



Advancing Independence and Community Integration for All: Supporting Individuals with Intellectual Disabilities Through High-Quality Home and Community-Based Services

The President's Committee for People with Intellectual Disabilities Report to the President

SEPTEMBER 2024



Disclaimer

The 2024 President’s Committee for People with Intellectual Disabilities (PCPID) Report to the President, *Advancing Independence and Community Integration for All: Supporting Individuals with Intellectual Disabilities through High-Quality Home and Community-Based Services (HCBS)*, reflects the views of PCPID citizen members including people with lived experience as individuals with intellectual and developmental disabilities, their family members, or professionals in the field. Although Federal agencies and departments were represented by ex officio members of the PCPID, this report does not reflect the views or recommendations of any agency or department of the U.S. Federal Government.

Information and data contained in this report were contributed by authorities in the fields of intellectual and developmental disabilities, disability research, workforce development, public policy, and other related fields. The personal opinions that such contributors may hold or choose to express outside of this report do not necessarily reflect the views of the PCPID, HHS, or other federal agencies.

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President's Committee for People with Intellectual Disabilities

Washington, D.C. 20447

President Joseph Biden
The White House
1600 Pennsylvania Avenue, N.W.
Washington, DC 20500

Dear Mr. President:

On behalf of the President's Committee for People with Intellectual Disabilities (PCPID), it has been an honor to serve your administration and the American people. Under your leadership, you have appointed individuals with intellectual and developmental disabilities (I/DD) to comprise the majority of those serving on the PCPID, marking the highest representation in its 58-year history. This increased diversity has greatly enriched the committee's focus and discussions.

The members of the committee appreciate the opportunity to submit for your consideration the 2024 Report, *Advancing Independence and Community Integration for All: Supporting Individuals with Intellectual Disabilities Through High-Quality Home and Community-Based Services (HCBS)*. The intended outcome of the report is to ensure all individuals with I/DD have the supports they need to live more independently and have opportunities to meaningfully engage within their communities.

The committee's report provides an environmental assessment of the current challenges, opportunities, promising practices, innovative strategies, and policy reforms necessary to increase the availability of high-quality, high-value HCBS for individuals with I/DD. The 2024 PCPID report is structured across four key focus areas. They include:

- Direct support professionals (DSP) and the DSP labor shortage crisis.
- Employment and how employment of people with I/DD can be supported to advance competitive integrated employment (CIE) in communities.
- Community living and the additional critical supports to promote the independence and community inclusion in the areas of housing, safety, technological supports, and transportation.
- Federal supports and the impact of federal entitlement programs, like Supplemental Security Income (SSI), Medicaid, and Medicare.

Thank you for accepting and considering the contents of this report. We are hopeful that the report will provide an increased understanding of the key barriers people with I/DD face to living full lives in the community and that the recommendations are useful insights for how to improve and strengthen HCBS.

Sincerely,

James T. Brett

James T. Brett, Chair

Enclosure

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Committee Profile

In 1966, President Lyndon B. Johnson established [The President's Committee for People with Intellectual Disabilities \(PCPID\)](#) to ensure the right to a “decent, dignified place in society” for people with intellectual disabilities. Since that time, the PCPID has served as a federal advisory body to the president and the Secretary of Health and Human Services on matters relating to persons with intellectual disabilities. The PCPID promotes policies and initiatives that support independence and lifelong community inclusion. The Administration for Community Living (ACL) within the U.S. Department of Health and Human Services (HHS) provides oversight and support for the PCPID. As an advisory committee, the PCPID does not receive an appropriation from Congress to administer federal funds. Thus, the PCPID does not administer grants, nor does it provide financial or technical assistance to individuals, groups, agencies, or organizations.

The PCPID provides advice and assistance to the president of the U.S. and the Secretary of Health and Human Services on a broad range of topics that impact people with intellectual and developmental disabilities (I/DD).¹ The goal of the PCPID is to improve the quality of life experienced by people with intellectual disabilities across the lifespan by increasing their independence, self-determination, and participation in all aspects of community life. The PCPID has 21 citizen members and 13 ex officio members. The 21 citizen members, who are appointed by the president, include people with I/DD and their family members, researchers, service providers and other professionals, community and business representatives, and systems advocates. The 13 ex officio members include the secretaries (or their designees) representing different federal agencies based in Washington, D.C. The PCPID is currently chaired by citizen member James T. Brett of Massachusetts.

PCPID Priority: High-Quality Home and Community-Based Services

The PCPID has prioritized high-quality home and community-based services (HCBS) for their report to the president with a focus on four key areas:

- **Direct support professionals (DSP)** and the DSP labor shortage crisis.
- **Employment** and how employment of people with I/DD can be supported to advance competitive integrated employment (CIE) in communities.
- **Community living** and the additional critical supports to promote independence and community inclusion in the areas of housing, safety, technological supports, and transportation.
- **Federal supports** and the impact of federal public entitlement programs, like Supplemental Security Income (SSI), Medicaid, and Medicare.

The PCPID met on July 28, 2022, to discuss potential topics for the report to the president. Following this meeting, the committee reached a consensus to focus on HCBS. Following the selection of this topic and the areas of focus, the PCPID formed four workgroups that started meeting in December 2022 to identify key policy challenges, assess current federal investments, develop federal recommendations, and learn about promising practices at the local and state levels.

There were multiple opportunities for the public to provide comments to the PCPID as they developed the report. The committee gave opportunities to provide feedback on the committee's deliberations through submission on the PCPID website and through written comments in advance of each public meeting (July 28, 2022; May 1, 2023; and March 21, 2024).

¹ Although the PCPID and report title specifically refer to individuals with intellectual disabilities, this report focuses on individuals with intellectual and developmental disabilities. The research cited in this report focuses on the population of persons with intellectual and developmental disabilities.

Overview and Introduction

There are approximately 7.4 million Americans living with I/DD.¹ HCBS provide critical services and supports that enable people with I/DD to live at home, decrease institutionalization, and promote well-being through continued community living.² Institutionalization can lead to loss of independence and decreased quality of life.³ For decades, the federal government has played a critical role in the development, establishment, funding, and oversight of HCBS for individuals with disabilities and older adults with chronic conditions. Generally, to be eligible to receive services covered by certain Medicaid HCBS programs, many of these individuals must meet an institutional level of care and for provision of HCBS, would require services provided in certain institutional settings. While there are many services and supports available for individuals with I/DD, there is still room for improvement. The PCPID believes it is both timely and imperative to offer an assessment of the current challenges, opportunities, promising practices, innovative strategies, and policy reforms necessary to increase the availability of high-quality, high-value HCBS for individuals with I/DD.

Federal Efforts to Advance HCBS

[Long-term services and supports](#) (LTSS) help individuals improve or maintain optimal functioning and quality of life. This includes assisting individuals with carrying out activities of daily living (ADLs) (e.g., dressing, walking, and eating) and instrumental activities of daily living (e.g., cleaning, shopping). LTSS encompasses coverage of services provided in an institutional setting (e.g., a nursing facility or intermediate care facility for individuals with intellectual disabilities (ICF/IID)) and home and community-based settings. LTSS are a variety of health, health-related, and social services, such as personal care and case management, which can be delivered in a range of institutional and home and community-based settings. Medicaid is the dominant public payor for LTSS in the U.S. Since 1965, the Medicaid program has required states to provide necessary nursing facility care for eligible individuals. However, no similar requirements exist for HCBS; states may choose whether to cover HCBS under their Medicaid programs. Section 1915(c) of the Social Security Act (the Act) authorized the [Medicaid HCBS Waiver Program](#) in 1981, allowing CMS to waive certain Medicaid program requirements to enable states to meet some LTSS needs in home and community-based settings. Specifically, for Section 1915(c) Medicaid HCBS Waiver programs, CMS may waive certain Medicaid statutory provisions that would otherwise require states to include all beneficiaries in the state (i.e., statewideness) in the Waiver program, to provide covered benefits to all beneficiaries in the same amount, duration, and scope (i.e., comparability), and/or to apply a single standard for determining an individual's income and resource eligibility (i.e., income and resource rules). CMS's approval of a state's 1915(c) Medicaid HCBS Waiver program (including waiver of one or more of these Medicaid program requirements) enables the state to offer HCBS to specific groups of individuals who, but for the provision of HCBS, would require an institutional level of care.

In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that Title II of the Americans with Disabilities Act (ADA), which mandates that public entities cannot discriminate against people with disabilities, requires public entities to provide services to individuals with disabilities in the most integrated setting appropriate to their needs. Enforcement of the [ADA's "integration mandate"](#) has enabled thousands of people with disabilities to live in their homes and communities instead of institutions by requiring states to provide more options that support individuals with disabilities to have greater independence, autonomy, and opportunities for community living. [Section 504 of the Rehabilitation Act](#) also includes an integration mandate and prohibits discrimination on the basis of disability in programs receiving federal financial assistance, as well as those conducted by federal agencies. In addition, [Section 1557 of the Affordable Care Act](#) prohibits discrimination on the basis of disability by certain entities, including those receiving federal financial assistance. HHS recently revised its regulations implementing Section 1557, including prohibiting covered entities from having or implementing a benefit design that does not

provide or administer health-related coverage in the most integrated setting appropriate to the needs of qualified individuals with disabilities.²

The [Deficit Reduction Act of 2005](#) created several new opportunities for states to support individuals in their homes and communities: providing for new HCBS programs. The Deficit Reduction Act added [Section 1915\(i\)](#) to the Social Security Act to allow states to provide HCBS to individuals who meet specific criteria but do not necessarily meet an institutional level of care. It also added [Section 1915\(j\)](#) to allow states to offer individuals the opportunity to self-direct state plan personal care services or select 1915(c) services without the need for a Section 1115 demonstration. The [Money Follows the Person](#) demonstration helps states rebalance from institutional care to HCBS by supporting individuals transitioning from institutions to the community.

The [Community First Choice Option](#) is a Medicaid state plan option established under the Affordable Care Act of 2010 by adding [Section 1915\(k\)](#) to the Social Security Act. Under a 1915(k) state plan amendment, states have the option to amend their state plan to provide home and community-based attendant services and related supports and receive a six percentage point increase to their federal medical assistance percentage (FMAP) for individuals who meet institutional level of care criteria.

In 2014, the Centers for Medicare & Medicaid Services (CMS) issued the [final HCBS Settings Rule](#), which, for the first time, set requirements for a setting funded through HCBS programs to be considered “home and community-based.” The rule’s goal is to ensure that people receiving HCBS experience the benefits of community living and have access to the broader community. The rule also requires a person-centered planning process for HCBS, which means that an individual receiving services directs the planning process and the plan reflects their own preferences and goals they set for themselves. States were given time to implement the rule and the transition period for complying with the criteria of a home and community-based setting expired on March 17, 2023.

The COVID-19 pandemic and public health emergency (PHE) greatly impacted the availability of HCBS and confirmed the urgent need to provide more integrated community alternatives to institutional care for people with disabilities.^{4,5} Section 9817 of the [American Rescue Plan Act of 2021 \(ARPA\)](#) offered states an opportunity to invest in their Medicaid HCBS, which, as of the quarter ending December 31, 2023, will result in additional spending of \$4,966 per beneficiary to strengthen HCBS, with a total of \$37.11 billion across all states.⁶ States proposed more than 1,415 discrete activities in the [Section 9817 ARPA spending plans](#), with workforce investments emerging as a top priority. In addition, CMS issued the [Ensuring Access to Medicaid Services Final Rule](#) in April 2024, which seeks to improve and increase access to HCBS, among other objectives.

As of federal fiscal year (FY) 2021, HCBS reflected 62.5% of Medicaid LTSS expenditures, up nearly four percentage points from the prior year. Since FY 2013, more than 50% of Medicaid LTSS expenditures have been on HCBS.⁷ **Exhibit 1** shows the HCBS and institutional rates of LTSS expenditures from 1988 through 2020.^{8,9}

² The effective date of this requirement is the first day of the first plan or policy year beginning on or after January 1, 2025. 45 C.F.R. § 92.1(b).

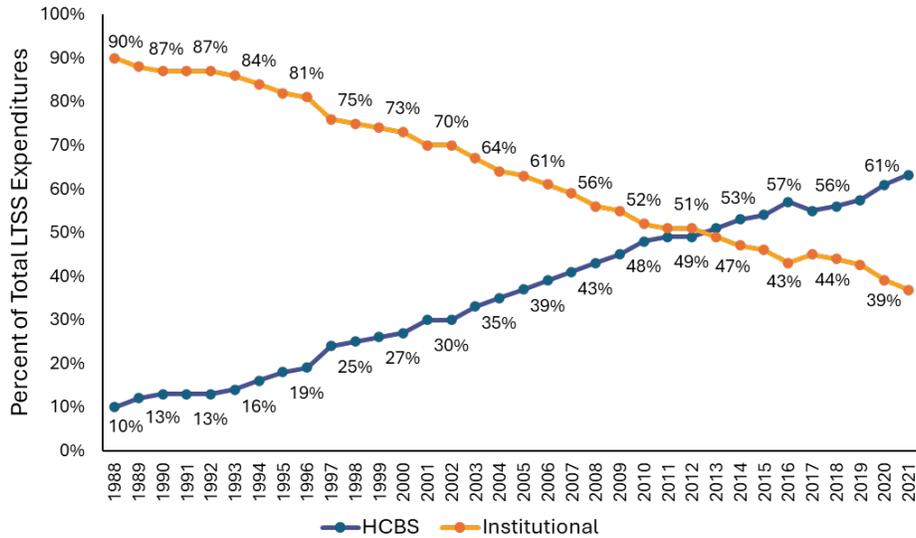


Exhibit 1: HCBS and Institutional Rates of Total LTSS Expenditures

(Source: Murray, C., Eckstein, M., Lipson, D., & Wysocki, A., 2023; Wysocki, A., Murray, C., Kachalia, A., Carpenter, A., & Stepanczuk, C., 2024)

Current Landscape of HCBS for Individuals with I/DD in Large State Facilities

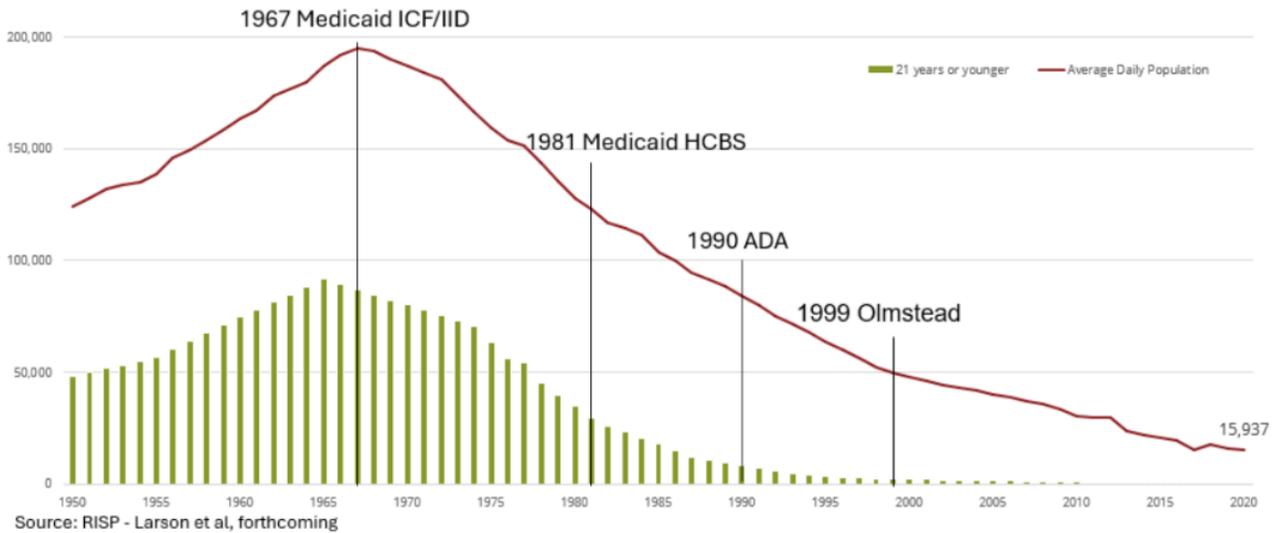


Exhibit 2: Children and Adults in Large State I/DD Facilities of 16 or More People, 1950 – 2020
(Source: University of Minnesota, 2023)

An estimated 19% of individuals with I/DD in the U.S. receive LTSS through their state agency.¹⁰ Of these individuals, 73% live with a family member or in their own home. Only 2% live in group settings with 16 or more people,¹¹ and **Exhibit 2** shows the declining number of children and adults in large state I/DD facilities from 1950 through 2020.¹² People with I/DD who receive HCBS account for higher Medicaid HCBS expenditures than other populations; in federal fiscal year 2018, people with I/DD comprised 43% of Section 1915(c) beneficiaries and 68% of expenditures.¹³ Nearly three-quarters of

individuals on waiting lists for enrollment in HCBS programs (72%) have I/DD, and people with I/DD wait an average of 50 months for services, well above the average of 36 months across all Medicaid HCBS waivers.¹⁴ Recruitment and retention of a [high-quality DSP workforce](#) continues to be a barrier to HCBS; according to the 2022 *State of the Workforce* survey, the average DSP turnover rate was 40.9%, and nearly half of responding agencies had to stop accepting new referrals due to staff shortages.¹⁵

Cross-Cutting Principles for High-Quality HCBS

The PCPID identified six principles it considered pivotal to strengthening and sustaining the nation's HCBS infrastructure to guide each workgroup:

- **Enhance self-advocacy:** Individuals with disabilities play a key role in increasing access to person-centered HCBS, preserving individuals' health and welfare, and improving quality of life outcomes. Investments in self-advocacy are important, such as access to self-advocacy and self-determination training, peer mentoring, and leadership development opportunities.
- **Promote person-centered planning and thinking:** Person-centered planning is essential to high-quality HCBS and requires a focus on the person, an understanding of the importance of choice and self-determination, and a commitment to full inclusion and access to the community.¹⁶
- **Ensure equity:** Ensuring equity in the availability and delivery of HCBS and mitigating disparities in access to services, availability of care, and service delivery are critical for supporting individuals with I/DD, particularly those who are multiply marginalized. HCBS must be designed in a way that protects against barriers that are perpetuated in public systems by disability, race, national origin, ethnicity, gender identity, and sexual orientation.¹⁷
- **Individualize supports:** There is a growing demand for individualized supports and flexible, self-directed service delivery options. HCBS must continue to evolve toward individualized service models and provide necessary supports.
- **Create seamless navigation:** Navigating services, coordinating resources, and understanding eligibility requirements across systems can be frustrating, time-consuming, and difficult for individuals with I/DD and their families. Many existing systems of navigation need to be sustained or tailored to support the unique needs of individuals with I/DD. States and local leaders can build upon the [No Wrong Door \(NWD\) System](#) initiative to simplify access to LTSS for individuals with I/DD.
- **Leverage technology:** Gaps in provider capacity, the growing role of technology in daily life, and emerging expectations on providers to measure and report on quality necessitate new strategies to effectively use technology. States can use the [Technology First](#) framework, which considers technology first in a discussion of available support options.

Focus Area 1: Direct Support Professionals

Overview

GOAL: Direct support professionals are provided the training, tools, resources, opportunities for professional growth and advancement, as well as compensation and non-compensatory benefits, that help them be successful in providing high-quality HCBS to individuals with I/DD and encourage them to remain in the field.

People with I/DD receiving HCBS rely on [DSPs](#) to help them complete activities necessary to live, work, and be a part of their communities. Families of people with I/DD rely on the DSP workforce to provide

reliable, quality services and supports so they can work and have respite from the day-to-day stressors of caregiving. For the purposes of this report, “DSP” is used as an overarching term to describe all forms of paid care supporting people with I/DD to live in their own homes and participate in the community. DSPs also may be referred to as direct care workers, personal care attendants, and home health aides, within and across states.

More than ever, the DSP position includes an expanded variety of responsibilities and expectations. Beyond helping individuals with I/DD meet their basic daily needs, DSPs are expected to support individuals in pursuing what matters most to them in various aspects of their lives and ensure optimal community integration and independence. DSPs support individuals with I/DD in developing a sense of belonging, meaning, and purpose through the development of solid relationships and friendships and the attainment of work and other meaningful and valued roles in their communities. DSPs also help individuals with I/DD advocate for themselves by promoting decision-making and self-direction. They model behavior vital to societal inclusion of people with I/DD, including presuming competence and focusing on individuals’ unique skills and talents rather than deficits and needs.¹⁸

The DSP workforce is one of the highest in demand in the U.S. The average vacancy rate among HCBS provider organizations for DSPs is more than 20%.¹⁹ The expansion needed in this workforce is unlikely to take place without significant changes in how DSPs are recruited, trained, and supported. The pipeline for people entering the direct support profession is not keeping pace with the number of DSPs needed by Americans with I/DD and their families.

Typical Roles of a DSP

- Supporting engagement with the community by providing:
 - Support in less congregate and more individualized settings
 - Job coaching
 - Employment support
 - Transportation
- Providing caregiving and support with activities of daily living, including:
 - Medication administration
 - Mobility assistance
 - Wound care
 - Accessing food
- Working with the people they support to advocate for rights and services, such as:
 - Accessing resources and opportunities in the community
 - Working with the employer to customize job duties
- Using creative thinking for accommodations to help people with disabilities be more independent
- Providing emotional support

Key Challenges

The Committee identified complex policy challenges that warrant urgent and persistent federal action.

Shrinking supply and growing demand of DSPs

The population of adults aged 65 and older in the U.S. is expected to increase dramatically in the next 40 years. Similarly, the life expectancy of adults with I/DD is growing due to medical advances and improved living conditions. At the same time, the number of adults aged 18 to 64 — the potential pool

of both paid and unpaid caregivers — is expected to remain relatively stagnant. With current turnover rates exceeding 40% and average vacancy rates over 20%, the predicted increase in demand and stable supply of potential DSPs will exacerbate current shortages.²⁰

Lack of professionalization of the DSP workforce

Many people perceive that the DSP role is a low-skilled job and not a career. Despite the publication of [CMS's Final Competency Set for Direct Service Workers](#) in 2014 and the availability of [DSP-specific competencies](#) developed by [National Alliance of Direct Support Professionals \(NADSP\)](#), many states have yet to adopt these or any other competency standards that include the breadth and depth of areas that are expected of DSPs.

Further, no unique labor category exists to differentiate the DSP profession in the American labor market. A national inventory of professional categories known as the Standard Occupational Classification (SOC) system exists to collect data on trends in different U.S. labor categories and help employers and workforce systems plan how to recruit, pay, and retain workers in specific labor categories.²¹ Because there has never been an occupation code developed specifically for DSPs, there is currently no way to accurately collect employment and wage data specifically for DSPs. The lack of data projecting the demand and supply for DSPs makes it difficult to set appropriate wage levels for DSPs and to make sure there is an adequate pipeline of DSPs to meet demand.

DSPs often lack the specialized training that is necessary for their full success as a support to a person with a disability.²² Frequently, DSPs are pushed into supervisory roles without adequate management experience, training, or professional development. Providers face a number of challenges in offering training, including low reimbursement rates, varied work locations and hours, and high vacancy rates, making it hard to cover work shifts while DSPs attend training.²³ Research across other sectors proves that developing a credentialing structure has true potential for systemic impact and could facilitate increased training for DSPs.²⁴ Specifically, a credential may benefit the field by establishing DSP wage stabilization, increasing tenure, and improving the quality of HCBS provided.

HUMAN SPOTLIGHT

Meet BJ Stasio, New York

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's experience during the COVID-19 pandemic was that it exacerbated the challenges with DSP staffing to support his daily living. As a result, BJ was faced with a choice to either stay in bed or sleep in his chair to continue with his daily activities. He had to make the tough choice to sleep in his wheelchair for over two years during the pandemic so he could continue working. Currently, BJ has DSP services and is 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: "I am simply seeking a 'hand up' to live the life I want to lead, I'm not looking for a handout from the government."



INNOVATION SPOTLIGHT

Through the [National Alliance of Direct Support Professionals' \(NADSP\) E-Badge Academy](#), DSPs, and Front-Line Supervisors (FLSs) can get credit for competency by achieving stackable electronic badges, or e-badges, which can then be used to attain nationally recognized NADSP Certification. The E-Badge Academy provides practical, tangible, and demonstrable recognition of the knowledge, skills, and practices of DSPs and FLSs. Twenty-nine states across the country are enrolled in the E-Badge Academy. They have experienced its transformational impact. As a result of their deep commitment to their support staff, more than 10,000 professionals have had 118,700+ e-badges reviewed, with more than 4,220 applying those e-badges to achieve NADSP Certification.

Federal Policy Recommendations

Consistent with the [2017 Report to the President](#) on the DSP workforce and aligned with several recommendations outlined in the Bipartisan Policy Center's [2023 Report on Addressing the Direct Care Workforce Shortage](#), the committee offers the following federal policy recommendations:

Recommendation 1.1: Develop a professional career pathway for the DSP workforce

Create a unique professional identity and labor category recognizing DSPs. The U.S. Department of Labor (DOL) via the Bureau of Labor Statistics should recognize “direct support professional” as a distinct occupation title within the next update of the SOC system and provide routine labor statistical reporting on this occupation.²⁵ Because the SOC system is only updated every few years, DOL should work with OMB to determine the quickest route to implement this new occupational title. The DSP occupation should be tracked in federal systems and data collections (e.g., SOC, Occupational Information Network (O*NET), Occupational Employment and Wage Statistics (OEWS)) to improve the accuracy of DSP workforce data.

Establish national professional standards. Under the [Direct Service Workforce Core Competency Project \(2011-2014\)](#), CMS provided states with general guidelines on the basic experience and skills DSPs should possess. The federal government should expand on this initial work by offering cross-systems guidance on provider qualifications and DSP competencies that reflect the current service landscape. Specifically, CMS should ensure through regulation and review of Medicaid HCBS programs that states identify provider qualifications that recognize DSPs as skilled practitioners who serve as community navigators, facilitating greater community and economic involvement for people with I/DD.

Develop national career ladders and credentialing opportunities. In 2010, DOL's Employment and Training Administration (ETA) approved [national guidelines for apprenticeship](#) standards for DSPs. These standards enable employers to use ETA's Registered Apprenticeship program to train DSPs in the long-term care sector of the health care industry. ACL and CMS should develop federal standards and work with DOL to implement specialized credentials and professional development opportunities for DSPs, ensuring that (a) people with intellectual disabilities are trainers and mentors, (b) programs are focused on competencies specifically identified for DSPs, (c) completion of training to meet standards is voluntary and occurs post-hire; and (d) that the credentials result in increased wages and access to benefits for DSPs.

Recommendation 1.2: Build a robust DSP pipeline for the future

Initiate and advance wage parity. CMS should ensure that states include living wages and compensation packages in their DSP rate-setting methodologies for LTSS to people with I/DD. Additionally, CMS should ensure through reviews of states' Medicaid HCBS programs that compensation rates include a living wage and benefits and reflect the appropriate status, value, and respect for DSPs.

Engage federal and state-level workforce and economic development initiatives. The U.S. Department of Education (ED) and DOL should engage the broader American workforce system to find solutions to this crisis by partnering with community colleges and using American Job Centers to develop and invest in career training and credentialing for DSPs.

Enhance marketing and recruitment to expand the pool of workers. ED, HHS, and DOL should focus on expanding the nation's pool of DSPs by:

- Issuing joint guidance discussing how states can use funding vehicles through the American Job Centers, Community Colleges, and Temporary Assistance for Needy Families (TANF) systems to accelerate and expand investments focused on building a Direct Support Professional career pathway.
- Providing training and technical assistance to state Developmental Disabilities agencies (DD agencies) to reduce DSP vacancy rates, improve retention, and promote efficient, high-quality long-term services and supports for people with I/DD.
- Sponsoring a national education and marketing campaign to promote awareness about the DSP profession and encourage greater participation by people with disabilities, men, retirees, and young adults across diverse racial, ethnic, and cultural groups. The [College of Direct Support](#) provides courses for staff who serve individuals with I/DD and could serve as a campaign partner or leader.

Recommendation 1.3: Diversify workforce solutions to adequately meet the growing demand for HCBS

Leverage technological solutions. ACL should provide technical assistance to states to promote the use of technology solutions in LTSS, such as remote monitoring, sensors, robotics, and smart homes to create efficiencies, reduce costs, and support community living for people with I/DD. CMS should issue guidance on the balanced use of remote monitoring technology that prioritizes the safety and privacy of individuals with disabilities and develop criteria for states to apply in implementing, funding, and monitoring this technology in home and community-based settings receiving Medicaid funding.

Offer guidance and technical assistance to ensure strong self-directed service delivery models. HHS should offer guidance and technical assistance to support individuals self-directing their care in Medicaid HCBS programs. Guidance should focus on:

- Awareness of how family, friends, and neighbors can be hired as DSPs under self-directed service delivery models.
- Promising practices for making self-direction a flexible, easy, and effective service delivery option for individuals with I/DD and their families.
- Clarification on what individual budgets can fund, use of resources to support the individual with I/DD in accomplishing the goals they have articulated in their person-centered plan, and how states can allow funding for planning and service coordination under individual budgets.
- Strategies to develop and offer training to ensure paid caregivers acquire the skills and qualifications to effectively support individuals with I/DD.
- Recommended standards and training programming for individuals with I/DD self-directing their services on their role as employers in achieving their personal goals while creating a supportive working environment for their DSPs.
- Key protections that should be put in place to prevent any individuals receiving HCBS from being coerced to choose one service delivery model (self-direction or traditional provider models) over the other.
- Recommendations for states to support DSP innovation, develop new service delivery models for providing HCBS, and expand self-directed service delivery models in HCBS programs.

Focus Area 2: Employment

Overview

GOAL: All individuals with I/DD have opportunities to meaningfully engage within their communities and have access to the appropriate supports and strategies to achieve and sustain competitive integrated employment (CIE).

Employers that hire workers with disabilities experience benefits, such as increased innovation, improved productivity, and enhanced reputation; however, rates of competitive integrated employment among people with disabilities remain low.²⁶ According to the American Community Survey, people with disabilities are less likely to work (40%) than their peers without disabilities (74.3%).²⁷ Compared to all people with disabilities, people with cognitive disabilities are even less likely to work and more likely to live below the poverty line. Almost two-thirds (65%) of the individuals in poverty long-term are people with disabilities.²⁸ In the U.S., individuals with disabilities who work full-time year-round are paid less than comparable individuals without disabilities.²⁹ Under- and unemployment of people with disabilities creates a significant economic burden while neglecting the myriad of benefits to employers that are gained by CIE.

Most people with I/DD express a desire to work in CIE, though only a minority of them have an opportunity to do so. According to the 2021-2022 National Core Indicators Survey, 16% of working-age adults supported by their state I/DD agency had a paid job in the community, while 47% of respondents did not have a job and wanted one.³⁰ Similarly, only about 1 in 5 people who receive employment or day services from a state I/DD agency received support to work in an integrated job.³¹ For individuals in day services who are not employed, 32% of respondents participated in facility-based non-work activities and 17% in community-based non-work, the latter of which is defined as individually chosen and scheduled activities for people with I/DD at locations in the community that people typically participate in and access.³²

Employment First is a national framework that emphasizes that all individuals are capable of CIE and prioritizes CIE for people with I/DD.³³ Many states signed Employment First legislation or executive orders to promote Employment First. The federal government offers individuals with disabilities greater opportunities for workforce participation, but individuals with targeted disabilities, which include [developmental disability and intellectual disability](#), still experience lower workforce participation rates. Among the more than 2.7 million federal employees reported in FY 2018 U.S. Equal Employment Opportunity Commission (EEOC) MD-715 reports, 259,164 (9.42%) were individuals who reported having a disability. Of those with a disability, only 46,383 (1.69% of the total workforce) had a targeted disability.³⁴

Key Challenges

Lack of adequate publicly-funded employment supports

Some state and federal agencies have not consistently prioritized employment in funding or practice. For example, although participation in sheltered work has declined, more Medicaid HCBS funding is spent by states on day habilitation and sheltered work than supporting individuals with I/DD in CIE. Through Medicaid HCBS programs, state and federal governments spend approximately \$500 million per year on day programs while spending slightly above \$100 million per year to support people with disabilities to participate in CIE.³⁵ Additionally, many state Medicaid HCBS programs do not provide adequate customized employment supports despite more than two decades of documented evidence. A lack of resources, education, access to benefits planning, and wrap-around supports can lead to family discouragement around employment.

Limited private-sector employment opportunities

Private-sector employment opportunities are lacking for individuals with I/DD in the nation's economic mainstream.³⁶ Lack of employer engagement is an often-overlooked cause of underemployment.³⁷ Employers who have significantly and intentionally invested in building a diverse and inclusive workforce often recognize that hiring persons with disabilities is a cost-effective way to build an inclusive workforce that is representative of the business's customer base, and that individuals with significant disabilities are an asset to the company — not a risk. People with disabilities offer diverse skill sets and unique insights that can help shape design and development for industry, resulting in products and services that appeal to a broader market share. Employers may need help funding the supports that workers with I/DD need to be successful in their employment (for example, embedding of job accommodations, customized employment practices/strategies). There is a lack of funding to scale and sustain inclusive apprenticeship, internship, and integrated work-based learning opportunities for individuals with I/DD. There also is a lack of sustained funding streams to cover additional specialized training and continual on-the-job supports (like job coaching, when not otherwise funded). Another barrier may be a lack of employer familiarity with federal antidiscrimination requirements, such as the obligation to provide reasonable accommodations absent undue hardship and the prohibition on discriminating against those who need such accommodations.³⁸ Greater employer awareness of the availability of low and no-cost job accommodations, such as HCBS-funded job coaches, could contribute to increased CIE. Finally, another barrier to employment is the fear many employees with I/DD and their families have that income from a job will jeopardize their eligibility for health care and other essential benefits. Employers, families, and self-advocates require long-term benefits planning support to help navigate various rules and regulations to ensure that workers with I/DD can earn and save optimally without being penalized or losing critical LTSS.

Little emphasis on promoting entrepreneurship and small business development

More emphasis is needed on promoting entrepreneurship and small business development among individuals with I/DD. According to a report by the National Disability Institute, approximately 1.8 million individuals with disabilities are business owners.³⁹ Entrepreneurship is a viable path to employment for many Americans, including individuals with disabilities. To achieve economic prosperity and independence, Americans with disabilities turn to self-employment and small business development at a rate that is nearly twice that of people without disabilities.⁴⁰ However, several barriers persist for people with I/DD in starting and growing their own businesses, including a lack of targeted technical and programmatic assistance as well as outdated attitudinal norms. Additionally, there is a lack of federal investment in training, funding, and programming, as well as a lack of data focused on entrepreneurs with disabilities.

INNOVATION SPOTLIGHT

Developing Inclusive Programs – Food Bank of Delaware

In partnership with the Delaware Restaurant Association and Delaware Department of Labor, the Food Bank of Delaware has initiated a new Kitchen School program offering free specialized training designed to provide employment opportunities for adults with disabilities in the food service and hospitality industries. The 12-week curriculum has been developed to include group instruction and individualized training in the Food Bank's industrial kitchens. Students will spend eight weeks in the Food Bank's industrial kitchen, an additional four weeks will be spent transitioning to permanent employment through on-site job coaching. The first cohort of students graduated from the program in January 2023. The Food Bank's professional chef instructors and job coaches train students to enter food-service workplaces, teach students kitchen safety, provide hands-on cooking skills training, teach sanitation procedures, and provide students an opportunity to earn a ServSafe® Food Handler Certification. Staff also provide instruction in soft skills and employer expectations using national industry-based guidelines and curriculum. Students receive support and develop an individualized plan needed to enter a workplace, including transportation options. Kitchen School staff then assist students in finding partner employers whose needs match student strengths and help the transition into a permanent workplace. Additionally, Kitchen School staff provide support to students and employers for at least one year after graduation. The Food Bank of Delaware also built an infrastructure that supports employing individuals with I/DD. Through a Specialized Training Employment Program (STEP), the Food Bank of Delaware integrated adults with disabilities into the workforce and are witness to the many benefits throughout the entire organization. STEP Leads are job coaches employed by the Food Bank that provide observation, oversight, and support to the team members to ensure their success.

“Everyone deserves a chance for success, and this program provides a path forward for a population that wants to work, is excited to work, and can be a contributor to the workforce in a big way.”

– Cathy Kanefsky, President & Chief Executive Officer, Food Bank of Delaware

HUMAN SPOTLIGHT

Working with a Job Coach – Paul's Story

For 16 years, beginning when he was in high school, Paul worked as a cart attendant at a store in Beloit, Wisconsin. In his job, Paul gathered stray carts from the parking lot and made sure the cart bays at the front of the store were full. Occasionally, he also greeted customers. Paul, who has intellectual and developmental disabilities and is deaf and legally blind, worked with the assistance of a job coach, who did not perform Paul's job duties but instead helped him stay focused, so he could perform his tasks. The employer never had to pay for the job coach's services. Paul consistently received pay raises and positive reviews that noted his honesty, integrity, and great attendance.

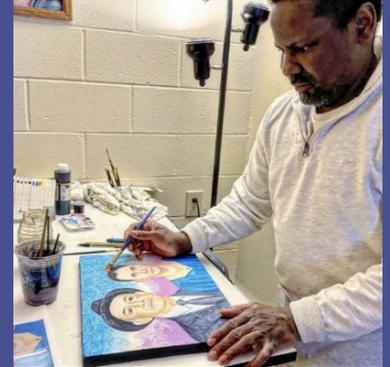
The employer fired Paul when a new manager had issues with his use of a job coach. Paul and his foster parent and guardian, Rose, reported what happened to the U.S. Equal Employment Opportunity Commission (EEOC), which after an investigation and conciliation, filed a lawsuit alleging that when the employer failed to accommodate Paul's disabilities and fired him, it violated the Americans with Disabilities Act (ADA). A jury found that the employer violated the ADA and should pay Paul \$5 million in punitive damages and \$200,000 in compensatory damages. Later, the court reduced the punitive damages to \$100,000. Paul also received more than \$122,000, including for lost wages. Rose later remarked, “Why wouldn't a person with a disability be able to have a job coach, if that's what they need to do the job?”



HUMAN SPOTLIGHT

Meet Alton

Alton started drawing when he was 14 years old. While art was always fun for him, his time at a day program in the 1990s allowed his creative passion to grow and his skills to develop. The staff in this program fostered Alton's talent and helped him learn new art techniques. After taking abstract art classes at Rhode Island School of Design and business classes on self-employment through the Rhode Island Developmental Disabilities Council (RIDDC), Alton expanded his art into portraits and began to promote his work. In 2019, he founded his own business, Alton Stuckey Portraits & Beyond, with help from an RIDDC grant. He uses his self-directed supports to fund production, distribution, and sales tracking. Today, Alton sells his multimedia artwork of people, pets, landscapes, and seascapes online, at art shows, and through his church. He advocates for more self-employment programs to help others start their own businesses. His advice to others is to tell people they can do it and don't give up!



Federal Policy Recommendations

The PCPID offers the following recommendations to support the advancement of individuals with I/DD in achieving and maintaining CIE:

Recommendation 2.1: Build employer capacity to recruit and retain workers with I/DD

Establish a national clearinghouse of employer resources. Employers require information they can easily access via a coherent and cohesive platform about strategies, available supports, and promising practices for successfully employing people with I/DD. This specialized clearinghouse could be integrated into an existing online platform housed by a federal agency administering disability employment programs, such as [ODEP's CIE Resources for People with Disabilities and Their Families](#).

Increase access to inclusive apprenticeships, internships, and work-based learning opportunities. Use resources across federally funded transition, Medicaid HCBS, vocational rehabilitation, and workforce development programs. An inclusive apprenticeship program is an apprenticeship program designed to be accessible to and inclusive of all candidates, including people with disabilities. Inclusive apprenticeship programs provide opportunities for people with disabilities, including individuals with cognitive, neurological, physical, mental health, and sensory disabilities, to gain credentials and skills to succeed in their desired careers. While several federally funded systems have some funding and programmatic resources to support inclusive apprenticeships and work-based learning opportunities, many of these programs are fragmented and disjointed. Guidance to support state and local governments in effectively using resources across various systems and initiatives is critical to expanding access to these opportunities for individuals with I/DD.

Offer and use federal tax incentives to encourage employers to hire, support, and retain workers with I/DD through customized employment, job carving or matching, supported employment, and job accommodations. Identify and point employers to existing tax incentives for hiring workers with disabilities. Federal tax policies provide incentives to employers that hire people with disabilities and encourage businesses to make worksites more accessible for both employees and customers. The current tax incentives, including the Work Opportunity Tax Credit, the Disabled Access Credit, and the Architectural and Transportation Barrier Removal Deduction, all of which are directed to people with disabilities, are underutilized. Reasons for this underutilization include a general lack of awareness by businesses that these incentives exist and the lack of employer motivation to take advantage of these financial incentives. Support the development of outreach efforts to employers about workplace accommodations and available federal tax incentives. Offer additional targeted federal tax incentives to encourage employers to hire, support, and retain workers with I/DD through customized employment,

job carving or job matching, supported employment job supports (e.g., job coaches), and accommodations.

Strengthen existing efforts to prevent and eliminate workplace discrimination against individuals with I/DD. This includes not only active enforcement of the ADA, Sections 501 and 503 of the Rehabilitation Act, and other antidiscrimination laws protecting individuals with I/DD but also more targeted outreach and education, including information about providing workplace accommodations, if needed, to individuals with I/DD, such as permitting job coaches to accompany workers on the job. Technical assistance, training, and outreach could help job applicants, workers, and employers understand their rights and responsibilities in the workplace.

Engage employers about the business benefits of hiring workers with disabilities. Sponsor a national marketing campaign to educate employers and offer technical assistance and training to support the successful employment of workers with I/DD in the economic mainstream. Focus the campaign on supporting employers in providing reasonable accommodations to individuals with I/DD. Provide training for employers on the benefits of job coaches and how to integrate employees with job coaches into their workforce. Increasing employer awareness about the cost-savings and effectiveness of providing workplace accommodations is critical to advancing disability employee workplace inclusion. Establish requirements among federal contractors to establish required organizational awareness, engagement of human resources, and employee training to establish best practice cultural norms around disability inclusion in the workplace.

Recommendation 2.2: Establish and invest in a federal CIE policy

Issue an executive order in the first 100 days of the publication of the PCPID report to establish a federal policy to promote CIE for individuals with I/DD. Key provisions of the executive order would include:

- Increase the existing Rehabilitation Act of 1973 Section 501 rules requiring each federal agency to adopt the goal of having 12% of its workforce be people with disabilities, and 2% of its workforce be people with targeted disabilities to 15% and 5%, respectively, and identify and mitigate barriers to meeting the current and future targets.⁴¹
- Invest in a federal hiring campaign focused specifically on individuals with targeted disabilities (including I/DD).
- Increase investments in specialized training and outreach designed to serve the needs of individuals with I/DD, for example, on providing reasonable accommodations in the workplace or offering cognitively accessible training on entrepreneurship from the Small Business Administration (SBA).
- Improve coordination to meet the needs of tribal communities, expanding on current efforts of DOL, ED, and the White House Initiative on Advancing Educational Equity, Excellence, and Economic Opportunity for Native Americans and Strengthening Tribal Colleges and Universities.

Prioritize CIE as the preferred outcome of employment services. Federal agencies should review their policies to advance competitive integrated employment for various publicly funded systems (e.g., state Medicaid HCBS programs, state vocational rehabilitation resources, Individuals with Disabilities Education Act (IDEA) Part B transition funding, and employment and training funding distributed through state workforce development agencies and American Job Centers). As such, federal agencies overseeing these programs should invest in sustained capacity building and scalability of education, vocational rehabilitation, HCBS, and workforce system providers to expand the availability of evidence-based practices that [lead to CIE for workers with I/DD](#) (for example, customized employment and individualized supported employment). Issue additional guidance on how to best support individuals with I/DD who have the most significant disabilities and highest support needs in solidifying CIE and integrated work-based learning opportunities.

Include additional investments in the president’s budget focused on CIE outcomes for Native Americans and Alaska Natives with I/DD living in or near Indian Country and Alaska Native Villages. HHS, through the Indian Health Service and in coordination with the Bureau of Indian Affairs, should conduct a needs assessment of tribal nations related to unmet needs among individuals with I/DD living in or near Indian country and Alaska Native villages. The data and information collected because of this assessment can be shared with tribal nations and used to develop future laws, policies, and procedures to address those unmet needs. The PCPID recommends proposing in the President’s Budget funding for a cross-systems federal demonstration grant for up to 20 tribes (\$2 million per year for five years) to pilot the creation and establishment of protection and advocacy offices to advance disability rights. The purpose of the funding is to seed the creation of HCBS for individuals with I/DD and other disabilities for communities that have limited access to them. The offices should also focus on promoting inclusive education, school-to-work transition programs within the tribal government, workplace development to better accommodate I/DD, including workplace advocates to help programs understand and accommodate employees with disabilities, in-home services and assistance, purchasing of accommodation devices (speech technology, hearing assistance, mobility devices, etc.), etc. An emphasis on self-determination programs and strategies that are informed and co-created with self-advocates works best.

Recommendation 2.3: Build the capacity of entrepreneurs and small business innovators with I/DD

Provide federal funding to support training, technical assistance, and resources to specifically aid small business owners and entrepreneurs with I/DD. Use inclusive apprenticeship programs to help entrepreneurs with disabilities shadow and learn from other business owners either inside or outside their sector. 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 to promote and encourage greater investments in small business ideas and entrepreneurs with I/DD.

Establish a dedicated role to support entrepreneurs with disabilities. Support Congressional efforts to pass bipartisan legislation introduced in late 2023 (the Supporting Disabled Entrepreneurs Act) and/or similar administrative actions via SBA to establish a coordinator for small business concerns unique to entrepreneurs with disabilities 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.

Focus Area 3: Community Living

Overview

Housing

GOAL: All individuals with I/DD can easily access affordable, accessible, and durable housing options in their communities of choice.

There are many policy and programmatic barriers that result in people with I/DD struggling to secure safe, affordable, accessible, and integrated housing. While ACL, the Assistant Secretary for Planning and Evaluation (ASPE), CMS, the U.S. Department of Housing and Urban Development (HUD), and the Substance Abuse and Mental Health Services Administration (SAMHSA) fund the [Housing and Services Resource Center \(HSRC\)](#), more federal support and collaboration is needed to address housing challenges. Although the Money Follows the Person demonstration supports some state Medicaid programs to assist Medicaid beneficiaries to transition from institutions into community living, further housing challenges remain. Lack of supply, rising prices, significant housing-related discrimination,

outdated programs and practices, and a lack of coordination among funding systems all pose major barriers.⁴² As people with I/DD leave their family homes, they frequently have no options other than group homes that are typically owned or leased by provider agencies. People in those settings may have little control over where and with whom they live, the services they receive, or the routines of daily life. For example, 54% of respondents to the 2022-2023 National Core Indicators-Intellectual and Developmental Disabilities (NCI-IDD) Report shared that they had a choice or some input in choosing where they live if not living in the family home. In addition, 30% of respondents in group settings reported input in choosing their housemates and 51% of respondents in group settings reported having choices in life decisions, including choice of residence, work, day activity, staff, and roommates.⁴³

The recognition that people with I/DD belong and have every right to live in the community has led to growing demand for community-based housing that meets individual choices. This demand is fueled in many ways by individuals choosing to leave institutional settings, by young adults attending inclusive schools, and by adults with I/DD who live with aging parents and family members. However, because people with I/DD are living in, or at significant risk of living in, poverty, housing of their choosing is often out of reach. With many relying on Social Security or Supplemental Security Income (SSI) benefits as their primary or sole source of income, they are generally priced out of housing markets across the country.⁴⁴

Safety

GOAL: All individuals with I/DD are able to receive the tools, training, education, and supports necessary to preserve their safety and welfare and pursue optimal health and well-being.

Individuals with I/DD should be able to safely live in their communities and obtain the skills, supports, and resources that prevent abuse and criminal victimization. However, individuals with disabilities are more likely to experience abuse than people without disabilities. Reasons for this include living in an isolated or segregated environment, fear of reporting abuse and experiencing retaliation, lack of communication access, and obstacles to reporting abuse, such as lack of knowledge on cognitive disabilities.⁴⁵

With the increased demand by people with I/DD to live in the community and trends in LTSS delivery in the community, it is vital to have strong community monitoring systems. However, there are many challenges, including some states not [reporting critical incidents properly](#) and staff lacking access to appropriate data for trending and tracking incidents. This may begin to be addressed in Medicaid given the CMS final [Ensuring Access to Medicaid Services Rule](#), or Access Rule. The Access Rule requires states to operate and maintain an electronic incident management system to identify, report, investigate, and resolve incidents regarding individuals receiving HCBS. However, it is also vital to have training resources for individuals with I/DD to know how to recognize and report abuse or when they have been a target of a criminal act. Similarly, responsive services, including the criminal justice system and survivor programs, need to know how to support people with I/DD if they have experienced abuse or are a target of a criminal act.

Technology Support

GOAL: All individuals with I/DD can easily access any personalized technological supports necessary to live, work, communicate, and thrive in typical community life, including but not limited to virtual, enabling, and augmentative technologies.

Technology provides access to employment opportunities, communications, human interactions, information dissemination, and tools for making life easier. Many people with disabilities consider technology a lifeline and a necessity for accessing all aspects of community life. Unfortunately, public policy has not kept pace with technological advances, and individuals with I/DD may face many

administrative and bureaucratic hurdles to accessing various technological supports they need to achieve optimal inclusion, independence, and personal autonomy.

Transportation

GOAL: All individuals with I/DD are able to acquire accessible, affordable transportation options to ensure they can accomplish their goals and fully engage in work, recreation, and community life while also achieving optimal independence and freedom.

Adults with I/DD require transportation to participate in work and leisure, access health care and other services, achieve optimal independence, and be fully included in the community. Many individuals with disabilities are unable to utilize public transportation due to lack of reliability, long rides, loud noises, or the behaviors of other passengers.⁴⁶ Without adequate individualized transportation options or cognitively accessible supports to access transportation, the reality of independent living and community inclusion remains out of reach for many people with I/DD. Many people with I/DD may also be unaware that their health insurance may cover non-emergency medical transportation (NEMT). Educating people on their benefits will allow them to access the transportation options available to them.

Key Challenges

Housing

Several policy challenges continue to impede access to affordable, accessible, and durable housing options for individuals with I/DD:

Systems navigation

Housing assistance and Medicaid HCBS programs typically lack cohesion and coordination. At the policy and programmatic levels, it can be extremely difficult to understand the different rules and requirements for accessing services. Support for individuals with I/DD and their families to figure out how best to use and combine services and resources available from both systems is lacking.

Lack of affordability

The high cost of living makes owning a residence or living independently for people with I/DD nearly impossible. Some people with I/DD are both employed and receive SSI and yet they still cannot afford a place of their own.⁴⁷

Exclusion from desirable areas

Individuals with I/DD are often unable to secure affordable and accessible housing options in desired areas (e.g., safe and accessible areas with low crime rates that are near publicly accessible transportation hubs).⁴⁸

Lack of information about housing during the transition process

Few school transition programs offer information resources or options for exploring housing opportunities for adolescents with disabilities. Transition activities must start earlier to help youth with disabilities access independent living and supportive housing opportunities.

Segregated communities, zoning restrictions, and discrimination

Settings created exclusively for people with I/DD or other disabilities do not promote true inclusion and serve as a barrier to community living. In addition, zoning restrictions limit the availability of housing options that could provide additional types of community living, such as accessory dwelling units, small group homes, and accessible multifamily construction. Individuals with disabilities also face discrimination from landlords in violation of civil rights laws.

Safety

Inconsistent regulations to protect individuals with I/DD

Federal and state efforts to protect individuals with I/DD from harm, physical and emotional abuse, or exploitation in their homes or places of residence and in any community setting are often inconsistent and fragmented. The federal government recently addressed the lack of national standards for adult protective services (APS) entities by publishing the [first federal regulation for APS](#) in May 2024. This is the first step toward creating federal guidelines for how APS entities should approach, engage with, and support individuals with disabilities who are at risk of or experiencing abuse or neglect.

Higher risk of spreading health conditions

Adults with I/DD are at higher risk of becoming susceptible to getting sick when they are required to attend congregate day programming when there is a situation like the flu or COVID-19 epidemic. Despite this knowledge, opportunities for individuals with I/DD to use HCBS funds in support of more individualized, integrated day activities are limited.

Lack of emergency preparedness training for providers

Local and state emergency response planning entities often lack sufficient understanding, knowledge, coordination, and commitment regarding durable and accessible accommodations for persons with I/DD and other disabilities during times of public emergency and natural disaster.

People with I/DD need more knowledge about safety protocols in their homes and natural surroundings and how to take care of themselves during an emergency.

Limited access to health and safety education

Additionally, people with I/DD need more training regarding their own bodies, what is appropriate touch, and how to advocate for themselves when they feel unsafe or like their voices are not being valued/heard. They also need resources related to financial exploitation or social media and/or web-based abuse.

Unfortunately, most health and safety education programs available across the lifespan are not accessible or tailored for individuals with I/DD.

Technology Support

Limited access to technology

Many individuals with I/DD lack sufficient access to remote or virtual supports, assistive technology (AT), and other enabling technologies, tools, and strategies. Access is inconsistent and fragmented across local communities and states. This lack of access creates major barriers to effectively communicating with and engaging people with I/DD. People with I/DD need to [learn how to use AT as early as possible](#), but unfortunately, many early childhood programs and schools do not proactively educate families and provide options for AT during individualized educational planning.

Limited funding to support technological advancements

An individual's technology needs change throughout their lifespan, and devices break or become outdated; federal and state funding is needed to support these changes over time. There are only a few durable medical equipment and AT refurbishment or replacement programs covered by Medicaid HCBS programs at the state level, but those that exist are quite successful in terms of improving access for beneficiaries and simultaneously reducing costs to Medicaid programs (e.g., Oklahoma, Kansas, and South Dakota). Channeling funding to these programs and expanding them to other states will ensure improved access to recent technological advancements nationwide.

Disparities in accessible communication

Antidiscrimination laws require forms of communication with the public be made available in plain language for people with disabilities, including in simplified language for individuals with I/DD. Unfortunately, ensuring materials are truly accessible for all individuals with I/DD in the public domain has been challenging.

Transportation

Lack of accessible transportation

Although public transit systems are generally required to be accessible, even today, there are major gaps in the availability of accessible transportation options for people with disabilities. For example, individuals may not be able to drive because of visual or cognitive impairments and public transportation may either be unavailable or in an inconvenient location.

Lack of training for navigating public transportation

Some individuals with I/DD rely on public transit and need training to successfully navigate public transit options. There are very few, if any, supports to teach people with I/DD how to use public transit, which leads to individuals with I/DD unable to access public transit independently.

Limitations on the use of NEMT

Although NEMT can be very useful for accessing health care services, Medicaid payment rates for NEMT can be limiting in terms of market value and restrictive in terms of use. Although CMS issued a [new NEMT reimbursement policy](#) in 2023, some individuals may still experience long wait times and distance limits on trips.

INNOVATION SPOTLIGHT

Living Well Rights Guides– Wisconsin Board for People with Developmental Disabilities (WPDD)

The Wisconsin Board for People with Developmental Disabilities (WPDD) has introduced the [Let's Talk About Rights Guides](#) and the [Know Your Rights Video Series](#), both designed to empower individuals with I/DD and train provider staff and families on the rights of individuals and how they can exercise those rights. Developed in collaboration with self-advocates, families, and professionals, these resources aim to enhance understanding and self-advocacy. The Let's Talk About Rights Guides cover topics such as decision-making, personal freedoms, health care rights, and safety. They provide practical advice on planning, understanding one's rights, and accessing necessary supports. The Know Your Rights video series complements the guides with engaging, accessible content that illustrates key rights, emphasizes the importance of self-advocacy, and encourages proactive participation in one's own life decisions. After implementing these resources at eight pilot provider sites, participants reported increased awareness of choices, rights, and opportunities for individuals with I/DD. Together, these tools foster greater independence and community inclusion for individuals with I/DD, ensuring they are well-informed, well-equipped, and confident in exercising their rights.

HUMAN SPOTLIGHT

Finding Home

["Finding Home \(Kansas\)"](#) (5 mins) is an MFP Rebalancing Demonstration participant video from rural Kansas that documents the transition of a young woman from an intermediate care facility for individuals with intellectual disabilities (ICF/IID) to community placement and the use of HCBS.

Federal Policy Recommendations

The PCPID offers the following recommendations to support individuals with I/DD in community living that promotes adequate housing, safety, technology, and transportation.

Housing

Recommendation 3.1: Launch a national housing education and awareness campaign

Launch a national housing education and awareness campaign on the negative impacts of rent increases. This should be a HUD/HHS campaign that incorporates the learnings from the [CMS Innovation Accelerator Program \(IAP\)'s Medicaid-Housing Related Services and Partnerships](#) and the [Housing and Services Resource Center \(HSRC\)](#) led by ACL, CMS, and HUD. The campaign should disseminate information to local governments, recipients under HUD's [Fair Housing Initiatives Program \(FHIP\)](#) or [Fair Housing Assistance Program \(FHAP\)](#), housing providers, and housing advocacy organizations about how rent increases decrease housing options for and negatively impact people with I/DD in relation to the federal subsidies they receive from housing vouchers and housing supports received under Medicaid HCBS.

Recommendation 3.2: Use funding to improve access to housing

Issue a joint funding announcement for HUD grant recipients. Using funding appropriated by Congress, HUD/HHS, in collaboration with the Department of Transportation (DOT), should issue a joint funding announcement for HUD grant recipients to collaborate and partner with state councils on developmental disabilities (DD councils) and centers for independent living (CILs) to help people with I/DD and other disabilities find roommates, affordable and accessible places to live, and well-trained DSPs in their local communities to assist them in participating fully in the community.

Designate funding to launch a joint grant program that incentivizes land use and zoning reforms. Funding should be provided to support HUD and ACL in launching a joint grant program (for example, planning grants or incentives for affordable housing construction and rehabilitation) that incentivizes land use and zoning reforms aimed at increasing density that facilitates the siting and development of accessible, affordable housing, particularly near transit hubs.

HHS, HUD, and ED issue joint guidance to educate individuals with I/DD on housing and HCBS options. ED's Office of Special Education and Rehabilitation Services (OSERS), HHS, and HUD should issue joint guidance that incorporates information on housing, financial/benefits planning, and HCBS into the transition planning component of the individualized education program (IEP) processes, to increase youth and family awareness of different housing and HCBS options available to individuals with I/DD. This joint guidance should include information on civil rights protections and enforcement options available to assist individuals facing barriers to home and community-based services.

Increase funding for fair housing for individuals with I/DD. The president's budget should include an increase in budgetary resources for HUD to create targeted, fair housing testing programs aimed at identifying patterns of discrimination against individuals with I/DD and developing enforcement priorities and guidance. Additional guidance could include suggested guidelines regarding factors to consider in determining the percentage or number of housing units that should be made accessible in all new developments. HUD could also provide additional technical assistance to housing choice voucher administrators regarding existing program flexibilities to provide increased subsidies and other support.

Safety

Recommendation 3.3: Promote regulations that increase protections for individuals with I/DD

Conduct studies that will strengthen APS to assure greater expediency and success of complaint, investigation, and oversight processes. ACL should conduct studies analyzing trends and differences in state APS infrastructure, highlighting promising practices, systemic areas of concern,

and suggested systemic-level remedies to ensure regulations are effectively implemented. The study should also include stories from self-advocates with disabilities and their families.

Strengthen emergency preparedness processes. Congress should amend the Public Readiness and Emergency Response Act (PREP Act), and subsequent regulations issued by HHS should ensure that Medicaid HCBS providers and federally funded consumer-led organizations, including DD councils and CILs, are required partners in state and local emergency planning processes. The U.S. Department of Homeland Security should collaborate with the U.S. Department of Justice (DOJ) and HHS to issue technical guidance to emergency response systems that defines durable accommodations and suggests service coordination/referral processes to assure that individuals with I/DD and their families have access to the information and are connected to the resources they need across systems. State DD services should also communicate with DD services in other states to provide supports for people with I/DD who may need to move to another state due to a natural disaster.

Recommendation 3.4: Strengthen knowledge, education, and awareness of issues impacting individuals with I/DD

Conduct studies on how the COVID-19 PHE impacted HCBS for individuals with I/DD. HHS should conduct studies, including outreach to partners such as DD councils, university centers for excellence in developmental disabilities (UCEDDs), protection and advocacy systems (P&As), CILs, and local and state self-advocacy groups, on lessons learned from the COVID-19 pandemic as it relates to the provision of HCBS specific to individuals with I/DD. The study should focus on 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 PHE. The study should include geographic diversity (rural, suburban, urban) and provider diversity (adult day care, day habilitation, assisted living, group home, supportive housing, supported living, etc.) to provide a landscape of unique challenges based on geography and/or provider type.

Ensure access to health education tailored for individuals with I/DD among school and Medicaid HCBS settings as well as state and local self-advocacy groups: The education should include learning about their bodies, including body parts and functions, privacy, learning how to say “no,” understanding what is appropriate, and being able to tell someone about unwanted contact without fear of retaliation. This requirement should be incorporated into IEPs and states would consider incorporating health education into the person-centered service planning process pursuant to the needs and preferences of the individual.

Technology Support

Recommendation 3.5: Revise federal regulations and guidance to promote technology advancements for individuals with I/DD

Offer technical assistance to local education agencies (LEAs). ED should offer technical assistance to LEAs and increase monitoring activities to ensure the [department’s January 2024 AT guidance](#) is implemented with fidelity.

Provide guidance on the importance of technological upgrades. CMS should issue guidance that includes promising practices related to establishing durable medical equipment and 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. Such efforts may require multiple policy communications, given the cross-cutting implications for Medicaid, Medicare, and Children’s Health Insurance Program (CHIP) programming. For example, guidance urging states to provide coverage of alternative communication technologies and devices for children under the age of 18 would be beneficial to assuring children with disabilities who cannot rely on speech to communicate can access effective communication and are engaged meaningfully in their home life, schools, and communities.

Increase HHS Office for Civil Rights and DOJ enforcement activities. The increase in enforcement activities should ensure accessibility gaps are addressed to promote inclusive community living options for people with I/DD.

Issue additional guidance on communications accessibility. HHS should issue additional sub-regulatory guidance on Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act regarding the use of plain language as a reasonable modification in communications (virtual, written, audio, etc.) so that individuals with I/DD are able to understand and engage in decisions regarding their HCBS.

Recommendation 3.6: Require all federal funding recipients to provide augmentative and alternative communication (AAC) as an auxiliary aid or service

Adopt a common framework for AAC. The federal government should adopt a common framework for AAC to make clear its meaning and the indisputable role it plays in the lives of people who require it to communicate. Guiding statutory language and regulations defining AAC differently across agencies creates challenges in providing equitable services and supports. Adopting a common framework for AAC will establish a shared understanding of AAC and baseline of requirements for providing AAC.

Require coverage of AAC items and services if doing so does not result in a fundamental alteration or undue financial and administrative burden. The federal government should require all recipients of federal funding to provide AAC as an auxiliary aid or service when necessary to ensure effective communication if doing so does not result in a fundamental alteration or undue financial and administrative burden to the recipients. Where personal devices and services are customarily provided as part of the recipient's programs or activities, then these personal devices and services should also be provided to persons with disabilities.

Ensure fair and equitable financing of AAC tools, methods, and support. Key federal agencies, including but not limited to ED and HHS, should align criteria and practices used in determining the need for and the federal program funding that supports access to AAC tools, methods, and support; such practices must be carried out in an effective, efficient, unbiased, and nondiscriminatory manner. These criteria and practices include:

- ED and HHS should bar recipients of federal funding from administering or using the results of standardized intelligence assessments or similar tests concerning persons who need AAC but lack effective access to it.
- CMS should issue clear guidance on the mandatory Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions and durable medical equipment requirements with respect to AAC coverage. Additionally, Medicaid state plan and HCBS waiver options should report compliance to confirm that they are administered in a manner that assures fair and equitable access to AAC regardless of race, ethnicity, disability, national origin (including primary language), or other protected class status.
- CMS should ensure that the new \$50 million grant program to enhance critical school-based mental health services to students who experience bullying, trauma, and related challenges is implemented in a manner that increases 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 vehicles or modes of expression. The National Deaf-Blind Equipment Distribution Program, which provides equipment to improve telecommunications accessibility to low-income individuals who are deaf-blind, could serve as an example for future initiatives.

Transportation

Recommendation 3.7: Provide federal guidance and funding to increase transportation accessibility for individuals with I/DD

Issue guidance to reaffirm accessibility of publicly funded transit systems. DOT should issue joint guidance with HHS and DOJ focused on transportation accessibility. The guidance should reaffirm that all publicly funded transit systems must be accessible and offer examples of promising practices in terms of local and state transportation models that are inclusive of or even prioritize people with disabilities. In addition, more states should elect the option to cover non-medical transportation so individuals receiving HCBS can access community services, resources, and other activities.

Fund infrastructure development and capacity-building innovation grants. DOT funding should expand on-demand & flexible response transportation models so that individuals with disabilities can access transportation in real-time when they need it.

Promote awareness of revised guidance on NEMT. Revised [CMS guidance on NEMT](#) offers [more expansive options](#) for states to fund NEMT and transportation education for individuals with disabilities, specifically individuals with I/DD. Recommendations include improved coordination between NEMT and public transportation networks to increase awareness of NEMT benefits among individuals with I/DD.

Focus Area 4: Federal Support Programs

Overview

GOAL: All individuals with I/DD can work, earn, and marry without jeopardizing their access to long-term supports and benefits available under Medicaid, Medicare, and Social Security.

Beyond HCBS, access to SSI and health care benefits through Medicaid and Medicare is essential for most Americans living with I/DD. SSI provides cash assistance to individuals with disabilities under age 65 and adults ages 65 and older whose incomes and resources fall below established thresholds. Nearly all states are required to grant Medicaid eligibility to SSI beneficiaries, and, in most states, such individuals are automatically enrolled in their state's Medicaid program by the Social Security Administration upon being determined eligible for SSI.⁴⁹ One-third of Medicaid beneficiaries who qualify on the basis of a disability receive SSI.⁵⁰

Because some federal programs on which people with I/DD rely or from which they could benefit are needs-based ones, the income people with I/DD earn from employment or the income and assets of their spouses can affect their eligibility. This means that people with I/DD may, in some situations, be discouraged from working or even marrying. Significant cost-savings could occur at the state and federal levels by updating the parameters behind these federal support programs to promote socioeconomic independence among people with I/DD and other disabilities.

Key Challenges

Income, asset, and resource limits are too low for Supplemental Security Income

SSI has the strictest resource limits of any federal program, as SSI beneficiaries are limited to only \$2,000 in assets other than a home, one vehicle, and household goods, among a few other resources.⁵¹ For married couples, the limit is \$3,000, which creates a "marriage penalty" because the limit for a couple is 25% less than the limit for two individuals.

Current beneficiaries who exceed the limits are suspended and then terminated from program participation if their savings remain above the limits, and they must repay any benefits paid while they are over the limit. Thus, the only way to build assets beyond the limit without the risk of losing SSI is through creating or opening an [Achieving a Better Life Experience \(ABLE\) Account](#) or [a special-needs trust](#).

Additionally, because many Medicaid HCBS programs generally are statutorily prohibited from covering room and board, SSI and the Supplemental Nutrition Assistance Program (SNAP) are, for most people with I/DD, their only means of paying housing, living, and food expenses when living in the community.

SSI's resource standard has been updated only once since the program's inception in 1972 and has not increased since 1989. As such, it is not reflective of current economic conditions and is not enough for individuals to pay for an emergency or save for the future.⁵² There are currently several legislative efforts before Congress to increase SSI's resource limits, ranging from \$10,000 per beneficiary to \$100,000 per beneficiary.⁵³ There are also legislative efforts to eliminate resource limits altogether, as other economic security programs have done.

Income, asset, and resource limits are too low for most state Medicaid programs

States have rules about which sources of income and assets are included or “countable” when determining Medicaid financial eligibility. Generally, for individuals who seek Medicaid on the basis of being 65 years old or older, or having blindness or a disability, states must use the SSI program's financial methodologies as a starting-point methodology to eligibility, but they are permitted to utilize “less restrictive” methodologies.⁵⁴ For example, under the SSI rules, an individual's home, one car used for household transportation, and a certain amount of funds for prepaid burial expenses are examples of assets that are excluded from the limit of \$2,000 for an individual and \$3,000 for a couple. A state Medicaid program would have to likewise exclude these assets in determining financial eligibility, but it could choose to exclude other assets, such as a second car or a certain amount of cash in a checking or savings account above the \$2,000/\$3,000 limits.

Thirty-four states have adopted the medically needy option to extend Medicaid to people whose incomes are too high to otherwise qualify but who have uncovered medical expenses that exceed their available income. Individuals seeking eligibility as medically needy use these uncovered medical expenses to “spend down” to the state's medically needy income level. Medically needy income limits vary across states but are typically very low. For example, many states that have elected to cover the medically needy impose a medically needy income level that is not greater than the SSI federal benefit rate.

Income and asset limits penalize couples wanting to get married

Individuals generally are not eligible for SSI — and Medicaid in most states — if they have resources more than \$2,000 or \$3,000 for a couple. Certain resources are excluded, most commonly a home, a car, and household goods and personal effects. Although there are spousal impoverishment provisions that protect the income and resources of a spouse of a person living in a nursing care facility, individuals receiving SSI typically experience reduced monthly benefits upon getting married that are less than the sum of two individuals' benefits.⁵⁵ The current income and asset limits hurt families by penalizing couples who wish to get married.

Lack of Medicaid HCBS portability restricts the ability of people with I/DD to move out of state

Because eligibility and enrollment in Medicaid HCBS programs cannot be transferred from one state to another, individuals with I/DD are prevented or greatly discouraged from moving to a different state. If they moved, they would have to give up their HCBS, complete an HCBS application for the new state's Medicaid program, and possibly wait to access HCBS, if approved for coverage. Although there is variability among each state's Medicaid HCBS programs, including eligibility requirements, covered services, and provider qualifications, individuals with I/DD should be able to move between states without losing coverage. In addition, a state's Medicaid HCBS program should also cover a person receiving HCBS with out-of-state providers located in border communities in adjacent states.

Provider agencies are not required to report to a resident how their SSI funds are spent

Provider agencies, which run group homes and licensed apartments, often collect payments from residents to cover room and board. The provider agencies are permitted to require residents' full SSI payments without any transparency to the resident as to how the funds are spent. Some individuals with disabilities do not have autonomy or control over their own money, including federal monetary benefits, and must relinquish control to third-party, (for example, Medicaid-enrolled HCBS provider agencies) without a transparent process for understanding how their money is spent on their behalf.⁵⁶ However, Medicaid's HCBS settings rule requires that the setting must be integrated in and support full access of individuals receiving Medicaid HCBS to the greater community, which includes "control over personal resources."⁵⁷

Medicare generally has a 24-month waiting period for people collecting Social Security Disability Insurance.

When Medicare expanded in 1972 to include individuals with significant disabilities, Congress stipulated that people with disabilities must first receive Social Security Disability Insurance (SSDI) for 24 months before gaining Medicare eligibility. This legislation was created to keep costs down and to avoid replacing coverage for a worker with a disability who is still receiving benefits under a private group health plan. Individuals with disabilities must undergo a lengthy process before receiving Medicare coverage. First, the Social Security Administration (SSA) must determine SSDI approval. Second, individuals with most disabilities must wait five months before receiving SSDI benefits. Finally, after receiving their SSDI benefits, most individuals must wait an additional 24 months before they receive Medicare coverage.

An estimated 1.8 million people with disabilities are in a waiting period for Medicare.⁵⁸ Since SSDI recipients are unable to work, they cannot access the principal source of coverage for people under 65, which is employer-sponsored insurance. Instead, people in the Medicare waiting period generally obtain coverage if they qualify for Medicaid or, if they can, pay the premium to continue under their former employer's plan under the Consolidated Omnibus Budget Reconciliation Act (COBRA). Nearly 39% of these individuals do not have health insurance coverage at some point during the waiting period, and 24% have no health insurance during this entire period. For those with COBRA or other private coverage at some point during the waiting period, which is 58% of individuals ages 55 to 64, the costs are very high.⁵⁹ Individuals waiting for a disability status decision and do not have health insurance can also apply for Medicaid or a private health plan through the health insurance Marketplace.⁶⁰

It is common that during these 24 months, vulnerable individuals will lose their health insurance because they can no longer afford other private health insurance plans. Estimates for Medicaid coverage during the waiting period range widely from 17% for individuals ages 55 to 64 to 40% in earlier research.

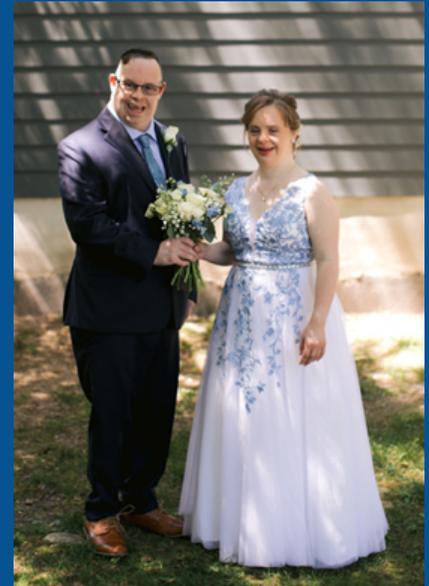
HUMAN SPOTLIGHT

Diana and Matt -- Can Love Conquer All.... Even SSI and Medicaid?

They were born only a few weeks apart. They grew up only a few towns apart. And since first meeting in 1982 at an early intervention program run by the Arc of Bergen County (NJ), Diana, Matt, and their families have been friends — often seeing and spending time with each other at school meetings and social events. But then, many years later, at a Valentine’s Day dance in 2009, Diana and Matt realized that their lifelong friendship was something more — much more. They realized that they loved each other and wanted to spend all their time together — at movies, at restaurants, anywhere and everywhere. Immediately, they became inseparable.

Indeed, the following year, Diana and Matt moved into a new independent living complex. Although they had separate apartments, the move helped to ensure that they could be together more often and share their lives in a more meaningful way. Several years later, Diana and Matt decided to take their relationship to the next level. On June 25, 2022, at the age of 40, they held a “commitment ceremony” with family and close friends.

Sadly, unlike other loving couples, Diana and Matt did not really have the option for a typical wedding and marriage, because as people with intellectual disabilities, they rely on federal and state programs that penalize married couples. In their case, the main concern is Medicaid and its built-in “marriage penalty,” which can result in Medicaid disqualification for spouses if their combined income and assets push them above set requirements. Simply stated, Diana and Matt would have sacrificed vital supports and services if they married. Granted, Diana and Matt love each other, and no one can ever take that away from them. But just like every other American, they deserve the opportunity to have an official wedding and marriage. It is not only their civil right. It is their human right.



INNOVATION SPOTLIGHT

ABLE Accounts

The ABLE Act, signed in 2014, authorized states to create tax-advantaged programs, or ABLE accounts, for individuals with disabilities to save and invest money. The accounts can be used for qualified disability expenses, including education, food, housing, transportation, employment training and support, assistive technology, and health care expenses. Individuals receiving federal benefits typically must have less than \$2,000 in savings, however ABLE accounts recognize the significant cost of living with a disability and ABLE account balances up to \$100,000 are usually not counted towards the SSI resource limit. To be eligible for an ABLE account, an individual must have a disability with an age of onset before turning age 26 and be eligible to receive SSI or SSDI benefits. By providing a financial safety net, ABLE accounts empower people with disabilities to achieve greater independence and improve their quality of life. In April 2024, [ACL spoke with Jody Ellis, the Director of the ABLE Resource Center](#), for more information on the importance of ABLE accounts.

Federal Policy Recommendations

The PCPID offers the following recommendations to support access to long-term supports and benefits available under Medicaid, Medicare, and Social Security:

Recommendation 4.1: Increase access to federal benefits

Increase SSI asset and income limits. Congress and OMB should work together to increase income, asset, and resource limits for SSI to \$10,000 for individuals and \$20,000 for married couples.

Eliminate the Medicare waiting period. Congress should eliminate the 24-month Medicare waiting period.

Eliminate “marriage penalties.” Congress and SSA should take steps via statutory and regulatory changes to eliminate “marriage penalties” by establishing “couple” limits that are twice as much as the “single” limits.

Recommendation 4.2: Limit provider access to individuals’ SSI funds

Establish rules for reporting SSI funds used for HCBS. CMS, SSA, and the Internal Revenue Service (IRS) should require HCBS providers to provide an itemized accounting of services upon which SSI funds are used. This will promote transparency in provider agencies’ access to residents’ SSI funds.

Recommendation 4.3: Promote reciprocity of HCBS benefits

Allow for cross-state portability of Medicaid HCBS. Congress should amend Title XIX of the Social Security Act to allow individuals with I/DD who move out of state to access coverage of services under Medicaid HCBS program(s) in a new state without having to undergo a waitlist process.

Conclusion

The federal government plays a key role in increasing high-quality, high-value HCBS for individuals with I/DD. We recommend improvements to the DSP workforce; promotion of competitive integrated employment; enhancements to housing, safety, technology, and transportation in communities; and changes to federal support programs, as demonstrated by the recommendations in the table below.

Focus Area		Recommendation
Direct Support Professionals		Develop a professional career pathway for the DSP workforce.
		Build a robust DSP pipeline for the future.
		Diversify workforce solutions to adequately meet the growing demand for HCBS.
Employment		Build employer capacity to recruit and retain workers with I/DD.
		Establish a federal Employment First policy and invest.
		Build the capacity of entrepreneurs and small business innovators with I/DD.
Community Living	Housing	Launch a national housing education and awareness campaign.
		Use funding to improve access to housing.
	Safety	Promote regulations that increase protections for individuals with I/DD.
		Strengthen knowledge, education, and awareness of issues impacting individuals with I/DD.
	Technology Support	Revise federal regulations and guidance to promote technology advancements for individuals with I/DD.
		Require all federal funding recipients to provide augmentative and alternative communication (AAC) as an auxiliary aid or service when necessary to ensure effective communication.
	Transportation	Provide federal guidance and funding to increase transportation accessibility for individuals with I/DD.
	Federal Support Programs	
		Limit provider access to individuals' SSI funds.
		Promote reciprocity of HCBS benefits.

Appendix A: The President’s Committee for People with Intellectual Disabilities

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