



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

Zoom Platform Meeting  
May 1, 2023  
~Minutes~

*Citizen Members (Present)*

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

James Meadours  
Lucy Meyer  
Tia Nelis  
Santa Perez  
Nick Perry  
Hillary Dunn Stanisiz  
Wendy Strauss  
James Trout  
Liz Weintraub  
Jordyn Zimmerman

*Ex Officio Members and Representatives (Present)*

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

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

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

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

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

David Mank  
Representing the Honorable Julie A. Su,  
Acting Secretary, U.S. Department of Labor

Brian S. 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

Leola Brooks  
Representing the Kilolo Kijakazi, Acting  
Commissioner, U.S. Social Security  
Administration

Larry J. Beat  
Representing the Honorable Gina  
Raimondo, Secretary, U.S. Department of  
Commerce

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

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

Andrés Gallegos  
Chairman, National Council on Disability

***Guest Panelists providing Public Input***  
(in order of appearance)

BJ Stasio, New York  
Nguungwan (Victoria) Afa, Tennessee  
Alton Stuckey, Rhode Island  
Joshua Drywater, Arizona  
Amanda Baker, Florida  
Vance Taylor, California  
Kira Meskin Schiff, Illinois  
Patrice Jetter, New Jersey

\*Bryan Russell, Florida (joined larger panel discussion with Amanda Baker)

***Administration for Community Living and Administration on Disabilities***

Alison Barkoff  
Acting Administrator  
Administration for Community Living

Jill Jacobs  
Commissioner, Administration on  
Disabilities

Jennifer Johnson,  
Deputy Commissioner, Administration on  
Disabilities

Sheila Whittaker  
Program Assistant, Administration on  
Disabilities

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

Selvin Garcia  
Community Living Program Specialist,  
Administration on Disabilities

## **The PCPID Virtual Business Meeting Proceeding Overview**

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

Jim Brett, PCPID Chair

Chairman Jim Brett called the PCPID meeting to order and welcomed the committee members and the public for joining the virtual meeting. Jim acknowledged that all 34 PCPID members registered their attendance to participate. Jim began his remarks outlining the history of the committee work to date. Following the full PCPID committee in July 2022, the committee reached consensus to focus on Home and Community Based Services (HCBS). The HCBS focus area was then broken down into four key areas in which workgroups were subsequently established. They include:

- Direct Support Professionals – This workgroup has been examining the DSP Labor Shortage crisis.
- Employment – This workgroup has been examining how employment of people with intellectual disabilities can be linked to advance competitive integrated employment in communities.
- Community Living – This workgroup has been examining additional critical supports to promote independence and community inclusion such as Education, Housing, Health, and Transportation.
- Federal Support Programs – This workgroup has been examining federal support programs such as Social Security and Medicaid.

Since December 2022, the four PCPID workgroups met to reflect on each of the four topic areas. Jim thanked the nine PCPID workgroup co-chairs for their commitment to lead this national dialogue. Jim also thanked PCPID members that joined the workgroups. Jim proceeded to explain that today's meeting goal was to collectively hear and reflect on the issues identified from each of the four workgroups. He noted that while multiple issues may have surfaced within each of the workgroups, they would drill down on one or two topical areas in which invited guests will share their experience or expertise. Committee members would then have an opportunity to ask the guest panel questions or share their thoughts with peers on the committee.

Jim introduced Robin Levine, the facilitator for the PCPID Meeting. Robin has worked in the intellectual and developmental disabilities field over 35 years. Robin currently is a Program Manager with the Columbus Organization. Robin facilitates statewide stakeholder meetings for the Pennsylvania Office of Developmental Programs where she provides training to professionals on best practices as well as federal and state regulations.

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

Alison Barkoff, Acting Administrator, Administration for Community Living

Alison Barkoff shared welcoming remarks. Alison's remarks also incorporated statements from Administration on Disabilities Commissioner Jill Jacobs who was not able to participate. Alison observed that we are now marking six weeks since the HCBS Setting Rule was implemented on March 17<sup>th</sup>. She noted that the Settings Rule is seen as fulfilling promises of the Rehab Act, the ADA, and the Olmstead Decision to ensure basic civil rights. And, since the implementation, she

shared we must all work together to ensure the implementation is successful. The committee has a special role with this work to help further inform and educate.

Alison highlighted the President's April 18<sup>th</sup> Executive Order focused on caregiving. She noted that as we seek full compliance with the Settings Rule, we must also find new ways to solve the Direct Care Workforce crisis. Last fall, ACL launched the National Director Care Workforce Capacity Building Center to serve as a hub for collecting federal, state, and local best practices in recruitment, training, and wages to facilitate partnerships.

Alison recognized the four PCPID workgroups for taking steps to identify major issues of importance to all who are dedicated to full inclusion of people with disabilities through community living. Alison thanked the committee members for their service and looks forward to learning from their combined wisdom.

### ***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. Since the Federal Register Notice was posted on April 4<sup>th</sup> about the May 1<sup>st</sup> public meeting, ACL invited the public to share comments with the committee about HCBS or other issues. Between the posting date of April 4<sup>th</sup> and April 28<sup>th</sup>, there were six public comments received. David summarized those comments for the committee.

Four of the commenters focused on advocating for Self Direction to ensure individuals with intellectual disabilities manage their own care and not be forced to live within an institution. They advocated Self Direction as the preferred HCBS placement. The commenters noted the operational barriers to effectively advance Self Direction within HCBS that were highlighted in David's remarks. David also shared comments from two commenters noting the aging population in the U.S. and advised that Self Direction be made sustainable beyond a parent's mortality and need more budgetary support.

A fifth commenter focused on the Direct Support Professional Labor Force Crisis. The commenter noted that it has been extremely difficult to hire caregivers to provide quality one on one care and there are not any day programs in his community. The sixth commenter came from an individual with an intellectual disability who wanted to bring attention to the committee about dyslexia. The commenter noted that we are increasingly living in a world of email and texts that is not in plain English and this has hindered his efforts to find employment within his community.

David shared that all comments received by ACL will be provided to the committee members in their entirety for their review.

### ***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. Nicole Jorwic followed and provided an overview of issues surfaced by the workgroup ranging from low wages for DSP workers, limited technology solutions, marketing

and recruitment to expand the pool of workers, lack of professional standards, and lack of career ladders and credentialing opportunities.

Joe Macbeth provided an overview of the role of the DSP within the national landscape and how it has evolved over time. Joe described the current workforce challenges and how workforce conditions deter progress with recruitment and retention. There has been a 43.3 percent annual turnover rate amongst DSP workforce. Joe highlighted how DSP is a highly skilled profession that serves in various roles from being a teacher, nurse, psychologist, occupational/physical therapist and counselor in this profession. Joe also observed how the role of the DSP workforce is evolving from historical perceptions to new ones in current environment. In moving forward, Joe acknowledged the importance of providing clarity about this work to employers and providers as well as the significance of having a common definition.

Two guest panelists provided public input.

*BJ Stasio, New York*

- BJ shared his experience as an individual with a disability and shared how DSP support impacted his life. As background, BJ is the co-Vice President of the Board of Directors of the Self Advocacy Association of New York state (SANYS) and has been employed by the New York Office for People with Developmental Disabilities for over 20 years, working on person centered planning, self determination training and education.

BJ described how his experience during COVID-19 exacerbated the challenges with DSP staffing in his daily living. As a result, BJ was faced with a choice to either stay in bed or sleep in his chair in order to continue with his daily activities. He explained he made the tough choice to sleep in his wheelchair over two years during the pandemic so he could continue working. Currently, BJ has DSP services and grateful for their support each day so he can be more active within the community and help advocate for others. At the same time, BJ described how he has stopped strangers in grocery store asking if they would like to work as a DSP in supporting him due to labor shortage in his community. BJ shared that he is seeking a “hand up” to live the life he wants to lead and not looking for a handout from government.

*Nguungwan (Victoria) Afa, Tennessee*

- Victoria shared her experience as a full time DSP for Core Services of Northeast Tennessee. Victoria has over 18 years of supporting people with intellectual and developmental disabilities and is currently in her final semester in a nursing degree program.

Victoria shared that her experience as a DSP was a leading reason why she went back to nursing school. During the first three semesters, she felt she had more experience than her classmates stemming from her experience as a DSP to administer medications. Victoria is grateful for her job as a DSP since it provided real world experience while in school. In her experience as a DSP, she described one incident when she joined her client for a medical appointment. The doctor spoke directly to Victoria and not the individual she was supporting. From that situation, Victoria explained that it’s important to not underestimate people with intellectual disabilities and we must meet them where they are at with level of understanding in providing care. It’s a mistake to form judgement that applies to all.

Following the panel feedback, the floor was open for committee discussion. One member explained that calling DSP workers as caregivers does not provide the level of respect it deserves. Another member noted the value of having a high school pipeline through vocational training to learn what a DSP does in the labor force and be on healthcare track. Another recruitment pipeline that surfaced by member highlighted the need to examine the immigrant workforce. There was agreement that the future of community living is Self Direction and there is a need to support DSP workforce. And, there was strong committee consensus or recognizing the importance of person, incentive planning in HCBS, and making sure that individuals themselves are driving that process.

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

Workgroup Co-Chairs – Eva Bunnell and Gabriel Martinez

Eva Bunnell opened the session and reflected that many of the issues discussed in the first panel were the same issues that surfaced with her daughter before she passed away and reiterated to the committee how important it is to find a way forward. Both Eva and Gabriel Martinez thanked the members of the workgroup for their participation on workgroup discussions focused on advancing meaningful employment. Eva identified issues that surfaced from the workgroup as barriers to meaningful employment. Gabriel highlighted that only 44 percent of adults with intellectual disabilities between the age of 21 to 64 are in the labor force. Eva noted that for those employed, a larger share of workers were self-employed in 2022 than those with no disability. Gabriel also highlighted the important role peer mentorship can have in the workplace. Two key areas were drilled down for this session to further examine new opportunities through invited guest panelists – (1) support for entrepreneurship and (2) support for people with disabilities in tribal nations.

Two guest panelists provided public input.

*Alton Stuckey*, Rhode Island

- Alton Stuckey shared his experience on how he achieved his dream of being a small business owner. Alton is a self-trained artist and uses pencils and charcoal to create calendars, landscapes, and portraits for customers. Alton shared he was 14 years old when he began to draw and was supported at the day program at the time. Alton later took abstract art classes at Rhode Island School of Design. Since owning his business in 2019, Alton acknowledged the support received from both family and the Rhode Island DD Council. Alton explained that owning his business has improved his quality of life through community engagement and economic opportunity.

Alton shared six recommendations for the committee: (1) Tell people they can do it and don't give up; (2) More self-employment programs to help people learn about how to start a business; (3) Funding from DD Medicaid Waiver to help people to buy necessary materials and supplies for their business; (4) Funding from VR to support business owners with disabilities; (5) Places in the community where people can go for production space (for artists); (6) Approval from Social Security to keep SSI checks and earnings from 1-3 year to get business off the ground.

### *Joshua Drywater, Arizona*

- Joshua Drywater, a Cherokee Nation citizen, shared his experience working to strengthen workforce and education programs for individuals with disabilities in the 22 federally recognized tribes in Arizona. Currently, Joshua is the Program Manager for Native Initiatives at the University of Arizona's Sonoran Center for Excellence in Disabilities. Joshua explained to the committee that it is important to recognize that each tribe and community has its own set of strengths, barriers, culture, and traditions. At the same time, he noted a common alarming challenge across the tribal nations was higher unemployment rates resulting in one in four native Americans to live in poverty.

Leading barriers identified include transportation, technology, and lack of services access and social services. Best practices identified include being culturally informed when providing services, having community based services to increase empowerment, maximizing family unit support, and recognizing the resiliency by native American population. In moving forward, Joshua recommends improved outreach and communication from the state or federal partners in reservations. The tribal nations need the Federal government support to increase employment opportunities to address existing poverty.

Following the panel feedback, the floor was open for committee discussion. Related to tribal issue focus area, it surfaced on the importance of cultivating relationships from small business owners with tribal communities to be effective. Relationship building must be developed to support workforce development in tribal communities. In this area, one member acknowledged that the best programs are developed within by tribal nations with federal support.

On matters related to issues not addressing tribal community, one member reflected how technology changed the landscape of employment and this has impacted the intake process in not always being accessible. Another member reflected that job developers are not skilled enough in providing support. Another member reflected on making the distinction between having a job and career and must emphasize the importance of career advancement opportunities for people with disabilities.

### ***HCBS / Community Living***

Workgroup Co-Chairs – Santa Perez and James Trout

Santa Perez opened the session and recognized the members of the workgroup. Both Santa and James Trout highlighted issues surfaced by the workgroup. They include assistive technology, disaster preparedness, education, housing, personal safety, and transportation. In response to increased climate change, the workgroup focused on the area of disaster preparedness.

Three guest panelists were introduced to provide feedback to the committee on the topic of disaster preparedness.

### *Amanda Baker, Florida*

- Amanda shared her experience in response to the impact of Hurricane Michael in 2018 while living in Panama City, Florida. In advance of the storm, she felt trapped since she could not go to a shelter because they could not accommodate in providing hospital beds. Amanda explained that experiencing the storm in her home was a traumatic experience. After the storm passed, Amanda was not able to leave her home due to a fallen tree

outside her door. And, Amanda's personal care attendants could not visit due to road conditions. One week after the storm and still living in her home without power, the temperature rose to over 100 degrees which exacerbated her health conditions further. Through the support of the Florida Developmental Disability Council, they were able to help her transition to build a new life in Tallahassee where she now works for Disability Rights Florida. In that process, Amanda described how she navigated bureaucratic hurdles in working with FEMA and Housing Authority to get services. Amanda closed her remarks by highlighting resources from Disability Rights Florida to support emergency preparedness.

*Vance Taylor, California*

- Vance shared his perspective as a state official in his current role as Chief of the Office of Access and Functional Needs at the California Governor's Office of Emergency Services (Cal OES). Vance leads a team to ensure individuals with disabilities are identified and integrated into the State's management systems before, during, and after disasters. From his experience, Vance shared that people with disabilities are disproportionately impacted after disaster strikes. His office seeks to identify needs in advance such as ensuring emergency shelters are physically and programmatically accessible.

Vance emphasized that the disability population also need to be proactive in their own preparedness in order to effectively navigate the emergency management landscape. A few simple steps could include registering in one's state system to get up to date emergency information such as California's Cal Alert system. In addition, the importance of developing a personal evacuation plan that may include identifying five people you can rely on for support in your social network. And, knowing what you must take with you when one must leave in a moment's notice such as medicine and chargers for a power wheelchair.

*Kira Meskin Schiff, Illinois*

- Kira shared her expertise as a Community Reintegration Advocate for a CIL and as Vice-Chairperson on an advisory committee with the Illinois Emergency Management Agency's Access and Functional Needs.

Kira identified several barriers for those who use and provide home and community-based services and acknowledged this population segment are often left out of emergency management services. She noted how that this has been barrier in her home state of Illinois due to coordination challenges between state agencies as she observed during the COVID-19 crisis. Kira noted that most of the DSPs are women, people of color, and immigrants which further the health disparities that already exist.

Kira observed poor communication has been a barrier on emergency preparedness. There are hurdles with access to technology and the Internet. And, the written material shared is not always available in plain English. To improve, agencies should follow the Americans with Disabilities Act (ADA) requirements on effective communication and be creative to use multiple vehicles to communicate a message such as both emailing and placing a phone call. And, Kira recommended improvements for people with disabilities to be counted in disaster preparedness data collection.



From a systemic level, Kira emphasized the importance of every state having an Access and Functional Needs Office; the importance of people with disabilities being at the table in planning to ensure equity; and improved coordination with CILs, State Councils on Developmental Disabilities, the ARC, and other disability led organizations on disaster preparedness.

Following the panel feedback, the floor was open for committee discussion. One member acknowledged Amanda Banker (panelist) for sharing her personal experience to help make life-saving changes in her community as well as helping the committee better understand. Another member acknowledged how the DSP workforce is putting themselves at risk to leave loved ones during times of crises to carry out their ethical responsibilities and emphasized we need to support them more in these situations. Other members joined and enumerated the points made by presenters on the importance of plain language to inform. In addition, both people with disabilities and DSP workforce being at the table for disaster preparedness planning to better support the intellectual disability population.

One committee member acknowledged the point raised by Vance Taylor on what states can and should do to build an effective disaster response system. Another member noted that the National Council on Disability issued a semi-annual report on disaster preparedness and further enumerated that the committee should explore a recommendation where special language gets added when federal funding to states occur to ensure people with intellectual disabilities can return to the community after a disaster.

### ***HCBS / Federal Support Programs***

Workgroup Co-Chairs – Shawn Aleong and Paul Aronsohn

Paul Aronsohn opened the session and recognized that while there are a lot of federal support programs for the intellectual disability population, the workgroup focused on two of the most popular programs – Medicaid and Supplemental Security Income (SSI). Paul recognized his co-chair Shawn Aleong and members of the workgroup and thanked them all for their leadership and support.

Paul explained to members of the committee that HCBS programs are often funded by state waivers. Waivers are part of state's Medicaid programs, but they provide a special group of services to a certain population. Waivers usually require medical and financial eligibility. Paul highlighted that both Medicaid and SSI income/asset limits are too low resulting in married couples being penalized. To support his point, Paul illustrated through tables comparing the income and asset amounts for an individual who is single and a couple in the Medicaid and SSI programs. As a result, marriage is a barrier out of fear of losing services and this issue should be further examined by the committee from both a financial and moral perspective. Paul also noted housing programs have income and asset limitations that can be looked at further by the workgroup. Shawn Aleong echoed the points made by Paul and felt it goes against the country's principles on how people with intellectual disabilities choose to live in getting married.

One guest panelist was introduced to provide public input.

*Patrice Jetter, New Jersey*

- Patrice highlighted in her comments the need to reform federal support programs so people with disabilities don't fear losing government benefits when getting married. As background, Patrice is an artist with a disability who experienced institutionalization and discrimination. Patrice successfully overcame many barriers and found employment as a crossing guard in her community. Patrice won over 100 medals in Special Olympics. In addition, Patrice developed and hosted the "The Trish Show" a public access television kids show and was featured in the Netflix series "Worn Stories".

Patrice shared her experience living in an institution over three years and described how she rebuilt her life after leaving. She was able to get her own apartment through Section 8 Housing voucher. She described how current government benefits is a challenge to pay bills and feels penalized when trying to earn extra income. Patrice shared she wishes she could get married, but the combined benefit would get reduced. Instead, she and her partner Carlos had a commitment ceremony. Patrice advocated that federal support programs need to get caught up with the times to ensure a better quality of life for people with disabilities.

Following Patrice's comments, the floor was open for committee discussion. Members of the committee praised Patrice for sharing her story and making a difference to increase awareness. The committee discussion focused mostly on ABLE accounts as a mechanism to save without losing SSI benefits. ABLE accounts are available majority of states and territories and legislation recently passed to increase the age limit from onset of disability before turning 26 to 46 years of age. Another member reminded the committee that this issue does go beyond savings and impacts the availability of community-based services. The workgroup co-chairs thanked the committee for their feedback as a good starting point for workgroup discussion.

***Closing Remarks***

Jim Brett, PCPID Chair

Chairman Brett thanked all the PCPID members for their participation in the meeting and the ideas they brought forward during the discussion. Jim shared with the committee his key takeaways from the meeting. Jim also noted that steps are already underway for the report writing to begin this summer. And, the PCPID committee will reconvene when the report is ready for review during the second half of the year.

Jim closed the meeting to acknowledge and reflect on the life of Judy Heumann, a trailblazer and the mother of the disability rights movement. Jim noted that just like many of the guest panelists that spoke before the committee during the meeting, Judy also gave remarks before a PCPID meeting and stated, "It is pivotal to create a society where there is an expectation that all individuals are living and integrated in the community, and receive proper services and support." Jim reflected that the PCPID time spent together to jointly address HCBS issues is building on Judy Heumann's legacy and vision.

***Meeting Adjournment***

Chairman Brett adjourned the meeting.