



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

PCPID Meeting
September 26 - 27, 2024
Day Two Meeting Minutes

Citizen Members (Present)

Jim Brett, Chair	Gabriel A. Martinez
Shawn Aleong	James R. Meadours
Paul Aronsohn	Lucy Meyer
Paul Boskind	Tia Nelis
Emmanuel Jenkins	Santa Perez
Kara Nicole Jones	Nicholaus Perry
Nicole Jorwic	Hillary Dunn Stanisiz
Cathy Kanefsky	James E.B. Trout
Matthew Brent Leonhard	Liz Weintraub
Joseph M. Macbeth	Jordyn Beth Zimmerman

Ex Officio Members and Representatives (Present)

Max Lapertosa, Trial Attorney	Kelly Buckland, Disability Policy Advisor
The Honorable Merrick Garland Attorney General of the US Department of Justice	The Honorable Pete Buttigieg Secretary of the US Department of Transportation
Jennifer Ackerman, Deputy Chief Human Capital Officer	Glenna Wright-Gallo, Assistant Secretary
The Honorable Deb Haaland Secretary of the US Department of the Interior	The Honorable Miguel Cardona Secretary of the US Department of Education
Larry Beat, Acting Director	Laura Davis, Disability Employment Program Manager
The Honorable Gina Raimondo Secretary of the US Department of Commerce	The Honorable Alejandro Mayorkas Secretary of the US Department of Homeland Security

Taryn Williams, Assistant Secretary
The Honorable Julie A. Su
Acting Secretary of the US Department of
Labor

Denise Leach, Social Insurance Specialist
The Honorable Martin O'Malley
Commissioner of the US Social Security
Administration

Jodie Sumeracki, Senior Policy Advisor
The Honorable Xavier Becerra
Secretary of the US Department of Health and
Human Services

Heather Nodler, Attorney Advisor
The Honorable Charlotte A. Burrows
Chair of the Equal Employment Opportunity
Commission

Jeanine Worden, Associate General Counsel
The Honorable Adrienne Todman
Secretary of the US Department of Housing
and Urban Development

Joan Durocher, General Counsel and Director
of Policy
The Honorable Claudia Gordon
Chair of the Board of the National Council on
Disability

Administration for Community Living and Administration on Disabilities (Present)

Alison Barkoff
Performing the duties of ACL Administrator
and Assistant Secretary for Aging,
Administration for Community Living

Sheila Whittaker
Program Assistant, Administration on
Disabilities

Jennifer Johnson
Acting Commissioner, Administration on
Disabilities

Selvin Garcia
Program Specialist, Administration on
Disabilities

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

Welcome / Call to Order
Jim Brett, PCPID Chair

Jim Brett opened the session by summarizing the previous day's meeting proceedings. Jim then explained that today's meeting focus would shift from identifying barriers to having a greater focus on discussing how the barriers are currently being addressed. The meeting would then conclude with a discussion by the committee to identify four or five specific topics to address in the 2025 PCPID report.

Part I – Surfacing the Barriers

PCPID Citizen Members: Describing one leading barrier you are observing in your community for People with Intellectual Disabilities and their Families

James Meadours, Texas

- James expressed concern about the challenges faced by frontline workers, especially those working for small "mom and pop" provider agencies in Texas. He highlighted the low pay, lack of benefits like health insurance and paid time off, and the difficulties they face, such as having to work multiple jobs to make ends meet. He shared the personal story of a dedicated worker, "B," who had to rely on a GoFundMe page to cover basic needs after missing work due to COVID-19. James called for better support for small agencies, more awareness of direct support workers' struggles, and the need to close more institutions for people with disabilities in Texas.

Lucy Meyer, California

- Lucy shared that after graduating from high school, she felt isolated as her friends moved on, leaving her without a place to go. However, through the Special Olympics, she was able to make new friends and find a sense of community, which helped her overcome the challenges of social isolation.

Hillary Dunn Stanisz, Massachusetts

- Hilary, a sibling of a person with Angelman syndrome, emphasized the workforce crisis affecting DSPs and frontline workers. She highlighted how low pay and high cost of living make it difficult for these workers to make ends meet, often leading them to work multiple jobs. This, in turn, affects the quality of care for individuals with I/DD. Hilary noted that the workforce shortage is at the root of many issues, including long waiting lists for services and higher rates of abuse and neglect. She also mentioned how individuals with the highest support needs are often left behind due to insufficient staffing in agencies.

James Trout, Virginia

- James shared his experience working for Source America, a nonprofit focused on helping people with disabilities secure and maintain gainful employment. Diagnosed with Asperger's syndrome at 15, James highlighted how he overcame challenges to live independently and find employment despite moving frequently during his youth. He acknowledged that while his success is rare, significant progress has been made in disability issues over the past 25 years. However, there is still much work to be done to

ensure that more people with disabilities can live independently and have adequate job opportunities.

Emmanuel Jenkins

- Emmanuel shared his personal experience of facing a housing crisis after the rent of his accessible home drastically increased, leading to his family's eviction. He emphasized the urgent need for accessible and affordable housing and transportation, advocating that transportation should not be limited to medical appointments but should support full participation in society, including everyday activities like shopping or visiting community spaces.

Jordyn Zimmerman, Ohio

- Jordyn emphasized the persistent lack of access and support for people with I/DD, starting in schools where most students with I/DD face segregation. This isolation leads to lifelong barriers to community involvement, employment, and support. She stressed that these early experiences foster negative perceptions of disability, limiting opportunities, and questioned how broader societal issues like healthcare and employment can be addressed if schools continue to exclude and marginalize individuals with disabilities.

Health Equity and Safety

Health Equity

Jennifer Johnson, Acting Commissioner, Administration on Disabilities

Jennifer Johnson discussed the challenges people with disabilities face in accessing equitable healthcare, emphasizing the various disparities and barriers that exist. Health is essential for living well in the community, and access to adequate healthcare is fundamental to this. Individuals with I/DD face difficulties in participating in work, education, and social activities. Health equity is a critical aspect of community living, as it impacts every part of daily life.

Jennifer shared that multiple barriers prevent people with I/DD from accessing healthcare, including disparities in preventive services, cancer diagnosis and treatment, and reproductive and mental health care. Communication challenges are twofold: (1) healthcare providers may struggle to effectively communicate with I/DD patients, and (2) individuals with I/DD may face difficulties in understanding their providers. Intersectional identities, such as race, gender diversity, and economic status, compound these disparities, making access to adequate care even more challenging for those from marginalized backgrounds.

Jennifer shared that there are several reasons for the healthcare disparities experienced by people with I/DD. They include:

- Complex health conditions and the need for multiple healthcare providers create additional challenges.
- Social determinants of health, such as lack of transportation or employment, further limit access to healthcare services.

- The limited availability of specialists and inadequate training of healthcare professionals in treating people with I/DD also contribute to disparities.
- Ableism and medical discrimination remain prevalent in healthcare settings, affecting treatment decisions and access to services.

Jennifer shared there are gaps in research and data, noting that people with I/DD are frequently excluded from clinical trials, which leads to insufficient evidence about the effectiveness of treatments for this population. Furthermore, there is a lack of comprehensive health surveillance data for people with I/DD, making it difficult to fully understand their healthcare needs and address disparities.

Jennifer shared survey results in a research study conducted by Dr. Iezzoni that provides insights into current perceptions among physicians:

- 80% of physicians believe that people with significant disabilities have a worse quality of life than those without disabilities.
- Only 40% of physicians feel confident in their ability to provide equal quality care to patients with disabilities.
- Just 57% of physicians strongly agree that they welcome patients with disabilities into their practices, indicating a lack of inclusivity.

Jennifer discussed the growing life expectancy of individuals with I/DD as a positive development but emphasized the need for continued efforts to increase life expectancy and promote health equity throughout their lives. She highlighted that healthcare systems must prepare for these changes by ensuring equitable access to healthcare that supports the physical, emotional, social, and economic well-being of people with I/DD. Johnson outlined the Administration on Disabilities' vision for healthcare where individuals with disabilities are treated with respect, and dignity, and have access to culturally competent, person-centered care.

Jennifer described several ACL ongoing projects aimed at improving health outcomes for individuals with I/DD. These include the Center for Transition to Adult Healthcare for Youth with Disabilities, which provides resources for transitioning youth; the PATH-PWIDD project, which integrates I/DD-related content into medical education; and the National Center for Disability, Equity, and Intersectionality, which addresses ableism and medical discrimination. Additional projects include the LINK Center, grants for states to address co-occurring I/DD and mental health issues, and the I/DD Counts initiative, which aims to improve data collection on the health of people with I/DD.

Following Jennifer's remarks, several members of the committee shared comments:

- Santa Perez recalled years ago not being told how much her body will change as she ages and how the body and mind change for people who have dementia, which are topics that should be discussed.
- Liz Weintraub shared her thoughts on the medical field's lack of belief in people with disabilities and the importance of building trust through understanding patients personally. Liz also stressed the need for plain language in medical settings, as she sometimes struggles to understand what doctors are saying.

- James Meadours expressed the need for medical professionals to receive better training on handling disclosures of sexual assault. He emphasized that incorporating information about sexual assault into medical training is essential for ensuring patient safety and health.
- Shawn Aleong added that in order to implement major changes, there has to be some form of training or certification for doctors or medical professionals.
- Jim Brett shared his experience from serving on the National Council on Disability, where they once focused on improving oral health and dental care for individuals with disabilities. After five years of effort, they successfully ensured that every dental school in the country included training in their curriculum focused on diagnosing and treating individuals with disabilities.
- Emmanuel Jenkins expressed concern about being asked for resources and knowledge by well-paid medical professionals without receiving compensation for his expertise. He emphasized that advocates are often willing to share their experiences and knowledge, but it is troubling when healthcare providers expect this support without offering payment. Emmanuel also highlighted a lack of access to crucial information about managing health conditions like diabetes, suggesting that people with disabilities are sometimes viewed as less deserving of such knowledge.
- Jordyn Zimmerman reflected on the lack of older augmentative and alternative communication (AAC) users in the community and expressed concern about the future of their community. She wonders where these individuals go and what happens to them, emphasizing the importance of examining these issues.
- Cathy Kanefsky pointed out that the disconnect in healthcare often lies with the insurance companies rather than the quality of providers. She mentioned having excellent healthcare professionals who have been involved with her family for a long time but face ongoing challenges with insurance denials for prescribed treatments. While she has the resources and determination to fight these denials, she acknowledges that not everyone has the same ability or financial means to do so, highlighting a disparity in access to care.
- Kara Jones expressed appreciation that she has a physician who trains medical students to help further improve healthcare practices.

Part II – Addressing the Barriers

PCPID Ex Officio Member Agencies: Initiatives for People with Intellectual Disabilities and their Families

Taryn Williams, Assistant Secretary, Office of Disability and Employment Policy (ODEP) U.S. Department of Labor

Taryn explained that ODEP is a non-regulatory federal agency that promotes policy and works with employers and the government to increase workplace success for people with disabilities. ODEP's mission is to develop and influence policy and practice to increase the number and quality of employment opportunities.

Taryn emphasized that strengthening the DSP workforce is important as DSPs provide crucial services to ensure that people with disabilities and their families can be a part of their community. ODEP is working to build capacity and strengthen the workforce. For example, in

2022, a meeting was convened with experts to identify the challenges faced by the workforce and provide recommendations to address the DSP crisis. From that meeting, a report was released on how to help address strategies by bringing more DSP professionals into the workforce. ODEP is currently working on another report focused on apprenticeship programs while earning wages.

Tia Nelis inquired if ODEP is working with vocational rehabilitation.

- Taryn confirmed that ODEP is working closely with the Rehabilitation Services Administration (RSA) which administers the vocational rehabilitation (VR) program. Examples include providing support to RSA to recompute VR funding through disability innovation funds. In addition, ODEP partners with RSA addressing barriers faced by youth and older adults to obtain successful employment outcomes.

Jordyn Zimmerman inquired if the role of the DSP has any relation to their practice (e.g., speech therapist, specialized doctor).

- Taryn confirmed that the DSP role is a part of a broader career ladder. The skills DSPs develop on the job relate to many other roles. One of the many ways to address the workforce crisis is to ensure that DSPs understand that their jobs can lead to other careers.

Kelly Buckland, Disability Policy Advisor, U.S. Department of Transportation

Kelly presented on the *Actions to Advance USDOT Disability Policy Priorities* project. Four pillars make up this project which include: 1) safe and accessible air travel; 2) multimodal accessibility of public rights-of-way; 3) access to good-paying jobs and business opportunities; and 4) accessibility of electric vehicle charging and automated vehicles.

Kelly explained that for safe and accessible air travel, they are examining programmatic enforcement of the Air Carrier Access Act, Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 508 of the Rehabilitation Act. As for the multimodal accessibility of public rights-of-way, they are advancing diversity, equity, inclusion, and accessibility in the DOT workforce. To enable access to good-paying jobs/business opportunities, they are addressing gaps in data on people with disabilities to inform policymaking. For EV charging and vehicles, they are ensuring all DOT meetings and resources are fully accessible to people with disabilities.

Todd Wilson, Team Lead for the Money Follows the Person (MFP) Demonstration Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services

Todd presented on the *CMS Resources for Supporting Adults with Intellectual and Developmental Disabilities and Their Aging Caregivers* project. The number of people with I/DD and caregivers is increasing. There are an estimated 7.43 million people with I/DD however only 21% receive services through state I/DD agencies. Given the national trend towards HCBS, experts expect increases in the number of individuals with I/DD living at home with aging caregivers. This increase will also increase demands on state and federally funded services (primarily Medicaid state plan and HCBS waiver programs).

Todd stated that most family members supporting an adult with I/DD are parents. Adults with I/DD often receive support from their parents and caregivers throughout their lives; as they age, they may be unable to support their adult children to the same extent because of illness or other health concerns. Other aging parents and caregivers may remain at home and require new support to meet their own needs and those of the person they support.

Todd shared CMS resources in his remarks. One of the resources highlighted was titled *State Spotlights: Supporting Adults with I/DD and Their Aging Caregivers*. This resource is intended to support state Medicaid and partner agencies in their efforts to develop, implement, and expand innovative strategies for supporting adults with I/DD living and cared for by aging caregivers. The resource focuses on interagency partnerships. Another state resource shared was titled *How State Agencies Can Anticipate and Meet the Needs of Adults with I/DD and Their Aging Caregivers*, which describes state policies and practices addressing current and future service system needs for serving adults with I/DD and aging caregivers.

James Meadours stated that in Texas, approximately 240,000 people are on the waiting list.

- Todd explained that the HCBS waiver program is a federal and state partnership, where CMS can work closely with states to listen to advocacy communities and understand their needs to build service systems; waiting lists can occur for basic service needs.

Liz Weintraub asked for clarification regarding the focus on children and young adults.

- Todd stated that HCBS services for people with I/DD are available across the lifespan.
- Jodie Sumeracki shared an [EPSDT guidance](#).

Jeanine LaFratta, Trial Attorney, HUD's Office of General Counsel, Office of Fair Housing, U.S. Department of Housing and Urban Development

Jeanine presented on behalf of the U.S. Department of Housing and Urban Development, OGC-Office of Fair Housing Office. Several civil rights compliance authorities include the Fair Housing Act, Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, Age Discrimination Act of 1975, Title II of the Americans with Disabilities Act, Architectural Barriers Act, Violence Against Women Act, HUD's Equal Access Rules, Section 109 of the Housing and Community Development Act of 1974, and Title IX of the Education Amendments Act of 1972.

Jeanine explained that Section 811 Mainstream Vouchers is administered by HUD's Office of Public and Indian Housing which includes special purpose vouchers for non-elderly persons with disabilities and enables individuals to secure housing in their communities. HUD encourages partnerships with various HHS agencies to help public housing agencies (PHAs) identify eligible persons and connect them with assistance. Since 2018, HUD awarded over \$500 million in funding to public housing agencies to support 50,000 new mainstream vouchers. PHAs awarded funding through competitive HUD Notice of Funding Opportunities (NOFOs) and they encourage preferences to assist people with disabilities transitioning out of institutional/other segregated settings, at serious risk of institutionalization, and with a current/at-risk/previous experiencing homelessness in permanent housing.

Following Jeanine's remarks, members asked questions or provided comments. James Meadours mentioned that HUD's process focuses on people with physical disabilities and less on people with intellectual disabilities. Hillary Dunn Stanisz asked if the mainstream vouching program provides the same process for people with intellectual disabilities.

- Jeanine stated that they are aware of this concern and are issuing guidance in compliance with Section 504 of the Rehabilitation Act. She explained that tenant-based vouchers include a range of I/DD qualifications under HUD's Section 811 program. Rather than general tenant-based, it is a special-purpose voucher for live-in aides to be addressed in reasonable accommodations.
- Max Lapertosa added the justice system view on the Fair Housing Act, stating that landlords must accommodate tenants with vouchers by accepting them.

Shawn Aleong shared that multimillion-dollar apartment complexes should set aside some units for people with I/DD.

- Jeanine explained that this has to do with various funding sources for housing developments. There are eligibility requirements that dictate occupants and set requirements. However, voucher programs can be tenant-based.

Shannon O'Neill, Education Program Specialist | Ashley Rizzo, Director, Training and Services Programs Division, Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education

Shannon and Ashley presented on *OSERS Inclusive Practices Initiatives*. OSERS' mission is to improve early childhood, education, and employment outcomes and raise expectations for all people with disabilities, their families, their communities, and the nation. Within OSERS, they explained the role of the Office of Special Education Programs (OSEP) and the Rehabilitative Services Administration (RSA). The mission of OSEP is to lead the nation's efforts to improve outcomes for children with disabilities, birth through 21, and their families, ensuring access to fair, equitable, and high-quality education services. Whereas RSA provides leadership and resources to assist state and other agencies in providing vocational rehabilitation and other services to individuals with disabilities. Some RSA grantee examples include 1) California Department of Rehabilitation's Pathways to Success Project funded by the Disability Innovation Fund; 2) preparation for STEM occupations through sector-specific specialist teams of rehabilitation counselors and business specialists leveraging artificial intelligence for customized support; and 3) focus on increasing opportunities for participants to prepare for, participate or advance in their identified careers utilizing career pathways strategies and services.

Liz Weintraub emphasized the importance of belonging. Teachers and the administration should be taught how to include people with disabilities.

- Shannon and Ashley agreed and explained that a culture of belonging should be instilled in schools by training educators. OSEP is funding training centers at the school and district levels.

ACL Community Living Initiatives

The RAISE Act - National Strategy to Support Family Caregivers

Greg Link, Director, Office of Supportive & Caregiver Services, Administration for Community Living (ACL)

Greg Link discussed the RAISE Act and its national strategy to support family caregivers, emphasizing the crucial role that these caregivers play in assisting individuals with disabilities across all age groups. Greg noted that the RAISE Act passed in 2018, was not an isolated effort but rather the culmination of years of legislative initiatives aimed at recognizing and supporting family caregivers. This historical context began with the establishment of the National Family Caregiver Support Program in 2000, which marked the federal government's acknowledgment of the importance of family caregiving.

One of the key components of the RAISE Act was the establishment of the Family Caregiving Advisory Council. This council comprises a diverse group of up to 15 non-federal members, including family caregivers and representatives from healthcare, human services, and local governments. In 2021, the council delivered an initial report to Congress, which laid the groundwork for the national strategy aimed at providing comprehensive support for family caregivers. Greg emphasized the importance of public engagement in developing the national strategy, noting that a request for information (RFI) received over 16,000 responses, 75% of which came from family caregivers themselves. This extensive feedback allowed for a deeper understanding of the challenges and needs faced by caregivers and informed the subsequent strategies developed by the council.

In 2022, the national strategy was delivered to Congress, outlining five key goals and nearly 350 specific actions committed by various federal agencies. Additionally, it provided a range of recommendations for states and communities to enhance support for family caregivers, thereby recognizing the complex and multifaceted nature of caregiving. Four core principles emerged from discussions within the advisory council: 1) centering the individual receiving support; 2) addressing the impacts of trauma; 3) promoting equity in support for underserved communities, and 4) tackling the direct care workforce shortage. These principles underscore the necessity of a holistic approach to caregiving, which recognizes the diverse experiences of family caregivers.

Greg characterized the strategy as a roadmap for change, emphasizing that it is not exhaustive or prescriptive but rather serves as a framework for various stakeholders to enhance their support for family caregivers. He concluded by noting that this is just the first edition of the strategy, with updates already in the works. Greg encouraged the PCPID members to leverage the resources provided in the strategy to further improve the support systems available for family caregivers.

Liz Weintraub inquired about solving the “sandwich generation” issue, which involves family caregivers who are responsible for both children (including those with disabilities) and aging relatives.

- Greg, in response, acknowledged that the Advisory Council is aware of this critical issue and shared there are plans to examine the issue more closely in future updates to the national strategy.

Liz also asked about the distinction between the terms “caregiver” and “support person.” She expressed a preference for the term “support person” and asked for clarification.

- Greg clarified that the RAISE Act focuses on unpaid family members and friends, hence the term “family caregiver.” However, it was noted that this relationship may be referred to by various terms, such as care partners or support persons, depending on the preferences of those involved. The distinction was made between unpaid family caregivers and paid direct support professionals, the latter of whom should receive appropriate training, benefits, and compensation for their work.

James Meadours raised a concern about people who lack family caregivers and rely heavily on the support system, which may not be sufficient as they age. He expressed concern about friends aging and potentially passing away, leaving people without assistance and the necessary skills or advocacy knowledge to navigate such challenges.

- Greg acknowledged the importance of this issue, particularly as both caregivers and care recipients’ age. He noted that the Advisory Council is already examining this topic and highlighted the critical need for self-advocacy training to empower both family caregivers and the individuals they support to effectively advocate for themselves and understand how to navigate their care needs.

Joe Macbeth, who serves as CEO of the National Alliance for Direct Support Professionals (NADSP), addressed concerns raised by family caregivers who are often scrutinized by authorities for not following care plans, leading to investigations and allegations of abuse or neglect. He noted the blurry lines between family caregiving and professional caregiving, questioning how to clarify and improve this situation.

- Greg acknowledged the frustrations family caregivers experience due to a shortage of paid professionals, particularly as services have shifted towards more person-centered and consumer-directed approaches. He agreed that the administrative requirements for family caregivers can be overwhelming and emphasized the need to reassess how these programs are managed. This includes ensuring that reporting, record-keeping, and training requirements are reasonable and feasible so that employing family members or friends as caregivers does not become a deterrent to providing support.

Health Equity and Safety

Health and Safety: Promising Practices from the Living Well Grants

Diana Caldwell, Vice President, The Lewin Group

Diana presented on *Health and Safety: Promising Practices from the Living Wells Grants*. There has been a significant shift to people with I/DD living in the community setting. Diana shared data on the benefits of living in the home and community-based settings, including that people with I/DD are more likely than their peers in institutional settings to make their own choices, have friends who are not paid staff and have paid jobs in the community. She noted, however, that according to the NCI-I/DD survey, more than one in five (21%) respondents to the survey reported feeling afraid in one or more locations. She also added that people with I/DD are more

likely than their peers without disabilities to experience abuse, neglect, or exploitation regardless of where they live.

Diana explained that AoD awarded eight five-year grants via two cohorts in 2017 and 2018 under the *Living Well Model Approaches for Enhancing the Quality, Effectiveness, and Monitoring of Home and Community-Based Services for Individuals with Development Disabilities* project. The purpose of the Living Well grants is to develop and test one or more model approaches to improve the quality of HCBS. The grant has two core components - Community Monitoring and Community Capacity Building. Diana concluded her presentation by highlighting the promising practices in the areas of systems change (in Idaho and Wisconsin), increasing awareness (in Alaska and Wisconsin), and self-advocate capacity building (in Idaho, Wisconsin, and Missouri).

James Meadours asked for clarification regarding safety in group homes.

- Diana explained that grantees are actively reviewing and highlighting issues related to this.

Tia Nelis stated that it would be helpful for self-advocates to be a part of “peer-to-peer” support.

- Liz Weintraub mentioned that in Maryland, self-advocates would directly speak with their peers for reassurance and a level of understanding.

Part III – The Future Road Ahead

Innovation – Advancements in Access to Technology Solutions

Jeanine Zlockie, Director of Technical Assistance & Special Projects, NASDDDS

Jeanine summarized the impact of COVID-19 on how technology is utilized. To help capture this in detail, Jeanine explained that NASDDD and Dr. Shea Tanis conducted a survey during the Fall of 2023. The survey research was titled Technology Solutions 2.0 Survey and 40 states participated. The three focus areas of the survey were the following: 1) funding for technology solutions; 2) operational specifications; and 3) benchmarking for system systems change. On funding for technology solutions, the research found that HCBS waivers remain the dominant funding vehicle and 93 percent of state developmental disability agencies listed the Medicaid HCBS 1915(c) as the primary authority used to purchase technologies. For the second area focused on operational specifications, the research found that 41 percent of the states used remote supports for supported living from 2019 to 2020. And, for the last area focused on benchmarking for systems change, Jeanine described the role of technology first states. Technology First can be best described as a framework for system systems change where technology is considered first in the discussion of support options available to individuals and families through person-directed approaches to improve quality of life.

Santa Perez asked for clarification regarding access to technology after graduating high school.

- Jeanine explained that if a person receives support through a waiver, they can receive technology support covered through waiver programs.

Jim Brett inquired about what states participate in technology-first waiver programs and activities.

- Jeanine confirmed that across the country, every state has various technology supports; they are adding remote services to waivers.

Shawn Aleong inquired if AI may have similar benefits for people with I/DD.

- Jeanine expressed that she hopes in the future, they can discuss how Artificial Intelligence (AI) would integrate into an HCBS architecture.

Emmanuel Jenkins inquired about incorporating technology into benefit packages. He also added the importance of encouraging providers to view technology as both a medical necessity and a broader support tool.

- Jeanine confirmed that states have full control over adding services to their waivers, which highlights the importance of advocating for technology.

Liz Weintraub asked if the employment-first initiative from approximately 20 years ago is similar to the Technology First initiative.

- Jeanine confirmed that there are parallels.

PCPID Members Reflect Key Leading Learning Moments from Two Day PCPID Meeting
PCPID Citizen Members / PCPID Ex-Officio Members

Paul Aronsohn emphasized the need for a stronger focus on important topics such as abuse and neglect moving forward since many colleagues shared their personal experiences.

Shawn Aleong mentioned the need to create a report that outlines the necessity for a specialized abuse unit within the Federal Bureau of Investigation (FBI) or Department of Justice to address neglect and abuse as well as reveal the challenges people with I/DD face.

Emmanuel Jenkins emphasized the necessity of establishing a unit within the justice system dedicated to addressing abuse and neglect, mental health, and various facets of abuse, including financial exploitation. In addition, supporting caregivers due to shortage is critical to prevent inadequate care.

Joe Macbeth discussed the urgent need to address human rights violations and the ongoing segregation, institutionalization, abuse, and exploitation of individuals with disabilities. The compelling and alarming data reveals that the workforce is often complicit in these abuses, which reveals the necessity to expose these underlying issues.

Jordyn Zimmerman expressed her appreciation of the discussions regarding abuse and neglect and emphasized the importance of focusing on individuals lacking access to effective communication tools, as this contributes to the risk of abuse.

Cathy Kanefsky mentioned that the current Direct Support Professional (DSP) system is currently a façade that contributes to the root causes of abuse and neglect.

Brent Leonhard agreed on the importance of focusing on abuse and neglect, and it would be beneficial to invite I/DD focus group members to share insights.

Hillary Dunn Stanisz shared the importance of including Augmentative and Alternative Communication (AAC) in these conversations since communication is a basic right. Solutions for the extensive waitlist and creating a report focused on abuse and neglect are also important discussions to consider.

Tia discussed the importance of focusing on sexuality training, as many individuals with disabilities are seeking this education. In addition, it is critical to design resources that ensure respectful inclusion of people with disabilities.

Santa Perez discussed the importance of educating individuals with disabilities to understand the changes their bodies will undergo as they age. From her personal experience, she noticed her body changed from her youth, and she was not informed about these changes.

Liz Weintraub highlighted three key takeaways focused on transportation, education, and employment.

Jim Brett emphasized the importance of considering individuals with diverse living experiences ranging from institutions, communities, and group homes, as well as their access to housing and waivers. Jim reflected that he had a brother with I/DD who did not have an advocate or voice. The PCPID meetings provide a poignant reminder of his brother's struggles and how valuable these committee discussions are to share experiences on issues that are critical. In order to maximize impact, Jim recommended that the report have a more narrow focus area, such as addressing the issue of abuse and neglect.

Lucy Meyer expressed her thanks for the opportunity to participate and hear from the committee. This strengthened her friendships as she is also a part of other disability organizations.

Kara Jones expressed the importance of assisting those who may not fully understand and reporting back to others.

Summary of Deliberations, Proceedings, and Next Steps

Jennifer Johnson, Acting Commissioner, Administration on Disabilities

Jim Brett, Chair

Jennifer Johnson shared sincere appreciation to the PCPID members for their hard work on the PCPID report and their engagement during the two-day meeting. She acknowledged how much content was covered and thanked the committee for their attention and commitment to each topic. Looking ahead, Jennifer indicated that the next steps would involve PCPID focusing on a topic for the next report. ACL will continue to coordinate and seek input from the PCPID members.

Jim Brett thanked everyone for taking the time during the two-day meeting. Jim thanked Robin Levine for her role as meeting facilitator. Jim thanked OIDD Director, David Jones for supporting the committee members to help finalize the 2024 PCPID report. Jim wished everyone safe travels home and adjourned the meeting.