Advancing U.S. Public Policy on Health Equity for Persons with Intellectual and Developmental Disabilities

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Acknowledgement: The authors gratefully acknowledge the contributions of the following individuals: Greg Robinson, Policy/Systems strand contributor, ideas for organizing structure and content; John Tschida, Policy/Systems strand contributor.

Abstract

The Healthcare Public Policy/Systems Design Strand of the American Association on Intellectual and Developmental Disabilities' (AAIDD) National Goals on Health Equity Meeting convened in June 2024 to outline a comprehensive set of national goals designed to foster equity and improve health outcomes. This paper synthesizes the insights of the diverse subject matter experts—including service providers, healthcare professionals, policy experts, and advocates—to identify critical policy priorities. These include ensuring equitable access to healthcare, promoting community inclusion, supporting self-directed health-related decision-making, bolstering effective caregiving and support systems, and addressing the evolving healthcare needs across the lifespan. The article critically assesses current care models, explores innovative technological and policy considerations, and recommends a strategic set of goals to promote quality, effective health care and health-related supports for the population with intellectual and developmental disabilities (IDD).

Introduction

Healthcare inequities within the population with intellectual and developmental disabilities (IDD) have been widely acknowledged for over two decades (US Public Health Service, 2001). Despite recognition by the American Medical Association (AMA) as an underserved population (Sullivan, 2011) and acknowledgement by the National Institutes of Health (NIH) that people with IDD are underrepresented in healthcare research (Pérez-Stable, 2023), policies that address these disparities remain ineffective, and the lack of action has resulted in significant consequences.

People with IDD experience a reduced life expectancy of 20 years compared to the general population, with over a third of deaths attributed to potentially preventable causes (Hosking et al., 2016). In the United States, people with IDD had the highest risk of contracting COVID-19 and the highest mortality risk after age (Gleason et al., 2021), a circumstance attributable to multiple factors, including congregant living settings, a high prevalence of comorbidities, and poor access to both preventive and effective acute care (Koks-Leensen et al., 2023; Landes et al., 2021; Seid et al., 2022). Additionally, people with IDD face challenges such as missed diagnoses leading to inappropriate care (Charlot et al., 2011), the lowest uptake of preventive services (Havercamp & Scott, 2015), and a higher prevalence of untreated chronic conditions including obesity, dyslipidemia, diabetes, and osteoporosis (Balogh et al., 2015; Henderson et al., 2008; Schrager et al., 2007; Zylstra et al., 2008). Addressing these disparities requires a broad examination of contributing factors coupled with focused and effective interventions.

The American Association of Intellectual and Developmental Disabilities hosted the 2024 National Goals on Health Equity Meeting on June 8–9, 2024. The subject matter experts assigned to the Public Policy/Systems Design Strand were service providers, advocates, managed care providers, disability researchers, healthcare providers, policy specialists, and included people with disabilities and family members. Structured discussions covered five core policy areas essential to the well-being and healthcare of individuals with IDD. These are: 1) Access to equitable healthcare, 2) Community inclusion and integration, 3) Support of health-related decision-making by the individual with IDD, 4) Availability of effective healthcare-related supports for persons with IDD, and 5) Ensuring that health needs can be addressed adequately throughout the lifespan.

The Public Policy/Systems Design Strand group proposed policy goals aimed at supporting research to establish best practices and encouraging innovation and development in each of these areas. The group reconvened in early 2025 after the original June 2024 meeting to identify the most pragmatic recommendations to achieve these goals, as well as to reflect and comment on data and research needs.

1. Access to Equitable Healthcare

In 2024, the U.S. Department of Health & Human Services Office for Civil Rights finalized revisions to regulations implementing Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of disability as it applies to healthcare and medical

treatments that receive federal funding in the provision of programs. Under Section 504, individuals with intellectual disabilities cannot be denied or receive limited treatment based on stereotypes, biases, or assumptions about their quality of life or potential burden on others.

Healthcare providers must not allow biases to influence their care planning and delivery, based on the mistaken belief that individuals with intellectual disabilities are less deserving of or unable to benefit from certain treatments. Section 504 promotes equity in healthcare access and experience by ensuring that people with intellectual disabilities are treated with the same dignity and respect as individuals without disabilities, and that their healthcare needs are met without discrimination (U.S. Department of Health & Human Services, n.d.).

Despite these mandates, people with IDD face significant barriers to accessing effective, equitable healthcare. Clinical settings often are not equipped to accommodate the needs of people with IDD, whether due to physical, sensory, or communication-related challenges (Krahn et al., 2024). Healthcare providers report feeling unprepared to deliver high-quality care to individuals with IDD, citing a lack of training specific to this population's needs (Phillips et al., 2004; Werner et al., 2013; Wilkinson et al., 2012). These systemic issues extend beyond outpatient care, creating disparities in urgent and inpatient care settings. Behavioral healthcare is especially impacted. People with IDD experience higher rates of mental and behavioral health needs than people without IDD, but inadequate coordination among state agencies, limited integration of care services, and a shortage of specialized clinical staff create care inequities that result in long wait times, delayed treatments, misdiagnoses, and the overprescription of psychiatric medications (Pinals et al., 2022).

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Such systemic inefficiencies lead to unnecessary hospitalization and elevated healthcare costs. A 2019 Government Accountability Office analysis found that average Medicaid expenditures for beneficiaries with IDD in six states were up to 500% higher than the average for all Medicaid beneficiaries with disabilities, a disparity associated with a higher prevalence of unresolved health issues in the IDD population (United States, 2023).

Develop Effective Models of Community-Based Health Care

Over the past two decades, various care delivery models funded by federal and state sources have been implemented to improve quality and efficiency of care. Medical Homes, a model encouraged by both Centers for Medicare and Medicaid Services and private insurers, aim to improve efficiency and control costs by assigning a primary care provider to coordinate care across a team of specialty, behavioral, and social service providers. This model, by design, restricts access to specialty providers outside of the assigned provider team. To date, there is minimal evidence that this model improves outcomes or care efficiency for people with IDD (Bonardi et al., 2024).

Medicaid Managed Care (MMC) is an attempt to coordinate healthcare and community support services through consolidated financing and outcomes measurements. Integration of services is delegated to care managers who are tasked with overseeing coordination of services (Ervin, 2025). However, actual integration methods (e.g., effective health information transfer from long-term support services (LTSS) to healthcare providers and intervention collaborations between healthcare providers and LTSS) have not yet been developed. Operating in at least six states, specialty clinics offer integrated ambulatory care tailored to individuals with IDD. They operate on diverse payment models, including federally qualified health centers, academic medical centers such as University Centers for Excellence in Developmental Disabilities (UCEDDs), and clinics accepting both private and public (Medicare, Medicaid) reimbursements (Ervin, 2025). These clinics were developed as a response to primary care settings that typically offer brief encounters and are often ill-equipped to manage patients with complex genetic profiles, disabilities, communication challenges, and intricate caregiving arrangements. To address these gaps, specialty IDD clinics provide modified spaces (e.g., larger exam rooms, wheelchair scales, specialized lighting), longer encounter times for improved communication, and integrated medical, behavioral, and sometimes dental care delivered by practitioners familiar with the unique needs of this population. However, these clinics serve far fewer patients than the total IDD population and are not equally accessible statewide. Critics argue that all healthcare should be inclusive. The Missing Billion Project emphasizes that "people with disabilities must be incorporated within mainstream health services, while acknowledging the need for focused attention... to remove barriers and improve access" (Kuper & Heydt, 2019).

Inclusive healthcare requires providers to offer unbiased, equitable care and demonstrate clinical and cultural competence with people with IDD, in line with Section 504 of the Rehabilitation Act of 1973 (U.S. Department of Health & Human Services, n.d.). Specialty societies offer certifications to validate these skills. For example, the National Association of Dual Diagnosis (NADD) offers a clinical certification focusing on mental health care for individuals with cooccurring IDD and mental illness (NADD, n.d.), while the Developmental Disabilities Nurses Association (DDNA) provides a competency-based certification for nurses (DDNA, n.d.). Additionally, the Alliance for Disability in Health Care Education (ADHCE) offers core competencies and related resources for both traditional education and continuing medical education. Unfortunately, however, medical curricula are currently limited by a paucity of research and well-vetted medical literature that can provide an evidence base for proper medical care (Dharampuriya et al., 2022).

While it remains the case that there is currently no consensus on the most effective model of care for those with IDD, future effective health service models do require the following characteristics: 1) physical space to accommodate effective and respectful care provision, 2) practitioners who have ready access to necessary health information and are skilled at managing the complex and often unusual needs of those with IDD, and 3) accessibility to all those who require these services.

Support Development of Technology for Equitable Quality and Access to Care

New and emerging health technologies hold the promise of improving access, safety, healthcare delivery, and health outcomes for Americans with IDD. The use of telehealth expanded healthcare access during the pandemic—due in part to temporary Medicare and Medicaid reimbursement policy changes (Friedman & VanPuymbrouck, 2021)—but other potentially more effective technologies remain underutilized. These technologies promote equal access to high-quality care by facilitating rapid information transfer and providing decision-making and execution support to healthcare providers (Abend, 2019; Dharampuriya & Abend, 2022). This not only enhances the quality of care but also can improve care efficiency, thereby reducing healthcare costs, and improves provider skill with point-of-care diagnostic and management guidance.

Health support technologies can also empower family caregivers and Home and Community-Based Services (HCBS) personnel, enabling them to detect risks and guide individuals toward appropriate care more efficiently. For example, health monitoring systems can supervise medication delivery and safety (Gallagher et al., 2021) and encourage personalized preventive care. They also can gather and frame observational information relevant to health that can be easily communicated with a healthcare provider, creating a necessary bridge between HCBS and healthcare providers to make healthcare encounters more efficient and effective.

Currently, 40 states have adopted Technology First policies that prioritize technological solutions for support planning before recommending traditional, in-person services (Technology First | State of the States in Intellectual and Developmental Disabilities, n.d.). However, the selection and implementation of health technologies vary greatly across states, and no standardized measures exist for assessing their quality and accessibility (Friedman, 2023).

Create Financing Models that Support Efficient, Accessible, and Equitable Care

In 2024, Medicaid provided health insurance coverage for nearly 80 million Americans and remains the nation's largest single source of healthcare financing (Williams et al., 2025). For the IDD population, Medicaid provides HCBS to 4.5 million individuals with disabilities, as well as covering early intervention services, school-based therapies, and necessary equipment often not covered by commercial insurance. Additionally, Medicaid funds job skills training, placement, and coaching, which facilitate meaningful employment opportunities for individuals with IDD. Overall, Medicaid provides 77% of essential services for the IDD population, making it crucial for their basic healthcare needs (Mohamed & O'Malley Watts, 2025).

Medicaid, a crucial program of support for the population with IDD, is administered at the state level, leading to a patchwork of varying eligibility requirements, covered services, and provider networks. This means that someone with IDD moving from one state to another may find that their current services are not covered or may have to navigate a new and complex system to access care. This creates disruptions in vital services as well as barriers to receiving care (Grossman, 2018). HCBS are crucial for many individuals with IDD, providing support for daily living, employment, and community integration. However, these services are particularly subject to state-level variation, and transferring them across state lines can be very difficult. This can lead to disruptions in essential support, forcing individuals and families to face gaps in care or long waiting lists in a new state. The difficulties with Medicaid portability can also create personal disruptions for individuals with IDD and their families. It can limit their ability to move for employment, education, or family reasons. It can also create significant stress and financial burdens as families struggle to navigate complex systems and ensure their loved ones receive the care they need. The state-based nature of Medicaid, therefore, creates a system where access to essential services for people with IDD is often tied to their state of residence, hindering their mobility and potentially jeopardizing their well-being when they move (Grossman, 2018; Maintaining Medicaid Eligibility When Moving Between US States, 2025).

In addition, current reimbursement structures for outpatient encounters promote rapid patient turnover and do not provide compensation for the additional time required to engage patients with significant cognitive and communication disabilities. This often results in ineffective encounters, with patients feeling that the visit was unhelpful or disrespectful (Kakara & Aysola, 2025). In 2011, the AMA proposed that persons with IDD be designated as a Medically Underserved Population by the Health Resources and Services Administration (T. E. Sullivan,

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2011). Such a designation would allow increased federal and state support for enhanced provider reimbursement, training, and the evaluation of new models of care. Most recently, the HeadsUp Act of 2023, which would designate people with IDD as a medically underserved population, was introduced to the 118th Congress to amend the Public Health Service Act to expand and improve healthcare services by health centers and the National Health Service Corps for individuals with developmental disabilities (118th Congress, n.d.-a). However, the act did not advance beyond subcommittee review.

National Goals: Access to Equitable Care

- Enhance Facility Accessibility: Support and enforce the implementation of physical and other access requirements for healthcare spaces and clinical workflows to accommodate mobility, communication, and sensory needs specific to people with IDD. Enforce compliance with Section 504 healthcare access provisions as part of healthcare quality monitoring.
- Expand Provider Training and Curriculum: Require medical, dental, and allied health programs to include dedicated IDD healthcare content as part of learning to provide person-centered care while incentivizing ongoing continuing education for current practitioners.
- Support Development and Use of Technology That Supports Individual Health and Provider Effectiveness: This includes monitoring systems that track health status and provide clinical information to care providers.
- Promote Integrated and Flexible Care Models: Pilot and evaluate both integrated inclusive clinics and specialty service models to determine best practices and identify

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those best served by each model type. Revise reimbursement structures to allow for patient-specific communication needs and care coordination.

- Facilitate Service Portability and Flexibility: Address barriers to Medicaid portability. Consider developing cross-state service access by standardizing eligibility verification (e.g., through a federally centralized master beneficiary database) and supporting telehealth and remote care models tailored for the IDD population.
- Designate People with IDD as a Medically Underserved Population.

2. Supporting Community Inclusion and Integration in Healthcare

Research shows that community inclusion significantly benefits people with IDD by enhancing quality of life, behavioral and mental health, employment, and education (Friedman, 2022). The committee identified key areas for optimizing healthcare through enhanced inclusion and cross-system collaboration. Full inclusion means ensuring individuals with IDD have equal opportunities to work, live, and participate in community life. Policies must integrate these principles into service design, delivery, and evaluation, with quality monitoring to ensure continuous improvement.

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (Stein & Lord, 2023) guarantees the right of all people to the highest attainable standard of health. However, structural barriers to effective healthcare delivery and attitudinal barriers by healthcare providers must be overcome before those with IDD can enjoy these rights in the U.S.

The current organization of ambulatory care prioritizes rapid patient turnover to maximize the daily number of patients served, and healthcare providers are held accountable for their

productivity (Bonde et al., 2018). However, persons with IDD often need more time than the average patient to communicate effectively and participate meaningfully in their care decisions. Additionally, obtaining information from a patient with IDD to make an accurate diagnosis is more complex than simply asking the patient direct questions and may involve multiple communications with caregivers outside the point of care. Without allowances for the time required for these activities, healthcare providers are disincentivized to provide high-quality, individualized care to this population. Care provision structures need to be developed that 1) allow flexible scheduling and personalized care plans and 2) ensure that healthcare delivery is adjusted to the communication and participation needs of individuals with IDD. Quality monitoring should capture whether these adjustments are meeting intended goals.

Embedding core principles of inclusion in healthcare design also means reforming health professional education and training. There is currently no standardized curriculum within medical schools or other healthcare-related disciplines besides dentistry that familiarizes practitioners with the care of those with IDD or helps them understand the broader social determinants that affect the health of individuals with IDD (Vi et al., 2023). This has been associated with biases held by some healthcare professionals that may contribute to suboptimal care (Desroches et al., 2019; Doherty et al., 2020). Curricula that remedy these deficits should be tracked for effectiveness of outcomes.

A structural barrier to full healthcare inclusion is the "siloing" of HCBS from mainstream healthcare services and the discoordination of medical, dental, and behavioral health services for people with IDD. While family and home-based caregivers, currently serving more than 800,000 Americans with IDD (Larson et al., 2021), are responsible for arranging healthcare services and implementing resultant care plans, they often do not have the knowledge to access the most effective services or the ability to provide healthcare providers (HCPs) with the information necessary to make proper diagnoses. HCPs, in turn, do not have ready access to necessary health history and health environment information or a clear understanding of how care plans can be reliably executed. As mentioned above (see Developing Effective Models of Community-Based Healthcare), MMC organizations aim to promote coordination in both healthcare and HCBS by unifying their payment and outcome accountability structure. However, to date, integration processes have not been developed.

Full inclusion will also require enhancing cross-system collaboration by creating incentives for healthcare systems to partner with community organizations, HCBS, and educational institutions. Such collaboration should be designed to facilitate seamless community integration, ensure that all stakeholders are aligned in their goal to address both clinical and social determinants of health, and support research into optimal care delivery structures and specialized care models that foster inclusion. The development of technologies that can help enhance communication and timely (i.e., point-of-care) information transfer between all stakeholders in the individual's care circle should be incentivized.

National Goals: Support Full Community Inclusion and Integration

- Embed Inclusion in Healthcare Design and Include Quality Monitoring: Develop policies that require community-based health services to ensure full inclusion by involving individuals with IDD in program design, service delivery, and evaluation.
- Support Research to Investigate Optimal Care Delivery Structures: These include specialized care models and inclusive care.

- Enhance Cross-System Collaboration: Create incentives for healthcare systems to work with community organizations, long-term services, and education sectors to support seamless community integration and address social determinants of health.
- Develop and Use Technologies That Assist Effective Communication: Technologies that facilitate timely information transfer across all stakeholders should be prioritized.

3. Health-Related Decision-Making by the Individual with IDD

Patient-centered care is considered the "gold standard," integrating the individual's needs, priorities, and values into healthcare decision-making. Self-determination and informed decision-making have been shown to enhance health outcomes, increase patient satisfaction, reduce costs, and improve the clinician experience (Krist et al., 2017). Nationwide, an estimated 41% of adults with IDD who receive state-funded supports have a guardian legally responsible for at least some healthcare decisions (Bradley et al., 2019). This rate varies significantly by state, with some states exhibiting much higher rates of guardianship. Guardianship and substituted decision-making can have a profound influence on an individual's healthcare choices and experiences.

Healthcare professionals too often defer to caregivers rather than engaging directly with the individual with IDD. In some cases, individuals may choose to involve a caregiver or designate a proxy. When this occurs, the individual's choice should be honored. Supported decision-making is an accommodation that individuals with IDD may choose to help them navigate healthcare decisions. The involvement of a proxy or support persons, when selected by the individual, should be recognized as a tool for facilitating self-determination—not a replacement of it (Nieuwenhuijse et al., 2024; Pham et al., 2024).

Shared decision-making – another decision making model which shares the acronym 'SDM' - is a collaborative communication process in healthcare in which clinicians and patients work together to make healthcare decisions, balance available information about risks and benefits and reach a health plan that is aligned with what matters most to the patient (Elwyn et al., 2012; National Quality Forum, 2017). For individuals with IDD to participate in shared decision making processes, there may be the need for accommodations and support from clinicians and others to ensure comprehension of the decision at hand, available options, and the articulation of values and preferences (W. F. Sullivan et al., 2020). Communication barriers can make it difficult for clinicians to fully understand a person's priorities and for individuals with IDD to receive and process information effectively (Koenig & Bishop, 2025).

National Goals: Promote Health-Related Decision-Making by Individuals with IDD

- Establish Supported Decision-Making as a Legal and Practical Accommodation: Promote legal frameworks and best practices including state level laws that recognize supported decision-making as a primary model, ensuring individuals with IDD can choose their support persons and participate actively in decisions
- Ensure Compliance with Communication Protocols: Develop and deploy tools (e.g., adaptive communication aids) that enable individuals with communication disabilities to express preferences, ensuring decisions reflect their values.
- Integrate Shared Decision-Making into Provider Training and Quality Monitoring: Embed patient-centered care principles and SDM into clinical education and healthcare quality metrics to uphold autonomy and recognize lived experience.

4. Community Supports Workforce

Individuals with IDD are frequently supported in various settings by family caregivers and/or direct support professionals (DSPs). Within the HCBS system, these supporters play critical roles in assisting with daily activities, accessing services—including healthcare and health promotion—and facilitating community participation. DSPs often serve as intermediaries, translating complex health information between individuals and healthcare providers. This role can be particularly challenging when DSPs have limited health literacy or face their own healthcare access barriers (Vetter et al., 2022).

The DSP workforce in the U.S., nearly 1.1 million strong, is predominantly composed of women (Laws et al., 2024), many of whom are the primary wage earners in households earning less than \$39,999 annually (Pettingell et al., 2023). High turnover rates have long plagued the DSP field, a problem intensified by the COVID-19 pandemic. Frequent staff changes result in a lack of continuity, impeding the recognition of health issues and communication with providers— ultimately impacting the health and well-being of individuals with IDD (Friedman, 2018; Ptomey et al., 2017).

To address these shortages, many states have introduced programs allowing family members to serve as paid caregivers. Evidence suggests that family caregivers may provide more reliable, cost-effective, and outcome-focused care compared to non-familial DSPs (Friedman & Rizzolo, 2016). However, to prevent conflicts of interest, such programs must ensure that service plans remain person-directed and reflect the preferences of individuals with IDD (Barth et al., 2020).

Federal initiatives, including funding through the American Rescue Plan Act (ARPA) in 2021, offered temporary financial support for HCBS system improvements, with a focus on DSP recruitment and retention (Ancor, 2024). All 50 states and the District of Columbia used a

portion of these funds to offer bonuses or increase DSP wages. From 2020 to 2023, the average DSP hourly wage increased by over 27% to \$17.34 (National Core Indicators, 2024). Still, DSP turnover remains high at 39.7% in 2023. Notably, ARPA funding is set to expire in March 2025.

In April 2023, Congress introduced the "Recognizing the Role of Direct Support Professionals Act," which would create a distinct Standard Occupational Classification (SOC) code for DSPs. This classification would allow for better data collection on DSP demographics, numbers, and wages (118th Congress, n.d.-b). Currently, DSPs are grouped under broader categories like home health aides, failing to capture the complexity of their role.

At the state level, initiatives also support DSP development. Minnesota is developing a DSP certification curriculum tied to higher pay, offered through higher education institutions (Moving Towards Guaranteed Pay Increases for Accredited DSPs, 2024). New York provides credentialing grants and career development opportunities through the National Alliance for Direct Support Professionals (Supporting and Strengthening the Direct Support Workforce, n.d.).

While promising, progress remains slow. DSP turnover decreased by just 8.9% from 2019 to 2023 (National Core Indicators, 2024). While wage increases are essential, additional improvements—such as better benefits, manageable workloads, professional training, and clear career advancement—are also needed to attract and retain qualified DSPs (Pettingell et al., 2023).

National Goals: Policy Recommendations to Strengthen the Community Supports Workforce:

- Improve Recruitment and Retention: Invest in livable wages, benefits, and career development opportunities for DSPs and family caregivers. Use robust data collection to monitor and evaluate workforce capacity-building efforts.
- Create a Dedicated SOC Code for DSPs: Support federal legislation to establish a unique classification, enabling accurate workforce tracking and policy development.
- Expand Training and Certification Programs: Promote standardized training and certification pathways to enhance DSP competencies and elevate the profession.
- Enhance Collaborative Care Models: Integrate DSPs and family caregivers into interdisciplinary care teams to improve continuity and patient outcomes. Fund research to evaluate the impact of these collaborative models.
- Maintain and build data collection efforts to support monitoring and reporting on measures of workforce stability.

5. Lifespan Considerations

As individuals with IDD age, they encounter new healthcare needs and transitions requiring increased autonomy, continuity of care, and specialized support. Transitions—such as from pediatric to adult care—can result in service gaps, especially with limited availability of qualified providers. Racial and ethnic disparities are often exacerbated during these times (Lotstein et al., 2010).

Individuals with IDD require tailored health services throughout the lifespan, including supports related to puberty, menopause, nutrition, and sexual health (Egan et al., 2022). Aging adults with IDD have higher rates of co-occurring physical and behavioral conditions (Kinnear et al., 2018). Approximately 25% live with aging family members and may face loss of care as caregivers

confront their own age-related health issues (Heller, 2017; Sanderson et al., 2017). These intersecting needs call for integrated, coordinated care models (Ouellette-Kuntz et al., 2016).

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) has identified the need for Medicaid waiver programs to support aging adults with IDD and their caregivers. While interest is high, such programs are not yet widespread (Barth et al., 2020).

National Goals: Promote a Lifespan Approach to Equitable Healthcare:

- Develop Integrated, Lifespan-Spanning Care Models: Create policies that support coordinated services from early childhood through end-of-life care, including pediatricto-adult transitions and supports for aging individuals.
- Implement Longitudinal Data Collection and Research: Invest in systems to track health outcomes, service utilization, and quality of life over time.
- Fund research focused on transitions and the impact of interventions across the lifespan.

Conclusion

Quality healthcare and outcomes for individuals with IDD depend on multidimensional policy reforms and coordinated, evidence-based systems change. By reducing barriers to equitable care, supporting inclusive communities, and strengthening person-centered decision-making, stakeholders can create a healthcare system that is truly accessible for individuals with IDD. Continued investment in research, data infrastructure, innovative care models, and workforce development is essential. The proposed national goals advocate for healthcare systems that are inclusive, adaptive, and empowering—ensuring dignity, autonomy, and quality care at every stage of life.

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