



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

Zoom Platform Meeting

March 21, 2024

Minutes

***Citizen Members (Present)***

Jim Brett, Chair

Brent Leonhard

Cathy Kanefsky

Gabriel Martinez

Hillary Dunn Stanisz

James Meadours

James Trout

Joe Macbeth

Jordyn Zimmerman

Kara Jones

Liz Weintraub

Lucy Meyer

Nick Perry

Nicole Jorwic

Paul Aronsohn

Paul Boskind

Santa Perez

Shawn Aleong

Tia Nelis

Wendy Strauss

***Ex Officio Members and Representatives (Present)***

Alyse Bass

Representing the Honorable Merrick Garland,  
Secretary, U.S. Department of Justice

Joan Durocher

Representing Claudia Gordon, Acting Chair,  
National Council on Disability

Larry Beat

Representing the Honorable Gina Raimondo,  
Secretary of the US Department of Commerce

Kelly Buckland

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

Adam Fishbein

Representing the Honorable Julie A. Su,  
Acting Secretary of the US Department of  
Labor

Tiina Urv

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

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

Jennifer Ackerman  
Representing the Honorable Deb Haaland,  
Secretary, U.S. Department of the Interior

Heather Nodler  
Representing the Honorable Charlotte A.  
Burrows, Chair of the Equal Employment  
Opportunity Commission

Glenna Wright Gallo  
Representing the Honorable Miguel Cardona,  
Secretary of the U.S. Department of  
Education

Jeanine Worden  
Representing the Honorable Marcia Fudge,  
Secretary, U.S. Department of Housing and  
Urban Development

Veta Hurst  
Representing the Honorable Michael Smith,  
CEO, Corporation for National and  
Community Service / AmeriCorps

***Administration for Community Living and Administration on Disabilities (Present)***

Alison Barkoff  
Acting Administrator Administration for  
Community Living

Jill Jacobs  
Commissioner, Administration on Disabilities

Jennifer Johnson  
Deputy Commissioner, Administration on  
Disabilities

Serena Lowe  
PCPID Report Writer

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

Sheila Whittaker  
Program Assistant, Administration on  
Disabilities

## ***Call to Order, Welcoming Remarks and Meeting Overview***

James Brett, PCPID Chair

Chairman Jim Brett called the PCPID meeting to order and welcomed the committee members and the public for joining the virtual meeting. Jim provided an overview of the committee's work to date. Jim reiterated that each of the four workgroups were charged with helping answer the following questions:

- Direct Support Professionals – How can we address the Direct Support Professional Labor shortage crisis?
- Employment – How can we further advance competitive integrated employment for people with intellectual disabilities?
- Community Living – How can we ensure the right critical support tools are in place to promote independence and community inclusion?
- Federal Support Programs – How can we ensure Federal support programs are fair and equitable in their service delivery?

Jim reiterated that during the May 2023 PCPID meeting, members of the public and scholars helped guide the committee's understanding through their testimony against each of the four focus areas. And, during the second half of last year, each of the four workgroups then carefully sifted through these issues in collaboration with PCPID Report Writer Serena Lowe. Jim explained that the objective of today's meeting is for each of the four workgroups to bring forward the issues and proposed recommendations for further reflection and discussion by the full committee.

Jim introduced Alixe Bonardi, the facilitator for the PCPID meeting. Alixe is currently vice president at HSRI and directs the organization's intellectual and developmental teams. Alixe is also a clinical assistant professor at the University of Massachusetts Chan Medical School and teaches in the Shriver Center's LEND Program to help train the medical community.

### ***Welcome Remarks from Administration for Community Living***

Allison Barkoff, Acting Administrator, Administration for Community Living

Allison Barkoff thanked the committee for their hard work in developing the PCPID report. Allison shared that ACL views community living at a crossroads and noted that the President called for significant investments in expanding HCBS to help people with disabilities live and fully participate in their communities.

Allison reported that Federal agencies have made it a priority to strengthen and expand HCBS. Allison highlighted several examples of progress made including the \$37 billion investment through the American Rescue Plan, the Medicaid Access Rule to increase and strengthen the direct care workforce, updating Section 504 of the Rehabilitation Act, and implementation of the HCBS Settings Rule.

Allison acknowledged that challenges continue to exist for people accessing HCBS. Barriers mentioned include the long state waitlists for Medicaid-funded HCBS and the direct care workforce being unable to hire and retain staff. To help resolve this, Allison emphasized the

importance of continued collaboration and advocacy to address community living as a possibility for people with disabilities.

Jill Jacobs, Commissioner, Administration on Disabilities

Jill Jacobs also thanked the committee members for the development of the PCPID report. Jill noted that the PCPID was created initially as a blue-ribbon committee under President Kennedy in 1961 and then became a more formal committee under President Johnson. Jill noted that this is the first time that the majority of the committee's citizen members have been people with intellectual and/or developmental disabilities and commended the value that those individuals bring to the committee. Jill acknowledged that the committee's decision to focus on HCBS was timely and relevant since the President recently mentioned Home and Community Based Services in a recent State of the Union address. Jill shared she was looking forward to hearing the committee's discussion of the various report sections that will eventually lead to the publication of the report later this year.

### ***Summary of Public Comments Received***

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

David Jones provided feedback to the committee members on the public comments received. A Federal Register Notice was posted on February 21<sup>st</sup> about the March 21<sup>st</sup> public meeting. In that notice, the public was invited to share comments with the committee about HCBS. There were 11 comments received. David summarized the 11 comments that addressed issues related to employment, caregiving, transportation, housing, and medical training.

### ***Summary of Report Development Activities***

Serena Lowe, ACL Contractor, PCPID Report Writer

Serena Lowe described the committee's work in developing the report. Each of the four workgroups identified policy barriers and proposed recommendations. Serena also shared the current structure of the draft PCPID report that introduces the area of focus, policy challenges/barriers, policy recommendations, and recent Federal investments. The report will also incorporate promising practices and narrative stories to show impact.

### ***HCBS / Direct Support Professionals (DSP)***

---

Workgroup Co-Chairs – Nicole Jorwic, Joe Macbeth, and Tia Nelis

Tia Nelis opened the session and recognized the workgroup co-chairs and members of the DSP workgroup.

Joe Macbeth highlighted several leading challenges to building a competent, capable DSP workforce. They include:

- The shrinking DSP workforce pipeline continues amid growing demand for HCBS.
  - Low wages disproportionately affect the DSP workforce especially, women and people of color, though national wages increased.

- DSP workforce has a high turnover rate.
- Recruitment and marketing strategies are not sophisticated enough.
- The lack of professionalization or career pathways for the DSP workforce discourages workers from remaining in the field.
  - A unique labor category is needed to differentiate the profession in the labor market.
  - Lack of professional standards and training is fragmenting the service.
  - Lack of career ladders is limiting further pathways to advancing in this work.
  - Insufficient training and preparation to support the workforce.
- Significant disparities with supply shortages versus constant growing demand require other solutions to address gaps in the HCBS provision.
  - Investment in HCBS technological solutions remains limited.
  - Over-reliance on traditional provider models due to complications and lack of investment in self-direction models.
  - Over-reliance on family caregivers results in socioeconomic implications and health consequences.

To help address these challenges, Nicole Jorwic shared Federal policy recommendations proposed by the workgroup. They are the following:

- Develop a professional career pathway by creating a unique professional identity, establishing national professional standards, developing national career ladders, and credentialing opportunities.
- Build a robust pipeline for the future by advancing wage parity, engaging Federal and state-level workforce and economic development initiatives, and recruitment efforts to expand the pool of workers.
- Diversify workforce solutions to meet the growing demand for HCBS by leveraging technological solutions and expanding self-direction models.

Nicole also shared state policy recommendations proposed by the workgroup. They are the following:

- Implement new approaches to incentivizing the hiring and training process.
- Invest in the workforce's professionalization and career advancement.
- Invest in models that empower experienced DSPs to lead the development of new models of the HCBS provision.

Tia Nelis shared remarks and emphasized the importance of including people with I/DD within the conversations and HCBS work of DSPs.

Following the presentation, the floor was open for committee discussion:

- Liz Weintraub asked if legislation exists to help address the issues and recommendations identified by the workgroup. In response, Nicole Jorwic noted there are three existing bills in Congress: 1) the Standard Occupational Code Bill, 2) the HCBS Relief Act, and 3) the HCBS Access Act.
- Cathy Kanefsky emphasized the importance of understanding DSP management.
- James Meadours mentioned that certain politicians may not support this legislation. There is a state-level variation in wages, in which for certain states, DSPs are paid \$9 and in

others, \$20. In response, Nicole Jorwic agreed and shared that state-level variation is the fundamental issue leading to this disparity. The HCBS Access Act can address wage and service gaps.

- Kara Jones highlighted the importance of training DSP substitutes to understand their role and responsibilities.
- Shawn Aleong stated that many DSPs are African American and come from a low-income background. In response, Joe Macbeth explained that this is directly related to the issue of financial resources. This can be addressed by confronting wages.
- Shawn Aleong added that it is critical to have trained DSPs in case of an emergency as we recently experienced with COVID-19.
- Liz Weintraub emphasized that people with I/DD need community support in order to remain living in the community.

### ***HCBS / Employment***

---

Workgroup Co-Chairs – Eva Bunnell and Gabriel Martinez

Gabriel Martinez and Cathy Kanefsky gave opening remarks. Cathy, a workgroup member, stepped in on behalf of Eva Bunnell who was unable to present during the Full Committee Meeting. Cathy recognized the members of the Employment workgroup.

Cathy provided an overview of the key policy challenges to promote competitive, integrated employment for individuals with I/DD. The barriers identified were the following:

- 1) Lack of Private Sector Employment Opportunities for Individuals with I/DD in the Nation's Economic Mainstream.
- 2) State and Federal Agencies have not Consistently Prioritized Employment in Funding or Practice.
- 3) Lack of Emphasis on Promoting Entrepreneurship and Small Business Development among Individuals with I/DD.

For the first policy barrier identified regarding the *lack of private sector employment opportunities for individuals with I/DD in the nation's economic mainstream*, Cathy noted that surveys have shown that people with I/DD would like to work more than they are currently employed. However, they face challenges since there is a lack of private-sector employment opportunities. Employers need support with funding unique supports that workers with I/DD need in order to be successful in their employment. This includes job accommodations, customized employment practices, and strategies. Cathy noted that state policy and investments have a big effect on how many people are working in integrated settings. Additionally, there's a lack of funding to increase access to inclusive apprenticeships or other training opportunities for individuals with I/DD. And, there is a lack of available support to help workers stay successful in their job.

To help address these barriers, Gabriel shared Federal policy recommendations proposed by the workgroup. They were the following:

- Establish a national clearinghouse of resources so that employers can more easily access information via a coherent and cohesive platform about strategies, available supports, and promising practices for successfully employing people with disabilities.
- Provide Federal funding to offset costs absorbed by private employers to hire internal job coaches and other costs associated with time other employees spend to provide ongoing on-the-job support to onboard and retain employees with I/DD.
- Promote/Fund Inclusive Apprenticeships/Internship/Work-based Learning Opportunities.
- Offer Tax Incentives to incentivize Employers to employ people with I/DD through unique recruitment/hiring practices, supported employment strategies, hiring of internal staff to support employees with I/DD, and job accommodations.
- Strengthen existing efforts to prevent & eliminate workplace discrimination against individuals with I/DD.
- Engage employers about the business benefits of hiring workers with disabilities.

For the second policy barrier identified that *state and Federal agencies have not consistently prioritized employment funding or practice*, Cathy noted that a key challenge is ensuring workers with I/DD get more guidance learning about various rules around earning and saving money so that they don't jeopardize their health care or their important benefits. Employers and vocational rehab coaches and workforce development specialists also need to have knowledge about benefits pay so they can help support their workers with I/DD. Despite 20 years of documented evidence based on customized employment, many state waiver programs still do not provide customized employment services. As a result, many providers have not invested in staff training to adopt customized employment or other best practices. Many families of individuals with I/DD have reservations about employment because they fear their loved ones with I/DD will be harmed in the workplace or will lose important benefits.

To address these barriers, Cathy then shared Federal policy recommendations proposed by the workgroup. They were the following:

- For Employment First, issue an executive order within 100 days of publication of the PCPID Final Report.
- Prioritize CIE outcomes through formula grants/funding to State HCBS Waiver Programs, State Vocational Rehabilitation (VR), Department of Education IDEA Part B Funding, and State Workforce Employment & Training funds.
- Build the capacity of employment agencies and HCBS/VR providers to expand the availability of evidence-based practices that lead to CIE for workers with I/DD.
- Build the capacity of the Federal government as a model employer of workers with I/DD.
- Issue additional guidance on how to best support individuals with I/DD who have high acuity and intense support needs in solidifying CIE opportunities.
- Additional investments to elevate focus on CIE outcomes for Native Americans with I/DD living in sovereign tribal communities.

For the third policy barrier challenge identified surrounding the *lack of emphasis on promoting entrepreneurship and small business development among individuals with I/DD*, Cathy noted that entrepreneurship offers an alternative path to traditional employment for individuals with disabilities. Over twice as many Americans living with a disability turn to those small business opportunities than people without disabilities. The Federal government does not provide many

resources or training to support people with intellectual disabilities who wish to start their own businesses.

To help address these barriers, Gabriel shared Federal policy recommendations proposed by the workgroup. They were the following:

- Promote SBA Loans and Innovation Labs that are Focused on I/DD-specific Entrepreneurship.
- Increase Disability Funds-Financial Assistance (DF-FA) awards via the Community Development Investment Funds.
- Provide Federal funding to support training, technical assistance, and resources to specifically aid small business owners and entrepreneurs with I/DD.
- Support bipartisan legislation introduced in late 2023 (the Supporting Disabled Entrepreneurs Act) and/or similar administrative actions via SBA to:
  - Establish a Coordinator for Disabled Small Business Concerns at the agency;
  - Collect voluntary demographic data from program applicants on disability status; and
  - Publish data on the participation of disabled entrepreneurs in SBA programs.

Cathy also provided an overview of state policy recommendations proposed by the workgroup to address all three key challenges identified previously. They were the following:

- Employment First states should –
  - Adopt and implement policies to promote Employment as the preferred outcome of day HCBS funding.
  - Prepare and incentivize HCBS providers to expand their focus on evidence-based employment services for individuals with I/DD.
  - Invest in becoming a Model Employer of People with I/DD.
- Support Employers of Individuals with I/DD: States should consider the following strategies –
  - Establish local and State tax incentives to cover additional costs of training and supporting workers with I/DD to successfully engage in competitive, integrated employment.
  - State Employer Promotion Campaigns.
  - Flexible Funding Partnerships between Employers and VR/Medicaid/Workforce to Offset Costs of Hiring Internal Staff to Support Workers with I/DD.
- Promote Small Business/Entrepreneurs with ID: States could take the following steps to promote individuals with ID who wish to start a small business or become an entrepreneur –
  - Offer microenterprise grants or long-term loans with favorable terms to individuals with I/DD.
  - Offer specialized training and technical assistance to support potential entrepreneurs with I/DD.

Following the presentation, the floor was open for committee discussion:

- Shawn Aleong shared that from his own personal experience when signing up for a job, he receives a letter stating he might lose his benefits because he has attained a job. Shawn also highlighted the importance of having people with disabilities in HR.



- Adam Fishbein suggested reviewing resources from the LEAD Center and the Department of Labor’s Secure Your Financial Future Toolkit.
- Cathy Kanefsky shared that organizations need to commit to hiring people with I/DD for full-time and part-time positions and they need to build internal infrastructures with job coaches and specialized training program leads rather than relying on external sources/organizations that often have high turnover.
- James Meadours shared his concerns regarding employment and the use of technology. For people with I/DD who want to apply for a job, they often have to use various technology platforms and tools.
- Jordyn Zimmerman added it’s important to discuss the need for careers and not just jobs.
- Heather Nodler reminded the workgroup that the EEOC focuses on alleviating barriers to employment through reasonable accommodation. Under the ADA, employers have a duty to provide effective accommodations to ensure employees and applicants have equal employment opportunities. That includes providing access to the job application process through accommodations - job coaches are one example.
- Santa Perez noted that one problem is that the job developers are not trained in certain areas.
- Jim Brett added that a successful job coach is invaluable when it comes to getting people with I/DD into the workforce. He’s not sure how effective the tax incentives are at hiring people with disabilities. Legislators have been including a requirement that 1-2 percent of the funds for public projects should be reserved for hiring people with disabilities. Setting aside a percentage of public funds that should be considered for people with I/DD. Cathy Kanefsky agreed with Jim, but would also advocate for funding to offset the cost associated with hiring the appropriate support staff needed.
- Liz Weintraub shared that people with I/DD need jobs that pay a livable wage.
- Tia Nelis added that careers are important to people with I/DD.
- Paul Aronsohn commented that the term ‘rehabilitation’ has outlived its usefulness – it suggests that people with disabilities are broken and need to be fixed. The use of this word needs to be revisited.

## *HCBS / Community Living*

---

Workgroup Co-Chairs – Santa Perez and James Trout

Joining James Trout in delivering presentation remarks for the Community Living section were James Meadours, Jordyn Zimmerman, and Kelly Buckland. James Trout recognized all the workgroup members of the Community Living workgroup.

James Trout provided an overview of how the Community Living section of the report is structured. This section will address the following issue areas:

- 1) Housing
- 2) Safety
- 3) Technology Supports
- 4) Transportation

On the first area focused on *housing*, James Trout highlighted the following policy challenges identified by the workgroup. They include:

- Lack of cohesion and coordination persists among Medicaid HCBS and housing assistance.
- Settings created exclusively for people with I/DD or disabilities do not promote true community inclusion or independence in the larger setting of the US.
- Specific voucher programs support people with I/DD to have access to housing, but there are still systemic barriers surrounding (a) discrimination against people with I/DD due to their income source and (b) utilization of assets/trust funds/savings.
- There is an insufficient supply of publicly funded affordable housing in desired areas to promote truly inclusive communities.
- Lack of awareness and planning around housing opportunities for adolescents with disabilities transitioning to adulthood may limit their vision of independent living options.
- Zoning restrictions limit the availability of housing options that could provide additional types of community living, such as accessory dwelling units, group homes, and accessible multifamily construction.
- Individuals with disabilities face discrimination from landlords in violation of civil rights laws.

To help address these barriers, James Trout shared the following Federal policy recommendations proposed by the workgroup:

- Fund HUD/HHS campaign to stakeholders about how rent increases negatively impact people with I/DD in relation to the Federal subsidies they receive from housing vouchers and Medicaid HCBS.
- HUD/HHS should issue a joint funding announcement for Fair Housing authorities to collaborate/partner with the DD and CIL networks to help people with I/DD & disabilities find roommates, affordable and accessible places to live, and well-trained direct care staff in their local communities.
- Congress should appropriate funding to be co-managed by HUD and HHS/ACL to launch a joint grant program that incentivizes land use and zoning reforms to facilitate the siting and development of accessible, affordable housing, increased density, and near transit hubs.
- The U.S. Department of Education's Office of Special Education and Rehabilitation Services (OSERS) should issue guidance on incorporating information on housing, financial/benefits planning, and HCBS into the transition planning and IEP processes, to increase youth and family awareness of different housing and HCBS options available to individuals with I/DD.
- Congress should increase funding for HUD to create targeted fair housing testing programs aimed at identifying patterns of discrimination against individuals with disabilities and increasing enforcement.

James Trout also shared the following state policy recommendations proposed by the workgroup:

- Participate in the Mainstream Voucher Program and ensure Fair Housing Authority is collaborating with the DD network and State Medicaid Agency/DD Agency to advertise available slots.

- Require a higher percentage of new apartments to be developed as fully accessible and offer tax incentives/penalties to incentivize builders to expand accessible housing development beyond the minimal Federal/State requirements.
- Define durable accommodations and educate and incentivize agencies to support persons with disabilities and their families in solidifying housing that includes durable accommodations.
- Pursue and encourage inclusionary zoning processes that increase the availability of community living units such as accessory dwelling units, group homes, and accessible multifamily construction.

For the second area focused on *safety*, James Meadours highlighted the following key policy challenges identified by the workgroup. The following issues were identified:

- *Welfare*: Inconsistent and fragmented efforts to protect individuals with I/DD from harm, physical and emotional abuse, or exploitation in their homes and in the community.
- *Health*: Adults with I/DD are at high risk of getting sick when they are required to attend congregate day settings.
- *Personal Safety*: People need more knowledge regarding their own bodies (what is appropriate) and how to advocate for themselves when they feel unsafe or like their voices are not being valued/heard.
- *Environmental Safety*: People need more knowledge about safety protocols in their homes and natural surroundings and how to take care of themselves.
- *Emergency Planning/Crisis Response*: Lack of understanding, knowledge, coordination, and commitment around durable accommodations. Also lack of accessible shelters/temporary housing, and impact on disability benefits when transferred across State lines due to an emergency.

James Meadours then shared Federal policy recommendations proposed by the workgroup. They were the following:

- *Welfare*: Strengthen Federal regulations and investments in the national Adult Protective Services (APS) structure to improve expediency and success of complaint, investigation, and oversight processes. ACL should conduct a study analyzing trends and differences in State APS infrastructure, highlighting promising practices, systemic areas of concern, and systemic-level remedies.
- *Health*: The U.S. Department of Health and Human Services should conduct a study in collaboration with Federally-funded disability entities (DD Councils, UCEDDs, P&As, and CILs) of lessons learned from the COVID-19 pandemic as it relates to the provision of HCBS specific to individuals with I/DD. This includes describing what worked well, barriers that were difficult to overcome, and steps that can be proactively taken by communities and States to protect individuals with I/DD in the event of another public health emergency.
- *Personal Safety*: Both in school and via Medicaid HCBS programming, require access to health education tailored for individuals with I/DD and incorporate such education/training into annual individualized education plans and annual HCBS person-centered service plans base.

- *Environmental Safety/Emergency Prep*: Amend the Public Readiness and Emergency Response Act (PREP Act) or subsequent regulations issued by the U.S. Department of Health and Human Services to ensure that home and community-based providers and Federally-funded consumer-led organizations (e.g. DD Councils and CILs) are required partners in State and local emergency planning processes. Also, require that all disaster preparedness education materials are written in plain language.

James Meadours also shared state policy recommendations proposed by the workgroup. They were the following:

- Include HCBS provider/State program representation on State and Local emergency planning advisory committees.
- Offer services within HCBS waiver programs so there are long-term reimbursable pathways for accessing advocacy training in personal safety and self-determination and then strategically partner with consumer-led organizations like self-advocacy groups and CILs to provide such services.
- Encourage stronger state-level investments in adult protective services. Hire more staff and offer more training in abuse and assault areas. Train staff to notice when behaviors are different than the usual everyday behaviors, as this often shows something unusual is happening.

For the third area focused on *technology support*, Jordyn Zimmerman highlighted the following key challenges identified by the workgroup:

- Access to remote/virtual supports, assistive technology, and other enabling technologies is fragmented.
- People with I/DD need to learn how to use AT as early as possible. However, many early childhood programs and schools do not proactively educate families and provide options for AT during individualized educational planning.
- Federal and State funding is needed throughout the lifespan for upgrades and newer devices. However, there are only a few Durable Medical Equipment (DME) /Assistive Technology (AT) refurbishment/replacement programs tied to Medicaid HCBS at the State level.
- Most public materials are not made available in plain language.
- Broadband access is still inconsistent in rural and other geographic areas.

To address these barriers, Jordyn shared Federal policy recommendations proposed by the workgroup. The recommendations were the following:

- The U.S. Department of Education should update guidance to urge local education authorities to include AT needed for students with I/DD and the importance of collaborating/ partnering with State AT grantees.
- CMS should provide guidance on the importance of establishing DME/AT replacement, recycling, and refurbishment programs to ensure opportunities for appropriate upgrades and newer devices across the lifespan for individuals with disabilities, including people with I/DD.
- Increase the U.S. Department of Health and Human Services (OCR) and the U.S. Department of Justice's enforcement resources, staff, and activities to ensure accessibility gaps are addressed to promote inclusive community living options for people with I/DD.

- The U.S. Department of Health and Human Services should issue additional sub-regulatory guidance surrounding the 1557 and 504 Rehab Acts regarding the need to ensure all communications are made available in plain language.
- Intermediate and long-term recommendations for assuring the fair and equitable financing of AAC methods, tools, and supports:
  - The U.S. Department of Education and U.S. Department of Health and Human Services should bar recipients of Federal funding from administering or using the results of standardized IQ assessments or similar tests concerning persons who need AAC.
  - CMS should issue clear guidance on the mandatory EPSDT and DME requirements as well as the State option and HCBS and other waiver provisions of the Medicaid statute should be administered in a manner that assures fair and equitable effective access to AAC.
  - The U.S. Department of Education should ensure that the new \$50 million grant program to enhance critical school-based mental health services includes increased access to AAC and demonstratively addresses the lifelong mental health needs of young people who need it.
  - The Federal Communications Commission should explore current as well as future ways that it could help subsidize the purchase of augmentative devices to access the Internet, video conferencing platforms, and other expressive purposes.

Jordyn also provided state policy recommendations proposed by the workgroup. They were the following:

- Require local education authorities to include assistive technology in individualized education plans.
- Initiate Gubernatorial “Technology First” Initiative to promote cross-systems prioritization of public resources to support technologies that assist, enable, and support people with I/DD to thrive optimally in education, employment, housing, and community living.
- Launch State partnership between State Medicaid agency and sub-operational entities and State AT coalition/grantee to support replacement, recycling, and refurbishment of DME and assistive technology for individuals with disabilities.
- Require all entities/recipients of Federal funding to afford AAC as an auxiliary aid or service if doing so does not result in a fundamental alteration or undue financial and administrative burden.

In addressing the fourth area focused on *transportation*, Kelly Buckland highlighted key challenges and barriers identified by the workgroup. The following issues were identified:

- All transits must be accessible, especially in rural communities where there is less transit available. Today, there are still major gaps in available accessible transportation options for people with disabilities.
- There are also very few supports to teach people with I/DD how to successfully navigate publicly available transit options.
- Medicaid HCBS rates for non-emergency medical transportation (NEMT) are often very limiting in terms of market value and restrictive in terms of use.

Kelly then provided the following Federal policy recommendations proposed by the workgroup:

- The U.S. Department of Transportation should issue joint guidance with the U.S. Department of Health and Human Services and the U.S. Department of Justice reaffirming that all publicly-funded transit systems must be accessible. Guidance should include examples of promising practices of local and State transportation models that demonstrate how they are inclusive or prioritize people with disabilities.
- With authorized funding from Congress, the U.S. Department of Transportation should invest in innovation grants to support infrastructure development and capacity building to expand on-demand and flexible response transportation models so that individuals with disabilities can access transportation in real-time when they need it.
- Revise CMS guidance on NEMT to offer more expansive options for States to fund NEMT and transportation education for individuals with disabilities, and specifically individuals with IDD.

Kelly also provided the following state policy recommendations proposed by the workgroup:

- Require drivers of public transportation systems to complete sensitivity training for different types of disabilities. This includes physical, intellectual, and social disabilities.
- Exercise existing strategies and flexibilities outlined in recent CMS guidance to assure expanded access to non-emergency transportation supports, and prioritize the inclusion of innovative transportation support strategies within new 1115 applications as it pertains to creating more expanded, inclusive transportation options specifically for persons with IDD.
- Invest in training for individuals with ID as part of their transition education in schools and also as part of available waiver services (HCBS) to learn how to successfully utilize public transportation options.
- Invest and incentivize the expansion of on-demand and flexible response transportation models so that individuals with disabilities can better leverage local transportation options to live, work, and thrive in typical communities.

Following the presentation, the floor was open for committee discussion:

- Shawn Aleong brought up the idea of requiring a certain number of high-rise units in new developments to be reserved for those who have IDD and significant disabilities.
- Santa Perez contributed by clarifying that the Community Living section of the report recommends that developers have more housing subsidies for people with disabilities and have a higher percentage of houses be built to be accessible.
- Adam Fishbein mentioned that there are certain laws in place related to this topic.
- Kelly Buckland clarified that two percent of housing needs to be accessible for individuals with vision or hearing disabilities, and five percent of units in any new apartment buildings need to be fully accessible. Kelly expanded on Shawn Aleong's comment and emphasized that a large issue is the affordability of accessible housing.
- Shawn Aleong surfaced the issue of wait lists, and the need to shorten wait times.
- Shawn Aleong expressed the importance of proper training for paratransit professionals to ensure that they provide proper services.
- Joe Macbeth proposed the idea that the intellectual and developmental disability sector does not invest in paid peer support. In other sectors, peer support is a major focus. Can we connect peer support with training on safety within the committee? In response, James

Meadours informed the group that he participates as a peer support and feels that peer support is important, and safety is also very important. He feels that having peer support plays a large role in safety.

- Santa Perez indicated that there are two different ways to talk about safety – personal housing and how to be safe in disaster preparation. She indicated that more people should be involved in disaster preparation.
- Liz Weintraub shared a comment about the importance of using plain language to allow people with intellectual disabilities to be part of the development process.
- Liz Weintraub also shared that issues with housing are related to issues with employment and DSPs. People with disabilities want to live in the community but they need jobs and support from DSPs to do so. It is all connected.
- Tia Nelis said everything mentioned about HCBS must be enforced to ensure people with disabilities can have a great life.
- James Meadours reminded the group that the report looks across many states when discussing issues related to home and community-based services to identify issues and propose solutions. He emphasized the need to help people feel safe and to increase accountability to assist people who have been harmed.
- Jeanine Worden touched on the housing shortage and recommended the PCPID members advocate for providing a higher level of accessibility in private housing, and more accessible housing funded by the Federal government.
- James Trout mentioned the importance of addressing grandfather laws and provided context that housing was initially excluded from ADA law development due to fear of gaining bipartisan support. A major concern was the potential impact on old buildings that would not meet ADA requirements.

### *HCBS / Federal Support Programs*

---

Workgroup Co-Chairs – Shawn Aleong and Paul Aronsohn

Paul Aronsohn and Shawn Aleong shared presentation remarks for the last section. Paul began by recognizing the members of the HCBS workgroup.

Paul Aronsohn highlighted leading key challenges by the workgroup in this focus area. They include:

- Income and asset/resource limits are too low (Social Security/Medicaid).
- Income and asset limits penalize couples wanting to get married (Social Security/Medicaid).
- Provider agencies, which run group homes and licensed apartments, are permitted to require residents' full SSI payments without transparency as to how the monies are spent (Social Security).
- Medicare has a 24-month waiting period for people collecting Social Security Disability Income (SSDI).

Paul provided an overview of the Federal policy recommendations proposed by the workgroup. The recommendations were the following:

- Increase SSI asset/income limits.

- Eliminate marriage penalties.
- Limit provider access to individual's SSI funds.
- Eliminate the Medicare waiting period.

Paul also provided an overview of state policy recommendations proposed by the workgroup. The recommendations were the following:

- Increase the asset and income limits.
- Eliminate marriage penalties in all State Medicaid programs.
- Eliminate all income and age limits in State Medicaid "buy-in" programs.
- Allow for cross-state portability of Medicaid HCBS.

Following Paul's remarks, Shawn Aleong further echoed the key challenges and recommendations from his experience.

Following the presentation, the floor was open for committee discussion:

- James Meadours discussed subsidy programs in relation to SSDI.
- Jim Brett inquired what barriers exist to prevent addressing these issues. In response, Paul explained that while politicians agree and want to address these issues, they have not made it a priority to continue advocating for them.
- Cathy Kanefsky asked for additional context regarding the asset limitation range. In response, Paul clarified that the Medicaid asset limitation ranges from state to state.
- Cathy Kanefsky asked if the ABLE account matching process is a common practice. In response, Paul Aronsohn stated that 401k is considered an asset by some states.

### ***Closing Remarks***

Jim Brett, PCPID Chair

Chairman Brett thanked the PCPID workgroup chairs and members for bringing forward before the full committee the policy challenges and proposing recommendations. Jim indicated that today's meeting discussion will be used to help further refine the draft PCPID Report to the President. Over the next month, the committee will receive a copy of the full report developed by the PCPID Report Writer for their review. The goal is to issue the final report this summer after a committee vote.

In closing, Jim mentioned that he opened the meeting with four exploratory questions for the workgroups. Jim shared that each PCPID member was a key voice during the afternoon meeting to help further promote the full participation of people with intellectual and developmental disabilities in their communities. The PCPID now has an opportunity to nurture these ideas further as one collective body. Chairman Brett adjourned the meeting.