



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

PCPID Meeting
September 26 - 27, 2024
Day One 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 Stanisz
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

Call to Order, Introduction of Meeting Facilitator
Jim Brett, PCPID Chair

Chairman Jim Brett called the PCPID meeting to order and welcome the committee members and the public. Jim introduced Robin Levine as the meeting facilitator. Robin followed Jim’s remarks to provide an overview of the administrative housekeeping items for the two-day meeting.

Remarks from Administration for Community Living
Alison Barkoff, Acting Administrator, Administration for Community Living

Alison Barkoff welcomed all members of the PCPID committee and public attendees. Alison noted that for the first time, the PCPID citizen members are a majority of people with intellectual and developmental (I/DD) – truly modeling the principle “nothing about us without us.” Alison emphasized the importance of home and community-based services (HCBS), and the need to strengthen the HCBS system, which is why the issuance of the PCPID report topic is timely and important.

Alison reminded the attendees that the President spoke about services and supports for disabled people in two State of the Union addresses, calling for significant investments in expanding HCBS to help people with disabilities live and fully participate in their communities. To help support the administration priorities, Alison highlighted steps the Department of Health and Human Services (HHS) took to strengthen HCBS. They include:

- The Medicaid Access Rule with its provisions, increases access to HCBS and strengthens the direct care workforce.
- The first update to Section 504 of the Rehabilitation Act in more than 40 years, including provisions related to the right to community living under Olmstead.
- Full implementation of the HCBS Settings Rule.

Alison also highlighted several innovative partnerships developed to jointly address issues. They include:

- Cross-agency efforts to implement the President's Care Executive Order and strategies to support the direct care workforce (DCW) through the ACL-funded DCW Strategies Center.
- Launching a partnership between HUD and HHS, called the Housing and Services Resource Center, to address the vexing issue of the lack of affordable, accessible housing and to coordinate the housing and services that make community living possible.
- Launching through the ACL-funded Link Center – a national resource helping expand services and support for people with I/DD who also have behavioral health needs – a 988 Policy Academy in partnership with SAMHSA.

Alison acknowledged that while we’ve seen progress over the past four years, many barriers that need to be addressed which include, long waitlists for Medicaid-funded HCBS, the shortage of professional staff in the direct care workforce, people authorized for services who still cannot get them, and discrimination and a lack of commitment to competitive integrated employment for people with disabilities.

Alison concluded her remarks by emphasizing that the PCPID committee acts as a change agent for people with disabilities. The PCPID report and its recommendations build on the progress already made and will help address the ongoing barriers faced by people with disabilities.

Remarks from The White House Domestic Policy Office
Rachel Patterson, Director of Disability Policy

Rachel Patterson opened her remarks by expressing her pride in the current administration for making the PCPID committee a majority of individuals with I/DD. She emphasized the importance of this achievement and how it aligns with the administration's commitment to disability rights. Rachel reflected on the significance of the first day of the PCPID meeting falling on the 51st anniversary of the Rehabilitation Act of 1973. She highlighted that President Biden co-sponsored the Act early in his career. Later, Section 504 — the nation's first disability civil rights law—was signed into law which marked a key victory in ensuring that recipients of federal funding could not discriminate against people with disabilities.

Rachel highlighted President Biden's ongoing efforts to prioritize home and community-based services as part of the nation's infrastructure through significant financial investments made to support these services. Rachel noted the Medicaid access rule, which now requires states to report whether people eligible for these services are receiving the support they need.

Rachel concluded her remarks by encouraging the committee to keep pushing forward, recognizing the critical role they play in advising the President. Rachel expressed gratitude for the recommendations made to date and emphasized that while progress has been made, there is still much work to be done to ensure full access to home and community-based services for people with disabilities.

James Meadours expressed concern about the extensive waiting list for HCBS in Texas.

- Rachel reaffirmed President Biden's efforts including the continued ask to Congress for more funding and incentives for states to address the problem. While the executive branch has done what it can, including having Medicaid work with states on access to services and maintaining eligibility, the solution ultimately requires action from Congress.

Sean Aleong questioned what policies are in place or being developed to prepare for future pandemics similar to COVID-19 that will prevent significant impacts on people with I/DD and especially people of color with I/DD.

- Rachel explained that President Biden initially created the Office of COVID-19 Response, which has now transitioned into the Office of Pandemic Preparedness and Response. This office is focused on preparing for future pandemics by improving public health monitoring, infrastructure, policies, and responses.
- Rachel noted that she works closely with this office to ensure that disability perspectives are included. She also highlighted their work on addressing long COVID through a dedicated office within the Department of Health and Human Services (HHS).

Remarks from PCPID Chair
Jim Brett, PCPID Chair

Jim Brett thanked Rachel Patterson and Alison Barkoff for their leadership during the pandemic and emphasized the progress made to support people with I/DD. Jim noted the significance of the PCPID proceedings in meeting for the first time in Washington, DC during this administration.

Jim outlined two key objectives for the meeting: 1) discussing the release of the 2024 PCPID report on HCBS and 2) preparing for the 2025 PCPID report by hearing about emerging issues facing people with I/DD. Jim emphasized the importance of public and federal partnerships in driving progress and announced that the meeting would feature discussions with various stakeholders, including academics and policy experts, to better understand the challenges facing individuals with I/DD.

On the release of the 2024 PCPID report, Jim acknowledged the commitment of committee members and workgroup chairs, detailing the collaborative efforts made since selecting the HCBS topic in 2022. Jim introduced Diana Caldwell to provide an overview of the 2024 PCPID report (Diana and her team supported the committee members with report writing).

PCPID 2024 Report to the President
Diana Caldwell, Vice President, The Lewin Group

Diana Caldwell provided an overview of the 2024 PCPID report. Diana outlined the structure of the report. Diana discussed the role of four workgroups that corresponded with chapters in the 2025 PCPID report. They are the following:

- *Direct support professionals (DSPs)*: Addressing the workforce shortage and advocating for professional career pathways, wage increases, and improved training standards.
- *Employment*: Encouraging competitive, integrated employment and supporting entrepreneurship among people with disabilities.
- *Community living*: Highlighting issues in housing, safety, technology, and transportation for individuals with I/DD.
- *Federal support programs*: Call for policy changes to improve SSI and Medicaid access, eliminate the "marriage penalty," and ensure the portability of HCBS benefits across states.

Members of the committee shared comments and questions:

- Tia Nelis emphasized the need for training people with disabilities on how to use technology since having access without knowledge is ineffective.
 - Diana confirmed the report references information on technology training for people with I/DD.
- Joe MacBeth provided general reflections on the report noting the topic addressed is very broad. He recommended the next report take a narrower focus. He reminded fellow Committee members that previous recommendations included in past reports have not been followed up on.

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

Shawn Aleong, Pennsylvania

- Shawn explained the importance of non-biased I/DD healthcare in public policies. People with I/DD reschedule their appointments since hospitals do not always have the appropriate equipment and sometimes discriminate against the person's disability, race, and/or sexuality. It is important to treat the person rather than the disability.

Paul Aronsohn, New Jersey

- Paul explained that during his time as a New Jersey ombudsman, many people came into his office to explain the systemic barriers they face, often resulting from the disconnect between policymakers and those who are directly impacted. Therefore, advocating for disability diversity in the workplace is important.

Paul Boskind, Texas

- Paul expressed the importance of involving people with I/DD. Since the system is broken, his vision of "disability pride" is declining.

Jim Brett, Massachusetts

- Jim worked as a state legislator to advocate for people with disabilities. In Massachusetts, the cost of living is not affordable; it may be beneficial to work with developers to build units set aside for people with I/DD to be a part of the community. Developers are receptive to the attractive tax incentive and can produce good intentions.

Kara Nicole Jones, Maryland

- Kara shared her experiences with traveling to an adaptive gym; she either travels via the paratransit or is driven by her mother. However, her mother cannot always provide constant care as she experiences her health concerns. Therefore, she needs assistance from provider agencies to provide short-term shifts (e.g., 2 – 4 hours) to support people with I/DD in participating in activities and integrating within the community.

Nicole Jorwic, Illinois

- Nicole emphasized the importance of community integration through the employment of people with I/DD in the workforce. A strong workforce will lead to progress and support people with I/DD to gain the independence they need.

Cathy Kanefsky, Delaware

- Cathy identified the lack of employment opportunities for the I/DD population and the DSP labor shortage. Cathy reflected on how transportation was a barrier for her son to get to his job and noted that it can't be a one-size-fits-all model as a solution within the disability community. Through research, they realized using Uber was the best solution for their son. Unfortunately, not everyone is aware of the different options available and we need to do a better job in communicating solutions for families. For the DSP

workforce, Cathy reflected that they are underappreciated and underpaid in our workforce.

Brent Leonhard, Washington

- Brent explained that tribal nations significantly lack resources for people with I/DD. Tribal nations should have access to the same services non-Tribal communities have.

Joe Macbeth, Vermont

- Joe stated that the HCBS infrastructure relies on the workforce which predominantly consists of women of color. Rather than continuing research, it is critical to enhance wages and career ladders.

Tia Nelis

- Tia stated that people with I/DD should not be limited to institutions and be a part of the community instead. Often, people with I/DD are institutionalized since these places are the only options.

Liz Weintraub

- Liz emphasized the importance of employment through her experience in the workforce. Since the cost of living is increasing, the minimum wage should be increased so that people with I/DD can have a real salary to afford the cost of living.

Santa Perez

- Santa stated that people with I/DD living in institutions often do not know how to advocate for themselves and say “no.” They should be provided opportunities to learn about available resources and how to advocate for their situations.

Summary of Public Comments Received

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

David Jones provided a summary of the eight public comments received in response to the August 23rd Federal Register notice. The comments highlighted various challenges faced by people with I/DD and their families ranging from education, housing, aging, and employment. Following the summary, a few members of the public who submitted comments had an opportunity to read their statements.

Statements from Members of the Public

Anne Marie Sack, a mother from Washington with a young child with DD, raised concerns about inequities in the education system. She advocated for all teachers to be trained in universal design for learning to ensure classrooms are truly inclusive. She also described her difficulties navigating the Developmental Disabilities Administration (DDA) system, noting that despite her daughter’s eligibility, accessing resources was nearly impossible due to bureaucratic red tape. Of the seven items her child was approved for, only one was successfully received. She also called for better support for parents as caregivers and emphasized the need for Washington's DDA to

pay parents for providing care, as many are unable to work because of their child's complex needs.

Elaine Wood from Colorado, who has over 38 years of experience in I/DD case management, stressed the need for a deeper understanding and application of person-centered thinking. She noted that while the term is often used, it is not implemented seriously in practice. Wood advocated for mandatory, consistent person-centered training at all levels of care, from direct support staff to leadership, to ensure services are meaningful and effective. She argued that without this understanding, services would continue to fall short in meeting the needs of those they are designed to support.

Katrina Hereford, now living in Tennessee, highlighted the gaps in transportation services for individuals with disabilities, particularly in rural areas. She noted that a lack of accessible transportation prevents individuals who want to work from doing so, especially in regions like the Southeast. Hereford called on the committee to consider promoting initiatives to improve ADA-accessible transportation options to enhance both employment opportunities and social inclusion for people with disabilities.

Jennifer Peterson from Massachusetts, with over 35 years of experience, emphasized the importance of training direct support staff and service providers on using assistive technologies. These technologies, such as remote patient monitoring devices and enabling tech, can significantly increase independence, self-reliance, and autonomy for people with disabilities. Peterson highlighted that while such technologies are becoming more available and affordable, many service providers lack the necessary training to help individuals fully integrate these tools into their lives. She advocated for better training and support in leveraging these technologies to improve the quality of care and services.

The committee members expressed appreciation for the thoughtful input to help guide their work and priorities in planning. Reflective comments from the members include:

- Cathy Kanefsky noted training was referenced, but it's important to also note who develops the training, who will conduct the training, who will pay for it, and how it will be marketed – this needs to be considered so the training is successful.
- James Meadours advocated the need for self-advocates to play a leading role in training direct support professionals, given that they are the ones receiving services. The speaker emphasized that self-advocates should be compensated for conducting such training, as they have valuable firsthand experience.
- Liz Weintraub agreed with James Meadours concerns reiterating "nothing about us without us." She also emphasized that people with disabilities, who are directly impacted by services, should lead the training of direct support professionals. However, they expressed concern that self-advocates are not always taken seriously, especially by those outside advocacy circles, due to a perceived lack of formal education.
- Tia Nelis shared that people with disabilities should be the ones conducting training on person-centered planning since they are the ones receiving the services. She is concerned that many professionals lack a true understanding of person-centered planning, despite claiming to implement it in their agencies. What professionals often think person-centered planning is and what it involves when done correctly are vastly different.

Professionals should receive training from those with firsthand experience, ensuring that person-centered planning is properly understood and applied.

- Shawn Aleong shared that it is important for the training to be in plain language so everyone can understand concepts and the context of the training.
- Kara Jones shared that it is important for whoever is being trained to listen to the individual with the disability, not their helper, parent, or anyone else.
- Joe Macbeth highlighted that direct support professionals often receive training primarily focused on regulatory requirements, such as first aid, CPR, crisis intervention, and fire safety. While these are essential, they are designed for worst-case scenarios and do not equip staff with the skills needed for everyday success in supporting people with disabilities. Joe highlighted crucial competencies, like building relationships, fostering inclusion, and helping individuals make informed decisions, are missing from the training. Although some receive person-centered planning training, they often lack the resources or staff to fully implement what they learn.
- Jordyn Zimmerman agreed with previous comments and emphasized that the development of training curricula must be led and supported by those most impacted by these systems. Without this necessary support, even if people with disabilities conduct the training, it won't have the desired effect.

Part II – The Current Intellectual Disability Landscape

Remarks from Administration on Disabilities

Jennifer Johnson, Acting Commissioner, Administration on Disabilities

Jennifer began by thanking all the committee members. Jennifer thanked the committee members for their efforts on the 2024 PCPID Report which identifies the issues and recommendations related to home and community-based services. Jennifer then proceeded to introduce a new PCPID member, Emmanuel Jenkins, founder of We Stand for Something. During this segment, Emmanuel Jenkins took the oath of office as a new member of PCPID.

Policy – Federal Regulatory Updates and Impact on I/DD Community from HHS

Section 1557 of the Affordable Care Act, Nondiscrimination in Health Programs and Activities

Dan Shieh, Associate Deputy Director, Policy Division Office for Civil Rights (OCR)

Dan explained that the Office for Civil Rights is a law enforcement agency that enforces the nation's civil rights and privacy laws in healthcare through policymaking, investigations, and rulemaking. Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act are two critical rules that protect the civil rights of people with disabilities in healthcare as well as human services.

Dan noted the four key points that go beyond the protections provided by the Section 1557 Rule: 1) health insurance reinstates the broad application to all health insurance; 2) language access requires coverage entities to ensure meaningful access to individuals with limited English proficiency; 3) sex discriminations restores the definition of what constitutes sex discrimination

(including sexual orientation and gender identity); and 4) emerging technologies prohibits covered entities from discrimination through the use of patient care automated health tools via AI. Under Section 1557, the definition of qualified interpreter is more robust than it is elsewhere, and it mirrors the definition of a qualified interpreter for an individual with limited English proficiency.

Section 504 of the Rehabilitation Act
Maggie Hart, Policy Advisor, Policy Division
Office for Civil Rights (OCR)

Maggie addressed the updates to Section 504 of the Rehabilitation Act; the new rule was published in May and went into effect in July. This only applies to recipients of federal funding from HHS, such as the initial receipts and their contractors. The rule clarifies and strengthens civil rights protections for people with disabilities.

The rule advances equitable health outcomes for people with disabilities by ensuring consistency with current law and addressing newer forms of disability-related discrimination. Maggie highlighted the different provisions in which the final rule makes changes: 1) Medical treatment – ensures medical treatment decisions are not based on biases or stereotypes about individuals with disabilities; 2) Value assessment methods – prohibits the discrimination use of value assessment methods and analytics; 3) Child welfare programs and activities – clarifies that the rule applies to child welfare programs and prohibits discrimination on the basis of disability in any federally funded child welfare program or activity; 4) web and mobile Accessibility – implements a standard to ensure non-discrimination in the use of technologies routinely used in health care setting; 4) Accessible medical equipment – Adopts the U.S. Access Board’s standards for accessible medical equipment; 5) Legislative Consistency – integrates new sections related to service animals and mobility devices; 6) Judicial Consistency – helps recipients better understand and comply with their obligations.

Maggie shared the [Section 508 Final Rule](#) and [Complaint Portal](#) links.

Ensuring Access to Medicaid Services Final Rule (Access Rule)
Jennifer Bowdoin, Director, Division of Community Transitions
Centers for Medicare & Medicaid Services (CMS)

Jennifer provided an overview of the *Ensuring Access to Medicaid Services Final Rule and the Managed Care Access, Finance, and Quality Rule* that were published in May 2024. The final rules establish national standards for access to care regardless of whether the care is provided through managed care plans or directly by states through fee-for-service. This update strengthens oversight of person-centered service planning in HCBS. Several key provisions impacting states are the following: 1) Require states to meet nationwide incident management system standards for monitoring HCBS programs; 2) Require states to establish a grievance system; 3) Require that states report on the percentage of payments for certain HCBS that is spent on compensation for direct care workers; 4) Require states to report on waiting lists in waiver programs and on service delivery timeliness for certain HCBS; 5) Require states to report

on a standardized set of HCBS quality measures and sets requirements for CMS to develop and update the measure set. These provisions will take effect between the years 2026 through 2030.

James Meadours expressed his concern about the housing waitlists in certain states, particularly Texas; these states should be challenged to offer more housing opportunities. For example, James, who will turn 58 this year, fears he may not receive housing services until he is 70.

- Jennifer suggested that those facing hardships due to the extensive waiting lists should express their concerns to advisory committees.

Adult Protective Services (APS)

Andrea Callow, Office for Policy Analysis and Development, Administration for Community Living (ACL)

Andrea shared that one in ten community-living older adults experience some form of abuse or neglect each year, and most abuse is not reported. APS programs across the country support older adults and adults with disabilities who experience, or who are at risk of maltreatment or self-neglect. APS programs investigate reports of maltreatment; conduct case planning, monitoring, and evaluation; and provide or connect people to a variety of medical, social service, economic, legal, housing, law enforcement, and other protective, emergency, or support services to help them recover. Historically, the rules and definitions for APS have varied from state to state. For example, Connecticut, Rhode Island, and Ohio currently only service older adults; however, they do not have a program for people with disabilities. Whereas Massachusetts, Louisiana, and Pennsylvania have separate programs for people with disabilities, states should have the flexibility to operate based on the understanding and scope of specific needs. On May 7, 2024, ACL released a final rule to establish the first federal regulations for adult protective services (APS) programs to provide more consistency in services across states. With the final rule, ACL aims to support the national network that delivers APS, with the ultimate goal of better meeting the needs of adults who experience or are at risk of maltreatment or self-neglect.

Following the presentation, PCPID members shared remarks. James Meadours stated that APS should be held accountable for their inactions, as they failed to adequately respond when some older adults were sexually assaulted. Shawn Aleong believes a specialized unit is needed to hold abusers accountable and properly handle these cases; reporting these cases to the police is not enough, as they tend to be mishandled. Liz Weintraub shared that she and other people with disabilities do not feel comfortable talking to an APS provider if something bad happens to them because of a lack of trust.

Data – Briefing on Emerging Issues

Sheryl Larson, Institute on Community Integration / Residential Information Systems Project / University of Minnesota

Sheryl presented on *The Intellectual and Developmental Disabilities Landscape: Residential Information Systems Project (RISP)*. This project addresses five key questions: 1) How many people have I/DD? 2) How many people with I/DD get paid support? 3) Where do people who

get support live? 4) How do the places people live in differ by age and by state? 5) How have the places people with I/DD live in changed?

Approximately 8.3 million people in the U.S. have I/DD with 6.1 million being children and 2.28 million being adults. Sheryl noted that 1.6 million people with I/DD are known to state I/DD agencies. Of that number, 11 percent are children and 44 percent are adults. Today, fewer than 16,000 people live in large state-run I/DD institutions. Sheryl also highlighted on a U.S. map the variation of access to services for adults with I/DD on caseload per 10,000 population.

Sheryl shared how the COVID-19 pandemic had an impact resulting in progress and continued challenges. For new progress, there was more technology introduced for remote support, expansion of integrated employment, and pay for families to provide care. However, the challenge deepened with the direct care workforce.

Sheryl shared three topic recommendations for PCPID to consider for its next report: 1) the direct support workforce crisis; 2) more research on how many people have I/DD; and 3) a focus on meeting the requirements of the 2014 HCBS rule.

Following the presentation, James Meadours, Emmanuel Jenkins, and Liz Weintraub asked for clarification on the development of intentional communities. Sheryl explained that the project examines waiver services in group settings. However, the current data is limited. The HCBS rule states that if funds are being allocated, then certain rights are instilled (e.g., access to food and visitors). In addition, the project separately collects data on state and non-state-operated institutions.

Jean Winsor, Institute for Community Inclusion / School for Global Inclusion and Social Development (SGISD) / UMass Boston

Jean presented on ThinkWork's *Advancing Employment and Opportunity for People with Intellectual and Developmental Disabilities*. Access to integrated employment relates to employment support, research and evaluation, systems change and policy, storytelling, and data and performance measures. The five key questions this project examines are: 1) How many people with I/DD are in competitive integrated jobs? 2) How do competitive integrated employment outcomes compare for people with and without disabilities? 3) How has participation in state I/DD agency employment and day services changed over time? 4) How does participation in integrated employment services differ by state? and 5) How many people with I/DD find jobs with help from state vocational rehabilitation agencies each year?

Jean shared the importance of having good data through the National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services, VR services and outcomes, National Core Indicators, American Community Survey, and Social Security Administration. The number of employment and day services reveals that more people are receiving services from their state to work in the community and enjoy recreation. Since employment relates to everything, the I/DD system needs to provide a clear focus on work and whole life supports, the belief that people can work, and support for people who want to work.

Jean described the higher-performing framework, which starts with leadership and values and then shifts into policy goals, financing, training and technical assistance, service innovations, and outcome data, which yields integrated jobs.

Tia Nelis asked for clarification regarding careers for people with disabilities.

- Jean explained that the project does not collect aggregate data on whether people access careers, but rather, individual stories.

James Meadours expressed his concern about people with I/DD applying for jobs online.

- Jean stated that there is still a lot of progress that needs to be made from a policy and case management level.

Emily Shea Tanis, State of the States in Intellectual and Developmental Disabilities / Kansas University Center on Developmental Disabilities

Shea presented on the *State of the States in Intellectual and Developmental Disabilities*, which collects and analyzes data on money, people, I/DD services, and support from state and national sources to understand advocacy, policy, programs, accountability, and systems change. The five key questions the project aims to understand are 1) How much money do states spend on people with I/DD? 2) What technology support do people with I/DD get? 3) How has spending changed over time? 4) How much do states pay for different kinds of services? and 5) How does spending differ across states?

Shea explained that public I/DD spending in the U.S. continued to increase from 1977 to 2021. And she emphasized that data accessibility ensures data empowerment. Shea shared four recommendations for PCPID to consider for its next report: 1) the creation of data infrastructures inclusively designed with people with I/DD; 2) consistency of terminology for programs and services across states and the nation; 3) evolving and accessible data literacy training; and 4) policies to protect and enhance data agency.

Following the presentation, Brent Leonhard inquired if the data included people from tribal nations. In response, Jean confirmed that the data collection includes tribal nations.

ACL Community Living Initiatives

The Link Center

Mary Sowers, Executive Director, National Association of State Directors of Developmental Disabilities (NASDDDS)

Mary introduced the purpose and structure of the Link Center, a Project of National Significance funded by the Administration for Community Living. The Link Center is designed to improve mental health services for individuals with I/DD, brain injuries, and other cognitive disabilities. Mary explained that the Link Center addresses the significant lack of access to mental health services for individuals with disabilities, which leads to trauma and negative outcomes. The current service systems in states are siloed, which hinders the delivery of person-centered support. Mary discussed the ambitious goals of the Link Center, which aims to drive system

changes at both the federal and state levels to ensure individuals with disabilities can access mental health services.

Mary stressed the importance of providing tools and training for clinical providers and direct support professionals to help them better serve people with disabilities who may also have mental health concerns. Mary emphasized that there have been longstanding barriers preventing people with disabilities from accessing these services, and the Link Center is committed to overcoming these challenges.

One of the key features of the Link Center is its steering committee, composed of 14 individuals with lived experience, representing diverse backgrounds and types of disabilities. Mary highlighted that the committee drives the priorities of the Link Center, ensuring that their work is truly reflective of the needs of those they aim to serve. The diversity within the steering committee, including those from different cultural, linguistic, and geographic backgrounds, ensures that a wide range of perspectives is considered in their efforts.

Mary also mentioned the role of shared learning groups, which are designed to provide critical information on mental health to various audiences, such as individuals with lived experience, families, direct support professionals, and clinical professionals. These learning groups allow the Link Center to address gaps in resources and provide tailored information based on the needs of each audience. The ultimate goal is to equip everyone with the right tools to support individuals with disabilities.

Finally, Mary discussed the Link Center's collaboration with federal agencies, including efforts to make mental health crisis services like the 988 Lifeline inclusive of individuals with disabilities. She acknowledges that more work is needed to ensure that mental health systems are universally designed to meet the needs of people with disabilities. Mary concluded by emphasizing the importance of breaking down outdated biases and policies that prevent people with I/DD from receiving proper mental health care.

James Meadours added that he likes the 988 system but believes there is a need for training and informing families, helpers, and people with I/DD about the services available with the 988 system.

- Mary agreed that there is work to do to ensure people with disabilities use the 988 system and get the right support.

Liz Weintraub mentioned mental health and mental health issues are just as important to discuss as physical health issues.

- Mary agreed, mentioning there is a lot of work to be done in recognizing mental wellness and recognizing how friendships and connections can help enhance an individual's well-being.

Tia Nelis pointed out that when people with disabilities have a bad day, it is often labeled as "having a behavior," unlike others who are simply seen as having a rough day. This unfair perception can lead to them being penalized.

Shawn Aleong added that people with disabilities who face problems are often demonized. He emphasized the need to change this perception.

Adjournment of Day 1
Jim Brett, PCPID Chair

Jim Brett thanked Robin Levine, Jennifer Johnson, and David Jones for their role in developing the meeting agenda and facilitating the meeting. Jim acknowledged that the agenda was packed in order to give members a wide range of information under a limited time. Jim requested members have more time for Q&A during Day 2 proceedings. Jim adjourned the meeting.