



President's Committee
for People with Intellectual Disabilities (PCPID)

Zoom Platform Meeting
July 28, 2022
~Minutes~

Citizen Members (Present)

James Brett, Chair
Shawn Aleong
Paul Aronsohn
Paul Boskind
Eva Bunnell
Kara Jones
Nicole Jorwic
Cathy Kanefsky
M. Brent Leonard
Joseph Macbeth

Gabriel Martinez
Lucy Meyer
Tia Nelis
Santa Perez
Nick Perry
Hillary Dunn Stanisz
Wendy Strauss
James Trout
Liz Weintraub
Jordyn Zimmerman

Ex Officio Members and Representatives (Present)

Monique Dismuke for Larry Beat
Representing the Honorable Gina Raimondo
Secretary, U.S. Department of Commerce

Andy Arias for Taryn Williams
Representing the Honorable Marty Walsh,
Secretary, U.S. Department of Labor

Jodie Sumeracki
Representing the Honorable Xavier Becerra,
Secretary, U.S. Department of Health and
Human Services

Sasha Samberg-Champion
Representing the Honorable Marcia Fudge,
Secretary U.S. Department of Housing and
Urban Development

Kelly Buckland
Representing the Honorable Pete Buttigieg,
Secretary, U.S. Department of
Transportation

Katy Neas
Representing the Honorable Miguel
Cardona, Secretary, U.S. Department of
Education

Laura Davis for Brian Parsons
Representing the Honorable Alejandro
Mayorkas, Secretary, U.S. Department of
Homeland Security

Joyce Walker-Jones
Representing the Honorable Charlotte A.
Burrows, Equal Employment
Opportunity Commission

Lisa Gray
Representing the Honorable Michael Smith
CEO, Corporation for National and
Community Service

Jim Baldwin
Council Member, National Council on
Disability

Leola Brooks
Representing the Honorable Nancy A.
Berryhill, Commissioner, U.S. Social
Security Administration

Guest Panel Presenters

Nancy Thaler
Senior Policy Advisor
Administration for Community Living

Catherine Fowler
University of North Carolina Charlotte
Cato College of Education

John Butterworth
University of Massachusetts Boston
Institute for Community Inclusion

Sheryl Larson
University of Minnesota
Institute on Community Integration

Jean Winsor
University of Massachusetts Boston
Institute for Community Inclusion

Amy Hewitt
University of Minnesota
Institute on Community Inclusion

Guest Public Citizens

Joanne Nicholson, Massachusetts, Brandeis University
Rebecca Shoniker, North Carolina, Parent of a child with an Intellectual Disability
Laurie Robinson, New York, University of Rochester Medical Center
Hugo Dwyer, New York, Voice of Reason (VOR)
Rachel Sandler, Pennsylvania, Self-Advocate

Administration for Community Living and The Administration on Disabilities

Alison Barkoff
Acting Administrator
Administration for Community Living

Jill Jacobs
Commissioner, Administration on
Disabilities and PCPID Designated
Federal Officer (DFO)

Jennifer Johnson
Deputy Commissioner, Administration on
Disabilities

Sheila Whittaker
Program Assistant, Office of Intellectual and
Developmental Disabilities, Administration
on Disabilities

David Jones
Director, Office of Intellectual and
Developmental Disabilities, Administration
on Disabilities

Jack Brandt
Community Living Specialist, Office of
Intellectual and Developmental Disabilities,
Administration on Disabilities

The PCPID Virtual Business Meeting Proceeding Overview

Call to Order, Welcoming Remarks and Meeting Overview

Jim Brett, PCPID Chair

Chairman Jim Brett called the PCPID meeting to order and welcomed the PCPID members and public joining virtually. Jim noted that the nation observed the 32nd anniversary of the *Americans with Disabilities Act* earlier in the week and hoped the transformative spirit of the Act would be a guiding principle for the PCPID's committee work to help further advance policies and initiatives that support the independence and lifelong inclusion for people with intellectual disabilities. Jim provided an overview of the meeting flow and shared feedback with the members on how to engage using the zoom virtual platform.

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

Both Alison Barkoff and Jill Jacobs shared welcoming remarks. Alison provided a brief overview of the charge of the committee and acknowledged how the committee is building off a legacy that began decades ago. She also noted that the work the committee will embark on is part of a long arc toward justice for people with disabilities and thanked the committee members for their service.

Jill Jacobs also echoed the welcoming sentiments of Alison Barkoff and thanked the committee membership for their service on behalf of the Administration on Disabilities. Jill noted that for the first time more than half of the citizen membership include individuals with a disability as well as representation from marginalized communities. Jill shared that the committee's work will result in a report that will be shared with the President. Jill also expressed thanks to members of the public that submitted feedback to the PCPID to help guide the committee's work.

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

David began his remarks in briefing committee members and the public about the results of the PCPID member survey. The internal member survey was launched on May 11th to all 33 members (Citizen and Ex Officio). The survey had been administered through survey monkey and had a 64 percent response rate. The seven questions were the following:

- [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 service delivery of services and supports for people with intellectual disabilities?
- [Q3] What has been the biggest impact of the COVID-19 pandemic on people with intellectual disabilities?
- [Q4] What are important issues facing individuals with intellectual disabilities who are part of racial and ethnic minorities, economically disadvantaged communities, and/or rural communities?
- [Q5] Result of ranking of PCPID should focus on as it relates to lives of people with intellectual disabilities. The ranking results were in the following order:
 - Home and Community Based Services
 - Employment
 - Education
 - Housing and Direct Support Professional Labor Shortage (Tied)
 - Health
 - Transportation
 - Formal and Informal Community Supports
 - Early Intervention
 - Child-care
 - Recreation
- [Q6] Question on sharing date options for committee meeting (resulted in 7/28/22)
- [Q7] Asking if members would be interested in chairing a workgroup (9 members were identified).

David proceeded to share insights on the feedback received from public input to help guide the committee's work. As background, on June 14th, ACL launched on its PCPID webpage an inbox for members of the public to "share a comment with PCPID". As of July 8th, 34 responses were received. David noted that the comments received had a strong response from parents and/or sibling caregiver to individuals with intellectual disabilities. David noted that the public sentiment was consistent with the views and concerns expressed by members of the committee against the internal PCPID survey. David provided a synopsis of the public input received. These addressed access barriers, HCBS/Direct Support Professional Workforce impact that resulted in impeding community inclusion, and citizen services.

David concluded his remarks by providing an overview of past historical reports published as the committee begins to weigh what topic to address during their term.

Briefing on Emerging Issues – Leading Three Takeaways PCPID Member Question and Answer (Q&A) to the Panel Presenters

Based on the internal polling feedback of PCPID members, experts were invited to brief committee members of leading issues or barriers in the different areas. Following each of the panel presentations, the members engaged with the panel presenters during a Q&A session.

Home and Community Based Services – Nancy Thaler, Senior Policy Advisor, ACL

Nancy shared her remarks addressing people served, people waiting for services, the workforce crisis, and quality / HCBS rule. In reporting data, Nancy noted that approximately 1.8 million people are receiving 1915(c) services; there are about 267 approved waivers in 46 states; and participants with ADD/ID/ID and those who are medically fragile comprise over 50 percent of the participants and utilize 67 percent of expenditures. On addressing the waiting list issue, Nancy reminded the committee that this is not determined by federal budget, but rather by state budgets. Federal agencies will match any dollar the states put up. However, access to services is being currently being impacted by the direct care workforce crisis.

Nancy shared that while every state defines intellectual and developmental disabilities differently, there are approximately 7.43 million people identified in the country as having this disability. Nancy explained that it's a misconception that all 7.4 million need services, but rather it's much lower around 1.5 million. However, the challenge is that the actual number of individuals on a waiting list nationally is not fully known since some states don't keep waiting lists. This is compounded by waiting list having different meaning in different states.

Nancy noted that the demand for people to provide care is growing faster than the labor pool available resulting in the intellectual disability population being at risk. The workforce shortage is limiting the ability of federal programs to safely maintain people in their homes and their communities. On addressing the quality of and the HCBS rule, Nancy concluded her remarks in sharing a slide that listed the 22 standards surrounding HCBS quality.

Employment – John Butterworth and Jean Winsor, University of Massachusetts Boston, Institute for Community Inclusion

John and Jean jointly presented. John noted that work is the heart of most people relationship to their community. John shared a graph showing how the nation struggled over the past 30 years to meaningfully improve integrated employment. He noted that in 2020, we reached 22 percent (individuals that were engaged in supports that helped them be part of the integrated labor force). This percentage has been the highest since 2001, but believes this number will drop as a result of the pandemic.

John referenced study conducted by National Association of State Directors of Developmental Disabilities on Communities of Practice during COVID-19. The study highlighted what families said was helpful during COVID-19 and what they wish to keep, adapt, or expand. A leading area identified was having peer to peer supports and peer to peer self-advocacy efforts. More specifically, the families valued that the support and services became more individualized through person centered planning. This allowed individuals to learn more new skills. During the pandemic, one example noted was how the intellectual disability population developed new technology skills to engage with others and build new relationships.

Jean echoed John's points surrounding the importance of employment within the community. She recognized that there is a transition happening from program model to a more individualized person-centered model. She concluded by identifying the three things Intellectual Disability 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 is needed in how we approach supports.

The committee took a five-minute break after the Employment focused presentation.

Education – Catherine Fowler, University of North Carolina Charlotte, Cato College of Education

Catherine addressed the public education system and how it is serving students with intellectual disabilities. She noted that approximately 15 percent of students in school have disabilities. Of those students, approximately 13 percent of those students are in the category of students with intellectual or developmental disabilities. She noted that as students get older, the gap between students who are served in classrooms with and without disabilities get more and more wider in segregated settings. As students get into high school, this population becomes increasingly more segregated which results in less likelihood to successfully graduate compared to an integrated classroom environment.

Catherine highlighted the predictors of post-school success for students with intellectual disabilities. They include:

- Inclusion in general education;
- Career awareness, work experience, paid work, and career and technical education;
- Autonomy, empowerment, and communication (including AT); and
- Family expectation.

Catherine noted that several federal laws (e.g. WIOA, IDEA, AT Act, DD Act) are inclusive of improving outcomes for intellectual disability population and emphasized that schools need to be part of the conversation around employment opportunities in order for this population to be equipped to take advantage of the opportunities as adults. Catherine also relayed that both the DD and VR agency need to be at the table when conversations are being held round Medicaid waivers and specific services covered with those. Catherine concluded her remarks noting the following three key takeaways in the area of education: 1) Interdisciplinary and interagency coordination are critical; 2) Investing in work-based learning experience in integrated settings is essential; and 3) Young people must have access to communication tools.

Housing – Sheryl Larson, University of Minnesota, Institute on Community Integration

Sheryl gave her remarks grouped in the following three key areas 1) Supporting families; 2) Access to supports; and 3) Individualized supports. In supporting families, Sheryl shared latest data collected on the following living arrangements:

- Family Home; Most people with I/DD live with family members (59%)
- Group Home; Group Home setting in residence of six or fewer people owned, rented, or managed by the organization or agency that provides services to the people in the home (16%)
- Own Home; a home owned or rented by one or more adults with ID/DD (11%)
- Institution; a residence of seven or more people owned, rented, or managed by the organization or agency that provides services to people in the facility (9%)
- Host or Foster Family home; a home or rented by an individual or family that provides supportive services to one or more people with ID/DD (5%)

With access to supports, Sheryl noted that in 2018, state I/DD agencies served 46 percent of adults with I/DD and 11 percent of children with I/DD; And, over 200,000 people were waiting

for Medicaid waiver funded support. With Individualized supports, Sheryl noted that settings that best support individualized services are the following: a person's home, a host or foster family home, the home of a family member, or small group settings where three or fewer people getting supports share a home or apartment.

In closing, Sheryl noted the following 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); and
- Providing individualized supports require affordable accessible housing.

Direct Support Professional (DSP) Workforce Crisis – Amy Hewitt, University of Minnesota, Institute on Community Inclusion

Amy opened her remarks with observation that the DSP workforce crisis is very significant and not a new one against its history. She shared that we currently have approximately a 12 percent vacancy rate in full time positions and 16 percent vacancy rate in part time positions. Amy believes the vacancy rate numbers will soon be higher stemming from the impact of COVID-19. She noted that this DSP workforce is educated with 73 percent beyond a high school degree, but they often get described as being uneducated. Amy also shared that by 2028, we will need 8.2 million employees coming into the various direct support worker roles.

Amy collaborated with another national center supporting DSPs to assess the impact of COVID-19. A key takeaway was that only 30 percent of the DSPs that responded that they earned extra money working as essential workers. And, there was significant wage disparities with African American DSPs in having wages that were lower than other categorical groups of DSPs. COVID-19 disrupted work patterns and schedules resulting in longer hours worked. This has led to a majority experiencing physical and emotional burnout, anxiety, and sleep difficulty within the DSP workforce. Due to this current work environment, Amy shared that it is critical to have mental health support for DSP workforce with employee assistance programs and mental health coverage including financial child-care and community connections.

In closing, Amy shared the following recommendations:

- Ensure the DSP workforce is identified as essential workers with the 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; and
- Find solutions in lessons learned from other female dominated professions (e.g. nursing, teaching, and social work).

After the Q&A session with the panelists, the PCPID Committee adjourned for a 15-minute break.

Public Input Feedback to PCPID

The chair recognized five individuals from the public who had an opportunity to read statements previously submitted through the PCPID inbox or separate letter shared with ACL:

Joanne Nicholson, Massachusetts, Brandeis University

- Joanne read statement focused on how parents with I/DD and their families are a vulnerable underserved population. She shared in her remarks how recent funding from PCORI resulted in series of Lab workshops with diverse stakeholders to highlight the experiences of mothers with I/DD, identify their needs, and solutions developed.

Rachel Sandler, Pennsylvania, Self-Advocate

- Rebecca read statement focused on societal perception of people with intellectual and developmental disabilities, lack of resources, unmet needs around HCBS, and pay for the Direct Support Professional workforce. She observed that people want to plan, but not know where to find resources and they need to be made more accessible. There is a need to provide quality caregivers and they need to get paid more.

Laurie Robinson, New York, University of Rochester Medical Center

- Laurie read statement focused on people with ID/Other Disability as it relates to aging and the need for health care practitioner training. She noted that aging in place is not always possible due to changes in physical, and sometimes cognitive function. And, nursing homes are not always a good option as the staff do not have the training or working knowledge of people with intellectual disabilities. Laurie recommended aging be added to the PCPID strategic plan.

Hugo Dwyer, New York, Voice of Reason (VOR)

- Hugo read statement focused on sharing his support for home and community-based services but also supporting the ICF system. He noted that his brother was well supported in an ICF. He also shares his support for the transformation of competitive employment, but felt some people are unlikely to ever be accommodated by businesses. The intellectual disability population works well in an environment with a job coach who is also a disability support professional that can look after their challenges. He recognized the DSP crisis and recommended that be an area of focus for the committee.

Rebecca Shoniker, North Carolina, Parent of a child with an Intellectual Disability

- Rebecca read statement focused on barriers within the education system, a need for systemic needs assessment, and lack of mental health and crisis services. As a parent to a child with intellectual disability, she shared that there has been a continual lowering of expectations for individuals with intellectual disabilities rather than continued research, planning and efforts to make independence within education system possible. And, there has been a lack of staff for jobs that work with individuals with intellectual disabilities.

PCPID Member Reflection on Emerging Issues

During this open forum discussion amongst PCPID members, Chairman Brett asked the committee members “What do you believe is the leading issue(s) that needs to get addressed by the PCPID and why?”. Committee members had an opportunity to openly reflect with their peers and nominate topics. Members identified several topics:

Paul Aronsohn surfaced the need to update both Social Security and Medicaid programs with more reasonable income/assess eligibility requirement combined with further examining the

marriage penalties issue that often make it difficult, if not impossible for people with intellectual disabilities to get married. Paul also recommended revisiting the DSP workforce report issued by the committee five years ago to assess what has changed.

Jim Baldwin recommended a focus on healthcare.

Hillary Dunn Stanisz recognized how it comes back to workforce issues; ensuring compliance with community rule; and how we think about person centered individualized services, particularly for those with high support needs.

Nicole Jorwick made a motion to do a report on access to home and community-based services and include the impact of the workforce. Employment services are funded through Medicaid.

Joseph Macbeth recommended that the PCPID 2017 Direct Support Professional report be revisited.

Cathy Kanefsky echoed support for all of the ideas surfaced and shared how her twin sons in early 30's who relied on DSPs since they were in the workforce. The food banks she oversees in Delaware has hired five people with intellectual disabilities. And, wages for staff for both people with and without disabilities have increased from \$15 to \$18 an hour. Cathy recommended setting up pilots in the workforce and reflected on success experienced after receiving a grant from Department of Labor to provide instruction around culinary training. Cathy noted that such pilots can be successfully expanded in other parts of the country in a national effort if the right people are in place.

Liz Weintraub recognized the 32nd anniversary of the ADA and shared her frustration of waiting to further advance the principles community inclusion around living and working.

Paul Boskind shared his observation from nursing homes who provide psychological services and not being able to sufficiently treat individuals with cognitive impairment or dementia.

Matthew Leonhard recommended the report take similar format to previous one issued in 2016 with various focus areas around enhancing and improving community living. This would include addressing employment and education in which the two can be linked in collaboration with housing and DSP. A report will need to include the needs of tribal communities.

Jim Brett noted that addressing health disparity work is currently being addressed by another agency with National Council on Disability (NCD) and may want to defer focus by this committee to prevent duplication. Jim indicated he would help coordinate any work NCD is doing with the work of PCPID. Jim Baldwin from NCD concurred.

Kara Jones relayed how DSP workforce in Maryland is in shortage and has been a struggle for her and her family. Kara shared that one caseworker has as many as 1,200 cases of families like her own. It has been a struggle to find staff to cover evening hours.

Santa Perez surfaced the DSP and how individuals with ID/DD are living longer and the need to recognize the different support needed.

Eva Bunnell noted the need around entrepreneurial opportunities within employment. The need to work with higher education and develop the workforce pipeline for direct care workers or start businesses for themselves to hire individuals. There is a need to collaborate with SBA to provide such funding opportunities. Eva also shared the need to review past reports to examine what has been both successful and impediments have been with implementation to help get over hurdles. And, whatever focus is chosen, the need to develop metrics for program outcome measurement. Eva indicated that if we don't take steps to measure, we will find ourselves in similar situation with recommendations not implemented ten years from now.

Lucy Meyer recommended a focus on education to address barriers individuals with intellectual disabilities face during process.

Tia Nelis shared with the committee that a lot of the topics being surfaced can be addressed under a report focused on HCBS. She also recognized how individuals coming to the U.S. as immigrants with disabilities are not getting the support needed.

Joseph Macbeth recommended the committee have an opportunity to read the DSP report issued by the Office of Disability Employment Policy (ODEP) and examine ways the committee can provide support. It was agreed the members would get a copy of the report that would get issued the following day.

Jim Brett recognized how the statistics shared during the meeting put an alarming spotlight around the DSP workforce issue. And, Nicole Jorwic noted that if we don't expand funding for HCBS, we're only going to be able to work around the fringes of the DSP workforce crisis. Wages are tied to Medicaid rates. Nicole recommended HCBS to include addressing the workforce and employment issues within the report. Joseph Macbeth concurred.

Jim Brett shared concerns on the wages of the DSP workforce and examine why the recommendations in the past report addressing DSP workforce was not followed through. Jim shared he recently received a report from an organization in western Massachusetts called Seven Hills foundation and they have a 40 percent vacancy rate with a continued high turnover and something needs to be done. Jim noted that we need to think outside the box similar to how the committee surfaced ABLE accounts several years ago as a solution.

Jill Jacobs observed that many of the issues that surfaced during the meeting today including DSP can be addressed within a report on HCBS. This includes caregivers as well as people providing support within communities addressing day activities. Such activities include learning how to use public transportation and grocery shopping. This report could include issues faced by tribal communities and immigrants as surfaced during the meeting. This report can also address the critical issue of funding.

Jim transitioned the discussion from committee discussion to a committee vote.

PCPID Committee Member Online Vote

Jim Brett directed the contractor assigned to support PCPID bring up on the screen the items surfaced for a committee virtual vote. However, the contractor experienced a technical snafu with the platform resulting in members not being able to vote real time. It was agreed that an

email (e.g. survey monkey survey) would go to the PCPID members for a vote and would then be subsequently announced to the public.

Closing Remarks

Jim Brett, PCPID Chair

Jill Jacobs, Commissioner, Administration on Disabilities

Both Chairman Brett and Commissioner Jill Jacobs thanked all the PCPID members for their participation in the meeting and the ideas they brought forward during the discussion.

Meeting Adjournment

Chairman Brett adjourned the meeting.