being met for the final report.

Table 3-4. Materials requested from DD Network programs – DD Councils, P&As, and UCEDDs

DD Councils
References used to identify needs and interests of people with developmental disabilities: ▪ Findings from UCEDD reports (copy or references) ▪ References from published literature ▪ Copy of P&A reports ▪ Copy of findings from DD Council-supported demonstration projects ▪ Copy of State agency reports ▪ Other copies or references of reports ▪ State Plan ▪ Copy of policy or practice to identify and select competent and experienced grantees ▪ Written list of collaboration goals/objectives ▪ Up to three examples of products developed in past calendar year through collaboration of three DD Network programs

Table 3-4. Materials requested from DD Network programs – DD Councils, P&As, and UCEDDs (continued)

Protection and Advocacy Systems

References used to identify needs and interests of people with developmental disabilities:

- Findings from UCEDD reports (copy or references)
- References from published literature
- Findings from DD Council Comprehensive Review and Analysis section of the State Plan
- Copy of findings from DD Council-supported demonstration projects
- Copy of State agency reports
- Other copies or references of reports
- Copy of written intake procedures
- Copy of intake form
- Forms, questionnaires or other documentation to measure client satisfaction
- Up to three examples of client representation agreements
- Up to three examples of closing letters to clients
- Copy of three brochures/announcements used in the past year to increase access to P&A services for traditionally unserved or underserved populations
- Up to three examples of community education materials
- Results of fiscal audit conducted in past calendar year to demonstrate financial solvency of P&A
- Written list of collaboration goals/objectives
- Up to three examples of products developed in past calendar year through collaboration among three DD Network programs

UCEDDs

References used to identify needs and interests of people with developmental disabilities:

- Findings from UCEDD reports (copy or references)
- References from published literature
- Copy of P&A reports
- Copy of DD Council comprehensive Review and Analysis section of the State Plan
- Copy of findings from DD Council-supported demonstration projects
- Copy of State agency reports
- Other copies or references of reports
- 5-year plan
- Up to three examples of curricula or syllabi that incorporate perspectives and interactions among a variety of disciplines
- Up to three examples of course syllabi developed by UCEDD faculty and staff and used in the past year that cover current practices and issues
- Up to three examples of course syllabi used in the past year that contain up-to-date content (e.g., required readings)
- Up to three examples of syllabi of courses conducted in the past year that incorporate disability content
- Up to three examples of course materials that demonstrate cultural competency
- Up to three examples of community services materials (e.g., recruitment brochure, forms) that demonstrate community services were person-centered, family-centered, and culturally competent
- Up to three examples of products disseminated, including one in which research findings were translated into lay terminology to demonstrate materials are accessible and understandable
- Written goals/objectives on which DD Network programs are collaborating
- Up to three examples of products developed in past year derived from collaborative efforts, if applicable.

3.3.4 Reliability of Findings

Because of the large amount of qualitative data that needed to be collected, Westat developed a Findings Form (Appendix H) to ensure not only that data collection teams were focused on the type of information that needed to be collected and analyzed, but also so findings could be organized and stored for easy retrieval.

Findings Forms were organized by the benchmarks, indicators, and performance standards developed from feedback from Validation Panels (see Section 2.4). Findings Forms benchmarks and indicators were comprised of structures, processes, outputs, or outcomes. For example, a well-supported Consumer Advisory Committee (CAC)[6] is a structural indicator for the UCEDDs. The Council indicator, *DD Councils provide or support self-advocacy and leadership development through education, training, and technical assistance for people with developmental disabilities and/or their families*, is a process indicator. An example of a P&A output indicator is *a culturally competent outreach mechanism*. An outcome indicator for collaboration among the three DD Network programs is *the achievement of common goals as a result of collaboration*.

Because there was so much information collected on each program, it was imperative that each Findings Form capture the most important information and not omit important items that would be needed for analysis. Thus, Westat examined the reliability of completing the Findings Forms and ensured that completion of these forms achieved a high standard.

To test the consistency of completing the Findings Form, the following steps were taken:

1. Westat obtained a transcript of all interviews from the first program visit.
2. The project director completed a Findings Form using the transcript. This was considered the "gold standard."
3. Each interviewer completed specific sections of the Findings Form.
4. The contents of the Findings Form were compared to the gold standard. Comparisons examined the nature of each item listed for each indicator.

Using this process, it was possible to calculate a percentage of items that were similar to the gold standard. The goal was to aim for 70 percent reliability. A staff member who did not achieve 70

---

[6] Although many UCEDDs call their committees by a different name, the term "CAC" will be used in this report for all UCEDDs.

percent received re-training and was asked to repeat the process until 70 percent was achieved. One staff member was asked to repeat the process once.

3.4 Findings (Program Achievements)

This sub-section describes findings for each program and collaboration by mapping these findings to the structural, process, output and outcome indicators contained in the Findings Forms tool we developed. Findings on State Councils, P&As, UCEDDs and collaboration are described separately.

3.4.1 State Councils on Developmental Disabilities (SCDDs)

We begin this section with a general description of State Councils, and then map the findings to the benchmarks and indicators.

3.4.1.1 General Description of the State Councils on Developmental Disabilities

State Councils on Developmental Disabilities (SCDDs or Councils) are charged with identifying the most pressing needs of people with developmental disabilities in their state or territory and addressing those needs through systems change and capacity building efforts that promote self-determination, integration and inclusion for people with developmental disabilities. The DD Act grants the Council the freedom to focus its resources on activities it believes will enhance the independence, productivity, self-determination, integration and inclusion of people with developmental disabilities and their families.

The DD Act mandates that each Council designate a State agency that will, on behalf of the State, provide support to the Council. The primary responsibility of the designated state agency (DSA) is to received, disburse, and manage the Federal allotment for the Council. The state plan must provide assurances that the staff and other personnel of the Council, while working for the Council, will not be assigned duties by the DSA or any other agency or entity in the state. Moreover, assurances must be provided that the DSA will not interfere with the “advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the

Council." Councils have the option of serving as its own DSA and also becoming an independent, non-profit organization.

In Fiscal Year 2010, $75 million was available to the 55 existing Councils (one in each state and U.S. territory). Six states in the National Independent Study received a minimum allotment in fiscal year 2011 of $478,797. The one sampled territory received $249,344. The maximum allotment received by sampled Councils was $4,373,416.

As noted in Council yearly Performance Progress Reports (PPRs), Councils used the funding received to engage in systems change, capacity building, self-advocacy activities, and advocacy activities that educate the public; developed and supported coalitions; informed federal, state, and local policy makers; demonstrated new approaches to services, supports and other assistance; provided outreach to those who might not come to the attention of the Council; assisted neighborhoods and communities to respond positively to people with developmental disabilities and their families; fostered interagency collaboration and coordination, including related Councils, committees and programs; and eliminated barriers and enhanced citizen participation.

3.4.1.2 Council Structures

Structures are the resources necessary to set processes in motion and keep them running (French & Bell, 1984.). We were particularly interested in those structures that enabled or impeded Councils' ability and capacity to meet the goals set forth in the DD Act. The structures examined (as per the Findings Form) included Council composition, the DSA, Council operations, Council staff, Council supports, and performance assessment.

Council Composition. The composition of the Council is essentially prescribed in the DD Act. Sixty percent of Council members need to be people with developmental disabilities or their family members, and the other 40 percent are to be representatives of appropriate state agencies and organizations. In addition to that, both the program visit protocols and the Self-Administered Questionnaire (SAQ) collected data on the areas of expertise and background of Council members. The SAQ also examined whether Councils have a full complement of members to carry out Council business.

Findings from the SAQ (Table 3-5) indicate few vacancies on State Councils (95.4 percent of all slots were filled). Slightly more than 25 percent of Council members are people with a developmental disability, and about 16 percent of Council members have an intellectual disability. A large percent of Council members are reported to have knowledge of policy and law related to people with developmental disabilities (79.6 percent), and about 40 percent were reported to have knowledge of business or finance. Less than 20 percent were reported to represent a minority in their state.

Table 3-5. Composition of sampled councils*

Indicators	No.	Percent	Range (%)	Denominator**
Council slots filled	523	95.4	80.0 – 100.0	548
Council members with developmental disabilities	158	28.5	15.0 – 45.5	555
Council members with intellectual disability	80	15.8	5.9 – 36.0	507
Council members with knowledge of policy and law related to people with developmental disabilities	379	79.6	29.2 – 100.0	476
Knowledge of business or finance	169	39.6	10.7 – 100.0	427
Representation of a minority in the state	76	18.7	6.5 – 44.1	407

* Source: Self-administered questionnaire

**Denominators differ because of missing data from some Councils

Key informant findings indicate that Council members included people with developmental disabilities, parents of people with developmental disabilities, self-advocates (including many graduates of Partners in Policy Making), state-level representatives of disability-related agencies (e.g., Division of Disability, Rehabilitation Services, Medicaid, etc.), providers (e.g., special education case manager, independent living center coordinator, executive director of local chapter of the Arc), attorneys, people with a background in conflict resolution, and people with knowledge of the community supports and services needed and available for people with developmental disabilities.

Designated State Agency. Each Council is mandated by the DD Act to have a DSA or to serve as its own DSA. Six out of 20 sampled Councils interviewed are serving as its own DSA. According to executive directors, being its own state agency affords the Council a level of independence from the government different from those Councils that have state agencies as their DSA. The remaining Councils show variation in the department in which the DSA resides (Table 3-6).

Table 3-6. Designated state agency (DSA) of study sample councils

- Department of Mental Health
- Department of Health and Social Services
- Department of Economic Security
- Department of Homeland Security
- Bureau of Statistics and Plans
- Department of Social and Rehabilitation Services
- Department of Health and Hospitals
- Office for Administration and Finance
- Division of Public Health
- Department of Health and Human Services
- Department of Human Services
- Division of Mental Retardation Services
- Agency of Human Services
- Department of Administration
- Own state agency (6)

Council Operations. Some Councils have sub-committees that are tasked with a specific activity or purpose of the Council. All sampled Councils have an executive committee, typically comprised of the Council chair and other officers such as a vice-chair, committee chairs, and sometimes the previous chair. The executive committee's main purpose is to act on behalf of the Council between Council meetings.

For some sampled Councils, the executive committee is the only standing committee. The rest of the committees for these Councils are ad-hoc and are established and dissolved by the chair as needed. Most Councils have a membership/personnel committee. For some, this is a standing committee, and for others it is an ad-hoc committee. This committee nominates new Council members, reviews candidates for Council membership, searches for and hires Council staff and conducts performance reviews for the executive director. Most Councils have a legislation or policy-focused committee, a grants committee, and a planning committee that focuses on the goals and objectives in the State Plan.

The majority of sampled Councils hold regular quarterly Council meetings. In addition to the regular meetings, several Councils reported holding subcommittee meetings on an "as needed" basis. Most Councils did not report having an attendance policy for Council members. Two Councils have a policy in place where a Council member who misses more than two meetings in a row would not be re-appointed for another term. Another state reported having the same attendance policy but is not able to enforce the policy. According to the executive director, the Council does not have the ability to "fire" someone from the Council but can only request a resignation. Two other Councils also have similar attendance policies (cannot miss more than two meetings in a row or half of the year's meetings), but do not report asking violators to resign. Instead, they communicate with the violator about the importance of attendance.

Council Staff. The Council staff is an important structure because it is the primary support system for Council members. Councils may require different types and amounts of support, so building and maintaining an appropriate staff is important for each Council's success. Because allotment amounts differ among the sampled Councils, the number of staff that each Council is able to fund also varies. Each Council has an executive director who is considered to be an employee of the Council. The executive director is hired by the Council and his/her performance is reviewed by the Council. Executive directors attend Council meetings but do not receive a vote in Council decision making. In most cases, executive directors lead the state planning process that includes collecting input, synthesizing the input, drafting the goals and objectives of the State Plan, and implementing the activities under the direction of the Council.

Council staff is typically comprised of people with expertise in program development and implementation or policy making. Council staff is generally tasked with developing and implementing systems change, leadership and community capacity activities. In a few states, Council staff serves as program managers to grantees that have been funded to provide these activities. Because of involvement in Council programs, Council staff is often involved in the process of identifying grantees for funding. Program visit findings indicate that the staff is involved in writing requests for proposals, reviewing proposals and selecting awardees. A small number of sampled Councils indicated that staff is involved in writing requests for proposals but not in the review or selection of awardees. Instead, these tasks are left to Council members, typically a subcommittee tasked with procurement.

Council Supports. Council members are supported by receiving an orientation to provide them with an understanding of their roles and responsibilities. They also receive support to better participate in Council meetings. Generally speaking, orientations provide information on the DD Act, the overall mandate and purpose of Councils, the current State Plan (Council goals and objectives), the committees that comprise the Council, and expectations of Council participation (e.g., attendance at meetings, membership on committees and sub-committees). At least three Councils also included information on ethics in the orientation, focusing on issues such as confidentiality and conflict of interest. One Council hired an outside organization to provide ethics training. Several Council members reported being assigned a mentor from within the Council who acted as an additional source of information for the new Council member.

The majority of sampled Councils provide an orientation to new Council members as they join the Council. The orientation is typically provided by the executive director along with other key staff and Council members. A few Councils hold an annual orientation, so new Council members would sometimes experience a delay between start date and orientation. In addition to orientation, the majority of sampled Councils send at least one Council member to the annual National Association of Councils on Developmental Disabilities (NACDD) technical assistance meeting.

All sampled Councils reported providing supports for Council members in order to facilitate participation in meetings, and all Council members we interviewed reported being very satisfied with the support they receive. Council staff and members both reported that the Council provides whatever support is necessary to ensure participation of a Council member. Examples of commonly used supports include reimbursement for travel, parking, and personal assistance; distribution of meeting materials several days prior to the Council meeting; communication support (e.g., sign-language interpreter.); personal support assistance (someone to transport a Council member to and from the meeting and assist the Council member during the meeting); use of simple language in the materials; use of assistive technology and pre-meeting reviews of the agenda and other meeting materials to ensure comprehension of the issues for discussion. As one Council member explained, "we have a pre-meeting if anybody wants it; particularly for self-advocates or new people who kind of feel like they may be under water. We offer the pre-meeting to explain anything." Half of the sampled Councils offer members a stipend for attending meetings and/or retreats. A few Councils reported that the stipends were offered only to members who met certain criteria (e.g., not employed by the Federal or state government). One Council member reported being provided a stipend in lieu of reimbursement for expenses.

Assessment of Performance. Westat reviewed the structures in place for assessment and self-evaluation of the Council. The majority of sampled Councils use two methods for self-evaluation. First, all Councils use a satisfaction or evaluation form at the close of each Council meeting to assess overall satisfaction with the meeting, effectiveness and efficiency of the Council. Many Councils reported that the findings from these evaluation surveys are compiled and presented to the executive committee of the Council for review. The second method for self-evaluation that most Councils reported is some type of annual self-evaluation, typically taking place during an annual Council retreat. During this annual self-evaluation, Council members and staff review the past year's achievements and the amount of money spent. They compare these achievements to the goals and objectives for the year contained in the State Plan. Several Councils reported using the PPR to organize this process.

To review Council staff, Councils use both a formal and informal process for annual performance review of the executive director. Typically, this review is conducted either by the Council Chair or executive committee. In addition, the executive director is charged with performance reviews for the rest of the Council staff.

3.4.1.3 Processes and Activities

Processes and activities set out in the Findings Form consist of planning, self-advocacy and leadership activities, systems change activities, and grantee selection for implementing Council initiatives. These are summarized below.

Planning and Priority Setting. Each Council is required to conduct a review and analysis of services, supports, and other assistance in the state or territory available to people with developmental disabilities and family members. Based on this review, the State Council must develop a 5-year State Plan to address the gaps and barriers identified from the review. This process involves two major steps: (1) obtaining input and other information on the gaps in services and supports for people with developmental disabilities; and (2) translating that input and information into the goals and objectives of the State Plan. The Plan is expected to reflect the true needs of people with developmental disabilities and family members in the state.

All sampled Councils collect input on the gaps in services and supports for people with developmental disabilities in the state. Councils collect input from a wide range of sources, including: people with developmental disabilities and family members; DD network partners (UCEDD, P&A); Federal and state agencies, such as Vocational Rehabilitation and the Substance Abuse and Mental Health Services Administration (SAMHSA); service providers; advocates; self-advocacy organizations; grass roots and community organizations related to disability; and disability-related resource centers and organizations. Program visit findings indicate that sampled Councils have informal networks that are used, among other vehicles, for collecting input for the planning process. Councils have large databases of email addresses of key stakeholders and have access to email databases of other organizations. In addition, many Councils have listServs that are used for soliciting input.

In addition to obtaining input from individuals, Councils often include other sources of data on gaps in supports and services. Most reported using reports written by the UCEDD(s) in their state as a source for planning. The Councils also referenced reports from other state agencies that provide services to people with developmental disabilities (e.g., Vocational Rehabilitation, Social Services), the budgets from these and other agencies, and national disability-related data sets and studies (e.g., Projects of National Significance [PNS] data projects). Many Councils used feedback from Council activities as input for the planning process. In one example provided by a Council executive director, the Council sends parents of people with developmental disabilities each year to a specific training around special education, "and every parent that we have supported financially to participate in that has given it the highest possible rating. What that tells us is that it is a good training. So…in our planning process, we are looking at…negotiating a direct relationship with them [those that provide the training]."

Councils use several different methods for collecting input on the gaps in services and supports. The most common methods are public meetings, listening sessions, and some type of survey. The surveys are typically available both electronically and in a paper and pencil version and are distributed to everyone in the Council's database, through partner organizations (service providers, advocacy organizations, state agencies) and to people attending a Council activity or meeting. A smaller number of Councils use the mail to deliver the survey, but mostly the surveys are delivered electronically. Other, less common approaches to gathering input include conducting telephone interviews with stakeholder key informants, focus groups with stakeholders, and attendance of other agency meetings to hear what people are saying. A few Councils provide two-way interactive television coverage of public meetings and focus groups to allow people otherwise unable to attend to participate.

The majority of sampled Councils collects input in collaboration with the P&A and UCEDD(s) in their state. In many of the states, the three programs together hold listening sessions and public meetings, combining resources and avoiding duplication of efforts. Almost half of sampled Councils rely on the UCEDD in their state to conduct some of the analysis of the data collected in the process. In some cases, the collection and analysis of data is done collaboratively between the Council and UCEDD (and often the P&A), but in other cases the analysis of data is conducted by the UCEDD and shared among the Network programs.

All sampled Councils reported making attempts to include people with diverse backgrounds in the information gathering process. Populations requiring special outreach include residents of rural communities, racial and ethnic minority populations, and people with developmental disabilities who needed multiple services. Most Councils indicated some success in obtaining input from racial and ethnic minorities in the state. Some rely on Council members and grantees to facilitate access and outreach to these communities, and other Councils use partner organizations and other network stakeholders for access. A few Councils reported experiencing difficulty accessing minority populations. One Council explained that its attempts to include the Latino/Hispanic community in the process were met with resistance because this particular population has a lack of trust in anything they believe is related to the government, especially anything that may be asking an individual to be "counted." A small number of Councils in the study sample reported that its Council is representative of the diversity of the state and, therefore, the feedback from Council membership is considered comprehensive.

All sampled Councils make accommodations to ensure that people with developmental disabilities are able to participate in the planning process. Most rely on the use of web-based surveys to accommodate people with developmental disabilities. In addition, many Councils offer reimbursement for transportation, the use of personal aids, assistive technology, sign language services, and other accommodations for people with developmental disabilities to attend in-person planning activities. Most Councils reported providing planning materials that had been written in simple language to ensure comprehension.

Once the input has been collected, the majority of sampled Councils hold a retreat or day(s)-long meeting that includes Council staff and some Council members. The intent is to synthesize findings and develop goals and objectives based on the findings. Councils typically divide the information into areas of emphasis and discuss each area individually. Some Councils reported also discussing the Council budget concurrently with the areas of emphasis so as to have a clear picture of the number of areas of emphasis that realistically could be funded. A small number of Councils hired an outside contractor to facilitate these meetings. As one executive director explained, this is the point at which the Council looks at all of the input collected and "asks the question—do we need to make changes to the State Plan based on these findings?"

At the end of the retreat or meeting, the products are often in varying stages of completion. Some Councils come out of the retreats with a full set of goals and objectives, and others come out with a prioritized list of areas of emphasis. Most Councils reported that the Council staff takes control of the synthesis at this point in the process, develops a set of goals and objectives, and submits them for review to Council members. As one Council executive director explained, the State Plan committee "categorize[s] all the information received within the different priorities; they take a bunch of different information and say, 'What is the critical theme that these five or six or seven things are related to?' We tend to come up with a list of priorities from that." However, a few Councils have Council subcommittee comprised of Council members to develop the goals and objectives. Regardless of who develops them, the goals and objectives are always presented to the Council for review and, ultimately, approval.

When asked about emerging and emergency issues, the majority of the Councils in the study sample indicated that they purposely write the State Plan in broad terms such that an emerging or emergency issue can be included in one of the areas of emphasis set forth by the plan. In some cases, though, an entirely new issue may arise, and the Council needs to decide how to address the issue. One Council executive director reported "if we identified an emerging issue, I would schedule a meeting with the executive committee…and say, 'we need to look at this in light of the other priorities that we have.' What we probably would do is have the executive committee make a decision on what they think is the appropriate way for us to respond." This executive director provided an example. An Autism bill was drafted, and the Council was asked to support and advocate for the bill. As the executive director explained, "there wasn't anything specific to the autism bill [in the State Plan]. But we looked at it and said, '…we need to do this' so we built it in and reallocated time towards working with the legislature, providing testimony."

Self-Advocacy and Leadership Activities. The DD Act states that Councils "may support and conduct activities to educate the public about the capabilities, preferences, and needs of individuals with developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills." Thus, all Councils support, in some capacity, a program designed to develop and enhance self-advocacy among people with developmental disabilities. All sampled Councils provide the opportunity for people with developmental disabilities to participate in self-determination or self-advocacy training. Generally speaking, the trainings teach individuals about the services that are available and what individuals can do for themselves to obtain the assistance that they need and want. In addition to offering training programs, most Councils offer limited funds for people with developmental disabilities and family members to attend selected disability-related conferences and meetings that provide opportunities for development and improvement of self-advocacy skills.

An additional example of self-advocacy activities came from one Council that provides a one-year fellowship to a person with a developmental disability to complete a disability-related project, such as developing a training module for peer-led self-determination training. Several Councils have adopted, a peer-led self-advocacy or self-determination training program. In these examples, people with developmental disabilities develop and deliver the training to their peers. In one example, Council members talked about the difficulty they had in bringing self-advocacy activities to the Native American population. The Council decided to train a Native American individual with developmental disabilities to provide self-determination training. This Council reported success in reaching that population for the first time as a result.

In addition to self-advocacy activities discussed above, Councils engage in activities with the goal of teaching people with developmental disabilities and others how to engage in activities directed at systems change (e.g., changes to policies, practice, or programs). Program visit findings suggest that this can be a powerful experience for people with developmental disabilities to have an impact on the system and to make a difference for someone other than themselves. Partners in Policymaking is a program that is supported by a large number of Councils, including many in the study sample. The program teaches leadership skills and techniques to develop positive partnerships with policy decision makers (e.g., elected officials, school personnel) and others who make policy decisions about services used by people with developmental disabilities and their families. Program visit interviews conducted with many graduates of the program indicate overwhelming satisfaction with the usefulness of the program, and many of the graduates have gone on to serve as advocates in the community. In one state, a Partners in Policymaking participant explained that the program "is kind of an all encompassing training about the history of disabilities in the world…getting into specific topics each month from education and how policy comes about, how to create community for people with disabilities, just whole life planning—pretty much just a really broad overview of everything I needed as a parent." Another participant (a parent) reported that "the whole program I can honestly say changed my life. Not only mine, but our family, and how we're going to move forward in dreaming big dreams for my son."

Councils do not always implement the full Partners in Policymaking curriculum, as developed by the Minnesota Council, and were instead revising the curriculum to fit their needs. In at least two Councils, the executive directors indicated that the Council was using a Partners in Policymaking curriculum (e.g., Partners "with a twist"), meaning that they made changes, omissions, and/or additions to the original curriculum.

Councils also offer other self-advocacy programs, such as training on developing an advocacy plan (identifying who needs to be involved, bringing people together), training on advocating for public policy (providing testimony, writing effective letters), and guardianship training. Recipients of some of these other programs report, "I learned about focusing on myself and how to become a leader" and "They taught you how to become a leader, what a leader should look like, self-confidence, public speaking, providing testimony."

For most of the trainings supported by the Councils, participants are asked to complete satisfaction surveys that elicit feedback on satisfaction with the content, the speaker, the format, the setting, and other related variables. Most of these surveys use a paper and pencil format and are collected immediately following the training. In a few instances, Councils used web-based satisfaction surveys, asking conference attendees to access the survey following the conference and provide feedback on the event. In addition to tracking satisfaction of people with developmental disabilities, these surveys also help to track participation. For Councils that contract with grantees to provide trainings and other programs, the monthly reports from the grantees appear to be a valuable evaluation tool. The monthly reports require the grantees to indicate progress made in terms of the goals set for the project.

Councils that support the Partners in Policymaking trainings seem to use a more formal approach to evaluating the program. Several sampled Councils reported implementing a pre- and post-training survey designed to evaluate knowledge acquisition, content competency, and learner satisfaction with the training as well as determine participant expectations for the training. In addition to the pre- and post-training survey, most sampled Councils also collect evaluation forms for each training session conducted. The Partners in Policymaking curriculum is comprised of multiple training sessions and Councils typically collect information following each session regarding competency and satisfaction with content, presenter, format and other related issues. A small number of Councils indicated that they encourage Partners in Policymaking participants to contact the training coordinator, Council staff or Council members with any concerns or questions about the program, opening the door for participants to call Council members and staff with feedback on the program.

Finally, most sampled Councils that support Partners in Policymaking reported having some method for surveying graduates of the program to learn how the graduates are using what they learned and how they have become involved in the disability community.

When asked about how they used the assessment data collected, most sampled Councils reported that feedback was used in future planning. Councils use the data in the planning process to develop the goals and objectives for the State Plan. Councils also use the data to highlight new areas of interest or need for trainings and help plan training sessions so they are more efficient and effective.

According to the DD Act, the State Plan for each DD Council is required to include a goal, for each year of the grant, to establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities. All sampled Councils reported that they have already established a self-advocacy organization and are in different phases of establishing the organization's independence from the Council. While several Councils described the relationship with the organization as informational (e.g., being available for consultation via telephone or email), most reported having a more formal relationship, defined by the provision of funding. One Council hired a consultant to visit self-advocacy organization offices in the state to assist in developing a sustainability plan that relied on the organization's own efforts instead of the funding efforts of the Council. The support to the self-advocacy organizations provided by the Councils falls into two general categories—financial support and provision of expertise. Some Councils provide both.

Most Councils reported providing the self-advocacy organization with some level of funding, including financial support to attend or host conferences and trainings, seed money for start-up activities, infrastructure grants (e.g., funding for office space, supplies, technical assistance, travel), and core grants. In addition to providing funding, several sampled Councils reported that they provide some technical assistance and training around the general topic of building the self-advocacy organization. For example, one Council described providing the organization with training on what it means to be a self-advocacy organization, what it means to form a group around self-advocacy, and how to recruit members for the organization. Another Council works closely with the self-advocacy organization to identify and tap into existing expertise in the disability network available to the organization (e.g., developing an organization web site and writing grant applications).

Self-advocacy and leadership development activities reported in the SAQ included attendance at self-determination conferences, participation in Partners in Policymaking, leadership trainings, self-advocacy skills development classes, and youth leadership forums. The number of individuals participating in these activities ranged from 56 in one state to more than 9,000 in another, according to findings from the SAQ. Three states reported more than 5,000 participants in their self-advocacy and leadership activities, while two reported fewer than 200 (Table 3-7).

Table 3-7. Participants in self-advocacy and leadership development programs among sampled councils*

Number of participants	Number of sampled states/territory
<200	2
200 – 399	4
400 – 999	4
1,000 – 4,999	5
5,000+	3
Missing	2
Total	20

*Source: Self-administered Questionnaire (SAQ)

Systems Change Activities. A major focus of all SCDDs is system change. In looking at systems change activities supported by the Councils, Westat examined how Councils organized themselves and others, how the issues were identified, which systems change tools or activities were used, and what the outcomes were of systems change activities (see Section 3.4.1.5).

Most sampled Councils reported being part of a larger advocacy group or coalition of stakeholders. These groups were often comprised of disability network stakeholders in the state or territory, such as the executive directors from the Council, P&A, and UCEDD, representatives from self-advocacy organizations, and representatives from other disability-related organizations. The intent of these groups, according to the Councils, is to support advocacy efforts for the good of the disability community. In one state, the Council reported organizing advocacy groups for different issues. For example, the special education collaboration, comprised of school superintendents, representatives from the state Department of Education, teachers, special education administrators, and advocates, worked to pass a bill requiring special education services to begin transition planning at age 14. In addition to the advocacy groups, many sampled Councils support or organize grassroots groups for systems change activities. Several Councils reported engaging in community organization activities so as to engage self-advocates and family members of people with developmental disabilities in systems change activities.

Mostly, Councils in the study chose issues based on the goals and priorities contained in the State Plan. In addition, several indicated that, sometimes, issues arise that are not necessarily part of the policy agenda for the year but need to be addressed regardless. These emerging or emergency issues often involve things such as impending budget cuts by the state legislature or multiple cases of abuse and neglect reported about a particular institution.

Based on the issues selected for systems change activities, Councils develop plans or approaches to the efforts. One Council described developing strategic plans with the advocacy groups (stakeholders) around the issues. Depending on the issue and the associated goal, the Councils engaged in a myriad of advocacy activities. Most of the activities fell into one of two categories: (1) activities designed to build awareness among the general public about disability-related issues, and (2) activities designed to educate and inform policy-makers about various disability-related issues.

Most sampled Councils reported using the media to disseminate information for the purpose of educating and informing the public about disability-related issues. Councils reported writing letters to the editor and editorials for local newspapers, alerting local news stations about situations involving people with developmental disabilities and lack of services or resources, collecting signatures for petitions, and distributing press releases about pending issues. In addition, several sampled Councils reported organizing large public gatherings with the intent of raising awareness about disability-related issues.

Sampled Councils engaged in a variety of activities to educate and inform policy makers about disability-related issues. All Councils reported developing materials to use for educational purposes. These materials include position papers, talking points, Q&A documents, and reports. In addition to these materials, most Councils reported participating in some form of presentation of the issues to members of the legislature. For example, several Councils hold annual legislative receptions that provide self-advocates and advocates the opportunity to speak with and provide information to legislators about the issues in the state. A few Councils reported delivering presentations to legislative committees, and others reported providing information to the general assembly. All sampled Councils indicated that a primary systems change activity frequently used is the support of self-advocates to provide testimony or meet with legislators on the issues. Often, Councils will work with self-advocates to develop testimony or talking points to be used by the self-advocate. A UCEDD in the state often provides information for these documents. The other common activity for systems change with policy makers is participation in the drafting of legislation to submit to the legislature for review and vote. Sometimes the DD Network successfully navigates the legislation and is able to bring a piece of legislation to vote. In those cases, systems change activities include meeting with legislators to discuss the legislation, providing support to individuals interested in testifying, and offering data and information to educate and inform policy makers.

Grantee Selection. All sampled Councils reported having a process for selecting grantees to implement their projects. Most Councils indicated that they follow state procurement regulations and offer a competitive grant program. According to program visit findings, all sampled Councils issue requests for proposals (RFPs) for programs or activities they want to fund. As proposals are received, the Council reviews and rates them.

All Councils have some type of a review committee for grant applications. Most of the committees are ad-hoc and change according to the project. These committees typically include Council members, staff, and individuals from disability organizations that have relevant knowledge and expertise. A smaller number of Councils have a standing review committee that is comprised of Council members and staff only and do not include outside members. One of the Councils reported providing orientation for review committee members to ensure that members are knowledgeable about the review process and are able to meet the responsibilities of being on the review committee. A few Councils also indicated that they ask review committee members who may have a conflict of interest to recuse themselves from the review process. Most Councils reported having written criteria for scoring and/or ranking the proposals. Review committees read and evaluate the proposals and recommend one project (or more if funding allows) to the Council or just the executive committee of the Council for funding.

Most of the sampled Councils did not have a policy in place for handling an unsolicited proposal but, nevertheless, reported that they do not accept them. A small number of Councils reported that they accept unsolicited proposals if they are related to a goal from the State Plan or review them periodically.

It is worth noting that, while all sampled Councils have a policy in place for funding proposals, not all of them actually do fund proposals. As one executive director explained, "we made a very conscious, philosophical decision that being a minimum allotment state we were not going to do pilot programs, that it was the voice of families and self-advocates who said 'you've done enough pilot programs.'"

3.4.1.4 Council Outputs

Council outputs (or products) described in the Findings Form consist of the 5-year State Plan, educational programs to build community capacity, and publications. These outputs are described below.

State Plan. All sampled Councils indicated that the State Plan is the guide that shapes all Council activities, whether ongoing or future activities. The goals and objectives set forth by the State Plan provide the Councils a base from which initiatives are developed. As one executive director described, "everything we do is based on the State Plan, the goals and the objectives. Does it [proposed initiative] relate? Does it meet our needs?" Some sampled Councils reported that the State Plan is distributed to other organizations to inform them of the Council's priorities. As described by an executive director, "every task force gets this [State Plan], every program planning committee gets this."

Community Capacity Outputs. All sampled Councils support efforts designed to improve the capacity of the community to support inclusion of people with developmental disabilities. Although not the only way to improve community capacity, many Councils attempt to improve community capacity by increasing community awareness, knowledge, skills, and abilities and improving the infrastructure for service delivery throughout the State. Councils work with appropriate collaborators or grantees to develop and implement strategies and activities for community capacity building, including provision or support of seminars, forums, workshops, demonstration projects, technical assistance, outreach, and public awareness.

The bulk of sampled Council community capacity programs efforts fall into one of three categories: (1) health care; (2) employment; and (3) education.

Health care related community capacity efforts provided by the Councils are mostly designed to educate health care providers about how to provide services to people with developmental disabilities in an effective and sensitive way. Several of the sampled Councils fund trainings for oral health care providers that teach them how to provide dental services to people with developmental disabilities. In one instance, a Council created a DVD of the training and distributed it more widely to other oral health care providers. Other examples of health care related programs provided by the Councils include scripts developed to assist providers and people with developmental disabilities in navigating health care appointments and disability sensitivity training for health providers.

Community capacity programs related to education offered by the sampled Councils focus on competitive employment. Several of the Councils developed trainings that teach employment specialists and job coaches about securing competitive employment for people with developmental disabilities and the concept of employment first, and moving people with developmental disabilities into integrated employment opportunities and away from sheltered workshops and other sub-minimum wage programs.

Sampled Councils also provided a number of community capacity programs related to education. Programs, such as Partners in Transition, focused on bringing together teams of transition specialists, secondary school and college faculty and staff, and employers to promote to the school district best practices around transition from school. Another similar project creates partnerships between secondary schools and higher education institutions and offers students with developmental disabilities the opportunity to participate in college courses. This provides these students with access to education that could facilitate the achievement of competitive employment outcomes. In addition, one Council supports a program for providers of early childhood education and daycare designed to promote strategies of inclusion and education about resources available.

Sampled Councils also provided community capacity programs related to other issues. For example, a small number of the Councils provide a program that focuses on bringing together justice system and law enforcement personnel to learn about helping people with developmental disabilities who have been a victim of a crime to navigate the legal system. Some Councils offer programs that promote inclusion of youth with developmental disabilities in recreational settings. For example, one Council partnered with the local YMCA to develop protocols for teachers with students with developmental disabilities, and another Council partnered with the local outdoor association to do the same.

The SAQ collected data from sampled Councils on the number of individuals that participate in Council-supported community capacity development activities (Table 3-8). More than 100,000 participants were reported by 17 sampled Councils, with a range of 197 participants in one Council to more than 44,000 in another. Four Councils reported more than 5,000 participants in their community capacity development activities. Participants, as reported by the Councils, included recipients of disability awareness media campaign materials, participants of oral health trainings for people with disabilities, participants of inclusion workshops, and recipients of information disseminated during general disability awareness activities.

Table 3-8. Participants in community capacity development activities among sampled councils*

Number of participants	Number of sampled states/territory
<200	1
200 – 399	3
400 – 999	4
1,000 – 4,999	5
5,000+	4
Missing	3
Total	20

*3 states did not report

Total no. participants = 103,167

Mean (SD) no. participants: 6,068 (12,178)

Median: 1,002.0

Range: 197 – 44,310

Councils typically collect satisfaction information from participants on the community capacity programs. The vast majority of recipients interviewed for this study reported being extremely satisfied or satisfied with the programs. One recipient reports that she was, "extremely satisfied…our affiliation with this program was sort of a shot in the arm for our entire campus. I think it changed the minds and attitudes of students, faculty, and staff administration." And another respondent stated, "I was actually amazed at the capabilities that this entire community had to embrace a population of students that had been excluded all these years."

Publications. Most of the publications distributed by Councils are developed to communicate promising practices identified through Council funded programs and research. Overall, most of the Councils in the study use the Council web site to disseminate information and findings from programs. Most Councils also present findings at conferences and meetings, both on the Federal and state level. In addition, some of the Councils have a regular newsletter that is sent to the Council listServ and distributed statewide.

3.4.1.5 Council Outcomes

In addition to structures, processes, and outputs, the SCDD Findings Form contained several indicators on program outcomes. Outcomes are the intended results of creating certain outputs or products (French & Bell, 1984). Long-term outcomes (e.g., increased access to supports and services; increased employment among people with developmental disabilities; improved transportation; increased independence, productivity, self-determination, integration, and inclusion) are achieved not only through the efforts of DD Network Programs, but also through the combined efforts of a large number of organizations, agencies, and individuals in a state. It is not possible to demonstrate directly that one or more of the DD Network programs were completely responsible for these types of long-term outcomes throughout the community; contributions from each program and other factors combine to result in improved outcomes. Thus, the National Independent Study focused more on the short-term outcomes that result from DD Network program contact with specific target audiences. The following section describes the short-term outcomes as reported by sampled Councils. We organized these outcomes into systems change outcomes, including changes to community practice, and outcomes related to self-advocacy and leadership.

System Change Outcomes. Councils engage in activities that often support changes to or maintenance of legislation or public or social policy to address opportunities for improvements to supports and services for people with developmental disabilities and their families. Interviews during program visits garnered several examples of these changes. Often in collaboration with other organizations, Councils reported that their systems change efforts resulted in:

- Creation of the Gold Alert system, which is modeled after the Amber Alert and designed to post an alert if someone with a disability goes missing,

- Passage of a bill allowing people with developmental disabilities to go out of the insurance network for dental services if their in-network dentist cannot or does not provide services to people with developmental disabilities,
- Passage of legislation requiring that funds from the sale of residential centers be put into a trust for community services,
- Passage of legislation approving a wage increase for direct service providers,
- Passage of legislation that mandates transition planning to begin at age 14,
- Increased appropriation of funding to address the Medicaid waiting list,
- Passage of legislation making it a misdemeanor crime to prohibit service dogs from schools and workplaces,
- Passage of legislation that revised the guardianship process, requiring that the least restrictive environments for people with developmental disabilities are explored before full guardianship is implemented, and
- Establishment of an Autism Commission tasked with obtaining "buy-in" from local and state governments on issues prevalent in the autism community.

Changes in Community Practice. Councils also engage in systems change activities that support changes to community practice to increase inclusion of people with developmental disabilities within the community. Examples provided by sampled Councils include:

- Changes made in the system for training law enforcement and judicial personnel on how to interact with people with developmental disabilities who are victims of a crime or are involved in a legal/judicial matter,
- Increases in inclusion of youth with developmental disabilities at local recreation centers by developing protocols for training teachers to include youth with developmental disabilities in activities,
- A coordinated transportation policy within county agencies, resulting in a provision that all vehicles owned or leased by county agencies must be available to other agencies for use.
- Increased community and home-based services, which resulted in the closure of four residential facilities,
- Introduction of a program, adopted by many day rehabilitation centers in the state that has dental hygienists go to the center weekly/monthly to provide services to people with developmental disabilities,
- Development of an organization (which is now an independent 501(c)(3)) that is tasked with supporting recruitment of competent direct care staff,

- Increased accessibility in all polling places in the state by allowing people with developmental disabilities the choice of polling place and early entrance to polling places,
- In collaboration with a large hospital, development of a program which produced protocols for health care providers and early intervention providers to better serve families of people with developmental disabilities, and
- Establishment of a modified high school diploma for use with youth with developmental disabilities who had not achieved "graduate" status but were transitioning out of high school.

Changes in Advocacy and Leadership. Lastly, Councils regularly engage in activities that support self-advocacy and leadership among people with developmental disabilities and family members. Councils were able to provide scores of examples of program outcomes related to advocacy and leadership among those who participated in these activities, including:

- Graduates of Partners in Policymaking who have gone on to become members of Councils,
- Graduates of Partners in Policymaking who regularly engage in systems change efforts,
- Graduates of Partners in Policymaking who run for state representative, City Council, and school board elected positions, and
- People with developmental disabilities and family members who provided testimony for various advocacy efforts.

3.4.2 Protection and Advocacy Systems

This section maps the P&A findings from program visits, SAQ results and program materials to the Findings Form contained in Appendix H. We begin with a general description of the P&A system and then describe P&A structures, processes and activities, and the outputs and outcomes achieved by P&As.

3.4.2.1 General Description

Subtitle C of the DD Act authorizes the establishment and implementation of P&A systems in each state, Puerto Rico, the four outlying areas (American Samoa, Guam, the Virgin Islands, and the Commonwealth of the Northern Marianna Islands), and the Native American Protection and

Advocacy Agency. The purpose of the P&A system in each state, territory, and agency is to protect the legal and human rights of people with developmental disabilities in accordance with subtitle C, section 143(a) of the DD Act.

The responsibilities of P&As funded under the DD Act are very explicit. According to 42 USC 15043 SEC. 143 of the DD Act, P&As have authority to pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of people with developmental disabilities within the State or territory and to provide information on and referral to programs and services addressing their needs.

P&As have authority to investigate incidents of abuse and neglect of people with developmental disabilities, including accessing records related to such instances. They have authority to access records of people with developmental disabilities receiving services, supports and other assistance, if the health or safety of the individual is in serious and immediate jeopardy or if the person has died; to develop goals and priorities through data driven strategic planning and work toward achieving those goals and objectives; to establish a grievance procedure for P&A clients or prospective clients; and to have access at reasonable times to any individual with a developmental disability in a location that provides services, supports, and other assistance, in order to carry out the purpose of the DD Act. P&As must be independent of any agency that provides treatment, services, or habilitation to people with developmental disabilities.

3.4.2.2 Structures

Structures described below consist of P&A funding, agency type, location, relationship with the governor and state agency, staff, and governing board composition and operations.

Funding. The Protection and Advocacy of People with Developmental Disabilities (PADD) system is one of several P&A funding sources authorized by the DD Act. Of the 20 P&As studied, most receive funding from seven P&A funding sources: Protection and Advocacy for Persons with Developmental Disabilities (PADD), Protection and Advocacy for Individuals with Mental Illness (PAIMI), Protection and Advocacy for Traumatic Brain Issue (PATBI), Protection and Advocacy for Individual Rights (PAIR), Protection and Advocacy for Voters Access (PAVA), Protection and Advocacy for Beneficiaries of Social Security (PABSS), and Protection and Advocacy for Assistive Technology (PAAT). An eighth possible funding source for P&As is the Client Assistance Program (CAP). Eleven P&As in the study also receive CAP funding.

P&As maintain complex accounting procedures so they are able to report the distribution of funds by funding source. While sometimes considered to be cumbersome, some executive directors see this disadvantage somewhat offset by the fact that having multiple funding sources allows P&As to serve certain individuals with developmental disabilities through one or more funding sources, depending on the issues involved. In addition, some P&A grants allow programs to carry over funds and some do not. Multiple funding sources enable P&As to provide consistent service delivery for P&A clients.

P&As do not charge clients or family members for their services. While most P&As in the study do not receive state funding, state-funded programs offer another possible funding stream. For example, one P&A houses a State-funded program to assist people with disabilities who have Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) claims.

The total allotment for P&As for the PADD program in 2010 was $40,203,250. P&As in seven sampled states received the minimum allotment ($384,693), and one territory received $205,808. The remaining allotments ranged from $646,370 to $2,009,118.

Agency Type. One P&A in the study is located within a university, 16 are non-profit agencies, and three are independent state agencies. Non-profit agencies are not part of state government and most often operate like private non-profit law practices. Whatever the agency type, the DD Act requires all P&As to act independently from the state.

Location. Sixteen P&As felt location was an organizational issue worth mentioning. Rural P&As report missing out on downtown/city walk-in traffic and have difficulty with client access to the P&A if public transportation is not available. Where distance is an issue or the state population is high, P&As operate out of satellite or regional offices. One P&A outsources all its individual advocacy cases to legal service organizations throughout the state. P&As operating in smaller states or territory find systemic advocacy easier because in-person meeting are likelier to occur more often and policy makers are more accessible. Being housed in a building shared by other disability-related organizations also was reported as an advantage.

Relationship with the Governor and State Agencies. The DD Act states that “nothing in the Act shall preclude a system from bringing a suit on behalf of individuals with developmental disabilities against a State, or an agency or instrumentality of a State.” Three P&As specifically reported no infringement on their activities on the part of the Governor or other state agencies with regard to the P&A's authority to litigate against local and state government. Nine P&As reported that they have litigated against the state. They reported having filed individual advocacy and class action suits against the state, including cases involving institutional housing for people with developmental disabilities, prisons, and death investigations. One executive director characterized the P&A as a "watchdog" with regard to the rights and treatment of individuals with developmental disabilities and maintain there are no issues that are "off the table" because of the relationship between the governor or state agencies. Another reported that specific state law facilitates P&A access authority. Regardless of agency type, most P&As agreed that "cultivating as collegial a relationship as possible with state officials" is important.

Staff. Most P&As operate with a combination of attorneys, advocates, paralegals, and administrative staff. However, staff size varies, as do responsibilities to which staff is assigned.

Among P&As in the study, size of staff ranged from 3 to 64 individuals. The P&A executive directors in the study have been in their positions from 2 to 33 years. Most are attorneys; two are not. At the time of program visits, two executive director positions were vacant; both positions have now been filled. Four P&As reported that the P&A governing board annually reviews the executive director's performance.

One P&A reported quarterly reviews for new staff tied to a work plan designed specifically for that person. A majority of the study P&As reported formally reviewing staff performance on an annual basis, at a minimum. Performance reviews include reviewing filed grievances in which a staff person is named, client satisfaction surveys, and case work and intakes. In some of the P&As, the executive director reviews senior staff and the legal directors review other staff and advocates. In another, there are regular supervision meetings between team leaders and attorneys. Case reviews range from ongoing case monitoring, formal weekly case review meetings, or full case reviews every four to six weeks during which team leaders mentor others on the team. According to one supervising attorney, "The mentor meets with the mentee or supervisee and goes through all of the mentee's cases." The executive director follows the same procedure for the mentors and the team leaders to model the procedure for the mentors. When asked to describe his performance review process, one executive director noted that he goes through people's basic job descriptions, job functions, related issues and concerns, training interests and needs, administrative issues such as maintaining complete case notes, and goals to be working toward during the year. In one P&A, each staff person writes a self-evaluation to share with his or her supervisor.

While some P&As have no difficulty attracting and keeping highly qualified candidates, others find it difficult to maintain staff. One P&A reported having difficulty recruiting because of staff salaries and geographic challenges. On the other hand, another P&A reported having 50 applicants for one recently advertised position. Still another described very low turnover and little need to recruit new staff.

All P&As reported having some bilingual staff. In general, P&A staff characteristics include:

- Connection to native communities and unserved or underserved populations,
- Former users of P&A services,
- Backgrounds in social work, psychology and counseling, legal aid, or work with people with developmental disabilities and their families,
- Experience in Medicaid and health care issues, ADA accommodations and compliance, general and special education, vocational rehabilitation, and transition and employment issues,
- Experience in litigation, research, and investigation, and
- Background in legislation, policy work, and fiscal management.

Governing Board Composition and Operations. Three P&As in the study are state agencies and one resides within a state university structure. The rest are private non-profit entities. Section 144(a) in the DD Act on the P&A governing board specifies that in a state in which the P&A is organized as a private nonprofit entity with a multimember governing board, or a public system with a multimember governing board, the governing board must broadly represent or be knowledgeable about the needs of the individuals the P&A serves; and a majority of board members must be "individuals with disabilities, including individuals with developmental disabilities, who are eligible for services, or have received or are receiving services through the P&A" or their parents, family members, guardians, advocates, or authorized representatives.

Data from the SAQ indicate that among all P&As included in this study, there are 13.3 percent of governing board members with a developmental disability and 5.2 percent with an intellectual disability (Table 3-9). P&As in the study also reported that almost 83 percent of their members have an understanding of the developmental disabilities population, and 86 percent have knowledge of policy and laws related to people with disability. Almost half have knowledge of business or finance (45.8 percent), and almost one-quarter of all governing board members represent a minority in the state.

Table 3-9. P&A governing board composition*

Characteristic	Number of board members	Percent**	Mean (SD)	Median	Range	Number of P&As reporting
Members with a developmental disability	33	13.3	1.8 (1.3)	1.5	0 - 5	18
Members with intellectual disability	13	5.2	0.7 (1.0)	1.0	0 - 4	18
Members who have an understanding of developmental disabilities population	206	82.7	11.4 (4.7)	11.5	4 - 20	18
Members who have knowledge of policy and laws related to people with disability	214	85.9	11.9 (4.0)	11.0	6 - 20	18
Members who have knowledge of business or finance	114	45.8	6.3 (4.5)	5.5	1 - 20	18
Member who represent a minority in the state	60	24.1	3.3 (2.1)	3.0	0 - 8	18

*Source: Self-administered Questionnaire (SAQ)

**Denominator is 249 (number of slots filled)

Data from the SAQ indicate that the size of P&A governing boards range from 6 to 21 members, with a mean of 14.9 and a median of 14.5 slots filled. Another DD Act requirement regarding the P&A governing board is that any vacancy in the board shall be filled not later than 60 days after the vacancy occurs. According to the SAQ, between October 1, 2008 and September 30, 2009, the total slots available was 268; 249 were filled and 19 unfilled, resulting in a vacancy rate of 7.1 percent. Moreover, 100 percent of all governing board member slots were filled in 11 P&As (Table 3-10). In three P&As, 90-99 percent of governing board positions were filled, and in four P&As, fewer than 90 percent of positions were filled. Two P&As did not report on governing board vacancies during that period.

Table 3-10. Percentage of board/commission slots filled*

Percentage of slots filled	Number
100	11
90-99	3
<90	4
Missing	2
Total	20

*Note: numbers are small so percentages are not calculated.

All P&As reported providing training and accommodations to help governing board members carry out their responsibilities. Training included orientation on specific roles of the governing board and member responsibilities, the P&A's goals and priorities, and issues related to the developmental disabilities community. One P&A reported that its auditor trains the board in fiscal policy and presents the audits annually to the board. Accommodations to enable members to participate effectively in board meetings include reimbursement of expenses, transportation when necessary, sending board materials in advance of meetings in multiple formats (Braille, large print, electronically) when necessary, meeting with board members before the meeting to go over materials, and sitting next to board members during the meeting to answer questions and make sure the member understands what is being discussed. All board members interviewed reported that they were satisfied that the P&A is providing whatever accommodations are needed.

When asked to describe their roles, responsibilities and activities in which they participate, governing board members reported the following:

- Providing feedback on the most important needs in the state and participating in the planning and priority setting process to help the P&A set annual goals, priorities, and objectives,
- Advocating for supports for individuals in their communities,
- Being familiar with the P&A mission and the work of the UCEDD, State Council on Developmental Disabilities, and other developmental disability programs in the state,
- Attending, participating in, and conducting P&A presentations,
- Overseeing the fiscal integrity of the P&A including reviewing the budget, meeting with auditors, and reviewing and accepting the audit,
- Helping with fundraising, and
- Helping with policy setting and sitting on Board committees.

In one interview, a Board member acknowledged not participating in P&A activities recently and not being able to describe Board policies.

Additional examples of governing board and management practices emerged during the study (Table 3-11).

Table 3-11. Examples of governing board and management practices

Practices
▪ Board meetings are conducted in a different city each time and Board members try to connect with the stakeholder organizations in each city conducting outreach for the P&A. ▪ Board members received training from a non-profit group that provides capacity-building training to other non-profits. Fundraising and Board governance were among the topics covered. ▪ The director of finance and administration and the director's accountant annually attend the National Disability Rights Network (NDRN) Fiscal Managers Conference for ongoing exposure to federal program staff who handle fiscal issues. They bring the information back to the Board, and the P&A make changes, as needed. ▪ The P&A prepares its budgets two years in advance. ▪ The P&A gives Board members an annual allowance to use to attend conferences for professional development. ▪ Board members actively participate in fundraising. ▪ Board members actively participate in outreach. ▪ Experienced Board members mentor new or less experienced members. ▪ Since the full Board meets only four times a year, committees that meet more frequently are organized to keep the Board members engaged and "feeling like they're part of what's going on."

3.4.2.3 Processes and Activities

Process indicators listed in the Findings Form for P&As consist of planning and priority setting, intake and assistance, and individual advocacy. For example, P&As meet with stakeholders in a variety of settings to plan and prepare their annual statement of goals and priorities (SGPs), implement standardized procedures for providing intake and assistance to callers[7] and potential P&A clients, and follow specific guidelines and rules of operation for interacting with individual advocacy clients.

Planning and Priority Setting. Like State Councils, P&As have a process for planning and priority setting that includes gathering input and other information to determine state needs and synthesizing all information to produce a plan that reflects the needs of people with developmental disabilities and family members in their state. Instead of a 5-year plan, however, P&As are required to conduct planning and priority setting activities on a yearly basis.

In general, all study P&As follow a process of input gathering and analysis; synthesis of input into goals, priorities, and objectives; staff and governing board review and editing; and final governing board approval. P&As follow several planning and priority setting processes and conduct many diverse activities for collecting input on the needs and priorities of people with developmental

---

[7] In this report, callers consist of those who call by telephone or appear in person at a P&A office.

disabilities and family members. In the words of one executive director, the result is input from a "very, very broad cross section of people." One executive director sums up the input process in these terms.

> Primarily, we get input from everyone—clients, supervisors, service providers, family members, professionals familiar with individuals with developmental disabilities and their families, parent support groups, our staff, our Board/advisory council, interviews with clients and post interviews for information about how they felt the services worked, public planning sessions at the start of each fiscal year. We also send letters to parents, guardians, clients, service providers, board members, individuals in the community. We advertize in the newspaper and journals. People are given 45 days to provide public comment. After 45 days, they can still provide public comment, but it has to be in writing or over the phone.

Over half of the P&As we visited identified specific unserved or underserved populations to whom they reach out to make sure their input is included in the planning and priority setting process. These groups range from ethnic minorities in poor rural parts of the state, to recent immigrant populations and others for whom English is a second language, to people with low prevalence disabilities who may find it difficult to travel to input gathering sessions, to individuals isolated in correctional facilities or group homes, to tribal groups who may be suspicious of outsiders and hesitant to attend and speak up at public meetings. According to one executive director, outreach to unserved or underserved populations is "part of the balancing act" as they balance limited resources with geographic challenges. Another executive director explained, "We use any venue that we can to reach rural areas and underserved and minority population there. Our most effective process is to try to piggyback on to the work of organizations that are a little more grassroots than we are."

In developing the SGP, sources of input are many and varied for P&As (Table 3-12). Most sampled P&As administer online surveys and use feedback from ongoing P&A activities. One P&A uses a dedicated phone line for six to eight weeks for people to call in and provide input. About half also conduct focus groups, obtain informal feedback from staff and the governing board, analyze telephone calls and rely on public planning sessions, hearings, and meetings. One P&A collaborated with the state's Council and UCEDD to co-sponsor a half-day focus group during which all give overviews of what they do and the roles they play in the state. This is followed by a question and answer session and quarterly meetings as a network to follow up on the input received.

Table 3-12. Reported sources of input for planning and priority setting

Source of input	Number of P&As reporting using the source
Online and other surveys, including client satisfaction surveys	18
Feedback from ongoing P&A activities	16
Analysis of telephone calls to the office	12
Informal feedback from staff and Board	11
Formal reports from staff, work groups, and Board	11
Focus groups, including tri-agency focus groups with the DD Council and UCEDD	10
Public planning sessions, hearings, and meetings	10
Contact with all major DD service providers, advocacy groups, and policy makers through attendance at their meetings, conferences, and other activities	9
Has a seat on, participates in activities of, or has regular meetings with or phone consultations with related state agencies or organizations*	8
Forums and "listening sessions"	7
Staff or Board retreat	6
Postings on P&A web site	5
"e-blasts" to people with developmental disabilities, family member, service providers, and advocacy groups	4
Notices in newspapers, journals, and newsletters	4
Review of records of all information and referral cases	4
Regular contact with the DD Council and UCEDD including sitting on their boards and attending their meetings	3
Feedback from Ombudsman and others going into institutions	2
Letters and postcards to stakeholders	2
Requests through various listServs	1
Formal needs assessment	1

*Examples are Governor's Council, Center for Human Development Council; People First; Division of Senior and Disability Services, Mental Health Advisory Council, Judge magistrate, Secretary of the Department of Health, Director of Developmental Disability Services Division, State Rehabilitation Council, DD Consortium, Disability Coalition.

The sentiment of many executive directors is that their P&A is constantly looking for public input, whether they are at regular governing board meetings or in the middle of a public comment period. They make note of what people are saying, the problems they are facing, and whether or not the P&As are addressing their issues.

More and more P&As are using electronic social networking media like Facebook and Twitter. One reported having 800 "friends" at the time of our interview Use of electronic social networking media appeals to a younger population and those who are isolated, live in rural areas, or do not have transportation and cannot get to public meetings or hearings.

Intake and Assistance. All P&As engage in intake and assistance to provide information and referral services. P&As provide these services as a way to support self-advocacy among callers, learn about systemic issues, increase public awareness about disabilities and disability rights, and direct individuals to appropriate P&A services.

The intake and assistance function at all P&As has several characteristics in common. A potential client approaches the P&A in person or by telephone, and an intake staff person or receptionist solicits basic information about the potential client including disability status and nature of the request. Information is collected via an intake form (either electronic or hard copy). The intake staff member determines if the request falls within the P&A's priorities or presents an emerging or emergency issue that warrants further review. The caller may be referred to another agency, provided with information and further resources, or referred for further consideration by a P&A attorney, advocate, team leader, or other P&A staff person. The staff person determines the appropriate response consistent with a case acceptance policy.

Most P&As have designated intake and assistance staff. Intake staff may simply answer calls, provide basic information, and pass the call on to an advocate or attorney for followup. According to one executive director, "The intake specialist is more of an "information gatherer." A call will come through or a person will walk in, be initially dealt with by the receptionist and then transferred over to the intake specialist." Other intake staff performs information and referral work, including a determination of whether or not a case needs to be referred to an attorney or advocate for followup. Intake at one P&A is rotated among four case advocates who specialize in different topic areas (employment, assistive technology, abuse and neglect, and special education). Another approach is to have a receptionist or support staff prescreen calls. If the call falls within the P&A's priorities, the call waits in a queue for the next available short term assistance team member to take the call and handle it on the spot. At one P&A, an "attorney of the day," staff member from the legal review team, or intake manager reviews every intake request daily and recommends how to proceed. An advocacy assistance manager also does a monthly review. At another P&A, cases are presented at weekly staff meetings, during which staff decide to accept or reject the caller as an individual advocacy client.

All P&As reported having written intake procedures as part of a procedures manual, although one intake staff member acknowledged that even though there is an intake procedure that all staff are well aware of, she was never provided with a written guide. In one P&A, as part of the orientation process, newly-hired staff at any level sits in with the intake person for a while to obtain an understanding of the types of issues that come through the office.

Intake and assistance activities are periodically reviewed by the executive director, intake supervisor, supervising attorney, or other person assigned to the task. P&As also use the data collected as part of the P&A intake procedure for monitoring daily operations and as input for future planning and priority setting. For example, senior staff can run database reports to make sure the intake procedures are being followed. One P&A seeks feedback from a random sample of callers on the usefulness of the information the caller received and whether the caller would contact the P&A again for help.

Between October 1, 2008 and September 30, 2009, the total number of initial calls through the intake process reported by all P&As in the study was 12,967 (five P&As in the study did not report number of calls). The number reported by each P&A ranged from 79 to 2,582, with a mean of 864.5 and a median of 524.0 calls. Five P&As reported that they received more than 1,000 calls during the reporting period, while one P&A received fewer than 100 calls during the reporting period (Table 3-13).

Table 3-13. Number of initial calls*

Number of calls	Number of states/territory**
< 100	1
100 – 199	3
200 – 499	3
500 – 999	3
1,000+	5
Missing	5
Total	20

*Source: Self-administered Questionnaire (SAQ)

**Note: numbers are small so percentages are not calculated.

P&As differed in their policy for the maximum response time to return calls. P&As reported in the SAQ that they have a maximum response time for returning calls to the P&A, most within 1-2 days. Between October 1, 2008 to September 30, 2009, they responded within their maximum response time to 92.1 percent of the calls.

One executive director describes the following when asked about responding to intake and assistance calls within a specific time period.

> The policy is for us to return a phone call within 48 hours, two working days. We try to keep that policy. The person in the position of returning most of the developmental disability calls, returns them within 24 hours.

> It's very rare that it goes outside that 48 hours, but it may be because a person is traveling during training. If someone is out for an extended period of time for vacation or whatever, we reassign those calls to the rest of the unit so that we try to keep that policy. When the receptionist takes that information, it goes onto what's called a desktop. When the staff person signs into her desktop, those calls that have come in will appear on her desktop and she'll know because it will say, new I&R [Information and Referral] and what the date, the problem, and the I&R deadline. For quality assurance, the front office will figure out what the deadline is and that triggers the return of the call.

Individual Advocacy. Individual advocacy consists of a variety of activities, including information gathering, storage and retrieval; analysis/evaluation of information; case-specific procedures and activities (such as advising and counseling clients, negotiating, litigating, reviewing cases); communicating with clients; maintaining confidentiality and privacy; documenting activities; closing the case and sending a closing letter; and providing information on the grievance procedure. P&A management also conducts client satisfaction surveys, trains staff on individual advocacy procedures, and follows procedures to ensure a high quality of representation.

Types of individual advocacy intervention are generally the same across all P&As (Table 3-14). The majority (more than 56 percent of individual advocacy cases) consists of technical assistance in self-advocacy (primarily responding to questions so the caller can obtain further information and services himself or herself) and short-term assistance. Litigation comprises only 6 percent of individual advocacy across all P&As.

Table 3-14. Type of individual advocacy intervention*

Type	Number	Percent**	Mean (SD***)	Median	Range
Technical assistance in self-advocacy	1,249	32.2	78.1 (150.4)	7.0	0 - 598
Short-term assistance	944	24.3	55.5 (40.0)	54.0	5 – 135
Investigation/monitoring	288	7.4	16.9 (22.9)	7.0	0 – 75
Negotiation	351	9.1	23.4 (34.5)	11.0	0 – 135
Mediation/alternate dispute	102	2.6	6.4 (16.7)	1.0	0 – 68
Administrative hearings	266	6.9	17.7 (31.5)	4.0	0 – 105
Litigation	232	6.0	14.5 (23.0)	3.0	0 - 90
Other****	261	6.7	32.6 (33.9)	31.0	0 - 94

*Source: Self-administered Questionnaire

**Denominator = 3,877

***SD = standard deviation

****Representative at meetings; determined once case is closed.

All P&As reported that they provide opportunities for individual advocacy staff to discuss cases in order to share ideas, learn from one another, and pass that learning on to the clients they serve. Each P&A reported some combination of multiple types of meetings. For example, six P&As reported that monthly staff meetings provide the opportunity for every staff member to share a case or an event in a case that might be of significance to the rest of the staff. One P&A reported that "The attorneys and advocates work in workgroups that contain staff from different regional offices and discuss cases monthly or as needed." Eight P&As reported weekly staff meetings, including weekly team meetings and case reviews. One P&A discussed the "group accountability" that comes from such reviews, and another discussed how the weekly review meetings are used not only to determine which cases to take on but also when a case is ready to be closed. Seven P&As reported having informal discussion and consultations, including updates with a litigation director or a supervising attorney. One P&A reported that the litigation director monitors litigation calendars to assure all judicial deadlines are met.

Several processes are in place to ensure that staff communicates effectively with clients. Although communication techniques varied across the P&A system, all P&As appeared willing and able to overcome most communication barriers with which a caller or client might present. One P&A noted that it documents everything in a letter for traumatic brain injury clients. One gives clients copies of all communications sent on his or her behalf. Another follows up mailings with a telephone call to make sure the client understands. Still another writes everything out and then goes over it with the client. Representation, closing letters, and other materials are written in plain or simple language. One program reported training its staff on use of plain language, and another reported training parents involved in special education in plain language.

For deaf or hard-of hearing clients, one P&A reported using video conferencing. Another P&A contracts with a center for the deaf for people with hearing impairments and trains staff on the latest technology and relay systems. Two P&As reported using alternative communication tools, such as picture cards and photos. Another reported talking about the names of services instead of the names of programs available so the client can understand more easily. One P&A reported that it does not offer Braille services, but it works closely with the UCEDD in its state which does.

As attorneys, P&A staff must adhere to confidentiality requirements established by the State Bar Association in the states in which they practice. Fourteen P&As reported that they have written confidentiality procedures. Some confidentiality procedures are part of employee handbooks, services manuals, and a code of ethics given to employees. Confidentiality policies cover everything from procedures for maintaining and password protecting paper and electronic client files (including case notes), checking files out of the office, conflicts of interest, electronic user policies and data encryption, protecting client privacy when meeting in and outside the office, escorting guests through the P&A facility, signed releases before discussing client issues with a third party, discussing cases among office staff, (including use of client number instead of name), and retention and destruction of files. Fourteen P&As also reported that they monitor to ensure confidentiality procedures are followed.

Staff from 18 sampled P&As confirmed that there are confidentiality procedures in place and they are aware of the policies. In addition, clients from 13 P&As in the study revealed that client confidentiality was not an issue. They reported meeting in a private office and in private when meeting outside the P&A and being asked for permission to allow the P&A to send correspondence via email, leave voice messages, or speak with a guardian or other third party on their behalf.

One P&A reported a confidentiality violation, which was followed up immediately with ethics training for the staff person as part of a corrective action plan. The P&A also provided staff training with a State Bar Association PowerPoint presentation on ethics training. In addition to standard attorney/client confidentiality requirements, one P&A reported new state law regulations covering standards for protecting personal information of state residents, including new safeguards to follow, new practices to implement to ensure the safeguards are being followed, and requirements that new practices be documented in a written information security program.

According to Section 143 A(2)(E) of the DD Act, each P&A system is required to "establish a grievance procedure for clients or prospective clients of the system to ensure that individuals with developmental disabilities have full access to services of the system." Each P&A in the study had a written grievance procedure or grievance form that callers or clients could use to file a grievance against the P&A. P&As reported informing callers about the grievance procedure at intake, when a case is closed regardless of whether the P&A is taking on the case or not, when the case is opened, as part of the representation agreement, or, as several P&As reported, "anywhere along the line." For example, one executive director reported, "Anytime we do an intake process, the person is advised of the grievance process at the time of intake and also when he/she gets a response from one of the managers as far as the level of service…They're pretty well advised of the grievance process at least a minimum of three times—at intake and when a case is opened and closed. Those are minimal points, but also anytime there's a substantial change (e.g., adding or not adding additional services)." According to the SAQ, the 20 P&A programs reported 13 grievances filed against their P&As between October 1, 2008 and September 30, 2009.

3.4.2.4 Outputs

Outputs are the intended results of using inputs and implementing specific processes (French & Bell, 1984). One way to think of outputs is to consider them as products. P&A outputs include SGPs and the forms, booklets, and publications that reflect the goals and priorities in the SGP; individual advocacy cases; and various outreach and community education trainings on a variety of topics.

Outputs of Planning and Priority Setting. P&As in the study provided several examples of how the planning and priority setting process resulted in tangible products or results (i.e., outputs), including ways in which the results of the SGP process were used. For example, there was wide distribution of the SGP through newsletters, web sites, and distribution at various meetings. P&A web sites are updated with annual goals and priorities including posting in different languages and posting a simplified version with hyperlinks for more detailed information. Orientation materials for new governing board members are updated based on new goals and priorities.

Individual Advocacy Cases. Individual advocacy caseloads can be considered outputs to the P&A outreach and intake processes. All P&As engage in individual advocacy. In the SAQ, P&As in the study reported opening 3,877 new individual advocacy cases (two did not report), between October 1, 2008 and September 30, 2009. The number of new cases opened by P&As ranged from 45 to 752, with a mean (and standard deviation) of 215.4 (221.0). The median number of new cases was 112.5.

Six states/territory reported that they opened fewer than 100 cases between October 1, 2008 to September 30, 2009, while three reported that they opened between 500 and 999 cases (Table 3-15).

Table 3-15. Number of new cases opened*

Number of new cases opened	Number of states/territory
< 100	6
100-199	6
200-499	3
500-999	3
Missing	2
Total	20

Note: numbers are small so percentages are not calculated.

Almost all P&As we visited reported handling special education and transition cases, as well as reasonable accommodation, abuse (e.g., seclusion and restraint), and neglect. Other types of individual advocacy cases handled by P&As included guardianship, Medicaid waivers and access to health care, supported housing and independent living, crime victimization, and food stamps. During the program visits, P&As reported that individual advocacy clients came from areas where public schools were likely to be inadequate, native populations, people in group homes and state or community facilities, parents of children (and adult children) with disabilities, populations' for whom English is not the primary language, and through investigations.

Outreach and Community Education Outputs. All P&As in the study engage in outreach and community education. Outreach consists of efforts to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of community outreach is to identify typically unserved and underserved populations who might benefit from P&A services and programs. 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. P&As offer a range of activities addressing various topics for diverse audiences.

As a form of outreach, P&As reported that they engage in recurrent activities such as presentations at conferences, fair housing conferences, Wellness Day, Disability Awareness Day, annual conferences of key stakeholder groups such as the Brain Injury Association and The Arc annual conference, and presentations on hiring people with developmental disabilities through employer breakfasts sponsored by the Department of Labor.

Some P&As are strategic in conducting their outreach activities. Staff in one P&A noted that when the P&A first decided to focus its outreach efforts, it charted the minority populations, low-income populations, and populations with disabilities in the state and narrowed its focus to the far western part of the state. At another P&A, one person is assigned to organize outreach. Her principal role is to develop and maintain an outreach plan and track all outreach opportunities. The outreach plan identifies the areas in which to conduct outreach and contains objectives of the outreach and activities under each objective.

One P&A conducts some of its outreach and education through the media and uses television and radio to provide information on the P&A and specific topic areas. One of the P&A's governing board members appeared on the public access television station to talk about the Medicaid waiver, housing, and transportation for people with disabilities.

All P&As travel to bring outreach and community education activities to the community. Their audiences include entire communities, minority populations, rural tribal communities, people with developmental disabilities and family members, service providers, employers, human resources personnel, school district personnel, the media, nurses, doctors, local clinics, hospital administrators, social workers, and teachers. Other recipients of P&A educational activities were Department of Corrections staff trained to comply with the Americans with Disabilities Act (ADA); police and crime victims; advocates for the State's Attorney Offices and state attorneys themselves; staff at a battered women's shelter; staff at community mental health agencies; walk-ins to a legal clinic at the Community Health Center where people seek medical care; Department of Labor staff trained on accommodations; medical professionals, families, and individuals at Veterans' Administration and other hospitals trained on traumatic brain injuries; office managers of doctors' offices about use of interpreters; physicians who provide services to people with developmental disabilities; city municipal court employees trained on employment discrimination; and staff at an immigration advocacy center.

P&A education consists of legislative briefings; leadership training for self-advocates; Individualized Education Program (IEP) trainings for teachers and parents; and disability awareness and sensitivity training for law enforcement personnel, bus drivers, and even people who work at baseball games. P&As also make presentations and conduct demonstrations on disability assistive technology and Section 504 accommodations in the classroom and workplace. P&As also collaborate with DD Network partners like the UCEDD to produce reports on topics such as restraint and seclusion for school districts. One P&A collaborated with the Department of Social Services to train staff throughout the state about services for children in foster care and a range of rights from Medicaid for healthcare, vocational rehabilitation, special education, voting rights, and social security. Another P&A maintains a Rights Clinic where a P&A staff member talks to institutionalized individuals about their rights.

3.4.2.5 Outcomes

Outcomes are the intended results of creating certain outputs or products (French & Bell, 1984). They represent the overarching goals of the P&A. P&A outcomes can be short-term outcomes (those that can more readily attributed to the work of the P&A) and long-term (those that can be affected by other programs and circumstances). Two of the most relevant short-term P&A outcomes are the effects of individual and systemic advocacy activities that can be attributed to the P&A.

Individual Advocacy Outcomes. SAQ data indicated that 18 out of the 20 P&As in the study reported closing 3,986 individual advocacy cases between October 1, 2008 and September 30, 2009. There were 4,983 client objectives addressed among these cases, with 4,269 or 85.7 percent of the client objectives reported as being successfully met. Asked to identify individual advocacy objectives met versus those addressed, two P&As reported 100 percent success rates, three had fewer than a 50 percent success rate, and eight out of 20 were successful between 75 and 99.9 percent of the time (Table 3-16).

Table 3-16. Individual advocacy success rate*

Success rate	Number**
< 50.0 percent	3
51.0 – 74.9 percent	5
75.0 – 99.9	8
100 percent	2
Missing	2
Total	20

*Source: Self-administered Questionnaire

** Numbers were small so percentages were not calculated.

P&As resolve a great many issues for clients and their family members. For example, a student with cerebral palsy was not receiving the transportation required by the IEP. The P&A filed a complaint asking for compliance with the IEP and won the case. The student is now receiving transportation to and from school. In another case, a student was inappropriately secluded and restrained in school, and the parent wanted the school to evaluate the child's behavior in light of a disability. The P&A

reviewed the IEP and helped the parent write a letter to the Department of Education. The school was found to be negligent, and corrective action was required. A corrective action plan was developed.

Systemic Advocacy Outcomes. P&As engage in systemic advocacy through a variety of strategies such as litigation, writing position papers, working through the media for press coverage, informing policy makers, providing testimony, co-counseling with other law firms, drafting legislation, strategizing to identify legislators who would support bills, and collaborating with other groups with an interest in protecting the rights of people with developmental disabilities and their families. Outcomes of systemic advocacy efforts include changes to or maintenance of legislation, public policy, or practice or services.

P&As reported much success in achieving systemic advocacy outcomes. Focusing on closing down residential facilities in collaboration with statewide disability partners, four institutions were closed down in one state as a result of P&A activities, and in another state dozens of large private residential facilities were reported to have closed due to the efforts of the P&A and its collaborators. To address poor conditions for children in a state-operated private residential treatment facility, the P&A informed the local media and one of the major television outlets about the poor conditions. The media did an exposé on the facility. The day the newspaper article was published, the governor made a surprise visit to that facility, and the facility was subsequently closed.

P&As have also been able to influence seclusion and restraint policy and practice. As a result of seclusion and restraint hearings in which the P&A participated, a state board now tracks all uses of seclusion not just by school, but also by students. The P&A is working to apply the same practice to restraint statistics. According to the P&A, tracking by student can reveal prevalence by disability. Related to seclusion and restraint, a P&A worked on banning corporal punishment. The bill enables parents of children with developmental disabilities to "opt out" if they determine their child's school uses corporal punishment. In addition, a bullying bill passed recently in one state. The bill calls for a statewide zero tolerance policy for bullying and provided training for teachers on preventing bullying and dealing with bullies.

Several P&A systemic advocacy issues are related to access to service. Beginning in January 2007, P&A staff in one state engaged in negotiations with a state agency on the state's failure to provide the full range of supports for children with developmental disabilities who are Medicaid eligible and entitled to receive Early, Periodic Screening, Diagnosis and Treatment (EPSDT) services. These services include case management and therapeutic and behavioral supports in their homes and communities. Subsequent to P&A negotiations, the Governor's budget for fiscal year 2009 contained an appropriation of approximately $2.4 million earmarked for EPSDT services. Of the $2.4 million, $700,000 was designated for case management for children, and the remainder, $1,725,000, was earmarked for therapies for children. This represented approximately 30 hours/year of case management services for 467 children who were not then receiving such services. At another P&A, P&A staff testified before legislative committees in support of a bill that made changes in identifying people in correctional facilities who might have developmental disabilities and/or mental illness. The bill required the Department of Corrections to consider trauma-related issues when evaluating and treating inmates and improves the planning process for when an inmate is about to be released from prison so treatment services can continue in the community.

Much of P&A systemic advocacy is accompanied by careful research and detailed position papers. However, some systemic advocacy issues require quick and immediate response by the P&A. Responding to a last-minute effort to amend a budget bill through changes to a grant-in-aid bill for special education, the P&A provided a critique of the effort, and the DD Network programs, including the P&A, contacted state legislators. As a result, the budget was approved with guaranteed funding for special education programs. As another example requiring quick response, the P&A responded to devastating weather conditions in its state by salvaging its main computer servers and electronic records from its offices, setting up quickly in another location to be available to clients, and changing its entire focus for the year to finding out where its clients were located. Some clients had been taken away from group homes and facilities and sent out of state. The P&A helped to return them to their home state and into shelters. They also facilitated changes to shelters that were not accessible, did not have personal care attendants available, and were unprepared to deal with people with developmental disabilities.

P&A systemic advocacy is not always fully successful. One P&A recently settled a nine-year systemic advocacy suit, resulting in some improvements to the logistics of the waiver waiting list. However, no progress was made in making the list shorter. The outcome, while a victory, was disappointing to the disability community. In another instance, a P&A opposed the administration of a proposal to eliminate the state's pharmacy program that fills in the gaps for pharmacy costs for seniors and people with disabilities enrolled in Medicare Part D. Program funding was restored, although a co-payment was instituted. Another partially successful outcome involved negotiation with the state Department of Education to put a disclosure in the IEP form for parents to know that they are supposed to be offered 12-month programs if they have children with particular types of disabilities. Instead of legislation, the Department wanted the disclosure requirement to be in the form of a regulation. The P&A drafted some very specific language that was adopted into the regulation, and the specific language was drafted into the IEP forms.

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

The description of UCEDD findings contains a general description and a summary of the structural, process, output, and outcome indicators mapped to the Findings Form.

3.4.3.1 General Description of UCEDDs

The DD Act authorizes funding for UCEDDs to carry out four core functions: (1) the provision of interdisciplinary pre-service preparation of students and fellows and continuing education; (2) the provision of community services; (3) the conduct of research; and (4) dissemination of information that demonstrates that the center is a national and international resource. UCEDDs are also required to engage in data-driven planning activities. To conduct all core functions UCEDDs must be able to maintain effective management structures and processes. Thus, all four types of indicators (structure, processes, outputs, and outcomes) were considered for all four core functions, as well as 5-year planning and governance and management.

3.4.3.2 Structures

Structural components are an integral part of a UCEDD meeting the goals of its core functions as set forth in the DD Act. The structures examined include UCEDD funding; UCEDD placement within a larger university hierarchy; faculty and staff; areas of emphasis designated by UCEDDs; and the composition of the CAC.

Funding. UCEDDs receive a core grant from ADD with the expectation that the grant will be used as seed money to support infrastructure so more funds will be raised. A grant awarded to a UCEDD from ADD in 2008 amounted to $520,000 per year. In Fiscal Year 2011, the core amount per year was $535,000.

As a group, UCEDDs reported that they submitted 1,171 grant applications between July 2007 and June 2009. On average, they were successful 80.7 percent of the time. All UCEDDs reported that they use their 5-year plan to ensure that outside money sources do not draw them away from their core functions and their identified goals and priorities. Common UCEDD outside funding sources include the National Institutes of Health, the Centers for Disease Control and Prevention, the U.S. Department of Education, the Health Resources and Services Administration, United Cerebral Palsy, Easter Seals, the Robert Wood Johnson Foundation, Autism Speaks, and various state agencies such as vocational rehabilitation, education, public health, and mental health.

To try to place in perspective the amount of funding acquired by all UCEDDs, given the amount of funding from ADD, we calculated the ratio between the total amount of funding received over the period July 2007 through June 2009 compared to the amount of the UCEDD grant (pro-rated for the same time period). Thus, a UCEDD with $4.3 million in external funding during the reporting period had a funding ratio of 4.2 to 1.0 (the lowest ratio).[8] With total funding of $63.9 million during the same reporting period, the ratio was 61.5 to 1.0 (the highest ratio). The overall funding ratio for all UCEDDs was 14.3 to 1. The ratio of all UCEDDs was greater than 4.0 to 1.0. Most UCEDDs, large and small, had a ratio of less than 20 (Table 3-17).

Table 3-17. Ratio of total funding to ADD funding*

Number of UCEDDs with a ratio of:	Ratio of total funding/UCEDD grant
< 10	8
10-19	7
20-49	3
50 – 74	1
Missing data	1
Total	20

*Source: Self-administered Questionnaire (SAQ)

UCEDD directors also reported that they receive support from their university. This often includes their building and basic infrastructure, such as utility bills and IT services. Many directors added that they either receive a return on their indirect costs or that all of their indirect costs are waived.

A number of UCEDDs receive funding through the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. This is a federal program funded by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau. There are currently 39 LEND programs, mostly aligned with UCEDDs. The study sample included 11

---

[8] The pro-rated amount of the ADD grant was $1.04 million.

UCEDDs with LEND programs and two that were working to establish a program at the time of their program visit. The goal of the LEND program is to provide leadership and interdisciplinary clinical training to undergraduates, graduate students, and postdoctoral fellows to better serve infants, children, and adolescents with disabilities. LEND trainees often come from disciplines such as audiology, nursing, occupational therapy and physical therapy, psychology, social work, and speech pathology.

Placement Within the University Structure. Compared to DD Councils and P&As, UCEDDs have the most varied organizational structures of the three ADD programs. All are associated with an accredited university, but the location of the UCEDD within the university's structure can differ. In the study sample, some UCEDDs are housed in medical schools, while others are associated with other university schools such as a College of Education and Human Development. Still others are centers that do not fall under any particular school, and one UCEDD in the sample is a 501(c)(3) tax-exempt non-profit organization with its own Board of Directors.

One result of placement within the university structure involves the type of students and trainees the UCEDD works with and the areas on which they focus. Those UCEDDs that are associated with medical schools reported that they have little access to undergraduates and thus have no courses geared toward them. However, some medical school affiliated UCEDDs are still able to provide internships or other training opportunities to undergraduates.

Faculty and Staff. A UCEDD's location within the university structure also may have staffing and financial implications. The salary of some UCEDD directors is covered by the university, while others are funded by their Center; and sometimes it is a combination of both. Most directors have a joint appointment in another academic department, such as Education, Psychology, or Child and Family Studies. Similarly, most UCEDD faculty members have a primary appointment in a separate academic department.

Westat found a lack of standardization in how UCEDDs define their faculty and staff. Some UCEDDs consider anyone affiliated with the UCEDD as a "UCEDD faculty or staff member," while others only consider those who have their full salaries paid out of the UCEDD budget to be UCEDD faculty or staff. With these diverse definitions of faculty and staff, UCEDDs reported in the SAQ a total of 1,325 faculty and staff among all sampled UCEDDs with a range of between 11 and 210. Most UCEDDs reported that they have fewer than 100 faculty and staff members (Table 3-18). Those reporting more than 100 faculty and staff may have a more inclusive definition.

Table 3-18. Number of UCEDD-affiliated faculty and staff in study sample*

Number of faculty and staff	Number of sampled states/territory
<50	7
50-99	7
100-199	3
200+	1
Missing	2
Total	20

*Source: Self-administered Questionnaire (SAQ)

Areas of Emphasis. Under Section 154 of the DD Act, those applying for or renewing a core center grant must provide a 5-year plan to ADD. Once the grant is awarded, this 5-year plan is expected to become the template for the UCEDD's activity over the next five years. Plans can be modified, if necessary, in annual reports submitted to ADD. The 5-year plan must include a projected goal related to one or more areas of emphasis for each of the core functions required by UCEDDs.

Although UCEDDs as a group focus on different areas of emphasis, almost all UCEDDs focus on education, employment, and health as areas of emphasis. Quality assurance and child care also receive wide attention. Housing, recreation and transportation appear to have the least attention from UCEDDs as areas of emphasis. There are a total of 10 areas of emphasis on which to focus, including an "other" category. Over a five-year period, four out of the 20 UCEDDs studied in the National Independent Study selected 9 or 10 areas of emphasis.

Consumer Advisory Committees. The DD Act mandates that UCEDDs establish a CAC that consults with the director regarding the development of the 5-year plan and participates in an annual review of and comments on UCEDD progress in meeting its goals. The composition requirements of the committee are stipulated by the DD Act and in general require members to be a majority of people with developmental disabilities or their family members and a minority of representatives from relevant organizations, State agencies, or community groups that are concerned with the welfare of individuals with developmental disabilities and their families. Thus, the CAC is expected to bring the perspective of personal experience with developmental disabilities as well as what is happening out in the larger community.

The DD Act stipulates that CACs may meet as frequently as they need to in order to carry out their mission but that meetings must occur a minimum of two times per year. Westat found that most

CACs meet in-person at the UCEDD between two and four times per year, although interim conference calls also take place. The meetings typically focus on providing CAC members with updates about what the UCEDD has been working on since the previous meeting. Study findings show that directors and staff make every effort to provide necessary accommodations to ensure meaningful participation by all members, especially those with developmental disabilities.

CACs serve as consultants to their UCEDDs in many capacities, with some having more extensive influence than others. Some CACs mainly function to provide input during the development of the 5-year plan and the subsequent monitoring of how the plan is being carried out throughout those five years. Others are involved in numerous other activities, such as:

- Playing a role in developing research ideas or observing projects in the field,
- Serving as guest speakers for courses or co-teaching courses,
- Serving as case studies for classes where students visit people with developmental disabilities in their homes to obtain hands-on experience,
- Reviewing materials before they are posted on a web site or distributed via mail,
- Helping to make web sites or campus areas (such as bathrooms or parking lots) more accessible,
- Helping to recruit participants for community services,
- Providing feedback when new curricula or courses are developed,
- Providing suggestions on job description when there is a vacant staff position,
- Helping write questions for focus groups,
- Helping to recruit and screen new CAC members,
- Attending brown bag lunches and other seminars on campus that focus on disability issues, and
- Serving as special consultants for specific research projects.

Most CAC members expressed complete satisfaction with their role and perceived influence on activities carried out by the UCEDD. However, a minority felt underutilized. They thought that their meetings served simply to update them on events sponsored by the UCEDD and that they did not have many opportunities to provide input or serve an advisory role.

In addition to a CAC, some UCEDDs have separate advisory boards comprised of people with developmental disabilities to provide input and perspective for specific projects. These advisory boards often contain members of the CAC as well as others who provide outside expertise.

3.4.3.3 Processes

Key UCEDD processes consist of planning and priority setting, delivery of interdisciplinary pre-service teaching and continuing education, and dissemination. These were mapped to the benchmarks and indicators in the UCEDD Findings Forms and are reported here.

Planning and Priority Setting. The DD Act stipulates that UCEDDs prepare and submit a 5-year plan as part of an application to ADD. The plan must include a projected goal related to one or more areas of emphasis for each of the core functions. The plan development process involves two major steps: (1) obtaining information on the needs of people with developmental disabilities and their families; and (2) translating that information into the goals and objectives of the plan.

Program visit findings indicate that most UCEDDs rely heavily on the input gathering processes implemented by their state's DD Council. Some UCEDDs rely exclusively on the DD Council for outside input, while others conduct their own stakeholder feedback gathering activities to supplement Council information. Specifically, Westat found that six of the UCEDDs visited had no process of their own to gather outside stakeholder feedback for their most recent planning cycle, while the remaining UCEDDs had at least one activity (survey, focus group, or public forum) designed to obtain outside feedback specifically for their most recent plan. Many states conduct information-gathering as a network of sister agencies working together to pool resources, even if the planning cycles do not align perfectly. UCEDDs also rely heavily on needs assessments conducted by other state agencies, such as Vocational Rehabilitation or the Health Department, or their state DD Council.

Compared to a more minimal effort in soliciting extensive outside feedback, UCEDDs spend significant time gathering and compiling input from their project activities. UCEDD faculty and staff, students, and members of the CAC (or supplemental project-specific advisory boards) play a major role in providing input for the planning process. Additionally, feedback about current activities such as community services and technical assistance is often obtained through informal discussion with clients and satisfaction surveys. Another important component is the ongoing information gathering that takes place when faculty members sit on various workgroups and committees throughout the disability community. This also keeps them abreast of new and emerging issues. As one director described the process, "our staff are just out in the community all the time." This was a common theme encountered on site visits and highlights that planning for some UCEDDs is an ongoing process, not an event.

Another component of the information-gathering process is the synthesis of available data from published reports. Nearly all directors mentioned using numerous state reports, while common national data sources included *Healthy People 2010* (US Department of Health and Human Services, 2000), census data, *The State of the States in Developmental Disabilities* (commonly referred to as the Braddock Report or DD Act Project of National Significance) (Braddock et al., 2008), and relevant articles in peer-reviewed journals.

There is less consistency among the UCEDDs in how the synthesis of available information leads to the creation of the 5-year plan. Some directors do most of the work, while others rely on faculty/staff or CAC workgroups to put the initial draft together. One UCEDD reported that it brought in a faculty member from another UCEDD to run a strategic planning session for its CAC members in preparation for work on the 5-year plan. Regardless of how the plan is developed, all UCEDDs reported that they obtain feedback on the plan from the CAC before it is considered final.

Another significant difference in the UCEDD planning process as compared to the process for the Councils and P&As derives from the fact that UCEDDs are largely dependent on funding from sources other than ADD. UCEDDs often focus their activities on topics in which they know funding is available. As one director reported, "since most of our funding is derived from external sources and because we must plan, secure funding, implement, evaluate, and disseminate projects that align with the training and experience of our staff, we are not able to be totally directed by the priorities of stakeholders. However, we do attempt to address the issues identified and prioritized by our stakeholders to the greatest extent possible."

Delivery of Interdisciplinary Pre-Service Teaching and Continuing Education. Section 153(2)(A) of the DD Act authorizes UCEDDs to engage in interdisciplinary pre-service preparation of students and fellows and continuing education. The goal of this function is to develop a cadre of individuals with the necessary knowledge, skills, attitudes, and values to increase the capacity of States to provide and/or influence supports and services for people with developmental disabilities and their families.

We found that the sampled UCEDDs identify four different types of students: (1) interdisciplinary pre-service students who are typically in a graduate or professional program (e.g., medicine, dentistry, social work); (2) students, often undergraduates, concentrating in disability and based in any number of departments (e.g., sociology, psychology, law, education, physiotherapy); (3) students throughout the university whose courses were infused with disability content and come from more than one department (e.g., mathematics, history, political science, journalism, psychology); and (4) continuing education students who were professionals already employed in a field related to the provision of services for people with developmental disabilities

Westat encountered diversity in this core function equal to the number of UCEDDs visited, with each one offering a different selection of courses, and training experiences to a different selection of students. Most UCEDDs offer no degrees and do all of their teaching within or in collaboration with other university departments. Some offer courses that can be taken by anyone at the university, while others interact only with graduate students. A full spectrum of degrees are offered to UCEDD students across the study sample universities—from an undergraduate minor in Disability Studies, to graduate certificates in Assistive Technology or Positive Support, to a Masters degree in Speech Language Pathology or Special Education, to a doctoral degree in Applied Behavioral Analysis.

According to data reported in the SAQ, a total of 637 "UCEDD students" graduated or completed a program during the study reporting period (July 2008 through June 2009). The mean number of UCEDD students was 32.6 (SD = 42.3), the median was 20, and the range was 0 – 168. Nine UCEDDs reported having fewer than 20 students who graduated or completed their program during the reporting period - July 2008 through June 2009 (Table 3-19). Two UCEDDs reported more than 50 students. These numbers do not include continuing education students.

Table 3-19. Number of students who graduated or completed program during reporting period*†

Number of students	Number of sampled states/territory
<20	9
20-39	6
40-49	2
50+	2
Missing	1
Total	20

*Source: Self-administered Questionnaire

†July 2008 to June 2009

Aside from traditional coursework, most UCEDDs also offer hands-on experiences to professional or graduate students in the form of internships, fellowships, or post-doctoral programs. These types of experiences are often found in UCEDDs associated with a LEND program, where the majority of the hands-on experiences consists of clinical or diagnostic procedures. They are also found in UCEDDs not associated with LEND programs, where students can work directly with schools, state agencies, or people with developmental disabilities and their families.

Despite the many differences in coursework and experiences, Westat found many common themes that cut across all centers. The most important theme was the interdisciplinary nature of the programs, which is in line with the DD Act's explicit mandate that UCEDDs be interdisciplinary. On the surface, UCEDDs are primarily interdisciplinary in at least two ways: (1) courses are taught from the viewpoint of multiple disciplines, and (2) their students come from multiple disciplines throughout the university (and sometimes from multiple universities). Most UCEDD faculty members have a dual appointment with the UCEDD and an academic department, and many UCEDD courses are cross-listed through more than one department. Many UCEDD courses are either team taught by multiple faculty members or were developed by a team even if they are taught primarily by one professor. Guest lecturers are also very common to these courses, often including professionals in the field or people with developmental disabilities or their family members who offer their life experiences.

The most common disciplines associated with UCEDDs are medicine, social work, nursing, speech pathology, education, psychology, nutrition, public health, occupational therapy, physical therapy, dentistry, genetics, audiology, and law/policy. UCEDD students we spoke to noted that having students/trainees and professors from all these different fields is an invaluable way to learn from multiple perspectives. In addition to classes offered by faculty associated with the UCEDD, many UCEDDs help diffuse disability content into courses offered throughout the university. Examples of this include English classes that focus on authors with developmental disabilities or business classes that emphasize the value of hiring people with a developmental disability.

Since developmental disabilities are such a broad category of study and expertise, the interaction of multiple disciplines is truly the cornerstone of the UCEDD experience. Many UCEDDs promote a team approach to providing supports and services to people with developmental disabilities, and most of the students that Westat interviewed highlighted the importance of this interdisciplinary education. One student described working with families in interdisciplinary teams which enabled her to observe what the other disciplines were doing and to make decisions about evaluations and interventions as a team. Another student described her previous training as in a "silo" and noted that after her experience with the UCEDD she could work more collaboratively with co-workers. Others mentioned that their experience with the UCEDD allowed them to be exposed to topics they never had encountered before and opened their eyes to alternate ways to approach issues. One student emphasized that the interdisciplinary focus taught her to "…deal with every aspect of the whole child."

Other common themes observed across UCEDD programs include a focus on teaching evidence-based practices and the use of case studies and other problem-based learning strategies. Many UCEDDs have people with developmental disabilities or family members on staff who contribute to classes and seminars as guest lecturers. Additionally, all the programs visited explained how they teach their students/trainees cultural competency and prepare them to work with traditionally unserved and underserved populations. This is typically done by bringing in people from different cultures to guest lecture, as well as offering experiences so students and trainees can interact first hand with diverse communities and populations.

The second component of UCEDD educational offerings is continuing education. This is typically geared toward professionals already working in the field who want to gain new skills or enhance ones they already have. Common categories of professionals taking these trainings include speech language pathologists, teachers and other school personnel, physical therapists, occupational therapists, social workers, and other direct service providers from places such as community rehabilitation centers. Sometimes the classes/trainings are tied to a state or local licensing requirement, such as the ones required for daycare providers. Examples of continuing education reported to Westat include autism training for special education coordinators, IEP training for teachers, trainings for state social workers in the child welfare department on procedures for working with a mother with a disability, inclusion training for daycare providers, trainings for hotel workers and bus drivers on how to work with a customer with a disability, and training for state mental health providers in working with children who have been exposed to trauma. UCEDDs tied to medical schools often provide Continuing Medical Education (CME) credits for physicians and nurses by organizing Grand Rounds that cover developmental disability topics.

Dissemination. The DD Act requires dissemination as the fourth UCEDD core function, "especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances."

Most UCEDDs use a variety of dissemination strategies to reach a diverse group of target audiences. The most common strategies include the use of a web site, newsletters (either paper or electronic), brochures, peer-reviewed publications, and presentations (either at professional meetings or out in the community). Many UCEDDs also try to publish their content in other university publications and use press releases to facilitate appearing on local radio and television stations and publishing articles in newspapers. A few are actively engaging in social media outlets such as Facebook and Twitter or posting videos to YouTube. Three directors mentioned posting videos to YouTube; three cited using Facebook, and one mentioned tweeting updates about their Center.

Some UCEDDs have completely moved away from mass mailings and now only send materials electronically to listServs and other distribution lists. One UCEDD has its own disability library. It keeps track of the number of people accessing materials on developmental disabilities and targets mailings to areas of the state where low numbers of people have accessed materials. The librarian also chooses one school system a year for direct mailings to K-12 special education teachers and also sends materials out to the National Library of Medicine's health library liaisons, public and health libraries in the state, and hospital libraries. A few other UCEDDs also mentioned distributing their materials to public libraries.

Target audiences for these dissemination efforts were fairly standardized across all UCEDDs in the study sample. They include people with developmental disabilities and their families, elected officials, other policy makers, paraprofessionals, colleagues and other researchers, advocacy groups, healthcare providers, state and local agencies, teachers and other school personnel, the university community, and the general public.

It appeared that much effort is invested to ensure that materials are accessible to people with disabilities. Web sites and other online materials can be accessed with screen readers, and many

UCEDDs make materials available in Spanish, Braille, and large print. Some UCEDDs have satisfaction surveys prominently displayed on the web sites.

Other strategies are used for special populations. One director noted that she uses more visuals in materials for individuals with intellectual disabilities, while another noted that the Native American population prefers oral presentations over printed materials. Materials are also reviewed by target audiences in order to ensure they are appropriate. Most UCEDDs ask their CAC members review materials before they are finalized. A simple "thumbs up" versus "thumbs down" method was noted by multiple UCEDDs as a way to obtain input from CAC members. Other ways to obtain feedback included satisfaction surveys after presentations, monitoring hits to the web site and whether emails have been opened, and sending surveys with mailed materials.

Many directors noted that it can be very difficult to get people to respond to surveys, whether they are electronic or mailed. For example, one UCEDD reported sending out over 900 satisfaction postcards with newsletters last year, and received eight replies. Another UCEDD reported that it hired a public relations firm to help make the UCEDD web site more visually appealing and accessible, and another sent staff members to a national training on web accessibility. Another director explained that "satisfaction is monitored by how much materials 'move;' how much do people use the materials and want more of them?"

3.4.3.4 Outputs

UCEDD outputs consist of the products of UCEDD research, products related to imparting faculty and staff expertise (i.e., information), and the community services UCEDDs provide.

Research Products. Research portfolios of the UCEDDs we visited appear to contain both breadth and depth. Most UCEDDs conduct applied research, which often includes policy analysis, system/program/intervention evaluations, and needs assessments. One executive director described the work of a UCEDD as "community-based participatory research."[9] Clinical or epidemiological research is most often conducted by UCEDDs that are associated with a LEND program.

---

[9] Community-based participatory research (CBPR) is research that is conducted as an equal partnership between traditionally trained "experts" and members of a community. In CBPR projects, the community participates fully in all aspects of the research process.

There are many common research topics that are being tackled by multiple UCEDDs. Currently, the most common of these is autism. Angles being explored include needs assessments, early screening tools, social skills research (such as increasing capacity and quality of life), epidemiology, and tools for teachers that use evidence-based practices. Additional topics run the full gamut of applied and basic research (Table 3-20).

Table 3-20. Examples of UCEDD applied and basic research

UCEDD applied and basic research
▪ Brain development and factors that affect cognition
▪ Medicaid waiver policy research
▪ Development of interventions involving positive behavior support
▪ Impact of inclusive classrooms
▪ Emergency preparedness for people with developmental disabilities
▪ Genetics
▪ Access to and availability of healthcare services
▪ Employment and transition
▪ Practices to promote self-determination
▪ Assistive technology and other communication aids
▪ Training and retention of quality direct service providers
▪ Development of infants with motor disabilities
▪ Homeless people with developmental disabilities
▪ Impact of parenting styles and attention levels on children with developmental disabilities
▪ Friendship and dating among people with developmental disabilities
▪ Prevention of disability using phototherapy for jaundiced neonates
▪ Improvement of educational outcomes of babies born with fetal alcohol syndrome

The ultimate goal of UCEDD research is to improve the lives of people with developmental disabilities and their families. Although difficult to ascertain, some research results may have a direct effect on this population. Other results can lead to changes in public policy or community practices or services. For example,

- Under the Medicaid Buy-In option in the Balanced Budget Act of 1997 and the Ticket to Work and Work Incentives Improvement Act (TWWIIA) in 1999, states were authorized to create Medicaid Buy-In programs to extend Medicaid coverage to people with disabilities who are employed. Most state Buy-In programs have an upper limit of 250 percent of the Federal Poverty Level, but states differ in how they count income and assets. Many UCEDDs are conducting policy assessments related to the Medicaid Buy-In program with results that show a justification for an increase to the asset limit. UCEDD findings help legislators to prepare for a vote on the topic.

- Direct service providers are individuals who provide care and training to those with developmental disabilities. High turnover and poor retention rates among staff are often cited as issues that adversely affect the quality of care for individuals who rely on these services. An online survey conducted by one of the sampled UCEDDs sought to develop a profile of job satisfaction and the influence of employment benefits on job recruitment and retention. The results of this survey suggest that an increase in wages, job benefits, and opportunities for advancement may improve retention and recruitment of direct service providers. These findings are being used to shape policy.

- Self-Employment Technical Assistance, Resources, & Training (START-UP/USA) is a Federally-funded program to further the development of self-employment as an employment outcome for people with disabilities. The program provides technical assistance and resources to further individuals' self-employment goals. Several UCEDDs are involved in the implementation of the program by providing data on capacity-building strategies and systems change models that are being implemented in their state. Information generated from these model programs is then disseminated nationally for replication and often leads to the formation of best practices.
- Many UCEDDs conduct work in the area of positive behavior support (PBS)—an assessment-based method to prevent and reduce challenging behaviors. This often involves technical assistance to school district personnel such as teachers, administrators, and behavior specialists. There is also a research and evaluation component to measure both fidelity and success in achieving outcomes. Research outcomes noted in this area of study include the development of new interventions, the refinement of best practices, and the development of processes that enable Medicaid funding to be used to support clinicians who use PBS.
- Following the results of a UCEDD study on transition of pediatric patients to the adult healthcare system, the state's largest children's hospital made drastic changes to its transition practices to implement a transition of care program. The state's largest adult healthcare system also started a transition committee and a transition clinic.
- One UCEDD's policy work on the Individuals with Disabilities Education Act (IDEA) and the application of the U.S. Copyright Law resulted in a procedural change in the procurement of textbooks and other instructional materials. The publishers now make textbooks available in a way in which they can be converted into accessible formats without violating the copyright laws.
- One state's move toward trans-disciplinary/multi-disciplinary service delivery for children with autism in lieu of the practice of individual expert-delivered service is heavily influenced by the UCEDD's pilot project in early intervention, stated one UCEDD director. The new approach also includes training the parents, as pioneered by the UCEDD.
- According to a UCEDD director, a UCEDD demonstration project successfully integrated a national screening tool for early identification of disabilities into a Spanish-speaking population. It is now a billable service in Medicaid, and culturally and linguistically unserved populations that were previously missing out on early screening, diagnosis, and intervention services are now being served.
- Under a contract with a foundation, a UCEDD worked with several disability experts to develop a functional definition of paralysis and conducted the first ever population-based probability survey of the prevalence of paralysis in the United States. The findings

were presented to Congress and used to pass the Christopher and Dana Reeves Paralysis Act, noted the director.

Additional examples of research outputs reported by directors are listed in Table 3-21:

Table 3-21. Additional examples of research outputs reported by UCEDD directors

Research outputs reported by executive directors
▪ Shaping policy related to direct service providers to increase wages and benefits and improve recruitment and retention
▪ Increasing the accessibility of public transportation and state parks
▪ Provision of mandates for insurance coverage for applied behavior and analytical services for children with autism,
▪ Provision of evidence on self-employment so it could become a standard vocational rehabilitation option
▪ Curriculum development to help classroom teachers promote self-determination and self-advocacy
▪ Assistance to children's hospitals so they could improve their practices in transitioning youth with developmental disabilities
▪ Development of best practices for the screening and education of students with autism
▪ Obtaining augmentative communication provided through the federal Telecommunications Access Device Program
▪ Change in school board practices around restraint and seclusion
▪ Research that led to the establishment of a national technical assistance center funded by the Office of Special Education Programs (OSEP) in the US Dept of Education,
▪ Demonstration of the benefits of inclusive classrooms
▪ Influencing a state Part C program (the section of IDEA that provides early intervention services to infants and toddlers) to move toward a "transdisciplinary-coaching" approach to service delivery in lieu of the practice of expert delivered individual therapists
▪ Redesigning the service delivery that accompanies deinstitutionalization, including clinical crisis prevention services

Community Services. Community services comprise another UCEDD output. Since UCEDDs routinely collect and analyze data from their community services, the line between community service and research can often blur, as was specifically pointed out by one director. Community services provided by sampled UCEDDs are technical assistance; model demonstration projects; clinical/diagnostic programs; and various other trainings geared toward people with developmental disabilities and their families, direct service providers, teachers and other school personnel, childcare providers, medical professionals, and the community at large.

UCEDD community services often consist of direct training for people with developmental disabilities. Often, a main focus of these trainings is self-advocacy. Recipients of these trainings reported that they had gained the confidence to do things like testify before the legislature or speak up about public places that are not accessible. One recipient spoke up about not being able to read the snack bar menu at a local movie theater and was successful in convincing the theater to provide the menu in both Braille and large print. Other trainings taught benefits planning to individuals receiving Social Security Administration disability benefits, while still others provide one-on-one assistance to children. An autistic child who was previously non-verbal, acting out, and did not have any social functioning skill, is now speaking in complete sentences, singing, and interacting with his peers socially. Another UCEDD collaborated with an independent living center to run a safety program for women because, we were told, women with disabilities have often been the victims of abuse at some point in their life. Many UCEDDs also run emergency preparedness trainings so that people with disabilities can prepare themselves in case of an emergency.

In addition to training people with developmental disabilities, UCEDD community services also consist of training for direct service providers. Content for these trainings addresses a wide variety of topics including self-determination, leadership development for supervisors, current practices specifically for early intervention, and best practices in all areas of providing services to those with developmental disabilities. One UCEDD created a database for its state where anyone who wants to work in early intervention must register and meet the standards, while another has created a 17-hour certificate program to help direct those in service professions to better serve their clients. Recipients of the training program reported that it made a difference in how they approach their work because they think about the kinds of differences they could make in the lives of people with developmental disabilities.

A third focus of UCEDD community services is training for teachers and other school personnel, often with a heavy emphasis on PBS. Many UCEDDs are providing technical assistance to schools to increase the number of teachers using PBS and thus hoping to reduce classroom disruptions due to inappropriate behavior and office referrals. One UCEDD reported that a public school it was working with saw suspensions decrease, student achievement increase, and fewer parents taking their children out of this school in favor of charter schools compared to previous years.

Other trainings and technical assistance for school personnel focus on topics such as universal design for learning, inclusive classrooms, writing IEPs, transition, special education laws, alternatives to seclusion and restraint, evidence-based instructional strategies, and how to measure intervention fidelity. A school administrator reported that the UCEDD trainings had “changed the entire focus and culture of [the] school district” and that they are now able to serve almost all their students with autism in a general education classroom. Additionally, some UCEDDs train teachers and school administrators in what is available in augmentative alternative communication and assistive technology and how to use the equipment.

In addition to offering trainings and technical assistance, some UCEDDs provide consultation services to schools and school districts in the performance of various behavioral assessments. Examples include neuropsychological and psychological assessment and consultation for a school that is a long-term treatment program for adolescents with behavioral and emotional problems as well as neurological or intellectual deficit; mental health and behavioral consultation to Head Start classes; and assessment of young children with developmental delays or disabilities using a transdisciplinary play-based assessment approach.

With 13 out of 20 sampled UCEDDs reporting employment as an area of emphasis, it is not surprising that UCEDD community services are often geared toward employment for people with developmental disabilities and assistance for youth in transition from school to work or higher education. One UCEDD runs a program where school districts select 18 to 21 year old students to attend a UCEDD program in life skills development, career exploration, portfolio development, interview preparation, and resume development. The first semester involves classroom activities as well as real world experience to practice navigation and social communication skills. The second semester consists of an internship. As an example of gaining greater independence through this program, one girl who was interning at a medical office reported that the program gave her experience in catching the bus by herself to travel to her internship, allowed her to be more social, and taught her how to advocate more for herself.

Another UCEDD employment program prepares people age 16 to 54 for community integrated employment. Components of this program include creation of a profile by both the individual and family, diagnostic evaluations to determine learning style, placement of the individual on a self-determination scale based on level of independence and ability to advocate, and determination of physical abilities as well as soft skills. Individuals are then taught about different career paths and given the opportunity to try out different jobs in a competitive work environment. After an internship period, the goal is to obtain a job. At the time of Westat's data collection, 16 people had been hired through this program. This same UCEDD also offers a week-long college experience for youth with developmental disabilities age 16 to 21. The program helps participants to identify personal goals in areas such as interpersonal life skills, leisure and career exploration, post secondary education, and advocacy. The program promotes successful transition to adulthood by giving participants opportunities to learn and practice skills necessary to achieve their goals. After completing the program, one young woman reported that she was now speaking up and participating in her IEP meetings and was able to make her own case for inclusion in a mainstream classroom. In her view, the program had given her the courage to speak at a transition conference to talk about her increased skill and confidence to be her own advocate for independence and integration into the community.

Another UCEDD takes the approach of assisting with microenterprises to encourage self-employment. One UCEDD put a team together to write a book designed for parents of transition age youth and young adults with the goal of helping them think about work as an attainable option. Other transition programs use manuals and trainers to help youths successfully transition from school to community. Some UCEDDs also provide direct technical assistance to supportive employment programs in their state or work with employers to identify customized jobs for someone with a disability.

UCEDD community services also work with generic service systems to improve inclusion for people with developmental disabilities. For example, UCEDDs provide training to childcare providers and parents. Some UCEDDs are involved with the federal Early Start Program which focuses on low income pregnant women and children from birth to age three. One program provides resources and supports to childcare programs so that they meet all of the Early Head Start standards and are inclusive, and provides services to children with identified disabilities or with developmental delays in the program. They also conduct home visits to provide families with services including screenings for dental, vision, nutrition, and hearing, as well as creating a plan for the family that takes into account their resources and goals. UCEDD faculty and staff are also working with state agencies to revise licensing standards for child care providers to ensure that the child care providers receive appropriate training to improve their services to children with developmental disabilities. Other informal interaction with parents can be as simple as showing a family how to download an iPad application to learn sign language. One mother reported to the UCEDD that this application was "changing their lives." Other parent trainings focus on navigating the IEP process and learning about the range of professionals who are available to provide clinical and diagnostic services.

The general public is also a target for UCEDD community service activities in order to improve awareness and opportunities for people with developmental disabilities. UCEDDs have provided disability awareness training to groups such as hotel workers, police officers, bus drivers, and attorneys. One UCEDD that runs a program to educate the community at large in disability issues reported that respondents overwhelmingly indicate that what they learn from the training is that people with developmental disabilities are just like everyone else.

Many UCEDDs provide direct services to people with developmental disabilities through clinical programs which either take place at the UCEDD or out in the community. Clinical services include diagnostic evaluations, socialization groups, family therapy, language development, physical therapy, genetic counseling, and referral recommendations.

Faculty and Staff Expertise. An important product of all UCEDDs is the expertise they impart to people with developmental disabilities and other target audiences, including research colleagues, patients, and the community at large who trust and rely on their services, trainings, and research. A common theme in the UCEDD interviews with recipients of UCEDD services or outside collaborators was overwhelming gratitude and respect for the work being carried out in these centers.

UCEDD faculty and staff impart their knowledge and expertise to research colleagues and policy makers by publishing in peer-reviewed journals and other types of publications and presenting their work at numerous types of venues. Among the faculty and staff reported on by 18 UCEDDs in the SAQ, the mean number of faculty or staff publishing in a peer-reviewed journal across these 18 UCEDDs was 11.8 (standard deviation 10.8), the median number was 7.5, and the range was 1-41 faculty or staff. Sixteen percent published at least one disability-related article in a peer reviewed journal during the reporting period of the SAQ. Ten sampled UCEDDs reported fewer than 10 faculty or staff in their UCEDD who had published at least one disability-related article in a peer-reviewed journal during the reporting period (Table 3-22). Authorship or co-authorship of disability-related technical reports and presentations at conferences and meetings were more frequent. Nine UCEDDs reported 10-19 faculty or staff members producing such technical reports, and 10-19 presenting at conferences during the reporting period (Table 3-22). Most UCEDDs had faculty or staff serving on disability-related advisory groups, boards of directors, commissions, the Governor's Council, or legislative committees. Provision of public testimony, participation in national or international task forces or other committees, reviews of books and journal articles, and participation in a funding agency's grant committee were less frequent among UCEDD faculty and staff.

3.4.3.5 Outcomes

Outcomes are the intended results of creating certain outputs or products (French & Bell, 1984). They represent the overarching goals of the UCEDD. UCEDD outcomes can be short-term (i.e., those that accrue to UCEDD target audiences and therefore can be more readily attributed to the work of the UCEDDs) and long-term (those that can influence the population but could have been affected by other programs and circumstances). We report here on the outcomes of pre-service students and trainees reported by executive directors.

Table 3-22. UCEDD faculty and staff involved with publishing and presenting on developmental disabilities from July 2008-June 2009

	Number of sampled UCEDDs						
Type of faculty and staff expertise	<10	10-19	20-39	40-49	50+	Missing	Total
Publication of at least one disability-related article in peer-reviewed journal	10	4	3	1	0	2	20
Authorship or co-authorship of a disability-related technical report or article, or disability-related chapters in books	6	9	3	0	1	1	20
Presentation on UCEDD faculty or staff disability-related research (including public policy analysis and evaluation) at conferences or meetings	4	9	3	0	2	2	20
Service on disability-related advisory groups, boards of directors, commissions, Governor's Councils, legislative committees, etc.	7	6	3	0	2	2	20
Provision of public testimony, made presentations, or provided consultation to legislators and other public officials	14	2	1	0	0	3	20
Participation in national or international task forces or other committees related to disability	15	2	1	0	0	2	20
Reviews of articles for a peer review journal, books, or book chapters, or other publications	14	3	1	0	0	2	20
Participation in funding agency's grant review committee	17	1	0	0	0	2	20

Pre-Service Student and Trainee Outcomes. One of the critical outcomes of the UCEDD programs is how their students and trainees use their training once they leave the UCEDD. UCEDDs make use of the National Information Reporting System (NIRS) to help track students at one, five, and ten years out. Many UCEDD directors pointed out that maintaining updated contact information can be difficult after students leave, resulting in less than complete followup. However, since mentoring is a major component of the interaction between faculty and students at most UCEDDs, anecdotal followup is also done via the informal communication faculty members maintain with their former students and trainees, including seeing them out working in the field.

According to UCEDD directors, most pre-service students either go on to further their education or transition into the workplace. Undergraduates or graduate students go on to higher degrees, including masters programs, PhD programs, medical school, or post-doctoral programs. The others move on to the workforce, many in the area of developmental disabilities. One UCEDD director not associated with a LEND program reported that its last evaluation showed that 20 out of 33 respondents were working with people who have disabilities, and that 19 reported that they work with underserved or vulnerable populations. Two directors who have UCEDDs that are associated with LEND programs reported that 65 to 70 percent and 70 to 80 percent, respectively, are working with people with developmental disabilities. Across all programs, the SAQ revealed that 38.9 percent of graduates or trainees who completed their program during the reporting period (July 2008 through June 2009) found work that would benefit people with developmental disabilities.

The jobs students obtain after their training with a UCEDD are as varied as the UCEDDs themselves. Examples include:

- Policy work for the Centers for Disease Control and Prevention,
- Needs assessment evaluator for a state mental health department,
- Working with children with developmental disabilities at a children's hospital,
- Maternal and child health planning for a local health department,
- Tenure-track positions with other universities,
- Social work,
- Clinical director of a behavioral analysis company,
- Special education teachers,
- Speech language pathologist for a special education department,
- Case management for a support services brokerage, and
- Autism specialist for a state department of education.

A majority of former students interviewed by Westat were very positive about their experiences with their UCEDD, highlighting the use of their education in their current positions and that the UCEDD was critical in helping to shape their career goals. A common theme heard from many students is that they use their training on a daily basis. They also stressed that one of the most important outcomes of their studies with a UCEDD was the connections they were able to make which helped them network and obtain positions in the field. One UCEDD graduate is director of the IDEA Part B program in his state. He reported that he "applies everything he learned in the program to better serve people with disabilities and their families." An undergraduate reported that she changed her major based on her experiences with the UCEDD at her school, while another former student stated that her UCEDD training "…completely shaped every aspect of my adult life which is pretty powerful for a training program."

We found similar results with professionals who participated in continuing education through a UCEDD. Many UCEDD directors mentioned that it is much more difficult to track how continuing education students use their training than their pre-service students. One even bluntly stated, "no one gives us money for that." Those interviewed stressed that they were able to use their skills immediately since most are already working in the field. Skills and attitudes gained include management skills for direct service providers; tolerance and understanding of people with developmental disabilities for professionals such as hotel employees, bus drivers, and daycare providers; and parents who can now advocate for their children, understand positive behavior support, or navigate the IEP process.

3.4.4 Collaboration

In addition to obtaining an understanding of all collaboration taking place at all DD Network programs, the statement of work for the National Independent Study also called for an examination of collaboration specifically among the three DD Network programs.

The DD Act does not define collaboration or specify how it should be achieved. However, it requires that program accountability measures include measurement of the extent to which the DD Network collaborates. The Act also requires reports to the Secretary of Health and Human Services that provide examples of coordinated activities among the Network. Section 104(a)(3)(D) and 105(1) state:

- Program Accountability/indicators of progress: At a minimum, the indicators of progress shall be used to describe and measure…(iii) the extent to which the members of the DD Network collaborate with each other to achieve the purpose of this title and the policy described in section 101(c).
- Reports of the Secretary: In preparing the report, the Secretary shall provide meaningful examples of how the councils, protection and advocacy systems, centers, and entities funded under subtitles B, C, D, and E, respectively…—have undertaken coordinated activities with each other …

Since the DD Act does not provide a definition of collaboration, the following is considered the working definition of collaboration for this evaluation:

- Collaboration is a well-defined relationship entered into by two or more individuals, groups, and/or organizations to achieve common goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (Backer, 2003).

Although it was well-understood that DD Network programs collaborate with many more agencies and organizations than the DD Network sister agencies in their state, this section of the report focuses primarily on collaboration among all three DD Network programs.

We addressed three basic components of collaboration among the three DD Network programs. The first component consists of the underlying infrastructure and resources available so collaboration can take place (e.g., regular meeting schedule, contribution of staff time, dollars, meeting room). The second component emphasizes the working relationship among the entities (the process of collaboration), and the third component relates to the outputs and outcomes resulting from the collaboration that takes place.

The DD Act does not specify the expected outcomes of collaboration, only that it must be done and reported on. For this evaluation, we considered the expected outcome of collaboration to be the achievement of short-term outcomes that result from achieving common goals set jointly by the DD Network programs (e.g., production of a brochure or report, changes in community practice, improved access to services, leaders in disability-related fields). The longer-term outcomes, relevant to the population or the community at large, were considered more difficult to attribute directly to the work of the DD Network programs.

3.4.4.1 Structures

To examine the structures necessary for collaboration, Westat collected data on the infrastructure that needs to be in place in order for the DD Network programs to collaborate, such as meetings among the three network programs, dedicated staff time for collaborative efforts, and other resources available for collaborative efforts.

Network Meetings. We collected data on the frequency and regularity of collaborative meetings. Approximately half of sampled state networks reported meeting monthly or quarterly to discuss collaborative efforts. These meetings were in person or took place by telephone. A smaller number of sampled state networks reported holding an annual meeting with the network to discuss collaborative efforts, and two of the sampled state networks reported meeting rarely or never. In these cases, it appeared that the executive directors did not agree on issues or geographical distance among network programs precluded regular collaboration.

Most of the sampled state networks reported having an informal approach to collaborative meetings. Often, these state networks would meet over lunch or after a meeting that they were all attending. As one executive director put it, "we are in the same place at the same time an awful lot" and are able to have impromptu meetings. In addition, the states that reported an informal approach communicated frequently over the telephone and email to discuss collaborative efforts. In many cases, the state networks that reported the informal approach to collaboration were also the ones that reported having worked together for many years and, thus, had a long history of working with one another and a strong working relationship. A smaller number of sampled state networks (about a quarter) reported having a more formal approach to collaboration meetings. These state networks have standing meetings (scheduled far in advance) and that are considered "official" meetings at which minutes are taken and distributed and the attendance of which is compulsory.

Staff Time. All sampled state networks reported that it is the executive directors of each program that are most invested and involved in the collaborative efforts. The executive directors typically set the collaboration agenda, determine how the work will be divided among the network programs, lead activities related to the collaborative efforts, and monitor progress of those efforts. In addition to the executive directors, other staff at many of the sampled state networks contributes to collaboration. Sampled state networks reported that program staff often attend collaboration meetings and engage in collaboration-related efforts.

Other Resources. When discussing collaboration among network programs, interviewees often mentioned other resources that were made available through the collaboration in order to further the effort. For example, several state networks indicated that one of the programs was typically able to provide office space, conference call technology, and/or webinar technology for collaboration meetings. The other resource commonly mentioned by respondents was funding various aspects of collaborative efforts. In some cases, one of the programs was able to underwrite the cost of attending conferences or other events. A few state networks indicated that funding for other aspects of collaboration are contributed by one or more of the programs, such as, payment for advertising of planned events, conference materials, travel to events, and facility fees. As one interviewee explained, the program that supplies the funding will vary and will depend on availability of funds and the collaboration issue.

3.4.4.2 Processes

To assess processes, we collected data on how the state networks determine which collaborative efforts to take on; how they determine who will lead and participate in the effort; how they communicate with each other about collaborative efforts; and how collaboration is monitored.

Identification of Common Goals. The majority of the sampled state networks described a two pronged approach to the identification of common goals: (1) identification of collaborative goals during the annual planning process, and (2) discussion of emerging/emergency issues.

More than half of sampled state networks reported incorporating collaboration planning into the annual network planning process. In most cases, these state networks engage in the planning process jointly and are able to discuss mutual barriers to inclusion. Several of the sampled state networks reported using a needs assessment survey to assess the needs of stakeholders in the state. Data from the surveys were reportedly used to identify common goals for collaboration. As the planning process evolves into identification of goals and objectives for each program, the sampled state networks reported that the programs would compare the plans/goals and objectives to see where they intercept and use that as a tool to identify the common goals of the network. For those sampled state networks that did not report using the planning process as a time to identify common goals, many reported discussing collaboration at other joint meetings, such as Board meetings, annual retreats, and task force meetings. In these cases, the sampled state networks were more informal in their approach to identifying collaborative goals. As one executive director explained, “it is second nature” and need not be formal because of the amount of communication among network programs.

Regardless of how the sampled state networks identify the common goals, all reported that the common goals need to, in some way, reflect each program’s goals and objectives. However, sampled state networks also report that issues will emerge that do not necessarily fall within the collaboration goals or the programs’ goals. In these cases, issues are often raised by one program during a monthly conference call or, informally, with the executive directors of the other two programs. Often, it is an issue that starts in one program and then the other two join the effort. For example, in one state, issues around seclusion and restraint in the school system were being investigated by the P&A because of complaints received. As work progressed, the Council become involved in a systemic approach to the issue (advocacy, legislative changes) and the UCEDD became involved when testimony and research were needed as support. As one executive director stated, collaboration planning "is a fluid process because of emerging issues."

Determination of Roles. Once the collaborative goals and agenda have been identified by the state network, the next step was typically to determine the role of each program. When asked how leadership of a collaborative effort was determined, all sampled state networks reported that leadership emerges naturally. The role of each program is determined based on skills and expertise. One executive director explained, "leadership and participant roles are naturally occurring things sometimes based on who brought the issue to the table, but not always; other times it is who has access to the resources, who has access to the connections to work the issue." And, as another executive director stated, "we are each willing to defer in the right places to others…we work with each other's strengths."

Regular Communication. One of the processes we examined was the way in which state network programs communicate and share information. The overall response to questions about communication indicates that the sampled state networks engage in a constant flow of information among programs that is often informal but usually on a regular basis. Approximately half of sampled state networks reported meeting monthly or quarterly to discuss collaborative efforts. Another quarter of sampled state networks meet annually or bi-annually to discuss progress and milestones around collaborative efforts. Approximately half of sampled state networks indicated that, because they all sit on each other's boards and are members of common committees and task forces in the community, communication is often piggy-backed on to other network meetings.

In addition, most of the sampled state networks reported communicating frequently via telephone or email. Much of this communication is informal in nature, but a number of the sampled state networks also send out formal updates on collaborative efforts via email. As one executive director explained, communication about collaborative efforts is critical so that, "…there's no duplication of effort or conflict in our approaches…"

Monitoring Progress. State networks do not appear to engage in formal monitoring unless the collaborative effort is funded (wholly or partially) through a grant or other funding stream that would require regular reporting. Informally, the sampled state networks explained that issues are typically taken to the lead program executive director for resolution and general oversight is managed by the lead program executive director.

3.4.4.3 Outputs

Outputs, in the case of collaboration, consisted of goals, projects, and products.

Goals. The collaboration goals identified by executive directors we spoke to mostly reflected the goals and objectives described in each program's planning document (e.g., State Plan, 5-Year Plan). About half of sampled state networks pull together the collaboration goals and develop a strategic plan or work plan for the state network. Typically, these plans are reviewed annually and revised based on findings and experiences from the previous year. One state network develops a memorandum of understanding (MOU) specific to each collaborative effort, and another state network was planning (at the time of the site visit) to begin using formal collaboration agreements (e.g., MOUs) for collaborative efforts.

Examples of common goals among the sampled state networks include:

- Closing/reducing the number of institutions in the state,
- Employment first for people with developmental disabilities,
- Limiting and regulating the use of seclusion and restraint,
- Increased accessibility in building and public spaces,
- Increased access to healthcare,
- Improved transition for youth with developmental disabilities,
- Improvements in special education,
- Increased participation of people with developmental disabilities in the legislative process, and
- Improved access to reliable transportation.

Within each of these goals, the sampled state networks engaged in a variety of projects and efforts to achieve outcomes.

Projects. The collaboration projects engaged in by the sampled state networks cover a range of topics and employ a variety of approaches. Overall, the projects can be categorized as: conferences; trainings/workshops; data collection; legislation/public policy; and public/community education.

Many of the sampled state networks support or sponsor conferences intended to communicate disability-related information to the community or specific groups. Examples of conferences include:

- Conference to educate people with developmental disabilities about the voting process and increase voter participation among people with developmental disabilities,
- Conference targeting developmental disabilities in minority populations,
- Conference promoting inclusion of people with developmental disabilities, and
- Conference on transition for parents and youth with developmental disabilities.

A wide variety of trainings and workshops were provided jointly by the sampled state networks (Table 3-23).

Table 3-23. Examples of training and workshop topics and their audience in sampled states/territory

Topics	Audience
Medicaid waivers	People with developmental disabilities
Positive behavior supports	Providers
Legislative process	Self-advocates
Disability sensitivity	Potential and current employers of people with developmental disabilities
Guardianship	Family members

Collaborative data collection projects included a survey to collect information from special education directors about use of seclusion and restraint, an assessment of the incidence of autism in the state, and added disability-related questions to police forms in order to collect data on the number of people with developmental disabilities who are victims of crime.

Collaboration among the state networks often takes place to meet systems change goals. Examples of the projects in which collaboration among the three DD network programs took place include:

- Attempt to revise the state law mandating that all provider agencies be mandatory voter registration agencies,
- Development of new legislation to extend the number of children covered by the IEP school programs,
- Legal enforcement of the ADA on accessibility and housing,
- Education of legislators on teaching positive behavior supports rather than using seclusion and restraint.

- Promotion of competitive employment for people with developmental disabilities among departments of vocational rehabilitation,
- Review of employment-related policy as it pertains to people with developmental disabilities
- Education of legislators about the need to close institutions in state/territory.

Educating and informing the public about inclusion of people with developmental disabilities is another area in which state networks often collaborate to achieve goals. Examples of these projects are:

- Outreach to increase awareness about Social Security work incentives among people with developmental disabilities,
- Participation in events and development of a booklet intended to promote adoption and awareness of universal design in housing,
- Outreach and provision of information to people with developmental disabilities about the importance of a voluntary registry for use during emergency situations,
- Initiatives designed to increase awareness and inclusion in oral health settings, and
- Support and promotion of job fairs.

Products. Collaborative efforts among network partners often result in the development and distribution of products related to the goals of collaboration. Westat collected data from the sampled state networks on the types of products developed from collaborative efforts. A number of sampled state networks explained that they develop joint informational products intended to inform the public about the network. Several sampled state networks reported developing a joint brochure, highlighting the three DD Network programs in the state and the services provided by each program. Many sampled state networks also reported publishing a regular newsletter from the network for distribution to people with developmental disabilities and other stakeholders. Also, several indicated that the individual programs' web sites are linked to one another so, for example, someone looking at the UCEDD web site will also be able to access the P&A and Council web sites from the UCEDD web site.

Many collaborative products are topical in nature and specific to a certain collaborative project. A number of state networks reported developing tip sheets, fact sheets or FAQs on specific topics such as guardianship, restraint and seclusion, and Medicaid waivers. Sampled state networks also reported developing booklets for distribution to various audiences on topics, such as, accessible housing design, ticket-to-work, and autism. Sampled state networks develop a number of training curricula on topics, such as, guardianship, positive behavior supports, transition, advocacy/self-advocacy, the legislative process, and special education.

Some collaborative products from state networks are targeted toward legislative system changes in the state. A large number of sampled state networks support testimony given by people with developmental disabilities to the local, state, or Federal legislature. Whereas the state networks are not actually providing the testimony, supporting facts and data used in the testimony are often provided by the networks. In addition, many of the sampled state networks collaboratively develop policy papers and reports based on collected data with the intent of educating legislators and their staff. Most sampled state networks have been involved in drafting or revising legislation.

Another product of collaboration is the coalitions and partnerships formed between the state networks and other organizations. In order to achieve collaborative goals, many state networks engage other organizations in the process. Often, these relationships are sustained beyond the scope of the collaborative effort. Examples of other organizations and agencies engaged with state networks on collaborative efforts include AARP, Commissions on Aging, centers for human development, departments of education, mental health agencies, and health care providers.

3.4.4.4 Outcomes

Ultimately, the structures, processes, and outputs of collaboration are expected to result in an outcome, often difficult to measure or attribute directly to the collaborative efforts of the three DD Network programs. Nevertheless, Westat attempted to collect data from the sampled state programs on the results or outcomes of their collaborative efforts. Executive directors reported changes to community practice and improved access to services and saw increased numbers of leaders in the community that they attribute to their collaborative efforts. Examples of reported outcomes are listed below.

Changes to community practice include:

- Increased services available to children with autism and their family members due to education provided by a state network on the use of positive behavior supports,
- Halted efforts of providers to weaken or limit oversight and monitoring of group homes,

- Adoption by the Division of Developmental Disabilities of state network supported standards for certification in positive behavior supports,
- Removal of the term “mental retardation” in the names of agencies,
- Legislation mandating that schools tell parents of any intent to use seclusion and restraint and also mandating that the schools collect data on the use of seclusion and restraint,
- Domestic violence legislation for which DD Network programs wrote language about interacting with people with disabilities in domestic violence situations,
- Agreement from the state Department of Education to set voluntary regulations about the use of seclusion and restraint,
- Closure of a state residential facility,
- Halting a bill that would limit the P&A’s authority to file suits on behalf of people in institutions,
- Passage of an insurance parity bill for children with autism, and
- Passage of legislation related to guardianship, allowing people under guardianship the ability to retain counsel without the guardian’s knowledge.

Improved access to services include:

- Improved accessibility at polling sites,
- Preservation of current services to people with developmental disabilities in the midst of significant budget cuts,
- Funding to purchase wheelchairs and buses to improve transportation and accessibility,
- Home based care for children who are on the waiting list for services,
- Legislation that will ameliorate the waiting list of services within 5 years, and
- Provision of group health insurance to cover early intervention for children with developmental disabilities up to age 3 and a certain dollar amount.

Finally, executive directors reported increases in the number of leaders in the community as a result of their collaborative efforts. These outcomes include the following:

- A large number of Council members and advocates are graduates of the Partners in Policymaking programs, supported by many state networks.

- State network fellowships have allowed people with developmental disabilities , professionals, and family members to achieve their goals in the disability community and become potential leaders in the community (e.g., one is a Kennedy fellow in Washington, D.C. working with legislators, and one is working on a disability-related Master's degree).
- Self-advocates are now employed by network programs and are in leadership positions due to advocacy trainings.

3.4.4.5 Summary

In summary, structures for collaboration among the three DD Network programs consist of both informal and formal approaches to collaborative meetings to set common goals, identify staff and other resources for meeting goals, and monitoring progress. Programs typically identified common goals during an annual planning process and/or as a result of discussion of emerging or emergency issues. Determination of roles appeared to naturally fall into place, depending on the issue, for most state networks. Communication between meetings varies. Typically it is ongoing and informal via telephone or email, with some state networks taking a more formal approach and meeting monthly or quarterly to discuss collaborative efforts.

State networks were able to report on a variety of collaborative outputs (e.g., brochures, workshops, conferences). State networks reported changes to community practice, improved access to services, and increased numbers of leaders in the community. These outcomes were typically achieved not only with collaboration among the three DD Network programs but also with a broad range of partners and collaborators throughout the state.

This page left blank intentionally.

A Refined Set of Standards and Performance Criteria

4

4.1 Overview

The initial request for proposal (RFP) for this study required that performance standards be developed and validated in Phase 1 of the study and applied in Phase 2 to a sample of Developmental Disability (DD) Network programs. Phase 2 was expected to consist of the collection of data to determine whether the standards were being met. The final report would produce a quantitative assessment of DD Network impact on people with developmental disabilities and their family, as well as a set of tools for the field—standards and performance criteria that could be used by the Administration on Developmental Disabilities (ADD) to meet its accountability responsibilities and the programs themselves as a means of self-assessment.

During Phase 1 of the project, it was determined that it would be difficult to develop valid final performance standards without an understanding of the range in which such standards might be met. Moreover, given the nature of some program goals (particularly those related to systems change), the development of quantifiable standards was seen as a particular challenge. Thus, Phase 1 consisted of the development of a working version of standards (see Chapter 2). These were intended to be used to develop data collection instruments to collect data to use in developing final standards and performance criteria in Phase 2.

In addition, since the original statement of work, the study was re-shaped, particularly surrounding the nature of the performance standards. New instructions for the study required the development of “suggested qualitative performance criteria based upon narrative descriptions, as opposed to quantitative measurement systems. The proposed performance criteria will be reviewed by stakeholders for validation purposes and revised according to consensual feedback, but will not include performance targets for explaining program impact” (Appendix J).

This section describes the consensual process that took place to develop draft standards and performance criteria, including the establishment of standards panels to provide feedback. Briefly, the process consisted of establishing the panels; developing Version 1 of the draft standards based on data collection findings; asking panel members to review, rate, and comment on Version 1 of the draft standards; developing Version 2 based on panel ratings, comments, and suggestions; asking panels to review, rate, and comment on Version 2 of the Draft Standards; and developing Version 3 based on panel ratings, comments, and suggestions. We also developed and followed specific instructions for keeping or eliminating draft standards and performance criteria in revised versions, based on the extent of agreement among panel members.

We also describe Version 3 of each program's Draft Standards and Performance Criteria and for collaboration in this chapter and end the chapter with our observations on the strengths and limitations of the standards development process and resulting product.

4.2 Process for Developing Draft Standards and Performance Criteria

4.2.1 Establishment of Draft Standards Panels

To establish draft standards panels, Westat and ADD discussed the characteristics that we thought panel members should have, including:

- An understanding of the needs of people with developmental disabilities,
- An understanding of the purpose of the programs,
- An appreciation for outcomes (e.g., experience with policy development and research),
- Involvement in the DD Network system, and
- A proven track record of self-advocacy.

In addition, like the first Validation Panel established in Phase 1 of the study, we wanted to obtain geographic diversity among panel members, a mixture of perspectives according to characteristics of programs (e.g., LEND program and medical school status for the UCEDDs, allotment size and public/private status for the Councils and P&As), and a mixture of program staff (senior and less senior level) and non-program staff, self-advocates, family members, and experts in the developmental disability community.

Westat sent an email (Appendix K) to all executive directors of DD Network programs and the three national association executive directors to request recommendations. We also obtained recommendations from ADD. We received a total of 186 recommendations. Using the criteria developed above, we identified 66 individuals to invite to be panel members.

A letter from the ADD Commissioner was sent to individuals who were identified inviting them to participate as a panel member (Appendix L). Westat followed up the letter with a telephone call to determine whether each invited person would be willing to participate in the panel process.

Three people were unable to participate and 63 agreed to become a panel member. There were three panels (Appendix M). The panel for the State Councils on Developmental Disabilities (SCDDs) contained 27 people (Table 4-1). The Protection and Advocacy (P&A) panel contained 24 people. There were 23 people on the panel for the University Centers of Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs). For consistency, three individuals were invited to be a member of all three panels; three were invited to be a member of the panel for both SCDDs and UCEDDs; one was asked to be a member of the panel for both SCDDs and P&As;[10] and one was asked to be a member of the panel for both P&As and UCEDDs. All panel members were asked to rate the draft standards and performance criteria for collaboration.

Table 4-1. Characteristics of draft standards panels

Program	Total number of panel members*	Number of self-advocates	Number of family members	Number of program staff	Number of non-program staff
State Councils on Developmental Disabilities (SCDDs)	27	4	3	15	6
Protection and Advocacy (P&As)	24	4	2	14	7
University Centers of Excellence in Developmental Disabilities Education, Research, and service (UCEDDs)	23	5	3	13	6

*Note: There is overlap in some categories, so separate columns do not add up to the total number of panel members in the first column. In addition some individuals sat on more than one panel.

4.2.2 Development of Version 1

The goal of developing standards and performance criteria was to provide ADD and its grantees with information that could help demonstrate the effectiveness of DD Network programs and

---

[10] Note: this individual declined panel membership on the P&A panel.

progress that is being made toward the goals laid out in the DD Act. The following definitions were used for this process (Exhibit 4-1).

Exhibit 4-1. Definition of standards and performance criteria

Draft standards –	Expectation[s] that must be met to be appraised at a particular level of performance.
Performance criteria –	What programs need to do or have to meet the standard.

Based on a careful review of all Findings Forms from sampled states and territory, as well as Self-administered Questionnaire (SAQ) findings and materials provided by programs, Westat developed Version 1 draft standards and performance criteria with the following premises: (1) they were associated with good outcomes (e.g., efficiency and effectiveness), (2) outcomes were related to the DD Act principles and goals, and (3) most but not all programs would be able to meet the standard. Early versions of performance criteria contained four levels—does not meet the standard, partially meets the standard, fully meets the standard, and exceeds the standard. Only one level—fully meets the standard—was retained in rating materials for draft standards panels. However, panel members were asked whether they thought each performance criterion met the standard, exceeded the standard, or was irrelevant to the standard.

Westat used a modified Delphi approach to develop draft standards and performance criteria to take to ADD (DeVos et al., 2006; Linstone & Turoff, 2002). The Delphi approach consists of a structured communication technique which relies on a panel of experts to reach consensus. In this case, the experts were those with expertise in the three DD network programs and issues of importance for people with developmental disabilities.

The primary task of panel members was to rate the draft standards and performance criteria. Westat first invited all panel members to a webinar to describe the background of the National Independent Study and provide instructions on rating. The webinar consisted of a PowerPoint presentation (Appendix N) and questions and responses. Those who were unable to attend one of the three webinars that were offered were sent a video-recording. Panel members were then sent both a hard copy package and an email with attachments of all materials and given the choice to rate with paper and pen or electronically. Packages contained:

- Rating instructions (Appendix O),

- Draft Standards – Version 1 (Appendix P),
- Rating Form - Version 1 (Appendix Q),
- Lists of panel members for all three panels (Appendix M), and
- A postage paid envelope to return completed ratings to Westat (to return the hard copy rating form).

Rating forms were developed from Version 1 of the Draft Standards and Performance Criteria so that each standard and performance criterion could be rated one at a time (Exhibit 4-2). Panel members were asked to read the instructions first. For each draft standard they were asked to indicate whether they agreed, were unsure, or disagreed that the program should be held accountable to the standard. To rate the performance criteria, they were asked to decide whether they thought the performance criterion should be required to meet the standard, whether it exceeded the standard, or whether it was not relevant to the standard. Space was available for comments on each standard and performance criterion; comments were optional. Panel members were asked to return their completed ratings to Westat.

4.2.3 Development of Version 2 of Draft Standards and Performance Criteria

The next step was to review all panel member ratings and comments, tally the ratings of draft standards and performance criteria for each panel and collaboration (Appendix R), and develop Version 2 of the draft standards and performance criteria based on the ratings and comments.

We developed rules for developing revised standards and performance criteria. For example, in the case of the SCDD standards:

- If 65 percent[11] 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 SCDD panel members. We reviewed the comments to see if we could clarify or improve the wording for those standards that remained.

---

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

Exhibit 4-2. Extract from P&A Rating Form

Protection and Advocacy (P&A) System
Draft Standards and Performance Criteria

C. 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:

- 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 wording changes.

Similarly for the SCDD draft 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 SCDD members. 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 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 wording changes.

Rules were similar for the other two programs and collaboration.

To be as transparent as possible, we provided panel members with an explanation of why we kept or changed draft standards in Version 2. Explanations of changes for each program and collaboration are contained in Appendix S.

The process for obtaining ratings for Version 2 of the draft standards and performance criteria was similar to the process used for Version 1. Panel members were asked to rate Version 2 draft standards and performance criteria and return their ratings to Westat. The package sent to panel members contained a cover letter with a summary of comments and explanations of changes (Appendix T), the rating results for Version 1 (Appendix R), Version 2 of the draft standards and performance criteria (with and without tracking) (Appendix U contains Version 2 without tracking), a rating form for Version 2 of the draft standards and performance criteria, panel member comments on Version 1 (Appendix V), and a postage paid return envelope. Panel members were again asked to return their rating forms to Westat.

4.2.4 Development of Version 3 Draft Standards and Performance Criteria

Westat again reviewed all ratings and comments, tallied the ratings of each panel (Appendix W), and developed Version 3 of the draft standards and performance criteria. Similar rules were used. Version 3 was then mailed and sent by email to panel members. The contents of the package again contained a cover letter with a summary of comments and explanations of changes (Appendix X), the rating results of Version 2 (Appendix W), Version 3 of the draft standards and performance criteria (with and without tracking) (Appendix Y contains Version 3 without tracking), and panel member comments on Version 2 (Appendix Z). Panel members were informed that this version (still a draft version) would be included in the final report to ADD. Those who were able to accept it were given an honorarium as a thank you for their assistance.

Our approach to making changes to Version 2 was similar to the one we used previously. For Version 3 of the SCDD draft standards and performance criteria 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 SCDDs, we took out the category (key function) headings (we agreed with some panel members that the categories of Council functions were 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.

To simplify the draft standards and performance criteria, we also took out the functional categories for the P&As. Like the SCDDs, 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. Again, we were unable to incorporate every single suggestion since sometimes panel members held differing viewpoints.

In Version 3 for the UCEDDs, we continued to use the core function categories 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.

Finally, for the draft collaboration standards and performance criteria, those that made it into Version 3 had received high ratings from panel members, while those that were deleted had received low ratings. We again tried to follow the suggestions of panel members for wording.

4.3 Description of Version 3

Westat developed Version 3 of the Draft Standards and Performance Criteria (Appendix Y) based on panel ratings of Version 2 and panel comments and suggestions. This section describes Version 3 of the draft standards and performance criteria for SCDDs, P&As, UCEDDs, and collaboration.

4.3.1 State Councils on Developmental Disabilities

Version 1 of SCDD Draft Standards and Performance Criteria contained nine standards and 53 performance criteria. By Version 3, the number of draft standards had been reduced to seven (Table 4-2) and the number of performance criteria to 29 (Appendix Y).

Table 4-2. Draft Standards, Version 3, State Councils on Developmental Disabilities

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.**
Standard 2.	**State Plans guide Council action.**
Standard 3.	**State Councils on Developmental Disabilities support the development of self-advocates and leaders among people with developmental disabilities and family members.**
Standard 4.	**Participants in Council self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.**
Standard 5.	**State Councils on Developmental Disabilities improve the capacity of communities to include and support community members with developmental disabilities.**
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.**
Standard 7.	**State Councils on Developmental Disabilities effectively fulfill their roles and meet their responsibilities.**

Version 3 is no longer organized by key function, although the draft standards still address the functions of planning, self-advocacy and leadership development, development of community capacity, system change, and governance and management. Four out of seven of the standards can be characterized as outcomes (Standard 4, 5, 6, and 7). Outcome standards are standards that apply to the outcome of goals.

4.3.2 Protection and Advocacy Systems

Version 1 of P&A Draft Standards and Performance Criteria contained 12 standards and 83 performance criteria. By Version 3, the number of draft standards had increased by one (to 13) (Table 4-3), and the number of performance criteria had halved (to 42) (Appendix Y).

Throughout this study, the P&As have been particularly vocal about the importance of standards that address outcomes and much less interested in standards related to process. The majority of draft standards focus on an outcome (draft Standard 3, 4, 5, 6, 7, 8, 10, and 12). Many of the PCs required to meet the standards, agreed upon by the P&A Draft Standards Panel, are structures, processes, or outputs.

Table 4-3. Draft Standards, Version 3, Protection and Advocacy Systems

Standard 1.	P&As identify the key issues, needs, and priorities of people with developmental disabilities in the state or territory.
Standard 2.	P&A SGPs are a guide to P&A action.
Standard 3.	The P&A intake process is fair, efficient, and effective.
Standard 4.	P&A caseload reflects the priorities set in the SGP.
Standard 5.	P&As provide high quality representation.
Standard 6.	Individual advocacy meets client objectives.
Standard 7.	P&As strictly adhere to confidentiality.
Standard 8.	P&A systemic advocacy improves access to supports and services and reduces abuse and neglect.
Standard 9.	P&As engage in effective outreach activities to identify unserved and underserved populations.
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.
Standard 11.	P&A Board of Directors sets policy and long range goals for the P&A and holds the executive director accountable for adhering to the policies and goals.
Standard 12.	P&As maintain an infrastructure that enables them to conduct key functions efficiently and effectively.
Standard 13.	P&As maintain operational independence from the Governor and the developmental disabilities service system of the state or territory.

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

Unlike the Draft Standards and Performance Criteria for Councils and P&As, those for the UCEDDs are organized by function—the four core functions contained in the DD Act, one standard for 5-year planning, and two for governance and management. Version 3 of the UCEDD Draft Standards and Performance Criteria contains nine standards (Table 4-4), reduced from the original 12 draft standards in Version 1. Version 1 contained 69 PCs, and Version 3 now contains 30 (Appendix Y).

Three out of the nine draft standards are outcomes—Standard 3, 4, and 7. Draft Standards 3 and 4 relate to the outcomes of interdisciplinary pre-service preparation and continuing education in which the goal is to develop a cadre of individuals with the necessary knowledge, skills, attitudes and values to increase the capacity of States to provide and/or influence services and supports for people with developmental disabilities and their families. Standard 7 is an outcome standard on dissemination.

Table 4-4. Draft Standards, Version 3, University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)

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).

Standard 2. UCEDD 5-Year Plans are a guide for UCEDD action.

Interdisciplinary Pre-Service Preparation and Continuing Education

Standard 3. UCEDDs advance practice, scholarship and policy that impact the lives of people with developmental disabilities and their families through pre-service training.

Standard 4. UCEDDs prepare students to work on behalf of a diverse population of people with developmental disabilities.

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.

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. UCEDDs may provide services, supports, and assistance through demonstration and model activities.

Dissemination

Standard 7. UCEDD dissemination bridges the gap between research and practice and reaches people with developmental disabilities and their families.

Governance and Management

Standard 8. UCEDDs leverage ADD funding and in-kind resources to achieve the goals of the 5-year plan.

Standard 9. UCEDDs maintain and support involvement from CACs.

4.3.4 Collaboration

There is one draft standard and five performance criteria for collaboration in Version 3 (Table 4-5). The draft standard states "All DD Network programs in the state or territory achieve one or more common goals through collaboration." All the draft PCs under this standard require a process to be carried out to meet the standard, including PC 1.5 which requires programs to document the outcomes of collaborative efforts.

Table 4-5. 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.

4.4 Strengths and Limitations of Standards Development Process and Outcome

To meet one of the important criteria of a successful evaluation—utility—stakeholder input and participation are essential (CDC, 1999). ADD has paid careful attention to such input and participation, and as a result, has required that stakeholders be a key ingredient in all aspects. The establishment and implementation of the Draft Standards Panels is a clear example.

Westat and ADD paid careful attention to the composition of these panels with attempts to seek participation from a broad group of stakeholders (e.g., DD Network program executive directors and staff, people with developmental disabilities, family members, advocates, policy experts, and evaluation experts). Moreover, every effort was made to include and assist people with developmental disabilities to ensure that their viewpoints would be heard. Emails and letters were written in simple language, as necessary, and Westat staff was available to work through all materials (Draft Standards and ratings materials) to assist those who indicated they wanted assistance.

The feedback we received from panel members was invaluable in helping Westat to better understand many of the nuances of all three DD Network programs. Moreover, many of the comments and recommendations from panel members resulted in improvements in language and clarity. Also, we thought it was important to develop objective criteria for revising standards and performance criteria, so although adherence to objective criteria resulted in exclusion of, what we thought, were some important standards, we nevertheless think the final product will be useful for ADD to use going forward in finalizing standards.

Nevertheless, as we reviewed Version 3 of the Draft Standards and Performance Criteria, the following issues are worth pointing out regarding draft standards for each DD Network program:

- The Council document contains four outcome standards (one on self-advocacy and leadership, systems change, community capacity and governance and management). Recognizing that the measurement of outcome standards can sometimes be burdensome and that Councils are volunteer organizations with limited time and funds to hire expertise, ADD may wish to re-visit whether outcome standards need to be developed for so many Council functions. We would recommend focusing on just two—self-advocacy and leadership development and systems change.

- Having said that, more work needs to be done with Councils to ensure consistency of definitions and a methodology for determining the extent to which the standards are being met. We suggest ADD weigh in with technical and resource assistance.

- For P&As, a number of the outcomes contained in earlier versions of standards and performance criteria were deleted as a result of panel consensus. Those remaining are sometimes focused on structures and processes. ADD may wish to return to earlier versions of the draft standards to see whether some of the deleted standards and performance criteria may prove useful.

- The UCEDD Draft Standards and Performance criteria currently contain three outcome standards. However, in our opinion, none of them sufficiently address the outcomes of the interdisciplinary pre-service preparation and continuing education function in a way that ADD will be able to determine on a national basis the extent to which students and trainees who complete UCEDD programs enter fields or become leaders to benefit people with developmental disabilities and their families. Although we recognize that such a standard requires considerable work on the part of UCEDDs and ADD to develop consistent definitions and methodology, we nevertheless consider it worth the effort.

These issues are discussed further in chapter 6.

This page left blank intentionally.

ADD Assessment 5

5.1 Overview

The original statement of work for the National Independent Study did not include an assessment of the Administration on Developmental Disabilities (ADD). However, when the new Commissioner of ADD began in 2010, she added this component to the study to reflect the partnership between ADD and its grantees in implementing the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The purpose of the ADD assessment is to better understand "how ADD supports the grantees in achieving the purposes of the Act," as well as to examine ADD's efficiency and effectiveness in supporting the DD Network programs (Appendix J).

The design of the ADD assessment was essentially a collection of retrospective and current data that related to ADD's structures, processes, outputs, and outcomes to be able to draw conclusions on effectiveness in assisting the Developmental Disabilities (DD) Network programs in meetings its obligations under the DD Act.

Westat used semi-structured interview guides to obtain information from ADD staff, Federal agency partners, national disability organization staff, the three executive directors of the national network disability associations, and staff from Projects of National Significance (discretionary grants funded by ADD). Up to nine individuals per category were identified with assistance from ADD. Interviews were conducted primarily by telephone. Interviews with the Commissioner of ADD and senior ADD management were conducted in person.

Westat also obtained budget and cost allocation data from ADD over time (e.g., 2005 - 2011) to assess changes in some of the key structures (inputs) for ADD, and also conducted a web-based survey of program executive directors. Data collected through interview and by web-based questionnaire related to a recent period (e.g., 2009 and 2010). Program materials were obtained from ADD or the ADD website and reviewed by Westat staff.

This chapter describes the data collection used in the ADD assessment, the feedback from ADD partners and stakeholders, and findings from the web-based survey of executive directors. The final section is a summary of findings.

5.2 Data Collection

Data collection for the ADD assessment consisted of interviews, document reviews, and the administration of a web-based survey. Sources of data are contained in Table 5-1.

Table 5-1. Sources of data for the ADD Assessment

Data sources	
ADD	▪ Commissioner ▪ Senior management ▪ Program specialists
Federal partners	▪ Administration for Children and Families (ACF) ▪ Center for Medicare and Medicaid Services (CMS) ▪ Center for Mental Health Services (CMHS) – Substance Abuse and Mental Health Services Administration (SAMHSA) ▪ Interagency Autism Coordinating Committee ▪ Office on Disability (HHS) ▪ Office of Disability Employment Policy (ODEP) ▪ Office of Special Education Programs (OSEP) ▪ Rehabilitation Services Administration (RSA), Department of Education ▪ Social Security Administration (SSA)
National disability organizations	▪ American Association of People with Disabilities ▪ The Arc of the United States ▪ Autism Society of America ▪ Council for Exceptional Children ▪ Easter Seals ▪ Epilepsy Foundation ▪ National Council of Independent Living ▪ Self-advocates Becoming Empowered (SABE) ▪ TASH
DD Network national associations	▪ National Association of Councils on Developmental Disabilities (NACDD) ▪ National Disability Rights Network (NDRN) ▪ Association of University Centers on Disabilities (AUCD)
Projects of National Significance	▪ PREParation for Emergencies and Recovery (PREP) Project ▪ Families Accessing Communities Together (FACT) ▪ Autism NOW ▪ Commonwealth Election Expansion Project ▪ Family Support 360 Family to Family Network in Virginia ▪ PAVE 360 - for Military families ▪ National Youth Leadership ▪ State of the States in Developmental Disabilities ▪ Hawaii Emergency Preparedness Special Initiative
Executive directors of DD Network programs	▪ State Councils on Developmental Disabilities ▪ Protection and Advocacy Systems ▪ University Centers for Excellence in Developmental Disabilities Education, Research, and Service

Preliminary Interviews. We conducted preliminary interviews with the ADD Commissioner, Supervisory Program Specialist, and Contracting Officer's Technical Representative (COTR) for the National Independent Study (Table 5-1). The purposes were to determine ADD goals and objectives of the ADD assessment, ascertain key ADD functions that guide ADD work, determine the important Federal agency partners and national disability organizations that could provide personnel to interview, and learn what materials we should review relevant to this assessment (e.g., annual report templates, Monitoring and Technical Assistance Review System [MTARS] background documents, ADD policies, technical assistance statements of work).

Developing Data Collection Tools. We developed qualitative interview guides for each category of respondent to be interviewed (Appendix AA) and submitted each to Westat's Institutional Review Board (IRB) for review and approval. We developed a web-based survey for completion by the executive directors of the three DD Network programs—DD Councils, P&As, and UCEDDs. We submitted the web-based survey for IRB review and approval and then submitted the web-based survey to ADD to submit to the Office of Management and Budget (OMB) for clearance. ADD received OMB clearance on June 27, 2011.

Data Collection. We used the semi-structured interview guides to obtain information from ADD staff, Federal agency partners, national disability related organizations, DD Network national associations, and Projects of National Significance. For example, given that one of ADD's key functions is administering the three DD Network programs, we developed questions about the structures ADD has in place to administer these programs (e.g., funding, policies, membership on interagency committees), processes ADD uses to monitor program compliance with the DD Act, and outputs that result from such processes (e.g., annual reports, an MTARS report). Although the ultimate outcome of ADD's administration of the three DD Network programs is efficient and effective programs that meet the principles and goals of the DD Act, there are other outcomes that also can be examined from the perspective of ADD staff (e.g., usefulness of reports to ADD) and Federal agency partners (e.g., ADD leadership in the disability policy community). These were also addressed in interviews.

We selected two program staff supervised by the ADD Supervisory Program Specialist and two supervised by the Contract Officer to complete our interviews of ADD staff. Conferring with the ADD Commissioner and senior staff, we selected nine Federal disability agency partners and nine national disability organizations for interviews, as well as the executive directors of the three DD Network national associations. In addition to funding the DD Network programs in all the states, Puerto Rico, and the U. S. outlying areas, the DD Act funds Projects of National Significance (PNS) under the statutory supervision of ADD. The PNS were not part of the original National Independent Study. They were included in the ADD assessment because they are familiar with the work of ADD and directly accountable to ADD. We randomly selected nine PNSs from the categories identified on the ADD website as active in fall 2010.

Potential respondents were initially contacted by email to describe the purpose of the study and the nature of the interview (Appendix BB). Followup telephone calls were made to arrange a telephone interview. All but one of the 37 individuals we contacted agreed to be interviewed.

Web-based Survey. Information from the DD Network programs themselves was critical to an assessment of ADD. We chose to use a web-based survey to obtain easily quantifiable data. Westat had already obtained considerable qualitative background information on the programs' interactions with ADD through the National Independent Study program visits. We used this information to inform the development of the web-based survey for the 60 executive directors currently participating in the National Study. We also invited the remaining executive directors of the three DD Network programs to complete the questionnaire.

5.3 Feedback from ADD Staff, Partners, and Stakeholders

This section is organized by structures, processes, and outputs and outcomes and describes feedback on ADD from ADD staff, partners, and stakeholders.

5.3.1 ADD Structures

Descriptions of the structures that the ADD has in place to administer the DD Act came from interviews with ADD staff and leadership. Federal partners, national organizations, and grantees of the Projects of National Significance, as well as background materials provided by ADD and the ADD web site. Some respondents were familiar with ADD and the structures that are in place to administer the DD Act. Other respondents' knowledge of ADD came from a limited contact on a specific project or initiative. ADD structures described below are its organizational structure, funding, and staff.

Organizational Structure. The ADD is located within the Administration for Children and Families (ACF). The ACF is the Federal Health and Human Services (HHS) agency that funds state, territory, local, and tribal organizations to provide family assistance (welfare), child support, child care, Head Start, child welfare, and other programs relating to children and families. Child and family services are provided by state, county, city and tribal governments, and public and private local agencies. ACF assists these organizations through funding, policy direction, and information services.

The location of ADD and the relative standing of the ADD Commissioner were mentioned by several respondents (ADD, Federal partners, representatives from national disability organizations), as having an impact on ADD's ability to administer the DD Act. ADD is positioned in ACF with agencies such as Head Start, Administration on Children Youth Families, and the Office of Family Assistance (which houses the Temporary Assistance for Needy Families [TANF] program). According to a number of respondents, these agencies are considerably larger and more closely aligned programmatically with the goals of the ACF compared to ADD. The ACF is charged with ameliorating extreme poverty and it ramifications on children, youth, families, and communities. The goals of ACF are achieved by providing services and resources to children, youth, adults, families, communities in need. The goals of the agencies within ACF such as Head Start, the Administration for Children, Youth and Families, or the Office for Family Assistance are derived from the umbrella agency.

This does not appear to be the case with ADD, according to key informants who indicate that ADD's goals emerge from the DD Act. According to these respondents, the activities of ADD and DD Network programs are not focused on provision of assistance and services as much as they are on systems change. This means that ADD's activities may not be seen to be actively contributing to meet ACF goals.

Although one Federal agency respondent reported that ADD fits well into ACF because of its commitment to people with disabilities which qualify as a vulnerable population under ACF's mission, a number of respondents described both internal and external ramifications of the current organizational structure. It was felt by many that, as a small agency working toward goals not shared by the umbrella agency or sister agencies, ADD has limited influence within ACF. Moreover, specific functions (e.g., making arrangement for reasonable accommodation of newly hired ADD staff; delivering funds to consultants and programs) are, for the most part, out of ADD's control. Yet, delays in carrying out these functions have a direct impact on ADD stakeholders and the regard in which stakeholders hold ADD.

A minority of stakeholders had a different perspective. One key informant reported that there is an emphasis on interoperability at ACF which encourages agencies to work together on issues of mutual interest. The example given to demonstrate this agency wide cooperation was a program called "Access to Assets" which provides a match for personal funding for education, home buying, and business development for recipients of ACF agency services. The respondent reported that ACF has integrated "Access to Assets" into all ACF programs including ADD.

One respondent also noted that the HHS Community Living Initiative has provided an opportunity for ADD to work toward alignment with ACF and HHS goals, and it was noted that ADD had a leadership role on the ACF Community Living initiative.

ADD Funding. Congress appropriates funds to ADD to support state DD Network programs (Table 5-2). The exact amount to each program is determined by Congress, and only the Projects of National Significance provide ADD with discretionary funds beyond the funds allotted for DD Network Programs. Between 2005 and 2011, funding of Projects of National Significance comprised between 7.5 percent and 8.4 percent of total ADD appropriations. The total ADD appropriations increased by 10.1 percent between 2005 and 2010. There was a slight downturn in funding between 2010 and 2011.

Table 5-2. ADD appropriations, 2005 – 2011*

Program	Appropriated Dollars ($) ('000s)					
	2005	2007	2008	2009	2010	2011
State Councils	72,496	71,771	72,482	74,316	75,066	74,916
Protection and Advocacy Centers	38,109	38,718	39,024	40,024	41,024	40,942
University Centers of Excellence	31,549	33,212	36,943	37,943	38,943	38,865
Projects of National Significance	11,542	11,414	14,162	14,162	14,162	14,134
Total	153,696	155,115	162,611	166,445	169,195	168,857

*Source: http://www.acf.hhs.gov/programs/olab/budget/fy2011apt_07D8.pdf

There was little discussion about the funding level of ADD among Federal and non-governmental stakeholders. One Federal partner noted that ADD has been successful in obtaining Federal dollars for developmental disabilities but indicated that Federal dollars do not always translate into a better quality of life for people with disabilities. On the other hand, a representative from a national disability organization thought that expectations were too high for ADD, given the small amount of money it was given.

ADD’s operating budget for staff, office space, equipment, supplies, and support services is funded by the ACF operating budget and not from a Congressional appropriation. This means, according to one respondent, that ADD competes internally for operating resources with sister agencies that provide ACF with the capacity to meet its goals.

Staff. The current ADD complement of staff consists of the Office of the Commissioner (including a Deputy Commissioner), Office of Programs Support, and Office of Innovation. The number of staff listed on the ADD web site is 26 (retrieved in December 2011). Recently, the function of the President’s Committee for People with Intellectual Disabilities and four staff were realigned to ADD as well (Federal Register, 2011).

Although it is clear that staff numbers have increased over the past several months, it was noted that ACF requires that newly hired staff enter at a grade level at least four levels below the level of ADD staff vacancies. Thus, vacancies at a GS-13 level were required to be filled at a GS-9 level. Two staff members expressed frustration that the current staff lacked fiscal expertise. One alluded to difficulties with the ACF business office resulting in delays in getting funds to programs.

ADD leadership also noted that with the current staffing level it was not possible for ADD to provide the level of technical assistance required by programs. Staff members expressed frustration that there were no funds for them to visit programs to see how they actually worked. Instead, ADD depends on the technical assistance contractors to meet program’s programmatic technical assistance needs.

5.3.2 ADD Processes

In our interviews with ADD and stakeholders, we asked respondents to consider the ways in which ADD administered the DD Act through announcing and awarding grants, monitoring and oversight of the programs and grantees, influencing and informing Federal policies related to people with developmental disabilities, and providing leadership to DD Network programs and grantees. Their responses regarding these processes are described below.

Grants Management. Management of Add grants is controlled through the Office of Administration in ACF. Thus, grants management is not entirely within ADD control. According to one respondent, the responsibility of ADD as established under the previous administration was described as “get the money out and ensure compliance with reporting requirements.” However, another respondent expressed frustration with the lack of fiscal expertise in the ADD staff. It was noted that ADD had difficulty “getting the money out on time.”

The view of some stakeholders on grants management was not positive. One respondent said “ADD is not yet a smoothly functioning agency. They still have difficulty administering their own grants.” Two other reported ongoing issues with the contracts office. One was sympathetic to the problems of ADD being “small potatoes” at ACF. However, he said he did not want to hear about having to deal with Head Start first. He wants his money at the start of the fiscal year so he can meet payroll and move forward.

Monitoring and Evaluation. The two major forms of monitoring and evaluation used by ADD are the yearly report and the Monitoring and Technical Assistance Review System [MTARS]. Each DD Network program has its own yearly report template. The MTARS process was established to monitor individual grant programs, address areas where grantees may benefit from technical assistance, and identify innovative practices that may assist other grantees. The MTARS process addresses five areas: (1) program compliance with the DD Act, (2) accountability and achievement of program goals, (3) collaboration with other DD programs within the state, (4) fiscal management, (5) technical assistance needs, and (6) innovative practices. The MTARS process consists of planning; a site visit conducted by a team of program peer reviewers, people with developmental disabilities and family members, a financial specialist, ADD central office program specialists, and an ADD coordinator; and post visit followup.

ADD staff reported spending the majority of time on monitoring and technical assistance. The technical assistance they described related to compliance with reporting requirements and assistance in spending down funding. Two staff members described monitoring on MTARS visits. Both respondents described the visits as extremely informative and educational for themselves. The MTARS visit was their means of becoming familiar with the programs and the nuts and bolts of program implementation. An external stakeholder, however, did not have the same high regard for MTARS visits and considered it burdensome and not worth the time or effort.

The Projects of National Significance described the monitoring their projects received as largely the provision of quarterly reports and telephone meetings. Although on the whole PNS grantees were satisfied with ADD monitoring of their grants, one PNS grantee was critical of ADD’s lack of monitoring around grant awards given out by DD Network SCDDs. She felt that ADD should strongly enforce the funding of best practices or programs that could establish best practices.

According to this stakeholder, there were grantees receiving money year after year to implement practices that were not "best practices" and never would be.

One Federal partner was of the opinion that the purpose of monitoring state programs was to ensure compliance with reporting requirements, not monitoring programs to ensure they were fulfilling the goals of the DD Act. On the other hand, another external stakeholder expressed frustration that ADD did not provide the level of monitoring and oversight required to ensure programs were fulfilling their responsibilities to people with developmental disabilities. He felt that the level of monitoring should be related to the DD Act, and the ADD office should know when programs were underperforming or having problems that impeded their ability to meet the needs of their clients. Moreover, he wanted ADD to do more to enforce non-compliance.

Technical Assistance. ADD is responsible for supporting or directly providing technical assistance to the three types of DD Network programs. Much of the technical assistance is provided through a contract with the three national DD Network associations—National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disability (AUCD).

The method and amount of funds available to contract with these organizations differ by program type. The monies given to the NACDD for technical assistance are taken out of ADD's discretionary PNS budget. In 2008, the contract was valued at $904,499 over a 2-year period to conduct technical assistance on behalf of State Councils on Developmental Disabilities. More recently ADD has been able to add funds to the technical assistance contract for Councils.

Under the Council technical assistance contract NACDD was required to:

- Disseminate topical information from multiple Councils and others,
- Compile, analyze, and disseminate state of the art training, demonstration projects, and practices from Councils whose work affects the lives of persons with developmental disabilities,
- Design and implement of targeted technical assistance that will support Councils as they carry out their mandated core functions (e.g., training events, on-site technical assistance visits, establishment of Communities of Practice)
- Develop and implement projects and activities that will enhance the ability of Councils to involve people with developmental disabilities in the operations of the program,

- Develop and implement project and activities that will enhance the ability of Councils to reach out, serve, and include people from culturally and linguistically diverse backgrounds in the operations and functions of the program, and
- Respond to other emerging technical assistance needs, as appropriate.

ADD co-administers a contract for the P&As with the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS) and the Department of Education, Rehabilitative Services Administration (RSA). SAMHSA administers the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. RSA administers the Protection and Advocacy for Individual Rights (PAIR) program under Section 504 of the Rehabilitation Act of 1973. ADD administers the Protection and Advocacy for Developmental Disabilities (PADD) program. PADD funding to the state P&A systems is based on the specific formula and criteria as defined in the authorizing legislation and regulations for each program.[12]

Money for technical assistance to P&As is taken off the top of the PADD appropriation in the amount of two percent. ADD has the discretion to increase that amount from other budget categories (e.g., Projects of National Significance). In 2009 when the P&A allotment totaled $40,024,000, the PADD technical assistance contract to the National Disability Rights Network was $800,480. one respondent noted that State Councils do not have a carveout for technical assistance in the same way as the P&As. She considers this an irony since the P&As are staffed largely by professionals (i.e., lawyers and legal assistants), while Councils are citizen boards without professional training and therefore may require more technical assistance than the P&As and UCEDDs.

The purpose of the P&A contract for technical assistance is to improve program performance (advocacy and capacity building), statutory compliance, and program outcomes (systems change) across the P&A systems. The contractor is expected to place special emphasis on the improvement of individual and systems advocacy to people with disabilities. Moreover, the contractor is expected to:

- Network and broker expertise for the P&A systems;

---

[12] In any case in which the total amount appropriated under section 145 [authorizations for appropriations for P&As] for a fiscal year is more than $24,500,000, the Secretary shall-

(A) use not more than 2 percent of the amount appropriated to provide technical assistance to eligible systems with respect to activities carried out under this subtitle (consistent with requests by such systems for such assistance for the year);

- Develop and implement legal and advocacy training;
- Develop and provide resource material and delivery of on-site and off-site training and technical assistance, including nationally organized training conference;
- Prepare PPRs to the Congress for SAMHSA; and
- Gather information and prepare periodic reports as requested by ADD, SAMHSA, and RSA to meet OMB and GPRA requirements.

The UCEDD technical assistance statement of work requires the AUCD to:

- Disseminate topical information from multiple Centers and others whose work affects the lives of individuals with developmental disabilities,
- Compile, analyze, and disseminate state-of-the-art training, research, and demonstration results policies, and practices from multiple Centers whose work affects the lives of persons with developmental disabilities through annual publications of innovative practices identified through the Monitoring and Technical Assistance Review System (MTARS),
- Convene experts, as needed, from multiple Centers to discuss and make recommendations for and respond to national emerging needs of individuals with developmental disabilities,
- Maintain a web portal that links users with every Center's website.
- Design and implement targeted technical assistance that will support the UCEDDs as they carry out the mandated core functions and/or address specific topical issues
- Assist around the ADD reporting requirements and the evaluation of overall program performance through:
- Organize technical assistance, as appropriate, to UCEDDs in the development of 5 year plans through:
- Provide targeted technical assistance to UCEDDs, as appropriate, following a Federal monitoring visit, and
- Respond to other emerging technical assistance needs, as appropriate.

In the past year, the UCEDD technical assistance services were reported to consist of an annual meeting, a director’s retreat, regional meetings around specific topics, and use of new technology to disseminate information including 54 webinars.

One respondent described a changing definition of technical assistance emerging from ADD. Under the previous administration he understood technical assistance to be geared toward assisting UCEDDs to be in compliance with funding agency requirements. Currently, his understanding is that ADD and the UCEDDs will work together to enable the UCEDDs to fulfill the goals of the DD Act to the very best of their abilities. They will do this by careful needs assessment, meeting identified needs, collecting, compiling and "chewing on" and then repackaging best practices so all can benefit.

ADD staff reported that a majority of their time was spent on grants issuance, awards, monitoring and provision of technical assistance. The type of technical assistance they described was largely related to compliance with spending and reporting requirements. Some staff recalled having had more interaction with programs in the past and developing deeper relationships and a better understanding of what the programs did. The result was the development of expertise in specific program areas. Several ADD staff members expressed a desire to visit the programs so they would know exactly how they worked. Two staff who had gone on MTARS visits expressed their appreciation in seeing programs "on the ground." Grantees on Projects of National Significance spoke positively of the relationship they had with ADD program specialists, although they reported little in the way of technical assistance.

Policy. ADD staff saw policy development as part of ADD's role. However, all staff reported that they did not spend much time on it. Most staff had served on or was serving on an interagency task force or work group (e.g., inclusive child care, emergency preparedness for people with developmental disabilities, autism, and employment), and staff thought ADD had played an important role surrounding emergency preparedness. One Federal partner saw the new Commissioner having a higher profile with Congress. He felt she elevated ADD's position in the conversations on disability policy.

Respondents from Federal agencies and national non-governmental disability organizations had little knowledge of ADD's activities around Federal and state disability policy. One respondent said he saw the potential and the need for ADD to impact Federal policy, but currently its position in the hierarchy did not give it enough "clout" to do so. Another respondent reported that ADD's impact on Federal policy came from its support of state activities, such as Partners in Policymaking that brought stakeholders into the process. Another respondent indicated that ADD was not providing leadership in the policy arena.

It was also felt that ADD's impact on Medicaid funding for people with developmental disabilities came from its identification and support of best practices through SCDD grants, university research, and litigation by P&As. Two Federal agency stakeholders mentioned ADD's contribution to the Community Living Initiative, the HHS initiative to promote Federal partnerships in developing and implementing strategies for people with disabilities to live a meaningful life in the community. ADD represents ACF in this effort.

5.3.4 ADD Outputs and Outcomes

ADD outputs consist of DD Network plans and yearly reports, as well as well-prepared DD Network programs to meet their goals and comply with the Act, best practices, and leadership. Arguably, the most important outcome for ADD is effective DD Network programs. This outcome is being addressed in other chapters of this report. The outputs and outcome described here consist of a summary of the feedback we received from key informants on best practices and ADD leadership.

Best Practices. With feedback and reporting from all State Councils, P&As, and UCEDDs, ADD is in a prominent position to provide the field with information on best practices. Along those lines, a Federal partner expressed a wish that ADD use the strongest assets it currently has to impact disability policy and services. He said he wanted to see ADD share all it learns from the state programs about how to deliver services, impact policy, and obtain community buy-in with the wider disability community. He also mentioned the impressive scope and efficiency of the developmental disabilities communications network. He said that too few people know what ADD does and how it does it in the states and territories.

A national disability stakeholder said she wished there was better communication on what the three state programs do. One of the PNS grantees said she would like to see ADD close the loop in the PNS projects it funds. She described a model in which PNS projects would be the testing ground for identification of ADD priorities and best practices for future programs. She thought PNS projects should have a national impact.

Leadership. There are many ways to provide leadership (e.g., articulating a vision, ensuring program quality, and advocating for the program within and outside government). Respondents had a variety of views about ADD's demonstration of leadership—past, present, and future—and how such leadership might be expanded. Although two respondents reported that ADD is providing leadership on disability (e.g., in HHS or through HHS initiatives), others saw leadership coming from the HHS Office on Disability.

One respondent sees the reauthorization of the DD Act as an opportunity that is presenting itself now to expand ADD's leadership role. This respondent saw the role of ADD in providing leadership on developmental disabilities directly related to ADD's ability to forge official relationships with the agencies that control the funding for disability services (e.g., Medicaid).

Others also thought that in order for ADD to exert a role as a leader in the disability community it needs to have some influence over the funds. One respondent said ADD should have a fiduciary relationship with state Medicaid offices. Another said it was important for ADD to be at the same level in the Federal hierarchy as the head of the offices that control the funds for disability services. Still another said ADD must engage developmental disabilities agencies as partners, specifically referencing the Centers for Medicare and Medicaid Services (CMS), Rehabilitative Services in the Department of Education, and the Social Security Administration. He said these agencies are the implementers as they control the funds. ADD must embrace its role of influencer.

Another stakeholder supported that statement when he noted that there is very little structural support in place for ADD to assume a more influential role with other disability agencies. Another thought the role of ADD should be that of a facilitator or coordinator. He said ADD must be the nexus point for Federal governmental agencies so that if the Department of Transportation, Social Security, or CMS has a disability issue they go to ADD.

One national organization said an overlooked role of ADD was the use of Projects of National Significance to address the data needs of disability organizations. "No one knows how well people with disabilities access primary care and preventive health services. There is not data available to determine access to accommodation technology." A PNS grantee said ADD should use data to serve as a quality improvement and planning tool keeping a finger on trends and outcomes of investments. The data can provide ADD with an important index of where the field is and where it is going.

5.4 Feedback from DD Network Programs—Web-Based Survey Results

Another facet of the ADD assessment was to seek feedback from DD Network executive directors on ADD roles, activities, and interaction with ADD. Westat administered a web-based survey to all DD Network executive directors, including those who participated in the National Independent Study. The methodology and findings for all executive directors are reported below. Findings for executive directors from the 60 sampled programs are contained in Appendix CC. Because numbers are small, percentages in Appendix CC are less meaningful than the ones reported for all executive directors below.

5.4.1 Methodology

Development of Questionnaire. To develop the web-based survey of DD Network program executive directors, we sought input from an Advisory Group comprised of an executive director from a SCDD, P&A, and UCEDD. The Advisory Group and Westat staff participated in an introductory webinar and three subsequent telephone conference calls. The Advisory Group reviewed and provided feedback on three iterations of the web survey. Westat submitted the fourth iteration to the Westat Institutional Review Board (IRB) and ADD, which submitted the questionnaire for OMB clearance.

The questionnaire contained 34 Likert-type scale questions and 5 open-ended questions (Appendix DD). Executive directors were asked about their:

- Perception of the roles ADD played in the past three years (e.g., monitoring individual programs for compliance and quality, evaluating the programs at a national level, advocacy on behalf of the programs, policy making at the Federal level on behalf of people with developmental disabilities, provision of technical assistance),
- Perception of the level of importance of each role,
- Perception of the level of importance to ADD of a list of activities,
- Perception of the level of importance of the same list of activities,
- Response regarding interaction with ADD that occurred within the past three years,

- Opinion of the value of each type of interaction, and
- Opinion on the activities they would like to see ADD do to help the programs meet their objectives.

Survey Implementation. Upon receiving OMB approval, all executive directors received a letter from the ADD Commissioner, informing them about the survey and asking for their participation (Appendix EE). Approximately one week after letters were sent, Westat sent an email to each of the executive directors providing them with the link to the survey, a username, and a password (Appendix FF). Approximately two weeks after the initial email was sent, Westat sent a reminder email to non-respondents. Another email was sent informing non-respondents of an extension on the deadline. Approximately one month after the initial email was sent, the survey was closed.

Letters and emails were sent to 179 executive directors—55 from the Councils, 57 from the P&As, and 67 from the UCEDDs. Included in the 179 were the 60 executive directors that had participated in the National Independent Study.

5.4.2 Findings

Findings are reported on survey response, ADD roles, ADD activities, and interaction with ADD. We also summarize comments provided by executive directors.

Response. A total of 129 respondents or 72.1 percent of executive directors completed the questionnaire (Table 5-3). The response rate among National Independent Study participants was slightly higher than the whole group (76.7 percent versus 72.1 percent). Among participants of the National Independent Study, UCEDD directors had the highest response rate, followed by Council executive directors. Among all executive directors, UCEDD director response was the lowest (67.2 percent), compared to 80.0 percent of Council executive directors and 70.2 percent of P&A executive directors.

Table 5-3. Survey response rates by program type and participation in national independent study

	National independent study participants			All programs		
Program	Number of responses	Number of surveys sent out	Response rate (percent)	Number of responses	Number of surveys sent out	Response rate (percent)
SCDD	16	20	80.0	44	55	80.0
P&A	13	20	65.0	40	57	70.2
UCEDD	17	20	85.0	45	67	67.2
Total	46	60	76.7	129	179	72.1

ADD Roles. We define a role as an expected behavior associated with a particular position or status in a group or organization. The first set of questions on the survey asked respondents to read through a list of roles and report (a) whether each had been a role of ADD's in the past 3 years and (b) how important the respondent thinks the role is. We were interested in examining not only what roles for ADD the executive directors think are important, but also whether there would be any consistency between the roles they think are important and the roles they think ADD has played in the past three years.

The following roles were perceived by the largest percentage of programs as ones played by ADD in the past 3 years (i.e., greater that 70 percent by all three programs) (Table 5-4):

- Ensuring state/territorial programs' compliance with the DD Act (Q1),
- Assessment of the impact of the National DD Network on people with developmental disabilities and their families (Q3),
- Provision of training on reporting requirements (Q15b),
- Monitoring contracts with technical assistance providers (Q15d), and
- Funding the national organizations (NACDD, NDRN, AUCD) to provide technical assistance to state/territorial programs (Q15f).

The role perceived by the smallest percentage of programs as one played by ADD in the past 3 years was imposing enforcement measures when a state/territorial program is out of compliance with the DD Act (Q2). This role also received a high percentage of don't knows from programs, as did a few other roles (e.g., entering into collegial relationships with a state/territorial program to work toward state, regional, and national improvements to services for people with developmental disabilities; identify best practices).

Table 5-4. Comparison of perception of ADD's role and importance of role—all executive directors by program type

Question	Program type	ADD's role in the past 3 years—percent reporting "yes"	ADD's role in the past 3 years—percent reporting "DK"	Importance of role—percent reporting "extremely important or important"
Q1. Ensure state/territorial programs' compliance with the DD Act.	Council	86.4	4.5	97.7
	P&A	90.0	5.0	95.0
	UCEDD	88.9	6.7	91.1
Q2. Impose enforcement measures when a state/territorial program is out of compliance with the DD Act.	Council	43.2	38.6	93.2
	P&A	55.0	32.5	92.5
	UCEDD	53.3	37.8	80.0
Q3. Assess the impact of the National DD Network on people with developmental disabilities and their families.	Council	72.7	13.6	95.5
	P&A	72.5	12.5	82.5
	UCEDD	93.3	4.4	91.1
Q4. Assess the impact of each state/ territorial program on the state/territory in which the program is located.	Council	50.0	20.5	75.0
	P&A	57.5	10.0	67.5
	UCEDD	62.2	22.2	77.8
Q5. Assess the collective impact of the state/territorial network on the state/territory in which the network is located.	Council	47.7	18.2	72.7
	P&A	60.0	12.5	57.5
	UCEDD	66.7	20.0	75.6
Q6. Articulate a vision for implementing the principles in the DD Act.	Council	65.9	9.1	90.9
	P&A	75.0	7.5	82.5
	UCEDD	82.2	8.9	95.6
Q7. Set performance goals for the three National DD programs.	Council	50.0	15.9	72.7
	P&A	42.5	10.0	42.5
	UCEDD	55.6	15.6	71.1

Table 5-4. Comparison of perception of ADD's role and importance of role—all executive directors by program type (continued)

Question	Program type	ADD's role in the past 3 years—percent reporting "yes"	ADD's role in the past 3 years—percent reporting "DK"	Importance of role—percent reporting "extremely important or important"
Q8. Assess the performance of each state/territorial program.	Council	65.9	11.4	90.9
	P&A	62.5	12.5	65.0
	UCEDD	73.3	6.7	80.0
Q9. Assess the performance of each of the National DD Programs.	Council	56.8	22.7	81.8
	P&A	50.0	20.0	75.0
	UCEDD	77.8	15.6	82.2
Q10. Advocate for the National DD Network.	Council	68.2	13.6	93.2
	P&A	72.5	12.5	95.0
	UCEDD	93.3	0.0	100.0
Q11. Participate with Federal partners in national policy making on behalf of people with developmental disabilities and their families.	Council	68.2	22.7	95.5
	P&A	77.5	17.5	95.0
	UCEDD	82.2	6.7	100.0
Q12. Assist and/or intervene on behalf of a state/territorial program when needed.	Council	65.9	18.2	97.7
	P&A	47.5	40.0	82.5
	UCEDD	40.0	48.9	91.1
Q13. Represent the interests of state/ territorial programs at national forums (e.g., Federal task forces, interagency work groups, national meetings).	Council	65.9	29.5	81.8
	P&A	67.5	22.5	85.0
	UCEDD	84.4	8.9	95.6
Q14. Enter into collegial relationships with a state/territorial program to work toward state, regional, and national improvements to services for people with developmental disabilities.	Council	43.2	31.8	68.2
	P&A	57.5	20.0	60.0
	UCEDD	48.9	40.0	82.2

Table 5-4. Comparison of perception of ADD's role and importance of role—all executive directors by program type (continued)

Question	Program type	ADD's role in the past 3 years—percent reporting "yes"	ADD's role in the past 3 years—percent reporting "DK"	Importance of role—percent reporting "extremely important or important"
Q15. Provide or support technical assistance to a state/territorial program. For example:				
a. Conduct on-site technical assistance visits.	Council	63.6	13.6	72.7
	P&A	60.0	10.0	37.5
	UCEDD	82.2	6.7	66.7
b. Provide training on reporting requirements.	Council	88.6	4.5	84.1
	P&A	80.0	10.0	65.0
	UCEDD	91.1	2.2	73.3
c. Identify best practices.	Council	50.0	22.7	77.3
	P&A	45.0	20.0	65.0
	UCEDD	57.8	22.2	84.4
d. Monitor contracts with technical assistance providers.	Council	70.5	27.3	72.7
	P&A	70.0	27.5	67.5
	UCEDD	75.6	17.8	80.0
e. Generate opportunities for knowledge sharing among state/territorial programs.	Council	65.9	20.5	84.1
	P&A	52.5	27.5	47.5
	UCEDD	71.1	13.3	82.2
f. Fund the national organizations (NACDD, NDRN, AUCD) to provide technical assistance to state/territorial programs.	Council	97.7	0.0	93.2
	P&A	97.5	0.0	100.0
	UCEDD	97.8	0.0	95.6

There were a number of differences among the three programs regarding what they perceived to be ADD's role in the past 3 years. More than 90 percent of UCEDDs thought one of the roles of ADD in the past 3 years was the assessment of the impact of the National DD network on people with developmental disabilities and their families, compared to 72.7 percent of Councils and 72.5 percent of P&As. UCEDDs also thought ADD has been playing the role of articulating a vision for implementing the principles in the DD Act (82.2 percent) (Q6), assessing the performance of each of the National DD Programs (Q9) (77.8 percent), and advocating for the National DD Network (Q10) (93.3 percent). This was considerably higher than the other two programs.

Small percentages (50 percent or less) of P&As thought ADD has been playing the following roles:

- Setting performance goals for the three National DD programs (Q7) (42.5 percent of the P&As, compared to 50.0 percent of the Councils and 55.6 percent of the UCEDDs), and
- Assessing the performance of each of the National DD Programs (Q9) (50.0 percent of the P&As, compared to 56.8 percent of Councils and 77.8 percent of UCEDDs).

There were also differences among programs regarding the importance of each role for ADD. Seventy percent or more of Council executive directors reported that most of the roles were extremely important or important. The only role for ADD that did not reach this level for Councils was entering into collegial relationships with a state/territorial program to work toward state, regional and national improvements to services for people with developmental disabilities (Q14). For P&As, using 70 percent as a cutoff point, there were many fewer roles that P&As thought were important for ADD to play, including:

- Assessing the impact of each state/territorial program on the state/territory in which the program is located (Q4) (67.5 percent),
- Assessing the collective impact of the state/territorial network in which the program is located (Q5) (57.5 percent),
- Setting performance goals for the three National DD programs (Q7) (42.5 percent),
- Assessing the performance of each state/territorial program (Q8) (65.0 percent),
- Entering into collegial relationships with a state/territorial program to work toward state, regional, and national improvements to services for people with developmental disabilities (Q14) (60.0 percent),
- Conducting on-site technical assistance visits (Q15a) (37.5 percent),

- Providing training on reporting requirements (Q15b) (65.0 percent),
- Identifying best practices (Q15c) (65.0 percent),
- Monitoring contracts with technical assistance providers (Q15d) (67.5 percent), and
- Generating opportunities for knowledge sharing among state/territorial programs (Q15e) (47.5 percent).

One hundred percent of P&As thought ADD should fund the national organization (NDRN) to provide technical assistance to state/territorial programs.

More than 70 percent of UCEDD executive directors thought it was extremely important or important for every role listed, except for one, to be a role of ADD. The one role was conducting on-site technical assistance visits (Q15a) (66.7 percent).

Respondents were provided with the opportunity to comment at the end of each questionnaire section. Several respondents noted the change in administration. A few noted that their responses were in regard to ADD before the change, and some chose responses based on ADD after the change. One of the most frequent comments was that the change in the administration has had a positive impact on the DD Network. Respondents commented that the new Commissioner has brought new leadership to ADD with an emphasis on communication within the Network and outreach to the community at large. In addition, several respondents indicated that they appreciate the new vision for the developmental disabilities community as introduced by the new administration. As one respondent stated, compliance is an important role of ADD's, but having a vision for the role of ADD in the developmental disabilities community is more important.

Another common response on ADD roles was a need among programs for ADD to have a stronger presence as an advocate for people with developmental disabilities in the Federal arena. Respondents want ADD to set a course to finding some consistency in policies, practices, and procedures that have impact on people with developmental disabilities. Other respondents suggested that ADD needs to work toward building a Federal alliance with other organizations, such as the Office of Special Education and Rehabilitative Services (OSERS) in the Department of Education and the National Institute on Disability and Rehabilitation Research (NIDRR), in order to assist in setting the national agenda for the developmental disabilities community.

A third common response in this section was the need for ADD to advocate for the programs when programs experience interference from the states. Multiple respondents stated that, despite the noninterference understanding that programs have with the states, states often interfere in the programs' abilities to meet their goals. Therefore, respondents feel that ADD should have more of a presence in the states and ensure that interference is kept to a minimum.[13] Similarly, respondents felt that ADD should take more of a leadership role in enforcing the DD Act. Respondents indicated that, often, there is interference from other organizations that keep states from being in compliance with the Act. These respondents felt that ADD should be more proactive in enforcing compliance with the Act. No examples were provided.

ADD Activities. Whereas roles are the characteristics and expected types of behavior of an organization, activities are what actually take place. The second section of the survey asked respondents to consider a series of activities and determine (a) their impression of how important the activity is to ADD, and (b) how important the activity is to the respondent.

The activity that all three programs perceive as important to ADD is the establishment and implementation of reporting processes to monitor compliance with the DD Act (Q17) (93.2 percent, 90.0 percent, and 86.7 percent for the Councils, P&As, and UCEDDs, respectively, reported that ADD thought this was extremely important or important) (Table 5-5). Of least importance to ADD, from the perspective of all three program executive directors, is:

- Developing technical assistance plans to improve state/territorial program performance on achieving goals (Q22) (56.8 percent, 47.5 percent, and 64.4 percent of Councils, P&As, and UCEDDs, respectively, reported this activity extremely important or important); and
- Learning about the details of their program (Q23) (22.7 percent, 30.0 percent, and 48.9 percent of the Councils, P&As, and UCEDDs, respectively, reported this activity extremely important or important).

The percentage of P&A respondents reporting on their own perception of the importance of each activity was consistently lower than the other two programs except for the establishment and implementation of reporting processes to monitor compliance with the DD Act (Q17). All programs agreed that the establishment and implementation of reporting processes for monitoring compliance was extremely important or important (greater than 80 percent in all three programs). On the other hand, compared to the other programs, the P&As reported lower percentages of extremely important or important on all other activities. Except for one activity (learns about the details of

---

[13] Examples of interference provided in key informant interviews were hiring freezes in state governments, failure of governors to replace Council members, and state travel restrictions.

your program, Q23), Councils reported consistently higher percentages of extremely important or important.

There were a number of "disconnects" between what the programs perceived ADD thought was important or extremely important and what the programs themselves thought was important or extremely important. For example,

- 68.2 percent and 65.0 percent of Councils and P&As, respectively, reported the assessment of performance of each National DD program was extremely important or important to ADD (Q20), compared to 90.0 percent of Councils and 72.5 percent of P&As perceiving this activity as extremely important or important,

Table 5-5. Impression of importance of activities to ADD versus impression of importance of activities to respondent - all executive directors by program type

Activity	Type of Program	Importance of activity to ADD—percent reporting "extremely important" or "important"	Importance of activity to respondent—percent reporting "extremely important or important"
Q17. Establishes and implements reporting processes to monitor compliance with the DD Act.	Council	93.2	95.5
	P&A	90.0	87.5
	UCEDD	86.7	84.4
Q18. Develops goals and expected outcomes for each National DD Program.	Council	70.5	77.3
	P&A	67.5	42.5
	UCEDD	77.8	75.6
Q19. Assesses state/territorial program performance.	Council	68.2	90.0
	P&A	65.0	72.5
	UCEDD	82.2	77.8
Q20. Assesses performance of each National DD program.	Council	61.4	79.5
	P&A	62.5	62.5
	UCEDD	84.4	86.7
Q21. Develops technical assistance plans to improve compliance with the DD Act.	Council	61.4	81.8
	P&A	45.0	70.0
	UCEDD	73.3	77.8
Q22. Develops technical assistance plans to improve state/territorial program performance on achieving goals.	Council	56.8	84.1
	P&A	47.5	62.5
	UCEDD	64.4	71.1
Q23. Learns about the details of your program.	Council	22.7	70.5
	P&A	30.0	62.5
	UCEDD	48.9	80.0
Q24. Organizes regional and national meetings to share knowledge and experience on specific issues (e.g., best practices).	Council	45.5	86.4
	P&A	47.4	57.5
	UCEDD	71.1	86.7

- 56.8 percent, 47.5, and 64.4 percent of Councils, P&As, and UCEDDs, respectively, reported the development of technical assistance plans to improve program performance (Q22) was extremely important or important to ADD, compared to 84.1 percent of Councils, 62.5 percent of P&As, and 71.1 percent of UCEDDs,
- 22.7 percent, 30.0 percent, and 48.9 percent of Councils, P&As, and UCEDDs, respectively, reported that learning about the details of their program (Q23) was extremely important or important to ADD, compared to 70.5 percent of Councils, 62.5 percent of P&As, and 80.0 percent of UCEDDs who ascribed high importance to that activity, and
- 45.5 percent, 47.5 percent, and 71.1 percent of Councils, P&As, and UCEDDs, respectively, reported that organizing regional and national meetings to share knowledge and experience (e.g., best practices) (Q24) was extremely important or important to ADD, compared to 86.4 percent of Councils, 57.5 percent of P&As, and 86.7 percent of UCEDDs.

The most frequent comment made by respondents on ADD activities was a desire for ADD to streamline the monitoring process. Respondents indicated that Program Performance Reports (PPRs) are not collecting meaningful information. In addition, respondents commented that the MTARs experience is very time consuming and cumbersome. Finally, some respondents indicated that participation in the National Independent Study was labor intensive and time consuming. Both ADD staff and stakeholders were asked about MTARs in key informant interviews. ADD staff reported the experience as very informative and educational for themselves, while stakeholders reported the experience to be a waste of time and resources.

Another common response about ADD activities was that technical assistance provided through ADD has been beneficial and has increased in effectiveness in the last two years. Respondents indicated that the technical assistance, as provided through the contractors funded by ADD, has been helpful to the programs.

Interaction with ADD. The third section of the survey contained questions about interaction between ADD and DD Network programs. Each respondent was asked to consider a series of interactions and determine: (a) whether the interaction had occurred between ADD and the respondent's program in the last three years, and (b) how valuable the respondent thinks the interaction is or would be to the program.

The largest amount of interaction occurred among all programs regarding participation in a technical assistance activity provided or supported by ADD (Q28) (95.5 percent of Councils, 87.5 percent of

P&As, and 88.9 percent of UCEDDs); and receipt from ADD of an email bulletin on a national issue (Q32) (100.0 percent of Councils, 95.0 percent of P&As, and 95.6 percent of UCEDDs) (Table 5-6). The least interaction in the past three years was for direct technical assistance (Q27) (54.5 percent for Councils, 35.0 percent for P&As, and 26.7 percent for UCEDDs) and feedback from ADD on program performance (Q33) (50 percent from Councils, 62.5 percent from P&As, and 77.8 percent from UCEDDs).

Programs had high regard for interaction with ADD in some instances and medium or low regard in others. Moreover, P&A perception of the value of the interaction was lowest compared to the other two programs for all types of interaction. The greatest number and percent of executive directors who reported extremely valuable or valuable was for participation in technical assistance provided or supported by ADD (Q28) (84.1 percent for Councils, 80.0 percent for P&As, and 86.7 percent for UCEDDs); and for the input their own program provided to ADD on a developmental disabilities issue (Q34) (75.0 percent for Councils, 75.0 percent for P&As, and 80.0 percent for UCEDDs). Less than 70 percent of executive directors of any program reported as extremely valuable or valuable the interaction that had taken place or would take place between their program and ADD on ADD's feedback on the program's annual report (Q26) and participation in a Monitoring and Technical Assistance Review System (MTARS) visit (Q30).

In a few instances, responses from one program varied widely with responses from the other two programs. More than 86 percent of UCEDD executive directors thought it was or would be extremely valuable or valuable if their center contacted ADD for advice or information on a technical issue (Q31), and more than 75 percent of UCEDD executive directors thought that feedback from ADD on the performance of their program (Q33) was or would be extremely valuable or valuable. Council and P&A executive directors had lower expectations (50.0 and 47.5 percent, respectively, on these two questions).

Table 5-6. Occurrence and value of interaction with ADD in the past 3 years - all executive directors by program type

Interaction scenarios	Type of Program	Interaction has occurred in the past 3 years—percent reporting "yes"	Value of interaction to respondent—percent reporting was or would be "extremely valuable" or "valuable"
Q26. ADD provided feedback on your program's annual report.	Council	84.1	63.6
	P&A	77.5	42.5
	UCEDD	95.6	68.9
Q27. ADD provided technical assistance directly to your program.	Council	54.5	75.0
	P&A	35.0	35.0
	UCEDD	26.7	51.1
Q28. At least 1 staff, per year, participated in a technical assistance activity provided or supported by ADD.	Council	95.5	84.1
	P&A	87.5	80.0
	UCEDD	88.9	86.7
Q29. At least 1 person, per year, from your Council, Board, or CAC participated in a technical assistance meeting provided or supported by ADD.	Council	95.5	77.3
	P&A	67.5	55.0
	UCEDD	66.7	71.1
Q30. ADD participated in an MTARS visit to your program (consider the last 10 years).	Council	81.8	52.3
	P&A	75.0	42.5
	UCEDD	62.2	37.8
Q31. Your program contacted ADD for advice or information on a technical issue.	Council	84.1	81.8
	P&A	47.5	50.0
	UCEDD	77.8	86.7
Q32. ADD sent at least one email bulletin on a national issue to your program.	Council	100.0	79.5
	P&A	95.0	62.5
	UCEDD	95.6	86.7
Q33. ADD provided feedback on the performance of your program	Council	50.0	65.9
	P&A	62.5	47.5
	UCEDD	77.8	75.6
Q34. ADD solicited and obtained input from your program on a developmental disabilities issue.	Council	65.9	75.0
	P&A	67.5	75.0
	UCEDD	71.1	80.0

In addition to looking at the perceived value of each type of interaction among all executive directors, whether or not an interaction had taken place, we also examined the perceived value of each type of interaction from only those executive directors who reported they had interacted with ADD on a particular item within the past three years (Table 5-7). The three types of interaction that the most respondents (at last 75 percent) identified as extremely valuable or valuable were:

1. ADD provided technical assistance directly to your program (Q27) (91.7 percent of Councils, 85.7 percent of P&As, and 75.0 percent of UCEDDs);

2. At least one staff, per year, participated in a technical assistance activity provided or supported by ADD (Q28) (88.1 percent of Councils, 88.6 percent of P&As, and 90.0 percent of UCEDDs); and

3. Program contacted ADD for advice or information on a technical issue (Q31) (83.8 percent of Councils, 89.5 percent of P&As, and 91.4 percent of UCEDDs).

Table 5-7. Value of interaction with ADD among those who reported interaction in the past 3 years - all executive directors by program type

Question item	Program	Percent reporting extremely valuable	Percent reporting extremely valuable or valuable	Percent reporting not valuable
Q26. ADD provided feedback on your program's annual report.	SCDD	29.7	70.3	16.2
	P&A	16.1	45.2	19.4
	UCEDD	16.3	69.8	7.0
Q27. ADD provided technical assistance directly to your program.	SCDD	41.7	91.7	0.0
	P&A	42.9	85.7	7.1
	UCEDD	41.7	75.0	0.0
Q28. At least 1 of your staff, per year, participated in a technical assistance activity provided or supported by ADD.	SCDD	42.9	88.1	2.4
	P&A	57.1	88.6	2.9
	UCEDD	47.5	90.0	2.5
Q29. At least one person per year from your DD Council, Board, or Consumer Advisory Committee participated in a technical assistance meeting provided or supported by ADD	SCDD	35.7	81.0	2.4
	P&A	44.4	81.5	0.0
	UCEDD	43.3	80.0	6.7
Q30. ADD participated in an MTARS visit to your program.	SCDD	22.2	55.6	11.1
	P&A	13.3	40.0	23.3
	UCEDD	14.3	46.4	28.6
Q31. Your program contacted ADD for advice or information on a technical issue	SCDD	51.4	83.8	0.0
	P&A	42.1	89.5	10.5
	UCEDD	37.1	91.4	0.0
Q32. ADD sent at least one email bulletin on a national issue to your program.	SCDD	31.8	79.5	4.5
	P&A	18.4	63.2	5.3
	UCEDD	27.9	86.0	0.0
Q33. ADD provided feedback on the performance of your program.	SCDD	40.9	68.2	9.1
	P&A	20.0	64.0	4.0
	UCEDD	22.9	77.1	2.9
Q34. ADD solicited and obtained input from your program on a developmental disabilities issue.	SCDD	31.0	82.8	13.8
	P&A	29.6	77.8	0.0
	UCEDD	37.5	84.4	0.0

Programs did not report value in the monitoring interactions with ADD. The two types of interaction that the most respondents reported as not valuable were:

1. ADD provided feedback on your program's annual report (Q26) (16.2 percent of Councils, 19.4 percent of P&As, and 7.0 percent of UCEDDs); and
2. ADD participated in an MTARS visit to your program (consider the last 10 years) (Q30) (11.1 percent of councils, 23.3 percent of P&As, and 28.6 percent of UCEDDs).

These findings are also reflected in findings from the interviews with ADD staff and stakeholders.

Most of the comments on interaction with ADD were positive. Respondents stated that they appreciate the technical assistance, training and information on best practices provided by ADD. In addition, respondents felt that ADD is helpful in assisting programs to connect with other programs.

Many of the respondents provided comments on the MTARs and PPRs. Specifically, they were disappointed that they had not received the final reports from their MTARs visits. Of those who had received the reports, several indicated being dissatisfied with the report, which apparently contained factual errors. In addition, some respondents stated that they do not ever receive any feedback on the PPRs submitted to ADD and suggested it would be helpful for programs if they did.

The other common thread among the comments from executive directors in this section was that the new administration at ADD is very accessible and has increased communication avenues for programs, making the flow of information more consistent and effective.

Final Comments on ADD. The last two questions of the survey provided respondents with an opportunity to comment on what else they think ADD should be doing (or doing more of) and what they would like to see ADD doing less of or not at all. The most prevalent comment from respondents was that the programs want ADD to increase its understanding of what is happening on the program level in each state and truly know each program. Respondents suggested that ADD should not just rely on the PPRs to evaluate performance but should spend more time understanding the nuances of each program. A few respondents suggested that ADD should employ individuals who had worked previously for one of the programs, thereby providing ADD with some increased knowledge of the inner workings of the programs. Along the same lines, many respondents indicated a desire to see ADD address the individual needs of the programs rather than trying to set standards and rules for all programs. As one respondent explained, the programs are not 'one size fits all,' and seeing them as such will only result in yielding low standards of performance for the programs.

Many respondents indicated that communication with ADD and information dissemination from ADD has increased greatly with the new administration. Many of these respondents also suggested that they would like to see things improve even more in terms of increasing communication with ADD. Some suggested that ADD should conduct meaningful site visits to the states, update the ADD website more frequently, distribute best practices to all programs, and disseminate a national email newsletter to the programs.

Several respondents indicated that ADD should be working toward building a coalition of national-level organizations (including Federal agencies) to increase knowledge among stakeholders and influence at the Federal level. Respondents felt that ADD should have more influence over Federal policy, which would make the job of the programs easier at the state level.

A number of respondents commented on the collaboration among network programs as mandated by the DD Act. Several respondents indicated that additional technical assistance on collaboration and information sharing would help programs be in compliance with this mandate. Other respondents suggested eliminating the requirement and allowing collaboration to occur more organically with the partners that make the most sense.

Overwhelmingly, the respondents indicated that the MTARs process needs to be eliminated or modified to enhance the quality and decrease the burden on programs. In addition, several respondents indicated that the programs should not need to engage in multiple measures of accountability (i.e., MTARs and the National Independent Study), and ADD should minimize the duplicative reporting required of the programs. Several respondents questioned whether funding the National Independent Study was an appropriate use of funds.

5.5 Summary of Findings

The ADD assessment was added to the National Independent study during the last year of its operation to assess ADD's effectiveness in supporting the grantees in achieving the goals of the DD Act. Data collection materials were quickly developed and administered using both qualitative and quantitative methodology. Perspectives were sought from a variety of stakeholders, and not surprisingly, there were often multiple and conflicting viewpoints. Nevertheless, a number of findings from the ADD assessment may be useful for determining how ADD can assist programs in achieving the principles and goals of the DD Act.

From the perspective of ADD staff and stakeholders, the following are key findings of the ADD assessment:

- ADD leadership and staff, as well as ADD stakeholders, view the role that ADD has played in the past with the disability community as minimal. There is optimism that this is changing.
- Some reported that ADD's placement in the ACF organizational structure was an impediment to simple everyday functions (e.g., hiring qualified staff, distributing grants to ADD grantees in a timely fashion, and obtaining reasonable accommodation for new staff that need it).
- Others saw ADD's placement in the ACF organizational structure as a mismatch between the goals of ACF and ADD.
- In the past, most of ADD staff's attention was placed on monitoring compliance of DD Network programs to the requirements of the DD Act.
- ADD provides little direct technical assistance to DD Network programs except for the assistance that is related to compliance and reporting on compliance. Most of the technical assistance provided to DD Network programs to assist them in achieving the goals of the DD Act is implemented by the three technical assistance contractors (NACDD, NDRN, and AUCD).
- ADD staff is interested in learning more about the DD Network programs. They appear frustrated that their role concentrates almost solely on compliance with the DD Act and the distribution and administration of grants. They saw the MTARS visits as particularly useful in learning about the specific intricacies of the programs.
- On the other hand, stakeholders and executive directors were critical of the MTARS experience, did not think it was useful, and reported that it was time-consuming and burdensome.
- Although the three national associations address the dissemination and implementation of best practices, it was perceived that ADD does little on its own in this arena.
- Among ADD stakeholders, there was some pessimism about ADD's future leadership role in the developmental disabilities community (both within and outside government) without a change in the control of funds for major programs and ADD's organizational placement in the Federal structure.

- There was clear satisfaction with the new Commissioner's open approach to reaching out to stakeholders.

Westat also administered a web survey to all DD Network executive directors. For the most part, executive directors also viewed ADD's role as maintaining compliance with the Act. The three programs differed in what they wanted ADD's role to be. They all thought the compliance role was important. Other important ADD roles considered to be important by Councils were enforcement of compliance, assessment of the impact of the DD network on people with developmental disabilities and their families, articulation of a vision for the system, assessment of program performance, advocacy for the National DD network, participation with its Federal partners in national policy development, intervention with states when needed, and funding the NACDD.

P&As saw many fewer ADD roles as important. However, like the Councils, they also thought compliance was important and that ADD should enforce compliance when P&As were out of compliance. They wanted to see ADD advocate for the National DD network, participate with its Federal partners in national policy making, and fund the NDRN.

UCEDDs also wanted ADD to ensure compliance with the DD Act but were not as interested in enforcement as the other two programs. Other important roles for ADD, according to UCEDD directors, were assessment of the impact of the National DD network on people with developmental disabilities and their families, articulation of a vision and advocacy for the National DD Network, participation with Federal partners in policy making, assistance and intervention at the state level when needed, and representation of the interest of states and territorial programs at national forums.

Executive Directors confirmed that many of the activities and interactions that took place between their program and ADD were related to monitoring compliance with the DD Act. They saw the technical assistance meetings particularly valuable. Feedback on their annual report was not considered to be valuable to programs; neither was participation in an MTARS visit. Some executive directors expressed dissatisfaction with the National Independent Study and thought it was an inappropriate use of resources. Programs voiced great satisfaction with the open communication process of the new ADD Commissioner.

In summary, programs appeared to be looking to ADD to meet its accountability and oversight obligations. However, they were not satisfied with the methods that have been used in the past (e.g., yearly reports and feedback on those reports, MTARS visits, and the National Independent Study).

It seems clear that DD Network programs see the importance of ADD's monitoring role and the usefulness of the development of performance standards. They appear open to receiving assistance from ADD in measuring such standards. Moreover, they were open to ADD taking on roles it had not been filling in the past – particularly, Federal policy making and the articulation of a vision for the system.

This page left blank intentionally.

Implications of Study Findings and Recommendations

6

The goals of the National Independent Study of the Administration on Developmental Disabilities Programs were to: (1) describe the effectiveness and achievements of the national Developmental Disabilities (DD) Network programs using a framework of indicators consisting of structures, processes, outputs, and outcomes; (2) finalize valid and reliable performance criteria for assessing the effectiveness and achievements of the programs funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act); (3) conduct an assessment of the Administration on Developmental Disabilities (ADD) that will provide information about organizational effectiveness and efficiency; and (4) provide ADD with findings from the project and recommendations for future program development.

This chapter addresses each of the National Independent Study's goals. First we summarize the achievements and effectiveness of the National Developmental Disabilities (DD) Network programs within the context of the draft standards and performance criteria that have been developed to date as part of this study. We then discuss the draft standards and performance criteria that have been developed and the issues and challenges that will need to be met for further development and use of such standards. The third section of this chapter summarizes our findings on the effectiveness and efficiency of the ADD. Finally, we make recommendations to ADD for moving forward in achieving its planning and accountability goals.

6.1 Achievements and Effectiveness of the National DD Network Programs

Chapter 2 of this report describes the development of a working version of standards and performance criteria. This working version was validated by Validation Panels in 2008 and was used to develop data collection instruments and other materials. Data were collected in 19 states and one territory using those instruments and materials. Chapter 3 summarized findings from all data collection. Findings were used to develop Version 1 of draft standards and performance criteria, and with the assistance of Draft Standards Panels, Versions 2 and 3 were subsequently developed. Version 3 of the draft standards and performance criteria (described in detail in Chapter 4 and contained in Appendix Y) is submitted to ADD in this report.

The question now becomes "What do the programs achieve as they relate to Version 3 of the draft standards and performance criteria?" [14] Therefore, we will summarize the findings from all data collection in this study using the draft standards and performance criteria developed thus far to organize this summary. We will summarize the findings for each DD Network program and collaboration separately.

6.1.1 State Councils on Developmental Disabilities

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.

The DD Act recognizes the unique role of State Councils on Developmental Disabilities (SCDDs or Councils) to identify the key issues, needs and priorities of people with developmental disabilities and family members in their state or territory. To meet the draft standards and performance criteria, Councils must seek input from a variety of stakeholders, including individuals and organizations, to make sure they are getting a full picture; and obtain input, in a variety of ways, to make sure they hear from all individuals that have something to say (not only those who speak English or can easily articulate their concerns), are not continually hearing from the same or the loudest or most persistent individuals, are not restrictive in the types of developmental disabilities they learn about, and are not only hearing from people and organizations in the major cities or in their own backyard.

Meeting these requirements can be both time consuming and expensive, and Councils, which are volunteer organizations, have little time and money to conduct an assessment even only every 5 years. Thus, Councils need to be efficient in how they obtain information on the issues, needs and priorities of people with developmental disabilities and family members. They not only need to speak directly to people with developmental disabilities and their advocates and representatives, but they also need to make use of reports and existing data and take advantage of the planning efforts of others in the state or territory with similar goals. Finally, the assessment of issues, needs and priorities cannot occur only every 5 years. Issues continue to arise, and needs and priorities may

---

[14] The data collection materials that were used to examine program achievements were not specifically designed to address Version 3 of draft standards and performance criteria contained in Appendix Y. However, many items in Version 3 overlap with the earlier version of benchmarks, indicators and examples of performance standards and address a large number of the same issues.

change. Councils need to make sure they are assessing these issues, needs and priorities all the time in ways that take advantage of the time spent on their daily work (e.g., reviewing feedback from self-advocacy and leadership programs or serving on community and agency boards and committees).

The Councils in this study appeared committed to this type of needs assessment as part of producing a 5-year State Plan. As a group, Councils used several methods for collecting input, although they primarily relied on feedback from public meetings, listening sessions, and often an electronic survey. Many were able to point to reports and other existing data they had used to examine the needs issues, needs, and priorities of people with developmental disabilities and their families. How much weight these reports played in identifying the final issues and priorities was not clear.

Although Councils reported that they sometimes had problems obtaining input from racial and ethnic minorities in their state or territory, some Councils nevertheless made valiant attempts to widen the net in obtaining input from a diverse group of individuals. Their attempts include the use of materials in languages other than English and simple language, as well as targeting specific groups that have had little participation in the past. All Councils pay special attention to providing accommodations to ensure the participation of people with developmental disabilities.

Many Councils reported that they collaborate with their sister agencies in the state to obtain feedback and in some cases analyze the data they receive. Mainly, they hold public meetings and listening sessions with representatives from all three programs in attendance. In some cases, they hand off the data that is collected to the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) in their state to analyze.

The synthesis of data—making sense of conflicting viewpoints and findings from a variety of sources—was almost always a separate Council process. Councils meet about four times a year, and during the year of State Plan development, one of those meetings is typically reserved for discussion of findings on issues and needs and development of priorities and goals for the next 5 years. Council staff is mainly responsible for synthesizing the data, and what they take to the Council for discussion and consideration needs to be digestible over one or two days.

Standard 2: State plans guide Council action.

If the planning process is consistent with the performance criteria in Standard 1, it is expected that the 5-year State Plan will truly reflect the issues, needs, and priorities of people with developmental disabilities and family members in their state or territory. Thus, it would be appropriate for the State Plan to become the guide for Council action over the next 5 years.

State Plans run the gamut with regard to understandability, specificity, the presence of measureable objectives, the presence of specific and measureable outcomes, and general usefulness. Activities listed in the Performance Progress Report (PPR) are consistent with the goals in the 5-year state plan since the PPR format is organized by State Plan goal. All state plans are broad enough in scope and wording to guide Council action, even in times of emergency or emerging needs. Moreover, Councils have an amendment process that most appear to adhere to closely, so as the environment changes, Councils are able to amend their State Plans accordingly.

Standard 3: State Councils on Developmental Disabilities support the development of self-advocates and leaders among people with developmental disabilities and family members.

All Councils in this study support the development of self-advocates and leaders among people with developmental disabilities and family members. This is reflected in their State Plans and yearly reports, as well as the grants they fund and the programs they support. Partners in Policymaking is a strategy many Councils use to meet this standard, and its importance is reflected in the website of a number of Councils where Partners in Policymaking is given special prominence and attention on the website home page.

Originally designed by the Minnesota State Council on Developmental Disabilities in 1987, the design and basic curriculum of Partners in Policymaking has taken hold nationally. Nevertheless, methods for recruiting program participants, the characteristics of those who participate, and fidelity to the original design are different across Councils that implement the program. Most sampled Council staff engaged in implementing Partners in Policymaking report that they collect statistics on the program and have some methodology for following up program participants to determine participant outcomes. However, the types of data that are being collected and the methods of data collection vary considerably.

For other self-advocacy and leadership programs, collection of data on participants seems to be rare. Thus, it is not clear whether Councils have actively reached out to people with developmental disabilities from the broad population of people with developmental disabilities in the state or territory. Whether participants are diverse in disability type, age, living arrangement, geographic location, socio-economic status, ethnic and racial group, and gender could not be readily quantified.

Our findings also showed that Councils were able to establish or strengthen a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities, and some Councils were able to demonstrate progress made by these groups.

Standard 4: Participants in Council self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities.

All Councils were able to demonstrate that some of the individuals who participated in their self-advocacy and leadership programs went on to become Council members themselves and members of groups whose mission was to improve the quality of life of people with developmental disabilities. However, followup of participants in Partners in Policymaking and other self-advocacy and leadership programs is not consistent. Each Council measures different outcomes in different ways. Thus, across the system, it is currently not possible to quantify the extent to which Partners in Policymaking or other self-advocacy and leadership programs produce such measureable outcomes on advocacy for oneself, advocacy for others, employment, and participation in boards, coalitions and advocacy initiatives.

Standard 5. State Councils on Developmental Disabilities improve the capacity of communities to include and support community members with developmental disabilities.

Version 3 of the Draft Standards and Performance Criteria provides examples of improved community capacity—increased community awareness, knowledge, skills, and abilities; improved access to supports and services; and improvements in the infrastructure for service delivery throughout the state or territory. Councils overall implement and support programs and initiatives that are geared toward achieving these outcomes. Their programs and initiatives focus on health care, employment, education, and other areas of emphasis described in each State Plan and yearly PPRs. Councils provide information, training, and technical assistance to people and organizations in the community at large, and they target efforts to those in the community at large that can increase and improve services, choice, and inclusion for people with developmental disabilities (e.g., health care providers, teachers, and employment specialists). Most Councils were able to provide examples of outcomes they attributed to community capacity activities.

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.

If we had to name two key initiatives on which Councils systemically and consistently focus, it would be self-advocacy and leadership development (described above) and systems change. In fact, these are highly correlated since many Council self-advocacy and leadership initiatives (e.g., Partners in Policymaking) focus on the provision of information and advocacy skills to effect systems change.

Councils as a group use all of the strategies listed as examples under Standard 6 to effect systems change—provision of funding to support systems change efforts, 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 promotion of changes to law, policy and practice. They actively engage with partners and collaborators, including DD Network sister agencies. Moreover, most Councils not only use staff to implement systems change initiatives, but also involve Council members in system change activities.

Councils seem to practice a formative type of evaluation of systems change efforts. Many who were engaged in systems change initiatives were continuously keeping track of short-term achievements and setbacks and adjusting accordingly. The documentation of outcomes of system change efforts was universal but inconsistent because there is no specific typology for reporting on these very complex outcomes. There is no doubt that Councils are able to report on system changes (all were able to give us laundry lists of outcomes both verbally and on tables they had prepared beforehand). However, all were reported in different ways, covering different periods of time, and with varying levels of background and specificity provided. Moreover, since so many aspects of these activities rely on partnerships and collaboration, it is all but impossible to disentangle or attribute successes to one organization.

We learned during our program visits and review of Council 5-year Plans and yearly reports that reporting on and understanding outcomes cannot be achieved with a few phrases on a table, as responses to a single questionnaire, or with a simple oral presentation. In many cases, an understanding of the achievement of Council systems change outcomes takes all three types of reporting mechanisms to truly achieve an understanding of the nature and extent of systems change.

In reporting systems change outcomes, it is not expected that Councils will achieve an outcome every year (or even every five years). However, the reporting of systems change needs to reflect interim outcomes that appear along a well-defined pathway—from issue to goals to strategies to interim outcomes to final outcomes. Recommendations to ADD on documentation of systems change outcomes appear in Section 6.4 below.

Standard 6 also addresses the identification, testing, and promotion of promising practices. Such activities were not universal among Councils we visited. Larger Councils are able to outsource these activities to contractors. Smaller Councils have limited staff and dollars and usually do not conduct full-scale demonstration projects. However, even some Councils with minimum allotments were able to promote new or innovative practices from time to time.

Standard 7. State Councils on Developmental Disabilities effectively fulfill their roles and meet their responsibilities.

There are many ways for Councils to meet their responsibilities. A Council that does so, according to the draft performance criteria, ensures its composition is consistent with the requirements of the DD Act and reflects the developmental disability population of its State or territory. Councils also need to ensure that Council members can do their job (by regularly attending meetings, playing an active role in Council activities, and being supported through orientations and ongoing education and training). To fulfill its roles and meet its responsibilities, according to the draft standards and performance criteria, Councils are expected to review the executive director's performance each year. They also must act professionally by using fair, transparent, and effective processes to select competent and experienced grantees, and they must maintain a system to manage grants and measure grantee results.

The Councils we studied all appear to be fulfilling their roles and meeting their responsibilities as per the performance criteria. There are few vacancies in State Councils (fewer than 5 percent overall), despite the fact that in most cases Governors of the state are the final arbiter of Council membership. Although Council executive directors themselves see this as a possible impediment, in actual fact, Council membership ranges from between 15 to 46 percent of people with a developmental disability and almost 16 percent of members with an intellectual disability. Moreover, Council member knowledge of policy and law related to people with developmental disabilities (about 80 percent of all Councils) puts them in a good position for the system change work they need to do.

Councils typically have four meetings a year. Thus, the work Council members do outside of Council meetings takes on particular importance. Larger Councils have sub-committees to take on review of grants and other roles (e.g., personnel and membership, planning, legislation and policy), and often (but not always) Council members become involved in Council activities. All Councils take minutes at their meetings, but, as a volunteer organization, most do not require or enforce attendance.

All Councils provide one-on-one assistance to Council members to facilitate their participation. Other ways of facilitating Council member participation include new member orientation, stipends, and travel reimbursement, use of simple language and simple concepts in materials, pre-meeting reviews of the agenda and meeting materials, and communication support (e.g., use of a sign-language interpreter). A few Councils reported that Council members receive ongoing education and training, and most send at least one Council member to the yearly technical assistance meeting conducted by the NACDD.

All Councils also have a process for selecting grantees, usually in conformity with state requirements and the goals and objectives in their State Plan. However, not all Councils are in the business of funding projects, and, instead, do all the work themselves.

6.1.2 Protection and Advocacy (P&A) Systems

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

Like the State Councils on Developmental Disabilities (SCDDs), P&As are required to identify the key issues, needs, and priorities of people with developmental disabilities in the state or territory. Unlike the SCDDs, the P&A planning process is yearly and results in a Statement of Goals and Priorities (SGP) on a yearly basis. Despite the shorter time horizon for planning, P&As nevertheless are expected to ensure that they collect data on behalf of a broad population of people with developmental disabilities (including those from previously unserved or underserved communities), from a variety of sources, and across the state or territory. To make sure they receive a valid assessment of the key issues, needs and priorities, this draft standard requires the use of a variety of methods (including accommodations for people with developmental disabilities and methods to break down language and cultural barriers) for collecting input to ensure they are able to obtain input with a variety of perspectives from different groups who may require different ways of participating in the process.

A planning process that takes place yearly needs to be efficient. One way to be efficient is to take advantage of the planning efforts of other organizations in the state, including reports and other data collection efforts by other relevant agencies (e.g., housing, transportation, labor, and education). Another is to partner with those who are familiar with unserved and underserved populations and can provide inroads into communities that might otherwise remain "closed off" to the P&A. The planning process also needs to consist of a compilation of the input obtained from all data collection vehicles and a consideration of the varying perspectives. Ideally, it needs to have provisions for revising goals and priorities between planning cycles when conditions, statutes, or priorities change.

The planning and priority setting processes we saw at P&As in the sampled states and territory all appear to cast a wide net in seeking input on issues, goals, and priorities for people with developmental disabilities and family members. Across all P&As, they seek input from a variety of sources using a variety of methods for obtaining input, including surveys, informal feedback from staff and Board, focus groups, social networking, and live online public meetings. They collaborate with their sister agencies in seeking input for the SGP.

In addition to gathering input from individuals and organizations, P&As also use the ongoing feedback from program activities (e.g., intake, outreach and communication) to identify the issues, needs, and priorities of people with developmental disabilities and family members. Many P&As also use data from existing reports to assess needs and priorities.

Standard 2: P&A SGPs are a guide to P&A action.

Once the SGP is approved by the P&A governing board and distributed for comment, there is wide distribution of the SGP through newsletters, the website, and at community meetings. Intake forms are updated by many P&As to be consistent with goals and priorities in the SGP, and staff is trained on SGP goals and priorities. These goals and priorities help to define the cases that are taken by the

P&A and the systemic advocacy issues that are addressed. Other activities, described in P&A yearly reports are generally consistent with the goals and priorities in the SGP.

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

The goal of the P&A intake process is to provide people who contact the P&A with appropriate services within the goals and priorities of the SGP. A fair, efficient, and effective intake process, according to the draft performance criteria, includes maintenance of written intake procedures, ascertainment of accommodation and necessary support services at intake, provision of training on intake procedures to new intake staff, periodic monitoring to determine adherence to intake procedures, and provision of ongoing professional development for intake staff. To be effective, the intake process needs to be successful in directing those who seek assistance to the appropriate level of assistance (e.g., referral, provision of information and resources, possible individual advocacy).

All P&As have written intake procedures. Most include the procedures for documenting client information in a computerized database and for priority case selection. Intake staff, for the most part, is trained on the intake procedures and updated on the year's goals and priorities. P&As report that executive directors, intake supervisors, supervising attorneys, and other management staff in the P&A periodically review decisions made by intake staff, although not necessarily adherence to intake procedures. Whether individuals who seek assistance from the P&A were directed to the appropriate level of assistance was difficult to ascertain. However, we were told that some P&As present cases at weekly staff meetings to determine whether or not to accept a case. Thus, it is a joint decision among different levels of staff. One P&A described a random survey of intake and assistance requests and seeks feedback on the usefulness of the information the caller received and whether the caller would contact the P&A again for help.

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

All P&As maintain procedures to guide the selection and processing of individual advocacy cases. P&As also reported that they select individual advocacy cases that are consistent with but not limited to the goals in the SGP. P&A staff we interviewed reported handling topics such as special education cases, guardianship cases, mental health issues, seclusion and restraint, and ADA compliance. These were all priorities in their SGP.

When emergency and emerging issues arise, all P&As have a procedure for addressing them. Sometimes it is an executive director decision to take on a case or issue. Other times it is a group decision or a decision of a supervisor to an attorney or advocate.

Standard 5: P&A provides high quality representation.

High quality representation, as defined by the one draft performance criterion under this standard, is having the infrastructure for reviewing and discussing individual advocacy cases. Although different at all P&As, such an infrastructure appears to exist.

All P&As provide opportunities for discussion of cases in order to share ideas, learn from one another, and pass that learning on to the clients they serve—at monthly staff meetings, at team meetings, and through formal case review meetings by a litigation director or supervising attorney.

Standard 6: Individual advocacy meets client objectives.

P&As report that they are successful in meeting client objectives, with two P&As reporting a 100 percent success rate (Section 3.4.2.5, Table 3-16). Across all sampled P&As, the success rate was 85.7 percent—that is, among 4,983 client objectives addressed during the reporting period of October 1, 2008 to September 30, 2009, 85.7 percent of those objectives were reported to have been successfully met. Three P&As reported less than 50 percent success. The majority met client objectives more than 50 percent of the time.

There is currently no performance criterion that lays out the expectation for meeting client objectives at a specific level of success. Moreover, the definition of "success" is not defined system-wide. Some P&As consider success to be the opportunity for a client to be heard. Others might have a more rigorous definition such as helping a client obtain services previously denied or obtaining a different guardian. Still others may see success as a satisfied client.

P&As attempt to obtain client feedback and satisfaction with P&A services, but their level of effort and success varies. Some distribute a satisfaction survey with every closing letter but do not expect to achieve a high response rate. Others rely solely on complaints they receive from clients, while still others are more rigorous and obtain feedback on both intake and at the close of individual advocacy cases. Methodology varies, with some attempting to obtain input on every closed case and others making a concerted effort to obtain feedback on everyone for short periods of time. All examine client grievances, but the number of grievances is low, and much can be missed by simply relying on the most egregious cases.

To further meet client objectives according to the draft standards and performance criteria, P&As are expected to have resources to ensure staff can communicate with any client whose case is taken; provide a written representation agreement (except in cases of emergency or time-limited circumstances); provide a closing letter that is written in understandable language and document the actions taken, results, and notification that the case is closed; inform individuals about the grievance process in writing when their case is turned down for individual advocacy and when an individual advocacy case is closed; and have a mechanism for gathering and assessing client feedback and satisfaction with P&A services.

Meeting client objectives also requires good communication between clients and P&A staff. Many P&As use language lines, interpreters, or the language skills of their own staff to communicate with clients who do not speak English, and discussions with individual advocacy staff reveal a high degree of experience and sensitivity to communication with clients with intellectual disabilities. Most P&As provide written representation agreements, some in simple language, or use other methods that are understandable to clients. Closing letters, also in understandable language, are common. Moreover, information on the grievance process appears to be available on multiple occasions to people whose case is turned down or closed.

Standard 7: P&A strictly adheres to confidentiality.

P&As follow a number of different types of procedures to adhere strictly to maintenance of confidentiality, including having a written confidentiality policy and structures in place to maintain confidentiality. Written procedures are part of employee handbooks, service manuals, and a code of employee ethics and include procedures for password protection of electronic client files and case notes, checking files out of the office, protecting client privacy when meeting in and outside the office, escorting guests through the P&A, and obtaining signed releases before discussing client issues with a third party. P&A clients we spoke to reported that they were comfortable with the confidentiality procedures that were upheld on their behalf, and the majority of P&A supervisory staff we spoke to reported that they monitor to ensure confidentiality procedures are being maintained.

Standard 8: P&A systemic advocacy improves access to supports and services and reduces abuse and neglect.

All but one P&A we spoke to currently performs activities related to systemic advocacy. As a group P&As use a variety of strategies to meet their systemic advocacy objectives, including writing position papers, drafting legislative language, obtaining press coverage, educating policy makers, monitoring residential facilities, monitoring existing databases, collaborating with developmental disabilities partners, and following up on identified patterns of abuse and neglect.

P&As were able to report on scores of systemic advocacy activities that improved access to supports and services and reduced abuse and neglect, including class action decisions and revised or new legislation. Some P&As reported that once an outcome is achieved (e.g., when a particular bill is passed into law) they are not satisfied to simply move on to the next issue. These P&As keep a careful watch on the environment to ensure that the law is appropriately implemented and that there are no negative unintended consequences. Often the fulfillment of one systemic advocacy objective creates new systemic advocacy goals.

Standard 9: P&As engage in effective outreach activities to identify unserved and underserved populations.

All P&As engage in outreach activities to identify unserved and underserved populations. What makes them effective, according to the draft performance criteria, is that they are ongoing, they target populations that are underrepresented or unserved, they are adjusted to reflect the cultural appropriateness and other needed accommodations for the target audience, and they are periodically reviewed so that outreach plans and strategies can be revised as needed.

In addition to the distribution of brochures and materials on the P&A and some of its activities, most of the outreach we saw consisted of presentations at conferences, association meetings, and other venues (e.g., hospitals and community fairs). The venues that were selected for outreach were all expected to bring in clients never seen before (e.g., those in the juvenile justice system or in foster care).

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.

All sampled P&As reported that they carve out time to provide education, training, and technical assistance to people with developmental disabilities, family members, and the community at large. In addition to people with developmental disabilities and family members, target audiences consist of state agency personnel (e.g., mental health, social work, vocational rehabilitation), clinicians who provide services to people with developmental disabilities, teachers, and the police.

P&As report that the education, training, and technical assistance they provide is culturally appropriate and targeted appropriately to each audience. Materials we saw confirmed this. Measurement of recipient satisfaction with education activities occurred, but not at every P&A or every event. P&As did receive ad hoc feedback from attendees about the outcomes of their interaction with the P&A. Feedback was typically positive.

Standard 11: P&A Board of Directors sets policy and long range goals for the P&A and holds the executive director accountable for adhering to the policies and goals.

Meeting this draft standard requires the conduct of an annual performance review of the executive director; actively working to fill governing board vacancies in a timely manner and documenting efforts to do so; maintaining a governing board with expertise in fiscal, policy, and legal issues and whose members are knowledgeable about the developmental disabilities population and issues; familiarizing all new governing board members with the mission and goals of the DD Act and the developmental disabilities-related goals of the P&A; and providing supports needed to facilitate meaningful participation by governing board members.

Using those criteria, most P&As are meeting this standard. Most reported conducting an annual performance review of the executive director, and all reported the provision of accommodations to help governing board members who need them to carry out their responsibilities. A governing board orientation was not always provided at all P&As for new members, and not all governing board members are necessarily knowledgeable about developmental disabilities issues. The vacancy rate in P&A governing boards is about 7.1 percent. Moreover, P&As report that, across all P&As, 13.3 percent of members have a developmental disability, 5.2 percent have an intellectual disability, 82.7

percent have an understanding of the developmental disabilities population, 85.9 percent have knowledge of policy and laws related to people with disability, 45.8 percent have knowledge of business or finance, and 24.1 percent represent a minority in the state.

Standard 12: P&As maintain an infrastructure that enables them to conduct key functions efficiently and effectively.

According to the draft standards and performance criteria for P&As, maintaining an infrastructure that enables P&As to function efficiently and effectively requires well-defined supervisory roles and responsibilities, the conduct of an annual performance review of all staff members, an independent audit each year with immediate attention to qualified findings, and a professional development budget.

Whether all P&As have well-defined supervisory roles and responsibilities was not directly ascertained. However, all were able to describe their staff complement and their roles and responsibilities including senior staff monitoring the work of less senior staff, attorneys monitoring the work of advocates, and management staff monitoring the work of intake staff. All reported that they conduct at least an annual performance review of all staff, and all reported receiving an independent audit each year. Most P&As provide professional development for staff. We did not address the issue of professional development budgets.

Standard 13: P&As maintain operational independence from the Governor and the developmental disabilities service system of the state or territory.

All P&As report maintaining operational independence from the Governor and developmental disabilities service system of the state or territory. Nine reported that they had litigated against the state. Nevertheless, most preferred to cultivate and maintain a collegial relationship with state officials.

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

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) (5-year planning)

According to the DD Act, the UCEDD network is required to demonstrate that it is "a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances." Thus, although it is important for UCEDDs to address the issues and needs of people with developmental disabilities and family members in their state or territory, meeting the objectives of all four core functions (including dissemination) requires a planning effort that casts a much wider net than that of Councils or P&As. Moreover, although many of the draft standards and performance criteria on planning are the same as those for Councils and P&As, the national and international nature of UCEDD goals may require these criteria to be balanced differently. For example, UCEDDs need to use a variety of sources in their 5-year planning, but their sources may sometimes lean more toward data-driven reports and relevant literature in the field of developmental disabilities if these reports focus on a wider population than that in their state. Those activities that do require a direct assessment of the needs of people with developmental disabilities and family members in the state will need to provide accommodations for those who need them and utilize methods for breaking down language and cultural barriers. However, such assessments may occur less often. Instead, UCEDDs may be able to rely more heavily on the planning efforts of other organizations in the state or territory (e.g., the Council).

The planning process we were told about by all UCEDD directors relied heavily on input from the Council planning process in their state, as well as the data obtained from various UCEDD community services and research activities and research reports. Some UCEDDs collected data through surveys and public meetings (often with the Council and P&A). Synthesis of data was typically driven by the director or another UCEDD staff member. Consumer Advisory Committees (CACs) were always consulted on the contents of the 5-year plan.

Standard 2: UCEDD 5-Year Plans are a guide for UCEDD action (5-year planning)

UCEDDs also differ from Councils and P&As in the extent to which their plans guide their activities, particularly when they are dependent upon the availability of funding for which to apply and staff expertise that is more likely to guide the plan than vice versa.

Nevertheless, UCEDD yearly reports indicate that they conduct research, community services, dissemination, and interdisciplinary pre-service preparation and continuing education that are consistent with the goals, objectives, and areas of emphasis in their 5-year plan.

Standard 3: UCEDDs advance practice, scholarship and policy that impact the lives of people with developmental disabilities and their families through pre-service training (Interdisciplinary Pre-Service Preparation and Continuing Education).

Pre-service training at a UCEDD, while unique at every UCEDD, contributes to the award of an academic degree, professional certificate, or advanced academic credential at most universities where UCEDDs are housed. Most also seem to offer (or are planning to offer) developmental disabilities-related courses and trainings based on content from a variety of disciplines. Moreover, UCEDDs have been creative in developing courses that bring together instructors from more than one discipline to students from a wide variety of disciplines. They also have been offering a wide variety of experiences outside the walls of the university through practicum placements, internships, and practical experiences with families of people with developmental disabilities.

The inclusion of research in UCEDD pre-service training (a performance criterion for this draft standard) was not something we addressed directly in our original data collection instruments. However, we did come across UCEDDs that integrated research methodology into the pre-service training experience, required students to develop and evaluate interventions for people with developmental disabilities, and included research findings on best practice into training content.

How to measure the outcome of pre-service training has not yet been resolved by UCEDDs as a group. To our knowledge, there is no clear definition of a "UCEDD student." There is no agreement on when to start following the student to assess outcomes, how to follow them up, or for how long. Finally, there is no agreement at this time on the particular outcome(s) to measure. In this study, we attempted to measure only what occurred during the reporting period—among those who were graduating or completing a UCEDD program, what were their future plans. This, of course, leaves out a good deal of important information, including what happened to each UCEDD graduate in future years. UCEDDs report that such information is collected through the UCEDD National Information and Reporting System (NIRS). However, followup is reported to be burdensome, and response rates, we are told, are extremely low. Measurement of the outcomes of continuing education students is limited.

Yet, by all accounts, an assessment of what happens to UCEDD students after they leave the UCEDD training program is not only entirely germane to the goal of pre-service training, but it is eminently measureable once ADD, with UCEDD assistance, decides what should be measured and resources are made available to conduct a rigorous followup. Moreover, we spoke to a number of students who currently work in fields related to their course of study in the UCEDD program, and key informants were able to provide a number of examples of positions UCEDD students/trainees have obtained that are beneficial to people with developmental disabilities. Thus, we know that such outcomes are being achieved. Section 6.4.4 contains a recommendation on interdisciplinary pre-service preparation and continuing education.

Standard 4: UCEDDs prepare students to work on behalf of a diverse population of people with developmental disabilities (Interdisciplinary Pre-Service Preparation and Continuing Education).

Through pre-service training, as well as research and community services, UCEDDs are preparing students to work with different types of disabilities (e.g., blindness, autism) through the use of case studies and other problem-based learning strategies and firsthand experience beyond formal training that leads to an understanding of the daily lives of people with developmental disabilities and their families. Moreover, some UCEDDs take advantage of the expertise of their CAC members by including them as guest lecturers and in other components of the training experience.

We did not learn of any special effort to enroll students or trainees from a culturally and linguistically diverse background.

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 (Basic and Applied Research).

The performance criteria for meeting this standard consist of involvement of people with developmental disabilities in the development, design, or implementation of research; publishing research findings on developmental disabilities in peer reviewed journals; and presenting research findings on developmental disabilities at local, state, regional, or national professional meetings and conferences.

Some UCEDD directors we spoke to include people with developmental disabilities in their research through their CAC or the use of advisory boards attached to specific programs or activities. CAC members also play a role in developing new research ideas, review and comment on research materials, assist in writing questions for focus groups, help to recruit participants for community services, and serve as consultants on some research projects.

UCEDD faculty and staff publish the results of their research in peer reviewed journals and venues that are likely to be read by disability advocates and people with developmental disabilities and family members (e.g., community newsletters). They also present their research findings locally and at national and international conferences.

Finally, UCEDDs provided scores of examples of the impact their research (particularly policy research) may be having on people with developmental disabilities. This includes research that, in their opinion, has changed Medicaid buy-in and waiver policies in their state, increased accessibility to public transportation and state parks for people with developmental disabilities, improved screening tools, changed school board practices around restraint and seclusion, and redesigned service delivery that accompanies deinstitutionalization, including clinical crisis prevention 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 (Community Services) - and may provide services, supports, and assistance through demonstration and model activities.

Much of the community service provided by UCEDDs consists of the provision of training or technical assistance for people with developmental disabilities and family members, as well as for professionals, paraprofessionals, policy makers, students, and other members of the community. Training and technical assistance are provided to a variety of people including direct service providers, special education teachers, parents, and child care workers. Other UCEDD community service consists of the provision of direct services to people with developmental disabilities through clinical programs (e.g., diagnostic evaluations, socialization groups, family therapy, language development, physical therapy, genetic counseling, and referral recommendations).

The performance criterion for this standard requires the provision of 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. UCEDDs were not asked consistently about the demographic or other characteristics of recipients of the community services they provide so it cannot be reported here.

Standard 7. UCEDD dissemination bridges the gap between research and practice and reaches people with developmental disabilities and their families (Dissemination).

According to the draft performance criteria, a UCEDD that meets this standard:

- Uses a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners (e.g., 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),
- Provides publications, materials and other resources in accessible formats.

- Provides accommodations for people with developmental disabilities to make training and technical assistance accessible,
- Seeks input on materials and resources from people with developmental disabilities and family members,
- Evaluates dissemination activities and results on an ongoing basis (e.g., monitors the number of website hits, conducts targeted surveys, follows up the use of materials), and
- Makes its products, resources, and materials available to other DD Network programs.

UCEDDs disseminate to a wide variety of audiences using a variety of dissemination modes and strategies. In addition to publication in peer-reviewed journals, UCEDDs also disseminate their research findings to providers and practitioners through newsletters, local publications, meetings, and other media. Efforts are made by a number of UCEDDs to reach people with developmental disabilities and family members through the UCEDD web site and the use of social media outlets (e.g., Facebook and Twitter). Moreover, several UCEDDs we spoke to seek assistance from their CAC by asking them to review materials and provide their comments.

Some UCEDDs pay attention to evaluating the reach of their dissemination activities by counting hits on their web site and conducting targeted surveys. We did not obtain information on UCEDDs making their products and materials available to other DD Network programs. However, such activities might best be handled centrally by AUCD and ADD in the system-wide distribution of best practices.

Standard 8: UCEDDs leverage ADD funding and in-kind resources to achieve the goals of the 5-year plan (Governance and Management).

UCEDDs are successful (some more than others) in obtaining outside funding, and with that funding, conducting activities that foster the principles and goals of the DD Act. Over a two-year period, UCEDDs as a group brought in more than $238 million excluding the ADD grant. Overall, the ratio of total UCEDD funding to the UCEDD grant was about 14 to 1.

UCEDDs also reported receiving in-kind resources from their department and university (e.g., office space, salary, use of the university infrastructure).

Standard 9: UCEDDs maintain and support involvement from CACs (Governance and Management).

All UCEDDs carry out the requirements of the DD Act by involving CAC members in the development of the 5-year plan and holding a minimum of two meetings each year. Many UCEDDs go further than that to involve members in UCEDD core functions, including pre-service training, research, community services and dissemination. Some hold meetings quarterly or even more often by phone. Attempts are currently being made to expand the diversity of some UCEDD CACs. All CAC members we spoke to were highly satisfied with the support they receive from their UCEDD to ensure meaningful participation. Some would like to have more involvement.

6.1.4 Collaboration

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

In addition to an examination of partnerships and collaboration among DD Network programs and other organizations, agencies, and individuals in a state or territory, we also examined collaboration among the DD Network programs themselves—Councils, P&As, and UCEDDs. The draft standard that resulted requires that DD Network programs achieve one or more of their common goals through such collaboration.

We interviewed all three executive directors in each state to ask about their collaboration—the structures they establish for collaboration, their collaboration activities, and the outputs and outcomes they produce as a result of such collaboration. Some of those who do not typically and easily collaborate have been able to set up a structure that includes identifying some common goals and working through them to implement goal-related activities. One state network develops a memorandum of understanding (MOU) specific to each collaborative effort, and another state network was planning (at the time of the site visit) to begin using formal collaboration agreements (e.g., MOUs) for collaborative efforts.

Executive directors from other states in which collaboration comes more naturally and regularly report an informal and fluid process. Usually, it is the senior management (executive directors) who meet to discuss collaborative projects, although staff from all three programs is assigned roles to implement related activities.

Common goals are often reported as long term (e.g. reducing the number of institutions in the state, improved access to reliable transportation). Activities range from efforts to promote or eliminate legislation, enforce legislation, and educate legislators. DD network programs often work together to produce fact sheets and other written materials and also organize conferences and meetings (including public meetings that are part of the planning and priority setting function).

We received many examples of outcomes that were attributed to collaboration among the three DD Network programs (e.g., domestic violence legislation, closure of a state residential facility, passage of legislation on guardianship). Some of these were completed well before the study reporting period. Moreover, a number of the outcomes attributed to collaboration among the three programs are modest (e.g., joint presentations at conferences, a joint newsletter). In addition, many of the system change outcomes reported by state networks resulted from activities in which additional partners and stakeholders were involved. Thus, it was not possible to attribute most of these reported outcomes to the collaboration efforts of the three DD Network programs alone.

6.2 Issues and Challenges in Developing Final Standards and Performance Criteria

The description of program achievements within the context of the draft standards and performance criteria provide a general framework for national DD Network program functioning. However, as a performance-based accountability tool, we believe that more work is needed to make them more useful to ADD and the programs themselves. Throughout the process of developing standards and performance criteria, we grappled with several issues related to standards and criteria development. Here we describe and discuss each of these issues.

6.2.1 What is a standard?

Throughout this study, we tested different standards-related terminologies and hierarchies. We started with the development of benchmarks, indicators, and performance standards, as illustrated below (Exhibit 6-1). Benchmarks were considered to be general standards or key expectations for each key function.[15] Performance standards were statements of the expectations that DD Network programs should be achieving, doing, or having at a national level. Indicators were what would be measured to determine whether the benchmarks and performance standards were being met.

Exhibit 6-1. Sample benchmark, indicator, and example of performance standards

Benchmark: Participants in self-advocacy and leadership activities supported by DD Councils use their knowledge and skills to advocate for themselves, advocate for others, and provide leadership to the developmental disabilities community and the community at large.

Indicators	Examples of Performance Standards
2.2.1 DD Councils and grantees evaluate DD Council-supported self-advocacy and leadership development activities to improve their programs.	▪ **The DD Council or grantees assessed participant satisfaction with DD Council-supported advocacy and leadership development activities implemented in the past year.** ▪ **Participants in DD Council-supported advocacy and leadership development activities implemented in the past year were satisfied or very satisfied with the activity in which they participated (i.e., report 4 or 5 on a scale of 1 – 5).** ▪ **The DD Council can provide examples of ways in which it used results of evaluations to make changes to self-advocacy and leadership development activities in the past year.**
2.2.2 Participants in DD Council-supported self-advocacy and leadership development activities: ▪ **Are nominated to become members of the DD Council;** ▪ **Become leaders or sub-committee members of the DD Council;** ▪ **Become members or leaders of other organizations that advocate on behalf of people with disabilities;** ▪ **Become members or leaders of other community organizations;** ▪ **Participate in DD Council or other advocacy efforts;**	▪ **The DD Council has a prescribed methodology for following up participants in DD Council-supported self-advocacy and leadership development activities to determine ways in which participants benefited from the activity.** ▪ **The DD Council or grantees followed up participants of self-advocacy and leadership development activities implemented in the past year after the activity ended to determine ways in which participants benefited from the activity.**

---

[15] In Phase 1 of this study we consulted with DD Network program working groups to identify the key functions for each program. Key functions are groups of activities that are implemented by all DD Network programs to achieve expected outcomes. All activities of DD Network programs fall under one of the key functions.

Exhibit 6-1. Sample benchmark, indicator, and example of performance standards (continued)

Benchmark: Participants in self-advocacy and leadership activities supported by DD Councils use their knowledge and skills to advocate for themselves, advocate for others, and provide leadership to the developmental disabilities community and the community at large (continued).

Indicators	Examples of Performance Standards
▪ Become an employee or volunteer of a disability advocacy organization ▪ Use the knowledge and skills they obtained to enhance their lives and become self-sufficient.	▪ The DD Council can provide examples in which participants in DD Council-supported self-advocacy and leadership development activities in the past 5 years benefited, such as: – Were nominated to become the Chair of the DD Council or of a DD Council sub-committee; – Became a leader or sub-committee member of the DD Council; – Became a member or leader in other organizations that advocate on behalf of people with disabilities; ▪ Became a member or leader in other community organizations; – Participated in DD Council or other advocacy efforts on behalf of people with developmental disabilities; – Helped a peer or mentored another person with a disability; – Became an employee or volunteer of a disability advocacy organization; or – Used the knowledge and skills they obtained to enhance their lives and become self-sufficient.
2.2.3 DD Council-supported programs led by people with developmental disabilities [(Section 124(c)(4)(A)(ii)(I)] improve.	The DD Council can give examples from the past 5 years that demonstrate the improvement of DD Council-supported self-advocacy organizations led by people with developmental disabilities (e.g., increase in the number of organizations, increase in size, financial independence, receipt of a grant).

The final version of standards presented to ADD (Appendix Y) now uses a different format and terminology (Exhibit 6-2). In that version, we defined standards as "expectations that must be met to be appraised at a particular level of performance." The performance criteria are what programs need to have achieved (outcomes or outputs), done (processes) or have (structures) to meet the standards. They are similar to the first hierarchical terminology in that they consist of a general standard (benchmark in the first version) and then more specific criteria to meet the standard.

We have no preference for one format approach over another, although the second appears to be more compact. Whatever format is used, however, we think it is critical that the final standards and performance criteria that are developed contain language that will call for specific expectations to be met at specific levels.

Exhibit 6-2. Sample standard and performance criteria

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.

6.2.2 Measurement – Qualitative versus Quantitative

The goal of this study was to develop qualitative performance standards based on narrative descriptions (Appendix J). Such standards seem entirely appropriate given the nature of the programs, which are given considerable latitude in how each one meets the principles and goals of the DD Act. However, because the draft standards and their accompanying performance criteria do not provide the specific expectations that must be met to be appraised at a particular level of performance, they fall short of providing ADD with information to know whether the achievements of the programs are adequate.

For example, all Councils were able to provide descriptions of Partners in Policymaking graduates currently participating in advocacy-related efforts. However, one Council provided two examples and another Council provided 20. Does that mean the standard is being met? Is a list of examples sufficient to demonstrate effectiveness in self-advocacy and leadership? If so, what is the minimum number that should be on that list? One P&A was able to provide documentation of several outcomes associated with its systemic advocacy efforts. Another does not do systemic advocacy at all. How should P&A systemic advocacy be rated as a system-wide function? Many UCEDDs provide students with experiences beyond formal training that lead to an understanding of the daily lives of people with developmental disabilities and their families. Should all UCEDDs be doing that to meet a national UCEDD standard? Are five examples of former students with disability-related careers enough?

Only ADD can set the criteria to decide whether the achievements of the DD network programs are good enough (reach a specific standard). In their current qualitative form, the standards and performance criteria do not do that.

6.2.3 Criteria Development

Even without quantifiable standards, this study has shown that ADD and the programs themselves can be proud of their achievements in support of the principles and goals of the DD Act. Consequently, none of the three programs need to be concerned about the final standards and performance criteria that will be developed. Instead, they need to consider these standards as something to strive for at a national level and/or maintain and to use themselves to improve their own program. Moreover, ADD should not expect or even attempt to obtain complete agreement among all executive directors and other stakeholders on specifications for the criteria. All have different perspectives, and if all were able to come to an agreement on the level at which standards should be met, one can only assume that the standards would be very low indeed and not likely very useful for program improvement purposes. Finally, it will never be possible to obtain perfect standards and performance criteria. ADD should be prepared to set standards and performance criteria quickly and change them if they do not appear to be as useful as hoped.

6.2.4 Process Versus Outcome Standards

During the development of standards for each of the national DD Network programs, there was considerable discussion about the type of standards that should be developed. The statement of work for this study required a framework of structural, process, output, and outcome indicators for measurement of standards. However, feedback from program staff and other stakeholders was that national standards should primarily consist of outcome standards. Stakeholders were less interested in the structures and processes set up to achieve goals or the number of outputs (products) along the way. Their primary interest was the nature and extent to which program goals were achieved and the outcome standards that applied to the achievement of goals.

We are in general agreement with these stakeholders and believe that many, but not all, national standards and performance criteria should be focusing on outcomes. Measuring outcomes, however, requires a rigorous approach to data collection which can be burdensome to programs with small staff and little expertise in evaluation or measurement. Therefore, we do not think that all functions addressed by the DD Network programs need to have national outcome standards and performance criteria. Moreover, we do not think it is necessary to measure national outcomes every year. ADD will still be meeting its oversight and accountability responsibilities with measurement approximately every 5 years. Nevertheless, even measuring some outcome standards will be a challenging undertaking. Thus, we think it will be necessary for programs to obtain resources and technical assistance from ADD and the technical assistance contractors to ensure all programs are collecting reliable outcome data that can be rolled up to the national level.

We also believe there is a place for processes and outputs in national DD Network program standards. For example, in some cases an outcome is difficult to measure and the important component of a function, in any case, is in the nature of the process and not the outcome. For example, in planning and priority setting activities where broad and inclusive planning and priority setting seem critical for identifying the true needs of the developmental disability community, national DD Network program standards that measure processes seem appropriate. In the case of UCEDD research, research outcomes (e.g., improvement of the lives of people with developmental disabilities and their family) seem particularly difficult to measure and to attribute to any one organization. On the other hand, output standards (e.g., number of peer-reviewed journal articles on developmental disabilities published by UCEDD-affiliated faculty and staff; number and percent of UCEDD-affiliated faculty and staff who publish research findings in peer-reviewed journals; number of presentations of research findings at local, state, regional, or national professional meetings and conferences) seem more measureable, as well as important to measure given the UCEDD mission.

6.2.5 National Standards

It was always the intent of this project to develop national DD Network program standards and performance criteria (also referred to as "system-wide standards") and not standards and performance criteria for individual programs in each state. The expectation was that we would develop national standards and performance criteria that would address expectations for the national SCDD network, the national P&A system, and the national network of UCEDDs. Although individual programs might want to use these standards to assess its own work, it was never ADD's plan to measure or report on the individual programs against these standards.

The approach to developing standards for each of the national DD Network programs was first to identify the major functions addressed by each of the national DD Network programs, and then, within each key function, to develop draft standards and performance criteria. This approach still appears to be useful. Moreover, there is now a better understanding of the key functions common to each of the three DD Network programs and the type of national standards and performance criteria (structures, processes, outputs, and outcomes) that are appropriate for each key function.

As they appear now, the draft national standards in Appendix Y consist of a separate set of standards for Councils, P&As, UCEDDs, and collaboration among the three programs. As ADD works with programs and other stakeholders to finalize these standards and performance criteria, we recommend that ADD focus on the key functions and type of standard presented in Table 6-1. The rationale for this approach is discussed below for each DD Network program. Corresponding recommendations are provided in Section 6.4.

Table 6-1. Key function and type of national standards and performance criteria for each DD Network Program

DD Councils	P&As	UCEDDs
▪ State Plan Development* ▪ Self-advocacy and Leadership** ▪ Systems Change**	▪ Planning and Priority Setting* ▪ Individual Advocacy** ▪ Systemic Advocacy** ▪ Outreach and Public Education*** ▪ Information and Referral*	▪ 5-year planning* ▪ Interdisciplinary pre-service preparation and continuing education** ▪ Basic and/or applied research*** ▪ Community services*** ▪ Dissemination of information*

*Process standards

**Outcome standards

***Outputs

State Councils on Developmental Disabilities. It appears from our data collection and interaction with Council staff and members throughout this study that all Councils carry out three major functions: (1) development of a 5-year State Plan; (3) the conduct of self-advocacy and leadership activities for people with developmental disabilities and family members; and (3) the conduct of systems change activities for achieving changes to systems and community practice. Thus, we recommend that national Council standards address these three functions.

However, with limited staffing and dollars, we do not think it is feasible for SCDDs to focus on outcome standards for all three functions. Instead, we recommend that Councils focus primarily on process standards for development of the State Plan since the important components of the process are the ways Councils are able to cast a wide net and ensure that there is broad inclusion in the process. For Council systems change and self-advocacy and leadership activities, the achievement of outcomes is of critical importance to ADD. These standards should be geared to assessing outcomes. It does not seem necessary to measure outcome standards on a frequent basis—every 5 years seems adequate.

Nevertheless, national outcome standards are a challenge to address. To be able to make statements about Councils as a group, measurement of outcomes needs to be consistent among programs, and definitions need to be clear and well-understood by all parties. ADD, either directly or through the contracts of the national association, needs to provide programs with technical assistance on how to collect data on these outcome standards.

Although all Councils implement self-advocacy and leadership activities, there is considerable variation among Councils with regard to the type of activities they implement. The exception is the implementation of Partners in Policymaking which has become, if not a "best practice," then at least a promising practice implemented by a large number of Councils. We recommend a national evaluation of Partners in Policymaking to determine whether such a program should become part of a national self-advocacy and leadership standard. Such an evaluation should examine recruitment processes, participant characteristics, program activities, and followup outcomes of Partners in Policymaking graduates.

The measurement of systems change outcomes is a particular challenge because, except for the one common issue of shutting down residential facilities, there is little consistency regarding the type of issues that are being addressed by Councils. The social, political and economic environment in each state requires the use of different strategies to produce systems change outcomes. Moreover, with the use of many partners and collaborators to meet systems change objectives, it is difficult to attribute success of an outcome to the Council or any other partner.

Given such inconsistencies, there does not appear to be any way to measure system change outcomes except qualitatively and within the context of clearly identified issues, goals, and strategies, with discussion of clear roles and responsibilities of partners and collaborators. We therefore recommend a multi-method approach to measurement of systems change outcomes similar to the methodology used to collect data on systems change for this study. This approach consists of a review of program materials prior to a site visit and in-person discussion with Council staff, Council members, and collaborators who participated in systems change efforts. This approach would place as much responsibility on ADD as the reporting Council. Councils would be asked to send ADD written materials prior to an in-person visit that will provide ADD with an understanding of the issues that are being addressed, the systems that need to be changed, the system change activities that have been taking place over time, and the program's partners and collaborators and each one's role. ADD staff would then need to read the materials and be prepared to ask questions and discuss the system change effort with program staff in person.

The in person program visit can be conducted in a number of ways. The goal is for the Council to impart information to ADD on the status of achieving specific systems change goals to date, the interim outcomes that have been achieved, the strategies that are set to move toward the long-term outcomes, and any longer-term outcomes that have been achieved. It is not always necessary to have achieved long-term outcomes as of a specific visit. However, it is critical that information be imparted in a way that ADD can grasp the often complex issues that require an understanding of the local environment and the path to achieving outcomes. A one-directional PowerPoint presentation will not work. An interactive approach has a better chance of being understood.

This approach will provide information to ADD on whether interim or longer term systems change outcomes have been achieved. However, it does not set a precise systems change standard. ADD will need to set such a metric (at the system level) to provide an accountability measure of systems change.

Protection and Advocacy Systems. The P&As have shown that they serve many useful functions in the states and territory that were studied. They appear to be highly regarded by their clients, partners, and stakeholders, and they passionately deliver services that do not appear to be covered by other organizations in the state or territory. The primary focus of their daily activities appears to be three-fold: (1) intake and the provision of assistance to those who contact the P&A, (2) individual advocacy; and (3) systemic advocacy. We therefore believe that the national P&A standards and performance criteria need to address these three functions.

We believe the P&As would be well-served with structural and process standards for the intake and assistance function. Since one of the most important characteristics of the intake and assistance function is the assurance that no one gets turned away due to language, cultural or disability barriers, structural and process standards and performance criteria should address the P&A system's ability to serve all those who require their services. For individual and systemic advocacy, it is the outcomes that matter. Thus, we recommend that, at a minimum, ADD establish outcome standards and performance criteria for individual and systemic advocacy.

The approach described above for Council systems change outcomes would basically be the same for addressing P&A systemic advocacy. For individual advocacy, P&As already have a sophisticated measurement system in place to record the outcome of each individual advocacy case (i.e., whether or not each issue addressed for a client has been resolved partially or completely in the individual's favor). We recommend that ADD produce a quantitative standard that will be able to tell ADD, on a national level, the extent to which P&As are achieving their individual advocacy client objectives. An example of such a standard would be that at least 50 percent (or another percent) of client objectives across the P&A system are resolved partially or completely in the client's favor.

University Centers for Excellence in Developmental Disabilities Education, Research, and Service. The Act specifically identifies the important functions that UCEDDs are required to conduct—interdisciplinary pre-service preparation and continuing education, basic and applied research (including policy analysis), community services, and dissemination. Among these core functions, some outcomes are easier to measure than others, particularly at a system level, so what is able to be reliably and validly measured may be the driving force that sets the direction that UCEDD national standards and performance criteria take.

For example, determining the extent to which UCEDD dissemination activities are able to reach target audiences (an outcome standard) may be more of an effort than UCEDDs need or want to make with limited resources. However, ensuring that certain audiences are always the target of UCEDD dissemination efforts (e.g., people with developmental disabilities, policy makers, other UCEDDs) may be a reasonable standard to set for dissemination activities nationally.

Outcomes related to pre-service preparation and continuing education seem critical to examine and capable of being reliably measured once some key definitions are resolved (e.g., the definition of a UCEDD student) and resources and technical assistance are provided to UCEDDs for rigorous and appropriate followup.

UCEDD research and community service activities appear much too diverse to develop a common outcome standard that would work across the national network of UCEDDs. Nevertheless, most would agree that UCEDD research needs to be of high quality (sometimes judged by publications in peer-reviewed journals) and relevant to people with developmental disabilities. Thus, output standards that address the quality and relevance of UCEDD research seem most appropriate for the research core function. The definition of UCEDD faculty and staff seems critical, and once ADD finalizes a clear definition, then it seems appropriate and useful (and not all that difficult) to have a standard and performance criteria that address the extent to which UCEDD faculty and staff publish in peer-reviewed journals and present their findings in other venues.

UCEDD community services may vary too much across all UCEDDs to arrive at a quantitative standard. Nevertheless, ADD needs to understand the nature and extent of community services carried out across the UCEDD network. Thus, we recommend that an approach, similar to the collection of information on systems change/systemic advocacy be developed to consistently measure community services throughout all UCEDDs. Examples of data that might be collected consist of goals, target audiences, processes for implementation, staffing, partners and collaborators (as appropriate), and internal evaluation, as appropriate.

Collaboration. We are convinced that DD Network programs that implement systems change/systemic advocacy activities are collaborating and that collaboration does not always include all three types of DD Network programs or only DD network programs. We do not believe a fair and sensible collaboration standard can be developed that would be meaningful for all states and territories, and we do not think ADD should be creating make work activities and reporting requirements for programs on collaboration.

Having said that, there may be some processes in which collaboration among DD network programs makes particular sense. For example, joint planning activities appear to be working well, as reported by many key informants we interviewed for this study. Moreover, the expertise of UCEDDs in the development of surveys and analysis of survey data can be particularly useful to those State Councils that have small staffs that may not necessarily possess the appropriate skills for data analysis. Programs have been talking about the disadvantage of being on different planning schedules ever since we began this study (probably before). Changes to the planning cycle so they are consistent with one another would go a long way in assisting all programs in collaborating usefully with one another.

6.2.6 Measurement of Individual Programs

The purpose of examining individual DD Network programs is to monitor compliance with DD Act requirements and measure the efficiency and effectiveness of each program. The measurement of each state DD Network program was not the focus of the National Independent Study. Nevertheless, our observations over the years and feedback from a variety of stakeholders form the underpinning of our comments on individual program measurement.

First, we think it is just as important to assess the quality and effectiveness of individual programs according to pre-defined standards as it is for the national DD Network programs as a whole. Moreover, unlike the national standards described above, it may be more appropriate to address individual program achievement with structural, process, and output standards instead of outcome standards. Structural, process, and output standards could be measured yearly (e.g., through yearly reports). If quantitative performance criteria are developed, then performance of all programs can be more easily rolled up to the national level.

ADD currently uses the PPR, annual report, and MTARS as monitoring tools for individual programs. These tools examine compliance and all functions of DD Network programs. MTARS is also used to identify areas in which technical assistance may be needed by individual programs. ADD stakeholders and DD network program executive directors have many concerns about the

MTARS process (including the burden it places on programs to gather data). Moreover, the annual reports, in their current format are often wordy, uninformative, and difficult to comprehend. We believe ADD needs to re-vamp the annual report so that programs can be assessed in a way that is useful to ADD and less burdensome for the programs.

To reduce the burden placed on all programs, we recommend that ADD restrict its yearly progress reports to measures that can be easily and quickly captured by programs (Table 6-2). The indicators in Table 6-2 do not represent standards. They are the data we recommend collecting to gauge whether individual programs meet standards (yet to be developed).

The process for the assessment of yearly progress also needs to have a followup component. This followup component needs to include careful assessment by ADD staff of DD Network program annual reports, provision of feedback to programs, and the planning of technical assistance with the program, as appropriate.

If individual program standards are developed and measured yearly, and appropriate followup is maintained, then the purpose of MTARS as a monitoring tool is partially being met. We believe there are still many reasons to visit individual programs in person (e.g., to assess systems change/systemic advocacy in SCDDs and P&As and community services provided by UCEDDs; to follow up concerns and plan technical assistance identified in yearly progress reports). We also think it is important that all programs be visited within a specified time period (e.g., at least every 5 years) so that ADD staff continues to build their understanding of the programs and establish better relationships. However, we do not think the expensive and time-consuming MTARS process needs to be continued as it currently exists.

6.2.7 Attribution

One of the cornerstones of DD Network activity, particularly as it relates to systems change efforts, is collaboration with partners who share the same basic goals of independence, inclusion and access to services for people with disabilities. Whereas collaboration is a powerful tool for meeting systems change objectives, such collaboration makes it difficult, without a rigorous research design (such as a randomized controlled trial) to attribute successes in systems change to a particular organization.

For example, many programs we reviewed had the goal of closing down residential institutional services for people with developmental disabilities. Impressively, between 1990 and 2009, the number of residents in large institutional settings throughout the United States declined from 72.5 million to 58.1 million (almost a 20 percent decline) (Braddock et al., 2011). Concurrently, public spending (per $1,000 personal income) on institutional and community services for people with intellectual and developmental disabilities was about the same in 1990 (about $1.60 per $1,000 personal income) and diverged dramatically up to 2009 when spending per $1,000 personal income was $3.67 for community and family services, and $0.68 for institutional services. Nevertheless, direct attribution to DD Network programs would be far beyond the scope of State Council outcome measurement for ADD, and probably not even feasible without an experimental or quasi-experimental design.

Such designs would be inappropriate for ADD to undertake for a variety of reasons, and we do not recommend it. However, we do recommend that ADD require the reporting of systems change outcomes to include clear descriptions of the partners that participate in systems change efforts and the role each one plays.

Table 6-2. Examples of measures on individual DD Network programs

State Councils on Developmental Disabilities

- Designated State Agency
- Type of organization (e.g., non-profit, government related)
- Sources of input for 5-year planning
- Methods of obtaining input for 5-year planning
- List of goals in 5-year plan
- List of self-advocacy and leadership development activities (education, training, and/or technical assistance)
- Number of people with developmental disabilities who participated in Council-supported self-advocacy and leadership activities
- Number of family members who participated in Council-supported self-advocacy and leadership activities
- List of activities related to identifying or implementing promising practices
- List of system change activities
- Goal of each system change activity
- Number of Council member positions or slots
- Number of Council member positions filled
- Number of Council members with a developmental disability
- Number of Council members with an intellectual disability
- Number of Council members with knowledge of business or finance
- Number of Council members who represent a minority in the state
- Number of Council meetings per year
- Number of Council members who attended at least 75% of meetings

Protection and Advocacy Systems

- Type of system (non-profit, government related)
- Sources of input for planning
- Methods of obtaining input for planning
- List of goals in Statement of Goals and Priorities (SGP)
- Number of initial contacts received during the reporting period
- Number of intake forms completed during the reporting period
- Maximum response time to initial calls to the P&A
- Number of calls responded to within maximum response time
- Number of new individual advocacy cases opened during the reporting period
- Type of intervention required for individual advocacy issues
- Number of individual advocacy cases closed during the reporting period
- Number of issues addressed among cases closed
- Number of objectives met for each issue addressed among cases closed
- List of systemic advocacy activities
- Goal of each systemic advocacy activity
- List of community outreach and education activities

Table 6-2. Examples of measures on individual DD Network programs (continued)

Protection and Advocacy Systems (continued)

- Target population of community outreach and education activities
- Number of grievances made during the reporting period because their case was not taken
- Number of grievances made during the reporting period due to dissatisfaction with how case was handled
- Number of governing board member positions or slots
- Number of governing board member positions filled
- Number of governing board members with a developmental disability
- Number of governing board members with an intellectual disability
- Number of governing board members with knowledge of business or finance
- Number of Council members who represent a minority in the state
- Number of governing board meetings per year
- Number of governing board members who attended at least 75% of meetings

UCEDDs

- Number of UCEDD-affiliated faculty or staff who authored or co-authored a disability-related technical report or article or disability-related chapter in a book during the reporting period.
- Total number of technical reports or articles and books chapters published during the reporting period
- Number of UCEDD-affiliated faculty or staff who presented on their disability-related research at conferences or meetings held during the reporting period
- Number of UCEDD-affiliated faculty or staff who served on a disability-related advisory group, board of directors, commission, Governor's Council, legislative committee, school board, or other group to study or advise on developmental disability-related issues
- Number of UCEDD-affiliated faculty or staff who gave public testimony, made presentations or provided consultation to legislators and other public officials during the reporting period
- Number of UCEDD-affiliated faculty or staff who participated in national or international task forces or other committees related to developmental disability during the reporting period
- Number of UCEDD-affiliated faculty or staff who reviewed articles for a peer review journal, books or book chapters, or other publications during the reporting period
- Number of UCEDD-affiliated faculty or staff who participated in a funding agency's grant review committee during the reporting period
- Number of funding applications applied for during the reporting period
- Number of funding awards made to the UCEDD or UCEDD-affiliated faculty or staff during the reporting period
- Amount of funding from outside sources (excluding ADD grant)
- Number of CAC meetings held during reporting period
- Number of CAC members who attended at least 75 percent of the meetings

6.3 Effectiveness and Efficiency of ADD

The purpose of assessing ADD was to examine ADD's efficiency and effectiveness in administering the DD Act, particularly as it relates to the assistance and support ADD gives to the DD Network programs in achieving outcomes that are consistent with the purpose and principles of the DD Act. If ADD is found to be efficient and effective in administering the DD Act, it does not necessarily ensure the DD Network programs and State DD Networks will achieve outcomes that are consistent with the purpose and principles of the Act. However, if there are weaknesses or limitations in the efficiency or effectiveness of the ADD, it was thought that such limitations might be acting as barriers to the three DD Network programs achieving their respective goals.

The assessment of ADD was both qualitative and quantitative. The ADD Commissioner and ADD staff were asked about the roles ADD currently play and the roles it played in the past, as well as the structures and processes ADD currently undertakes to implement those roles. Stakeholders (Federal disability partners, external developmental disability organizations) were asked about ADD's place in the Federal disability community and the community at large. Information was also gathered on ADD selection and monitoring of Projects of National Significance.

We believe that ADD's key responsibility is the administration and oversight of the DD Act. Such a role incorporates a wide variety of activity, including:

- Awarding and announcing grants,
- Monitoring compliance of the DD Network programs with the DD Act,
- Ensuring work of the DD Network programs and Projects of National Significant is efficient and effective,
- 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]), and
- Providing leadership and direction to the DD Network programs and the PNS grantees.

To meet these roles, ADD needs to have the appropriate infrastructure, including staff and other resources. Our impression was that the infrastructure is changing, and that ADD is acquiring more staff. However, the agency is limited in building a qualified and experienced staff complement within the Federal infrastructure and ACF policies. Nevertheless, there seems to be strong satisfaction among ADD stakeholders with the direction ADD is moving under the leadership of the ADD Commissioner. This bodes well for the DD Network programs.

6.4 Recommendations

With greater attention to reductions in government spending, accountability, and performance-based management (see Appendix A), it is critical for all government agencies and departments, including ADD, to set up systems for measuring performance and to set standards and criteria for acceptable achievement. Moreover, the ADD assessment demonstrated that there is general support for ADD to set performance goals for and assess each state/territorial program and the three national DD Network programs. In addition, ADD stakeholders and DD Network programs (to varying degrees) favor additional roles for ADD, including the articulation of a vision to implement the principles in the DD Act, participation in national policy making on behalf of people with developmental disabilities, assistance and/or intervention on behalf of a state/territorial program when needed, and identification of best practices. Thus, we recommend that ADD move forward to finalize the national standards for each DD Network program that will provide ADD with the performance-based data it needs for good management and accountability, as well as strengthen its infrastructure and processes to take on the additional roles seen as important to its stakeholders.

We offer six types of recommendations to ADD – recommendations on: (1) the process for producing final standards; (2) national SCDD standards; (3) national P&A standards; (4) national UCEDD standards; (5) measurement of individual programs; and (6) ADD's future role.

6.4.1 Process for Producing Final National Standards

1. Move forward immediately to finalize the specific standards for each program that will provide ADD with the performance-based data it needs for good management and accountability.

The National Independent Study has taken more than six years to provide ADD with draft standards and performance criteria and a general assessment of achievements. Along the way, program staff and stakeholders have provided considerable input into the process, much of it useful and informative. With government agencies currently required to reduce their budget and use data to improve policy and operational decisions, now, more than ever, there is a need for performance-based management by all government agencies. Thus, it is critical that ADD finalize a set of national performance standards for each national DD Network program to assess the performance of the three programs it funds.

2. As part of the process for finalizing standards and performance criteria, ADD should take advantage of earlier versions of draft standards that may prove to be useful.

There has been considerable input into the process of developing standards for each of the three DD Network programs. The result of these efforts is a final list of qualitative standards that received the most consistent acceptance from those who participated in the final validation process for standard development. Along the way some useful and important standards may have been left behind because they were felt to be too rigorous or not precisely worded. We believe ADD may find some of these rejected standards of use in the development of final standards. Previous versions of standards are contained in Appendices B, P, U, and Y.

3. Set standards that give clear and specific expectations that can be measured to determine the extent to which those expectations are reached or exceeded.

Westat was asked to produce qualitative performance criteria based on narrative descriptors. We believe the draft standards and performance criteria that have been produced are useful in setting out a general direction for the three DD Network programs. However, they do not provide specific expectations that must be met for programs to be appraised at a particular level of performance (the definition of a standard). National standards need to be clear and set specific, measureable expectations so ADD will be able to assess the extent to which programs are meeting or exceeding expectations. Such standards will help ADD to meet its performance-based management responsibilities.

4. Just set some levels and see how it goes.

Even without quantifiable standards, this study has shown that ADD and the programs themselves can be proud of their achievements in support of the principles and goals of the DD Act. Consequently, none of the three programs need to be concerned about the final standards that will be developed for each program. Instead, they need to consider these standards as something to strive for and/or maintain. Moreover, ADD should not expect or even strive for complete agreement on all standards since complete consensus will likely result in watered down standards. Finally, ADD should be prepared to change the standards if they do not appear to be as useful as hoped.

5. Finalize separate national standards for each of the three DD Network programs with the understanding that:

    e. The standards focus primarily on outcomes, with some process and output standards, as appropriate;

    f. Measurement of the achievement of national standards is conducted approximately every 5 years (i.e., not yearly) using a rigorous measurement methodology;

    g. Structural, process, and output indicators are reserved primarily for individual program performance that should be measured more frequently than national standards; and

    h. Programs will receive resources and technical assistance from ADD to conduct data collection for measuring the extent to which national standards are achieved.

Given the different functions and goals of each of the DD Network programs, standards will need to be different for each program. Nevertheless, each set of standards will need to have certain elements in common as well as specific assurances from ADD. For example, we believe that most, but not all, national standards should be focusing on outcomes. Measuring outcomes, however, requires a rigorous approach to data collection which can be burdensome to programs with small staff and little expertise in evaluation or measurement. Fortunately, it is not necessary to measure national outcomes every year; ADD will still be meeting its oversight and accountability responsibilities with measurement approximately every 5 years. Nevertheless, programs will need to obtain resources and technical assistance from ADD and the technical assistance contractors to ensure all programs are collecting reliable data that can be rolled up to the system level.

6.4.2 Recommendations for State Councils on Developmental Disabilities

6. Finalize national standards for State Councils on Developmental Disabilities on three functions: (1) development of a 5-year State Plan; (2) the conduct of systems change activities for achieving changes to systems and community practice; and (3) the conduct of self-advocacy and leadership activities for people with developmental disabilities and family members.

Although Councils conduct a variety of activities, it appears that all Councils conduct activities related to development of a 5-year State Plan, systems change, and self-advocacy and leadership. Other Council functions are either specific to the Council environment (e.g., governance and management) or can be subsumed under another function (e.g., activities to improve community capacity). Moreover, many Councils, which are volunteer organizations, do not have the resources to address more than a few national standards. The three functions in Recommendation 6 appear to be given the most attention by all Councils. Thus, in finalizing standards for State Councils, we recommend that ADD and Councils focus on these three functions—(1) development of a 5-year State Plan; (2) the conduct of systems change activities for achieving changes to systems and community practice; and (3) the conduct of self-advocacy and leadership activities for people with developmental disabilities and family members.

7. Finalize process standards for Council development of a 5-year State plan.

Although generally speaking, national standards should address program outcomes, in the case of the development of the 5-year State Plan, the most important ingredient appears to be the assurance that Councils are casting a wide enough net in their assessment of issues, needs, and priorities, with appropriate attention to accommodation to overcome any barriers that may exist, to ensure there is broad inclusion in the process. Thus, process standards appear more appropriate than outcome standards in this case.

The following are examples of process standard performance criteria for the SCDD 5-year State Plan:

- Collection of 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.
- Use of 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.
- Use of information from the planning efforts of other organizations in the State or territory to increase planning efficiency.

8. Finalize outcome standards for self-advocacy and leadership.

Outcomes for self-advocacy and leadership appear particularly critical to understanding the effectiveness of Councils. Thus, we recommend that ADD use outcome standards for this function. Examples of outcome standards for self-advocacy and leadership are:

- Promotion of 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.

- Documentation that participants in self-advocacy and leadership development activities use the knowledge and skills they obtained from these activities (e.g., 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).

9. Conduct a system-wide evaluation of Partners in Policymaking to determine whether such a program should become part of a national self-advocacy and leadership standard.

Partners in Policymaking is used in many Councils to meet their self-advocacy and leadership objectives. This program has a long history but, to our knowledge, has never been examined to determine whether it is appropriate as a system-wide best practice. We suggest ADD sponsor an evaluation of the Partners in Policymaking program with the expectation that the findings from the evaluation will be able to shape the national self-advocacy and leadership standards for State Councils.

10. In measuring outcomes for systems change, use a multi-method measurement approach that puts as much responsibility on ADD as the program.

There are many challenges in measuring national systems change outcomes, including the fact that there is little consistency regarding the specific type of issues that are being addressed by Councils, the political and socio-economic environment in the states and territories, systems change goals, and the specific strategies that are used to produce each systems change goal. Moreover, with the use of many partners and collaborators to meet systems change objectives, it is difficult to attribute success of an outcome to the Council or any other partner. Consequently, we recommend that ADD use a qualitative approach to examining systems change outcomes. Such an approach would put as much responsibility on ADD as the program. Programs would be expected to send ADD written materials prior to an in-person visit that will provide ADD with an understanding of the issues that are being addressed, the systems that need to be changed, the system change activities that have been taking place over time, and the program's partners and collaborators and their role. ADD staff would be expected to read the materials and be prepared to ask questions and discuss the system change efforts with program staff and collaborators in person.

The purpose of the in-person discussion is to further elucidate system change efforts and progress. One method for conducting the in-person visit contains the following steps:

- Prior to a site visit, obtain written information on the specific systems change issues being addressed (issue; short-term and long-term goals; strategies; summary of activities since last visit; summary of activities in past year; staffing, partners and collaborators and each one's role; short-term; interim; and long-term outcomes (if any).

- Organize individual and group meetings with those with key roles in SCDD systems change activities. Individual meetings will take place with key staff members to ascertain their role, responsibilities, and activities that have taken place and to clarify issues that come up in reading background material. The group meeting will consist of key staff and partners to understand the roles and responsibilities of all players and the short-term, interim, and long-term goals that have been met.

- After the site visit, summarize findings and conclusions. The result of this process should be able to ascertain:

  - Clear and well-defined systems change goals,

  - Clear and well-defined responsibilities among staff and partner collaborators,

  - Achievement of stated goals (short-term, interim, and long-term, if appropriate), and

  - Plans for meeting future goals.

This approach will provide information to ADD on whether systems change outcomes (or interim outcomes) have been achieved.

6.4.3 Recommendations for the Protection and Advocacy System

11. Focus national standards for the Protection and Advocacy System on three functions: (1) intake and provision of assistance to those who contact the P&A; (2) individual advocacy; and (3) systemic advocacy.

Like the Councils, we do not think P&As should be put in the position of measuring the outcomes of all functions they carry out. We have selected three P&A functions that appear to be ones most germane to P&A goals: (1) intake and the provision of assistance to those who contact the P&A; (2) individual advocacy; and (3) systemic advocacy.

12. Finalize process standards for the P&A intake and assistance function that underscore the assurance that no one gets turned away due to language, cultural or disability barriers.

One of the critical characteristics of an effective P&A intake and assistance function is the assurance that anyone who contacts the P&A will be served in some way and that no one gets turned away due to language, cultural, or disability barriers. We believe that structural and process standards can handle this important feature of P&A intake. Outcome measures would be nice to have (i.e., that the intake staff sent the caller on the appropriate pathway of service). However, measurement of such an outcome would be particularly burdensome to minimum allotment P&As. Therefore, we recommend that ADD establish structural, process, and output standards and performance criteria for P&As that require:

- Availability of resources to ensure staff is able to communicate with any person who contacts the P&A and any client whose case is taken,
- Provision of information on the grievance process in writing or other appropriate forms of communication to people with developmental disabilities whose case is turned down for individual advocacy, and clients whose case is closed, and
- Use of a valid mechanism for gathering and assessing client feedback and satisfaction with P&A services.

13. Use a multi-method qualitative approach for measuring P&A systemic advocacy outcomes.

The outcomes of systemic advocacy seem particularly germane to the effective functioning of all P&As. However, the issues that were raised for SCDDs for the measurement of systems change (e.g., inconsistency of goals, strategies, partners and collaborators and their roles) are similar for P&As. Thus, we recommend that P&As use a measurement approach for systemic advocacy that is similar to the approach described under SCDD Recommendation 10 above.

14. Produce a quantitative standard and performance criteria for individual advocacy that takes advantage of the measurement system in place at all P&As to record the outcome of each individual advocacy case (i.e., whether or not each issue addressed for a client has been resolved).

All P&As have a computerized measurement system in place to record the outcome of each individual advocacy case (i.e., whether or not each issue addressed for a client has been resolved). This information is reported yearly in the P&A PPR. Thus, all P&As are in a very good position to measure quantitative individual advocacy outcomes according to a precise, quantitative outcome standard and performance criteria. An example of such a national outcome standard is that *at least 50 percent of client objectives are resolved partially or completely in the client's favor*. There may be another percentage ADD finds more appropriate. Whatever the percentage, we highly recommend that the P&As be held to a quantitative outcome standard for the individual advocacy work they do.

6.4.4 Recommendations for University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs)

15. Produce national standards for all four UCEDD core functions.

The DD Act requires UCEDDs to conduct four core functions: (1) interdisciplinary pre-service preparation and continuing education, (2) basic and applied research (including policy analysis), (3) community services, and (4) dissemination. Since the DD Act expressly requires these four functions, we think it is important to address all four core functions with standards. However, we do not think that there need to be outcome standards for each core function.

16. Establish and use process standards for UCEDD dissemination activities.

Although dissemination outcomes are measureable, we believe it would be burdensome for all UCEDDs to measure them. Instead, it seems more important for UCEDDs to ensure that certain audiences are always the target of UCEDD dissemination efforts (e.g., people with developmental disabilities, policy makers, other UCEDDs) and that they are targeted appropriately. Such assurances require the establishment and measurement of process and output standards. Examples of process and output standards for dissemination are:

- Use of a variety of dissemination modes and strategies to disseminate information and research findings to providers and practitioners,
- Provision of publications, materials and other resources in accessible formats, and
- Seeking input on materials and resources from people with developmental disabilities and family members.

17. With assistance from the UCEDDs and AUCD, finalize a clear definition of UCEDD-affiliated faculty and staff member and a UCEDD-affiliated student.

UCEDDs are not consistent in how they define UCEDD-affiliated faculty, staff, and students. Such concepts need to be clearly articulated before standards on pre-service preparation and continuing education and research can be developed and reliably measured.

18. Finalize outcome standards and a process for measuring quantifiable outcomes of pre-service preparation and continuing education.

The establishment of outcome standards for pre-service preparation and continuing education are expected to follow quickly once clear definitions of a UCEDD student and the outcomes of interest can be established. Examples of such standards are:

- Interdisciplinary pre-service students who completed their course of study work to benefit and affect the quality of life of people with developmental disabilities.
- Among those students who participated in a UCEDD-related program, disability is an important component of further education, career or their daily lives.

19. Finalize quantifiable output standards for UCEDD research activities.

The goal of UCEDD research is to improve the quality of life of people with developmental disabilities and family members. However, the impact of research occurs over many years and is a cumulative process dependent on research findings from scientific endeavors worldwide. Thus, it does not appear appropriate to establish outcome standards for UCEDD research. On the other hand, it does seem feasible to establish standards based on the quality of UCEDD faculty and staff and the relevancy of their research. Such factors are measurable using output indicators (e.g., the percentage of faculty and staff who publish in peer-reviewed journals within a specific period of time).

20. Establish and measure structural and process standards for UCEDD community services.

UCEDD community services appear to be too diverse to develop and measure outcome standards. Nevertheless, it is important for ADD to have an understanding of the types of community services that are being provided, the target audience(s) and goals, processes for implementation, staffing, partners and collaborators (as appropriate), and internal evaluation, as appropriate. We recommend a measurement procedure that captures such information (on paper and in person) at least every five years.

6.4.5 Measurement of Individual Programs

21. Restrict yearly progress reports to the measurement of easily captured data that provide ADD with a quick snapshot of program status each year.

ADD currently uses the annual report and MTARS as monitoring tools for individual programs. Both examine compliance and all functions of DD Network programs. MTARS is also used to identify areas in which technical assistance may be needed by individual programs. ADD stakeholders and DD network program executive directors have many complaints about the MTARS process (including the burden it places on programs to gather data). Moreover, the annual reports, in their current format are often wordy, uninformative, and difficult to comprehend. We believe ADD needs to re-vamp the annual report so that programs can be assessed in a way that is useful to ADD and less cumbersome for the programs.

To reduce the burden placed on all programs, we recommend that ADD restrict its yearly progress reports to measures that can be easily and quickly captured by programs (see Table 6-2 for examples). If quantifiable, these measures can also be rolled up to a system-wide measure.

22. Examine individual program statistics within the context of individual program standards and follow up with programs to ascertain reasons for not meeting standards and technical assistance that may be required.

The process for the assessment of yearly progress also needs to have a followup component. This followup component needs to include careful assessment by ADD staff of DD Network program annual reports and planning technical assistance with the programs, as appropriate.

23. Revise or eliminate the MTARS process.

If individual program standards are developed and measured yearly, and appropriate followup is maintained, then the purpose of MTARS as a monitoring tool is partially being met. We believe there are still many reasons to visit individual programs in person (e.g., to assess systems change/systemic advocacy in SCDDs and P&As and community services provided by UCEDDs; to follow up concerns and plan technical assistance identified in yearly progress reports). We also think it is important that all programs be visited within a specified time period (e.g., at least every 5 years) so that ADD staff continue to build their understanding of the programs and establish better relationships. However, we do not think the expensive and time-consuming MTARS process needs to be continued as it currently exists.

6.4.6 ADD's Future Role

24. Establish and maintain the ADD infrastructure required to expand ADD's role.

ADD's primary role is the administration and oversight of the DD Act. That role consists of a variety of activities, including awarding grants, monitoring compliance with the requirements of the DD Act, participating in Federal policy making, and articulating a vision as part of a leadership and direction function. There was strong agreement among many stakeholders that in the past ADD was primarily meeting its administrative and oversight role through activities related to awarding grants and monitoring compliance with the requirements of the DD Act. This study showed broad support for ADD to expand its primary role into activities related to the provision of leadership and direction to the developmental disabilities community (including DD Network programs and PNS grantees) and participation in Federal policy making on behalf of people with developmental disabilities.

Such expansion, however, will require more staff with the background and experience for fulfilling these roles and better placement in the Federal disability community so ADD can be more influential and be heard.

25. Coordinate and support the development, evaluation and dissemination of best practices for use by the DD Network programs and the developmental disabilities field.

As administrator of four programs that further the quality of life of people with developmental disabilities (including Projects of National Significance), ADD is in a perfect position to identify promising practices in service delivery, evaluation, and research. Through its program of Projects of National Significance, such practices could be evaluated nationally. Those found to be effective and appropriate for local adaptation could be further developed into practices for all states and territories to use, as appropriate. Finally, the three national associations (NACDD, NDRN, and AUCD) have an important role to play in disseminating these best practices and providing technical assistance with their implementation. A coordination role for ADD would keep the process moving.

References 7

Backer, T.E. (Ed). (2003). *Evaluating Community Collaborations*. NY: Springer Publishing.

Braddock, D., Hemp, R & Rizzolo, M.C. (2008). *The state of the states in developmental disabilities: 2008*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Braddock, D., Hemp, R., Rizzolo, M.K., Haffer, L., Tanis, E.S., & Wu, J. (2011). *The state of the states in developmental disabilities 2011.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado.

Centers for Disease Control and Prevention. (1999). Framework for program evaluation in public health. *MMWR,* 48(No. RR-11): 1-40.

De Vos, E., Spivak, H., Hatmaker-Flanigan, E., and Sege, R.D. (2006). A Delphi approach to reach consensus on primary care guidelines regarding youth violence prevention. *Pediatrics,* 118: 31109-31115. Last retrieved at: www.pediatrics.org/cgi/content/full/118/4/e1109 on June 13, 2011.

Elinson, L., Ho, P., Lynch, L., Thomas, C., Stewart, K.R., Palan, M.B., Gollapudi, B., and Frey, W.D. (2008). *Developmental Disabilities Program Independent Evaluation (DDPIE). Task 7: Final Report.* Prepared under Contract No. 233-02-0087 for the Administration on Developmental Disabilities, ACF, November, 2008.

Federal Register, Statement of Organization, Functions, and Delegations of Authority; Administration on Developmental Disabilities, Volume 76, Number 226 (Wednesday, November 23, 2011)] [Notices]. Pages 72418-72420, FR Doc No: 2011-30176. Last retrieved at http://www.gpo.gov/fdsys/pkg/FR-2011-11-23/html/2011-30176.htm on December 19, 2011.

French, W., and Bell, C., Jr. (1984). *Organization development: Behavior science interventions for organization improvement.* Englewood, NJ: Prentice-Hall.

Katz, D. (1978). *The Social Psychology of Organizations*. New York: Wiley.

Linstone, H.A., and Turoff, M. (Eds.). (2002). *The Delphi Method: Techniques and Applications.* Last retrieved at: The Delphi Method: Techniques and Applications--Harold A. Linstone and Murray Turoff (Eds.)--1975 on June 13, 2011.

Miles, R. (1980). *Macro organizational behavior*. Glenview, IL: Scott Foresman.

U.S. Department of Health and Human Services. (2000, November). *Healthy people 2010: Understanding and improving health* (DHHS Publication No. 017-001-001-00-550-9). Washington, DC: U.S. Government Printing Office.