The President’s Committee for People with Intellectual Disabilities (PCPID)

Business Meeting

July 28, 2022
12:00 PM to 4:00 PM EST
Call to Order, Welcoming Remarks, and Meeting Overview

Jim Brett
PCPID Chair
Welcome Remarks from Administration for Community Living

Alison Barkoff
Acting Administrator
Administration for Community Living

Jill Jacobs
Commissioner, Administration on Disabilities
Administration for Community Living
Results from Internal PCPID Member Survey and Public Input; Overview of Past PCPID Reports Issued

David Jones
Director, Office of Intellectual and Developmental Disabilities
Administration for Community Living
I. PCPID Member Survey
PCPID Member Feedback – Narrative Questions

• **Q1**: What are the biggest policy barriers to community living for people with intellectual disabilities?

• **Q2**: What are innovative practices within federal, state, or local programs that promote effective delivery of services and supports for people with intellectual disabilities?

• **Q3**: What has been the greatest impact of the COVID-19 pandemic on people with intellectual disabilities?

• **Q4**: What are important issues facing individuals with intellectual disabilities who are a part of racial and ethnic minorities, economically disadvantaged communities, and/or rural communities?
From the list below, please rank the areas PCPID should focus on as it relates to the lives of people with intellectual disabilities - Please rank 1 (highest priority) to 9 (lowest priority). Please enter a numerical ranking for each topic area.
PCPID Member Feedback – Administrative Feedback

• **Q6:** Please check off which dates you are available to meet virtually this summer for a full committee meeting.

• **Q7:** Would you be interested in chairing a workgroup during your term?
II. Public Input Feedback to PCPID
III. PCPID Published Reports
Historical Published PCPID Reports (2011–2017)

- **2017** – America’s Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities, and the U.S. Economy

- **2016** – Strengthening an Inclusive Pathway for People with Intellectual Disabilities and Their Families

- **2015** – Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities

- **2012** – Managed Long-Term Services and Supports

- **2011** – People with Intellectual Disabilities: Critical Supports that Promote Independence, Full and Lifelong Community Inclusion
Briefing on Emerging Issues – Leading Three Takeaways

**Home and Community Based Services (HCBS)**
Nancy Thaler  
Senior Policy Advisor  
Administration for Community Living

**Employment**
John Butterworth  
University of Massachusetts Boston  
Institute for Community Inclusion

Jean Winsor  
University of Massachusetts Boston  
Institute for Community Inclusion

**Education**
Catherine Fowler  
University of North Carolina Charlotte  
Cato College of Education

**Housing**
Sheryl Larson  
University of Minnesota  
Institute on Community Integration

**Direct Support Professional Workforce Crisis**
Amy Hewitt  
University of Minnesota  
Institute for Community Inclusion
Home and Community Based Services (HCBS)

Nancy Thaler
Senior Policy Advisor
Administration for Community Living
Overview of HCBS Topics to be Covered

• People Served

• People Waiting for Services

• The Workforce Crisis

• Quality and the HCBS Rule
People Served in the HCBS Waiver Program

- 1.8 million people receiving 1915 (c) services
- 267 approved 1915 (c) waivers in 46 states & DC
- Participants with ASD/ID/IDD and who are Medically Fragile comprise over 50% of the participants and utilize 67% of expenditures.

- ASD/ID/DD
  - 114 waivers for 741,600 people (41.2%)
  - Expenditures in the top quartile states
  - $68,000 - $123,000

- Medically Fragile
  - 25 waivers for 162,000 people (.9%)
  - Expenditures in the top quartile of states
  - $68,000 to $184,000

- Children SED
  - 17 waivers - no of people unknown
  - Expenditures unknown
Leading Three HCBS Key Takeaways

• Waiting Lists to Enroll in Medicaid HCBS Services
  • Impact of State Budgets

• Access to Service
  • Impact of the Direct Care Crisis

• Quality of Services – and the HCBS Rule
  • Choice
  • Inclusion
  • Rights
7.43 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2018.

21% 1.55 million people with IDD were known to or served by state IDD agencies
18% 1.31 million people with IDD received long-term supports or services through state IDD agencies

FY 2018 RISP Infographics
What proportion of people with IDD get publicly funded supports?

For every person with IDD getting publicly funded supports, four more people with IDD do not.

https://risp.umn.edu/infographics
University of Minnesota Institute on Community Integration
Number of People with ID/D Receiving Services in the Community – a State by State Picture

Medicaid Waivers include 1115 Demonstration Waivers, 1915(a, b, and b/c Managed Care Waivers) and 1915(c) Home and Community Based Waivers.

Select one or more % by Bar chart of waiver recipients are available to select specific years. Waiver includes: 1115, 1915 (a) (b) (b/c), 1915 (c). Click on a line to view data. Download options on lower right.

Medicaid Waiver Recipients per 100,000 of the Population 1996-2018

https://risp.umn.edu/infographics
University of Minnesota Institute on Community Integration
The HCBS Workforce Crisis

• 1.3 million new workers will be needed by 2029

• The demand for services is growing faster than the labor pool

• People are at risk. The workforce shortage is limiting the ability of federal programs to safely maintain people in their homes and communities.

Quality and the HCBS Rule

1. The setting was selected by the individual.

2. The individual participates in unscheduled and scheduled community activities in the same manner as individuals not receiving Medicaid HCBS services.

3. The individual is employed or active in the community outside of the setting.

4. The individual has his/her own bedroom or shares a room with a roommate of choice.

5. The individual chooses and controls a schedule that meets his/her wishes in accordance with a person-centered plan.

6. The individual controls his/her personal resources.

7. The individual chooses when and what to eat.

8. The individual chooses with whom to eat or to eat alone.

9. Individual choices are incorporated into the services and supports received.

10. The individual chooses from whom they receive services and supports.

11. The individual has access to make private telephone calls/text/email at the individual’s preference and convenience.

12. Individuals are free from coercion.

13. The individual, or a person chosen by the individual, has an active role in the development and update of the individual’s person-centered plan.

14. The setting does not isolate individuals from individuals not receiving Medicaid HCBS in the broader community.

15. State laws, regulations, licensing requirements, or facility protocols or practices do not limit individuals’ choices.

16. The setting is an environment that supports individual comfort, independence and preferences.

17. The individual has unrestricted access in the setting.

18. The physical environment meets the needs of those individuals who require supports.

19. Individuals have full access to the community.

20. The individual’s right to dignity and privacy is respected.

21. Individuals who need assistance to dress are dressed in their own clothes appropriate to the time of day and individual preferences.

22. Staff communicates with individuals in a dignified manner.
EMPLOYMENT
Employment
Emerging Services and the New Reality

John Butterworth
Jean Winsor

July 28, 2022
Number in Employment and Day Services

- **Non-work**: 650,057
- **Facility-based work**: 21.7% (100,000)
- **Integrated employment**: 0 since 2001

Source: ICI National Survey of State IDD Agencies

Highest since 2001
Participation in integrated employment services

Source: ICI National Survey of State IDD Agencies
What Families Said Was Helpful During COVID-19 and Wish to Keep/Adapt/Expand

Peer to Peer

Self Advocacy Peer to Peer

More Individualized

Person Learned New Skills

Source: Fall 2020 Innovation Roundtable discussions from the Community of Practice for Supporting Families project
Systems: What We Have – What People Want

**Program Model**
Hours and activities defined by program

**Individualized Person-Centered Model**
Work; socialization; continuous adult learning; civic participation; support hours flexible and defined by person
Employment is a basic part of how we connect many of the “important to” aspects of life such as relationships and social roles, status, routines, places to go, enjoyable or activities that allow for increased opportunity in life.

Our work is not isolated from the rest of lives, rather it is woven into it.
Employment Relates to Everything

The ID system needs:

1. A clear pathway from non-work to work

2. Belief that people can work and responsive goals and action steps

3. A fundamental shift in how we approach supports
John Butterworth
john.butterworth@umb.edu
Jean Winsor
Jean.winsor@umb.edu

www.ThinkWork.org
www.selnhub.org
www.StateData.info
Additional Resources

Employment: How we measure success
State Employment Leadership Network

Guidance for conversations: Identifying and designing pathways towards rewarding employment
State Employment Leadership Network

Agency Change Toolkit: Ten elements of organizational transformation
Institute for Community Inclusion, UMass Boston

Community Life Engagement Toolkit
Institute for Community Inclusion, UMass Boston

Weathering the pandemic: Employment and day service delivery
Rie Kennedy-Lizotte & John Butterworth

State Employment Leadership Network

Think Work!
EDUCATION
PCPID/ EMERGING ISSUES: EDUCATION

Catherine Fowler, PhD/ UNC Charlotte and National Technical Assistance Center on Transition: the Collaborative
Educational Environments of Students with Intellectual Disabilities

Percent of All Students with Disabilities

- Majority of School Day in Regular Classroom Setting
- Partial School Day in Regular Classroom Setting
- Majority of School Day in a Separate Setting

Percent of Students with ID

- Majority of School Day in Regular Classroom Setting
- Partial School Day in Regular Classroom Setting
- Majority of School Day in a Separate Setting
Predictors of Post-School Success for Students with Intellectual Disabilities

- Inclusion in General Education
- Community Experiences
- Career Awareness
- Work Experiences
- Paid Work
- Career and Technical Education
- Autonomy
- Empowerment
- Communication (including AT)
- Family Expectations
Capitalizing on Opportunities

WIOA
IDEA
HEOA
Perkins V
AT Act
DDA

...
3 Key Take Aways

Interdisciplinary and Interagency Coordination are Critical

Investing in Work Based Learning Experiences in Integrated Settings is Essential

Young People Must Have Access to Communication Tools
Resources Relevant to Students with ID

→ Work-Based Learning for Students with High Support Needs
→ Predictor Implementation Self-Assessment and List of Predictors of Post-School Success
→ Developing School-Community-Business Partnerships
→ National Report on Employment Services (ICI)
→ Perkins State Plans and Data Explorer (OCTAE)
→ Inclusive Postsecondary Education (ThinkCollege)
Follow-up on Education

- www.transitionta.org
- ntact-collab@uncc.edu
- Catherine Fowler, chfowler@uncc.edu
Housing and Residential Services for People with IDD

July 28, 2022
Sherri Larson, Ph.D. Director,
Residential Information Systems Project
University of Minnesota
Institute on Community Integration
Key Issues

Supporting Families

Access to Supports

Housing
I. Supporting Families
Living Arrangements

- Most people with IDD live with family members
  - 85% of people with IDD in the United States
  - 59% of long-term supports and services recipients
- Huge state variations
- Deinstitutionalization continues
Growth in Medicaid Waiver Support for People who Live with a Family Member

<table>
<thead>
<tr>
<th>Year</th>
<th>Family No Waiver</th>
<th>Family with Waiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>325,650</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>391,859</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>482,479</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>503,641</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>569,020</td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td>588,594</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>634,988</td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>661,166</td>
<td></td>
</tr>
<tr>
<td>2014</td>
<td>714,910</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>792,030</td>
<td></td>
</tr>
</tbody>
</table>

Source: RISP
II. Access to Supports
Access to Supports (2018)

• State IDD Agencies serve
  – 46% of adults with IDD
  – 11% of children with IDD

• 200,000+ people were waiting for Medicaid Waiver funded supports

• Adult prevalence estimates are very old
Adult LTSS Recipients per 100,000 by State

- 252 per 100,000 average
- 73 to 805 people per 100,000 range

HCBS Waiver  |  ICF/IID
---|---
NV | NM | AZ | FL | SC | CO | VA | NJ | NC | TX | OK | IL | MA | UT | LA | CT | CA | RI | DC | ID | SD | AK | MD | WI | VT | OR
III. Individualized Supports
Individualized Supports

• Required for Medicaid Home and Community Based Services funding
• People in smaller settings have more choice, are more satisfied and have better outcomes.
• Settings that best support individualized services
  – A person’s own home with supports as needed
  – A host or foster family home
  – Family Home
  – Small group settings of three or fewer people getting supports
### Living Arrangements Other than Family Home

<table>
<thead>
<tr>
<th>Category</th>
<th>Congregate 4+ people</th>
<th>Families Wanting New Congregate Settings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1...</td>
<td>242,093</td>
<td>63,279</td>
</tr>
<tr>
<td>2...</td>
<td>248,734</td>
<td>90,969</td>
</tr>
<tr>
<td>2...</td>
<td>258,085</td>
<td>85,563</td>
</tr>
<tr>
<td>2...</td>
<td>250,718</td>
<td>102,644</td>
</tr>
<tr>
<td>2...</td>
<td>262,306</td>
<td>127,459</td>
</tr>
<tr>
<td>2...</td>
<td>245,943</td>
<td>145,066</td>
</tr>
</tbody>
</table>

The size of congregate settings continues to decrease but some families want to build new congregate settings such as intentional communities or farmsteads.
Challenges

Prioritize supports for people living with family members or in individualized settings

Access to supports differs within and across states
200,000 + people are waiting

Providing individualized supports requires affordable accessible housing
Supplementary Resources
Resources

Residential Information Systems Project https://risp.umn.edu/

30 years of Community Living https://acl.gov/30years

IMPACT newsletter (https://ici.umn.edu/series/14)

ACL’s Housing and Services Resource Center https://acl.gov/HousingAndServices

Institute on Community Integration Policy Research Briefs and Policy Forums http://z.umn.edu › icipolicyforum

Charting the Lifespan for Families of Individuals with IDD https://supportstofamilies.org/
ICF/IID Use Declines as HCBS Waiver Use Explodes

ICF/IID Intermediate Care Facilities of Individuals with Intellectual Disabilities
Contact Information

Sheryl Larson, Ph.D.  Research Manager 3
612.624.6024  larso072@umn.edu

Research and Training Center on Community Living
Institute on Community Integration (UCEDD)
University of Minnesota, Twin Cities

Office 1-338
2025 East River Parkway, Minneapolis, MN 55414

The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people
DIRECT SUPPORT PROFESSIONAL WORKFORCE CRISIS
Direct Support Professional Workforce Crisis

Amy Hewitt
University of Minnesota
Institute on Community Inclusion
A 30 year National Problem

- Low wages
- Unaffordable benefits
- Limited training & development
- Lack of career advancement opportunities
- Challenges in recruiting and retaining high-quality employees
- Low quality services and poor outcomes for people receiving supports
## Things we know about DSPs

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
<th>Source/Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary wage earners</td>
<td>~70%</td>
<td>Hewitt et al 2021</td>
</tr>
<tr>
<td>Disproportionately women</td>
<td>84%</td>
<td></td>
</tr>
<tr>
<td>Disproportionately BIPOC</td>
<td>55.4%</td>
<td>NCI, 2020</td>
</tr>
<tr>
<td>Mean wage</td>
<td>$13.61</td>
<td>Nat’l NCI, 2022</td>
</tr>
<tr>
<td>Rely on public assistance</td>
<td>~50%</td>
<td>PHI, 2020</td>
</tr>
<tr>
<td>PT/FT status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part time</td>
<td>31%</td>
<td>Nat’l NCI, 2020</td>
</tr>
<tr>
<td>Full time</td>
<td>69%</td>
<td>Nat’l NCI, 2020</td>
</tr>
<tr>
<td>Turnover rate</td>
<td>40%</td>
<td>Nat’l NCI, 2020</td>
</tr>
<tr>
<td>Terminated from their positions</td>
<td>17%</td>
<td>Nat’l NCI, 2020</td>
</tr>
<tr>
<td>Vacancy rate</td>
<td>12.3% (FT); 16.4% (PT)</td>
<td>NCI, 2020</td>
</tr>
<tr>
<td>Education</td>
<td>73% education beyond h.s.; 27% h.s. only</td>
<td>Hewitt et al 2021</td>
</tr>
</tbody>
</table>
Direct care job openings 2018 - 2028

PRE-pandemic!

8.2 Million
• Only 30% reported extra money working as essential workers
  • Of those majority $1 – 2
• Disparities evident in wages and household incomes
• Disruption and change
  • work patterns, schedules, locations, type
• Extreme hours worked
• Majority had decline in work-life status (worse or much worse 54%)
• Mental health and wellness challenges
  • Physical and emotional burnout 50%
  • Anxiety 47%
  • Sleep difficulties 38%

Source: Hewitt et al, 2021
Mental health support

- Employee assistance
- Ensure health plans have robust mental health coverage
- Wellness training and support programs
- Financial, childcare and caregiver community connections
Other recommendations

- Ensure the DSP workforce is identified as essential workers with same benefits in every state, DC and US territory.
- Identify, address and eliminate wage disparities at organizational, state and national levels within this workforce.
- Professional recognition and wage equity for all DSPs.
- Pay wage that correlates with skills and enhance wages through career paths that recognize new skill development with higher wages.
- Eliminate wage compression through better methods for getting wage increases to DSPs.
- Find solutions in lessons learned from other female dominated professions (e.g., nursing, teaching, social work).
Contact Information

Amy Hewitt - University of Minnesota
• Email: hewit005@umn.edu
PCPID Member Question and Answer to the Panel Presenters
Break

15 minutes
Public Input Feedback to PCPID
PCPID Member Reflection on Emerging Issues

• As a committee member, what do you believe is the leading issue(s) that needs to get addressed by the PCPID and why?

• Committee Members Nominate Topics
Break

5 minutes
PCPID Committee Member
Online Voting
Closing Remarks

Jill Jacobs
Commissioner, Administration on Disabilities
Administration for Community Living

Jim Brett
Chair, PCPID
THANK YOU