



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

Full Committee Meeting

March 21, 2024

12:00 PM to 5:00 PM EST

Call to Order, Welcoming Remarks, and Meeting Overview



Jim Brett
PCPID Chair

Welcoming Remarks from Administration for Community Living



Alison Barkoff
Acting Administrator, ACL



Jill Jacobs
Commissioner,
Administration on Disabilities

Summary of Public Comments Received



David Jones

Director, Office of Intellectual and Developmental Disabilities

Summary of PCPID Report Development Activities



Serena Lowe
PCPID Report Writer

Workgroup Discussion

To support the development of the PCPID report, each of the four workgroups:

- Identified policy challenges, barriers and proposed recommendations to prioritize;
- Discussed overall flow and key themes to be highlighted; and
- Identified innovative models, promising practices, and human narrative stories to be integrated throughout the PCPID report.

Proposed General Format for Each Section of the PCPID Report

- Introduction to the Area of Focus (Overview, Statistics, Context)
- Policy Challenges / Barriers Identified
- Recent Federal Investments to Address Challenges
- Proposed Federal Policy Recommendations
- Proposed State Policy Recommendations
- Other Sections
 - Spotlights in Innovation
 - Human Narrative Highlights



HCBS / Direct Support Professionals (DSP) Workgroup

Policy Challenges Identified and Proposed Recommendations

HCBS / Direct Support Professionals (DSP)

Workgroup Members

Co-Chairs:

- **Nicole Jorwic**, *Citizen Member*
- **Joe Macbeth**, *Citizen Member*
- **Tia Nelis**, *Citizen Member*

Members:

- **Kara Jones**, *Citizen Member*
- **Cathy Kanefsky**, *Citizen Member*
- **Hillary Dunn Stanisz**, *Citizen Member*
- **Wendy Strauss**, *Citizen Member*
- **Jodie Sumeracki**, *Ex Officio Member*
- **Liz Weintraub**, *Citizen Member*

Key Challenges to Building a Competent, Capable DSP Workforce

- 1. Shrinking DSP workforce pipeline continues amid growing demand for HCBS.**
 - Low compensation persists for DSP workers.
 - Poor business acumen and workplace culture impact workforce retention.
 - There is a lack of sophisticated marketing/recruitment strategies to expand DSP pool.
- 2. Lack of professionalization or career pathways for DSP workforce discourages workers from remaining in the field.**
 - Lack of a unique labor category prevents workforce systems from differentiating the DSP profession in the American labor market.
 - Lack of professional standards leads to a fragmentation in service delivery.
 - Lack of career ladders and credentialing opportunities limits clear pathways for DSP advancement.
 - Insufficient training and preparation for DSP roles puts DSPs and the individuals they support at risk.

Key Challenges to Building a Competent, Capable DSP Workforce (Continued)

3. Huge Disparities with Supply Shortages versus Constant Growing Demand requires Other Solutions to Address Gaps in HCBS Provision/Capacity

- Despite new technological interventions that can support optimal independence and community integration, investments and leveraging of HCBS technological solutions remains limited.
- Complexities & lack of investment in self-direction models result in an over-reliance in traditional provider models of HCBS delivery.
- Over-reliance on family caregivers has tremendous socioeconomic implications and unintended health consequences for caregivers and individuals with I/DD alike.

The Role of DSPs in Facilitating High-Quality HCBS



Proposed Federal Policy Recommendations

1. Develop a Professional Career Pathway for DSP Workforce

- Create Unique Professional Identity (DOL/BLS/OMB)
- Establish National Professional Standards (CMS)
- Development of National Career Ladders and Credentialing Opportunities (DOL/HHS)

2. Building a Robust DSP Pipeline for the Future

- Initiate/Advance Wage Parity (CMS)
- Engage Federal & State-Level Workforce & Economic Development Initiatives (ED/DOL)
- Marketing & Recruitment to Expand the Pool of Workers (HHS/ED/DOL)

3. Diversifying Workforce Solutions to Adequately Meet Growing Demand for HCBS

- Leveraging Technological Solutions (HHS—CMS, ACL)
- Explore and Expand Self-Direction Models (HHS-CMS)

Proposed Federal Policy Recommendations

- 1. States should Implement New Approaches to Incentivizing the Hiring and Training of Direct Support Professionals**
- 2. States should invest in the professionalization and career advancement of Direct Support Professionals**
- 3. States should invest in models that empower experienced Direct Support Professionals to lead the development of new models of HCBS provision**

Full Committee Discussion



HCBS / Employment Workgroup

Policy Challenges Identified and Proposed Recommendations

HCBS / Employment

Workgroup Members

Co-Chairs:

- **Eva Bunnell**, *Citizen Member*
- **Gabriel Martinez**, *Citizen Member*

Members:

- **Alyse Bass**, *Ex Officio Member*
- **Adam Fishbein**, *Ex Officio Member*
- **Glenna Wright-Gallo**, *Ex Officio Member*
- **Cathy Kanefsky**, *Citizen Member*
- **Max Lapertosa**, *Ex Officio Member*
- **Brent Leonhard**, *Citizen Member*
- **Lucy Meyer**, *Citizen Member*
- **Heather Nodler**, *Ex Officio Member*
- **Nick Perry**, *Citizen Member*

Key Resource Referenced

Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities (2016)

The report addresses:

- Overall Capacity Building
- Capacity Building for Youth
- Building Capacity in the Marketplace
- Capacity Building to Decrease Reliance on Section 14(c) Special Wage Certificates
- Capacity Building for Federal Agencies

Key Challenges to Promoting Competitive, Integrated Employment of Individuals with I/DD

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; and
3. Lack of Emphasis in Promoting Entrepreneurship & Small Business Development among Individuals with I/DD.

Proposed Federal Policy Recommendations

1. Building Capacity Among Employers

- 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 supports 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.

Proposed Federal Policy Recommendations

2. Establish a Federal Employment First Policy & Investment Framework

- 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 capacity of employment agencies and HCBS/VR providers to expand availability of evidence-based practices that lead to CIE for workers with I/DD.
- Build Capacity of 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.

Proposed Federal Policy Recommendations

3. Building Capacity of Entrepreneurs and Small Business Innovators with I/DD

- 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.

Proposed State Policy Recommendations

1. **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 focus on evidence-based employment services for individuals with I/DD.
- Invest in becoming a Model Employer of People with I/DD.

2. **Support Employers of Individuals with ID: 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 (CIE).
- 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.

3. **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.

Full Committee Discussion



HCBS / Community Living Workgroup

Policy Challenges Identified and Proposed Recommendations

HCBS / Community Living

Workgroup Members

Co-Chairs:

- **Santa Perez**, *Citizen Member*
- **James Trout**, *Citizen Member*

Members:

- **Kelly Buckland**, *Ex Officio Member*
- **James Meadours**, *Citizen Member*
- **Brian Parsons**, *Ex Officio Member*
- **Nick Perry**, *Ex Officio Member*
- **Wendy Strauss**, *Citizen Member*
- **Jodie Sumeracki**, *Ex Officio Member*
- **Jeanine Worden**, *Ex Officio Member*
- **Jordyn Zimmerman**, *Citizen Member*

How We Organized Our Section

Our workgroup identified four topical areas to address:

- *Housing*
- *Safety*
- *Technology Supports*
- *Transportation*

Housing – Key Challenges Identified

1. Lack of cohesion and coordination persists among Medicaid HCBS and housing assistance.
2. Settings created exclusively for people with I/DD or disabilities do not promote true community inclusion nor independence in the larger setting of the US.
3. Specific voucher programs support people with I/DD to have access to housing, 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.
4. There is an insufficient supply of publicly-funded affordable housing in desired areas to promote truly inclusive communities.
5. Lack of awareness and planning around housing opportunities for adolescents with disabilities transitioning to adulthood may limit their vision about independent living options.
6. 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.
7. Individuals with disabilities face discrimination from landlords in violation of civil rights laws.

Housing – Proposed Federal Policy Recommendations

1. 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.
2. 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 & accessible places to live and well-trained direct care staff in their local communities.
3. 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, near transit hubs.
4. 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.
5. 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.

Housing – Proposed State Policy Recommendations

1. Participate in Mainstream Voucher Program and assure Fair Housing Authority is collaborating with DD network and State Medicaid Agency/DD Agency to advertise available slots.
2. 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.
3. Define durable accommodations and educate and incentivize agencies to support persons with disabilities and their families in solidifying housing that includes durable accommodation.
4. 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.

Safety – Key Challenges Identified

1. **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.
2. **Health**: Adults with I/DD are at high risk of getting sick when they are required to attend congregate day settings (examples: flu or COVID epidemic).
3. **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.
4. **Environmental Safety**: People need more knowledge about safety protocols in their homes and natural surroundings and how to take care of themselves.
5. **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.

Safety – Proposed Federal Policy Recommendations

1. **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 study analyzing trends and differences in State APS infrastructure, highlighting promising practices, systemic areas of concern, and systemic-level remedies.
2. **Health**: 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 (including 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).

Safety – Proposed Federal Policy Recommendations

3. **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 (IEPs) and annual HCBS person-centered service plans base.
4. **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 assure 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.

Safety – Proposed State Policy Recommendations

1. Include HCBS provider/State program representation on State and Local emergency planning advisory committees.
2. Offer services within HCBS waiver programs so there are long-term reimbursable pathways for accessing advocacy training in personal safety and self-determination. Then strategically partner with consumer-led organizations like self-advocacy groups and CILs to provide such services.
3. 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.

Technology Supports – Key Challenges Identified

1. Access to remote/virtual supports, assistive technology and other enabling technologies is fragmented.
2. 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.
3. Federal and State funding are 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.
4. Most public materials are not made available in plain language.
5. Broadband access is still inconsistent in rural and other geographic areas.

Technology Supports – Proposed Federal Policy Recommendations

1. 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.
2. CMS should provide guidance on the importance of establishing DME/AT replacement, recycling and refurbishment programs to assure opportunities for appropriate upgrades and newer devices across the lifespan for individuals with disabilities, including people with I/DD.
3. 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 assure accessibility gaps are addressed to promote inclusive community living options for people with I/DD.
4. The U.S. Department of Health and Human Services should issue additional sub-regulatory guidance surrounding 1557 and 504 Rehab Act regarding the need to assure all communications are made available in plain language

Technology Supports – Proposed Federal Policy Recommendations (Continued)

5. The following are 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.

Technology Supports – Proposed State Policy Recommendations

1. Require local education authorities to include assistive technology in individualized education plans.
2. 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.
3. 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.
4. 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.

Transportation – Key Challenges Identified

1. 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.
2. There are also very few supports to teach people with I/DD how to successfully navigate publicly-available transit options.
3. Medicaid HCBS rates for non-emergency medical transportation (NEMT) are often very limiting in terms of market value and restrictive in terms of use.

Transportation – Proposed Federal Policy Recommendations

1. 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.
2. 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.
3. 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 I/DD.

Transportation – Proposed State Policy Recommendations

1. Require drivers of public transportation systems to complete sensitivity training for different types of disabilities. This includes physical, intellectual, and social disabilities.
2. 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 I/DD.
3. 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.
4. 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.

Full Committee Discussion



HCBS / Federal Support Programs Workgroup

Policy Challenges Identified and Proposed Recommendations

HCBS / Federal Support Programs

Workgroup Members

Co-Chairs:

- **Shawn Aleong**, *Citizen Member*
- **Paul Aronsohn**, *Citizen Member*

Members:

- **Alyse Bass**, *Ex Officio Member*
- **Veta Hurst**, *Ex Officio Member*
- **Paul Boskind**, *Citizen Member*
- **Leola Brooks**, *Ex Officio Member*
- **Lisa Gray**, *Ex Officio Member*
- **Denise Leach**, *Ex Officio Member*
- **Jodie Sumeracki**, *Ex Officio Member*

Key Challenges Identified

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

Proposed Federal Policy Recommendations

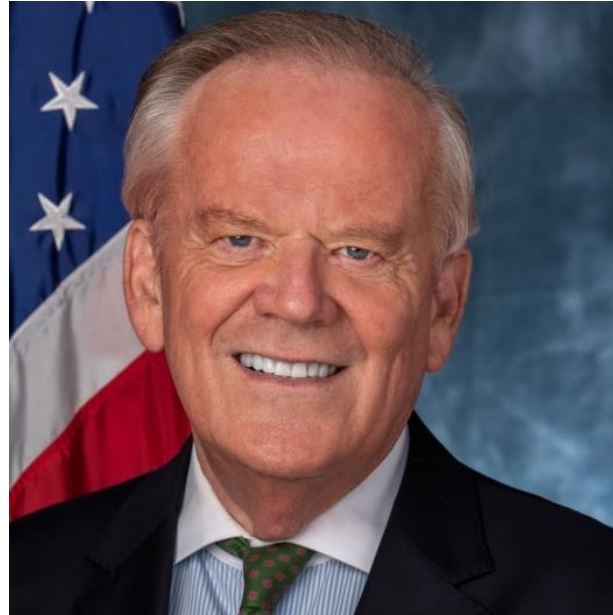
- 1. Increase SSI Asset/Income Limits:** The Federal government should increase income and asset / resource limits. States should be encouraged to increase their respective income and asset limits on programs tied to SSI eligibility.
- 2. Eliminate Marriage Penalties:** The Federal government should eliminate “marriage penalties” by establishing “couple” limits that are twice as much as the “single” limits. States should be required to eliminate “marriage penalties” by establishing “couple” limits that are twice as much as “single” limits.
- 3. Limit Provider Access to Individual’s SSI Funds:** The Federal government (via SSA/CMS/Internal Revenue Service) should limit provider agencies’ access to residents’ SSI funds and should require an itemized accounting be given to the resident.
- 4. Eliminate Medicare Waiting Period:** The Federal government should eliminate the Medicare waiting period or make exceptions for people with disabilities.

Proposed State Policy Recommendations

1. Increases in the asset and income limits - aligned with the SSI increases - for all State Medicaid programs.
2. Elimination of the marriage penalty in all State Medicaid programs.
3. Elimination of all income and age limits in State Medicaid "buy-in" programs.
4. Allow for cross-state portability of Medicaid HCBS (to allow individuals with I/DD who move out of state to continue to access waiver services/HCBS in a new state without having to go back through eligibility determination and waitlist process).

Full Committee Discussion

Closing Remarks / Next Steps



Jim Brett
PCPID Chair

THANK YOU