The Role of Healthcare Financing and Delivery Systems to Promote Health for People with Intellectual and Developmental Disabilities

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Abstract

People with intellectual and developmental disabilities (IDD) face significant health disparities due to structural inequities, healthcare access challenges, and fragmented financing and delivery systems. This paper presents key recommendations for improving healthcare financing and delivery systems developed at the American Association on Intellectual and Developmental Disabilities (AAIDD) National Goals for Health Equity for People with IDD meeting in June 2024. Strategic priorities included enhancing data collection and integration, developing standardized quality metrics tailored to people with IDD, and reforming healthcare financing to ensure equitable access to specialized care. The group also recommended increased development, regular evaluation of innovative healthcare financing and delivery models, and further research and advancement of health and wellness technologies specifically targeted to people with IDD. Finally, person centered approaches, informed by people with IDD and their families, were identified as critical to ensuring meaningful and effective reforms. While challenges remain, this paper emphasizes the urgent need for systemic changes to promote health equity and improve healthcare for people with IDD.

Key Words: Financing, Delivery, Healthcare, Data, Wellness, Person-Centered

Introduction

The approximately 8 to 10 million people with intellectual and developmental disabilities (IDD) in the United States have poorer overall health, more chronic conditions, and less access to quality healthcare than the general population (Havercamp & Bonardi, 2022; Johnston et al., 2022; Larson et al., 2024; Pham et al., 2024). They are more likely to have diabetes, epilepsy, asthma, and hearing loss (Liao et al., 2021) and live shorter lives than those without IDD (Cooper et al., 2020; O'Leary et al., 2018; Reppermund & Walker, 2021).

The health disparities faced by people with IDD have been linked to a combination of structural inequities, such as inadequate community and social support systems, as well as certain biological risk factors (Dean et al., 2021; Johnston et al., 2022). Unequal access to healthcare further exacerbates these disparities (Krahn et al., 2015; Whittle et al., 2018). While at significant risk for poor health outcomes, people with IDD often encounter barriers to receiving quality healthcare, including insufficient accommodations, ableism, and biases, in addition to a lack of knowledge, experience, and skills among healthcare providers (Alshammari et al., 2018; Lagu et al., 2022; VanPuymbrouck et al., 2020).

Healthcare financing and delivery systems present significant challenges in meeting the health needs of people with IDD (Ervin, 2025; Shady et al., 2024). The complexity and inconsistency of insurance programs and insufficient funding for specialized care create a myriad of barriers for people with IDD (Bonardi et al., 2024; Bryan et al., 2023). Additionally, poor integration between healthcare services and community support systems, compounded by limited access to qualified care providers, further restricts access to comprehensive health services (Doherty et al., 2020; Havercamp & Bonardi, 2022). These challenges result in fragmented and unequal access to physical and behavioral healthcare services for people with IDD (Marquis et al., 2024; Pham et al., 2024).

This article outlines recommendations to address these challenges by highlighting research, policy, and practice recommendations from the "Healthcare Financing and Delivery Systems" section of the American Association on Intellectual and Developmental Disabilities (AAIDD) *National Goals for Health Equity for People with IDD* meeting. This meeting was held on June 7th and 8th, 2024. A team of nine academics, practitioners, policy staff, and people with lived experience met over two days to identify the most pressing research and policy priorities for healthcare financing and delivery systems for people with IDD.

Key Recommendations for Improving Healthcare Financing and Delivery Systems

Recommendation 1: Enhance Data Collection and Integration

The lack of comprehensive, integrated data is a significant barrier to addressing healthcare disparities for people with IDD (Administration on Community Living [ACL], 2019; ACL, 2025; Havercamp et al., 2019; Krahn, 2019). Current health data systems are often fragmented and fail to capture the full scope of IDD-specific health needs. By improving data collection, infrastructure, and integration across healthcare, social services, and education systems, we can better identify health trends and more effectively track progress in reducing disparities.

Currently, people with IDD are often excluded from key health data systems, which hinders the development of targeted, evidence-based interventions and policies. (Dhopeshwarkar et al., 2024; Šiška et al., 2024; Wu et al., 2023). The absence of disaggregated data limits our understanding of the intersectional impact of factors such as race, ethnicity, socioeconomic status, and geography on health outcomes within the IDD community (Landes & Turk, 2024; Williamson et al., 2023). As a result, policymakers, researchers, and advocates face significant challenges in making informed decisions that could promote health equity and improve the overall quality of life for people with IDD.

The exclusion of people with IDD in national surveys, both from the sampling frame and by not including targeted questions, creates a significant blind spot in understanding their needs and experiences. (Havercamp et al., 2019; Rosencrans et al., 2021). This oversight contributes to their invisibility in national datasets, perpetuating inequities and hindering efforts to address systemic disparities. Compounding this issue is the complexity and fragmentation of existing data on IDD populations, which often resides in siloed systems that are difficult to integrate. These challenges create significant barriers to effective policy making and service delivery by limiting access to comprehensive, reliable, and actionable data.

Due to strict privacy regulations, lengthy approval processes, and the need for specialized agreements to handle sensitive information, Medicare and Medicaid data are notoriously difficult for researchers to access (Ayanian & Buntin, 2024; Doshi et al., 2016). These challenges are particularly problematic for research on people with IDD, as the majority of this population relies on these programs for healthcare coverage. Limited access to this data restricts researchers' ability to analyze healthcare utilization, costs, and outcomes, leaving significant gaps in understanding the disparities and barriers faced by people with IDD. This lack of insight hinders the development of evidence-based policies and interventions, ultimately perpetuating inequities and preventing meaningful progress in addressing the healthcare needs of this population.

Platforms that integrate fragmented data sources are critical for providing a comprehensive understanding of the health needs of people with IDD (ASPE, 2022). The current fragmentation of data—spread across healthcare systems, social services, educational institutions, and government programs—creates significant barriers to analyzing the complex and intersecting factors that shape healthcare outcomes for this population (Bonardi et al., 2019; Dahm et al., 2017). By consolidating these diverse data streams into integrated systems, researchers, policymakers, and service providers can more effectively identify trends, needs, and gaps in care. For instance, integrated platforms enable a deeper exploration of disparities in funding allocations, the impact of different financing models, and variations in access to essential healthcare services across geographic and demographic groups.

Comprehensive, integrated data systems are invaluable for informing targeted interventions and evidence-based policymaking (Dinora et al., 2020; Schalock et al., 2017). Moreover, robust, integrated data systems would improve the quality and accessibility of healthcare for people with IDD by empowering providers with actionable information, streamlining care coordination, and enabling more personalized approaches to treatment. Ultimately, these platforms are foundational for addressing health inequities and ensuring that people with IDD receive the comprehensive, high-quality care they need and deserve.

Targeted Focus Areas for Research, Policy, and Practice

- *Improve data collection and integration.* Connecting data from healthcare, social services, and education helps better understand the health needs of people with IDD, track trends, and address disparities.

- *Address data gaps and exclusion.* People with IDD are often left out of health data, making it hard to address their needs. Including them in surveys and disaggregating data by factors like race and socioeconomic status will highlight disparities.

- *Expand access to health data.* Limited access to health data, including Medicare and Medicaid data, hinders research on healthcare for people with IDD. Easing access to this data can reveal disparities and guide policy development.

- *Develop integrated data platforms and evidence-based interventions.* Fragmented data complicates understanding the health of people with IDD. Secure, integrated platforms can consolidate data, improving decision-making and resource allocation.

Recommendation 2: Develop Standardized Quality Metrics

The development of standardized quality metrics focused on health outcomes for people with IDD is critical to ensuring equity and consistency in care (Bogenschutz et al., 2022; Pham et al., 2024). These metrics would enable a unified approach to assessing and improving health outcomes across diverse financing and delivery systems, addressing a long-standing gap in data-driven strategies for this population.

The current fragmentation in quality metrics within the U.S. IDD service system presents a substantial barrier to identifying systemic issues and improving health outcomes (Dhopeshwarkar et al., 2024; Havercamp & Bonardi, 2022). This fragmentation arises from the diversity of financing mechanisms, including Medicaid waivers, state-funded programs, and private insurance, each of which applies different standards and reporting requirements. Additionally, service settings—ranging from institutional care to home- and community-based services (HCBS)—operate under varying regulations and quality measures, further complicating efforts to assess and improve care (Barth et al., 2020).

The lack of standardized quality metrics makes it difficult to compare provider performance across settings and states, limiting the ability to track outcomes systematically

(Bogenschutz et al., 2022; Doody et al., 2019). Without consistent benchmarks, identifying disparities in access and outcomes—such as variations in preventive care, crisis intervention, or long-term support services—becomes challenging. This inconsistency hampers efforts to implement evidence-based interventions that address overarching challenges like workforce shortages, service accessibility, and equitable healthcare delivery for people with IDD.

The challenges associated with fragmented quality metrics for people with IDD are exacerbated by the inadequacy of existing measures, which often fail to capture the complexity of their health needs (Hart & Msall, 2022; Havercamp & Krahn, 2019). People with IDD experience a range of unique health concerns, including higher rates of chronic conditions, complex medication regimens, communication barriers, and increased reliance on long-term services and supports (LTSS) (Havercamp & Bonardi, 2022; Johnston et al., 2022). However, most quality metrics used in healthcare settings are designed for the general population and do not account for these specific factors. This leads to significant gaps in care, as traditional performance indicators may not reflect critical aspects of IDD health care, such as the effectiveness of behavioral health interventions, access to specialized services, or person-centered outcomes like autonomy and community integration. Without tailored metrics, it becomes difficult to measure disparities in health outcomes, track service effectiveness, or develop policies that meaningfully improve care for people with IDD.

Furthermore, the lack of standardized, IDD-specific quality measures limits efforts to promote health equity (Dharampuriya & Abend; Krahn et al., 2023). While tools like the National Core Indicators (NCI) surveys provide valuable insights into service experiences and individual outcomes, their adoption and consistency across states have varied (Caldwell & Machledt, 2022). The recent endorsement of 14 National Core Indicators-IDD measures by the

National Quality Forum (NQF) represents a critical step toward addressing these gaps by establishing rigorous, person-centered quality metrics tailored to IDD populations. The HCBS Final Access Rule contains requirements about quality measures and, although it applies only to the Medicaid-insured population, may be an opportunity for private payers to adopt similar measures.

Targeted Focus Areas for Research, Policy, and Practice

- *Develop inclusive quality measures*. Work with people with IDD and families to develop standardized quality measures to better reflect their health priorities and experiences.
- *Integrate IDD-specific indicators*. Incorporate IDD-specific quality metrics into broader healthcare reporting systems to improve health outcomes and reduce disparities.
- *Standardize quality metrics across systems.* Develop consistent quality metrics across various healthcare delivery models and funding streams to improve care coordination and data collection for people with IDD.
- *Enhance accountability through quality metrics*. Use standardized metrics to track eligibility, access, and outcomes, ensuring accountability in service delivery and improving care for people with IDD.

Recommendation 3: Reform Healthcare Financing

In the United States, the financing of healthcare services is characterized by a mix of private and public payers that operate and are regulated at both the federal and state levels.

Insurers have important roles in healthcare financing. Insurers essentially provide direct payment for services to providers through 1) fee-for-service models, where a set amount is paid for each service provided to a patient, or 2) capitated payment models, where a set amount is paid to cover a given patient for a certain period, rather than tying payments each specific service.

While most Americans are covered by private insurance through their employer or through the individual marketplace (Keisler-Starkey & Bunch, 2024), people with IDD are overrepresented in public insurance programs (Ervin & Merrick, 2014a). Nearly all public insurance coverage for people with IDD is through Medicaid [public insurance program covering low-income children and families, pregnant women, people with disabilities, and people aged 65 and older administered through a federal-state partnership], either alone (58%) or with dual Medicare [federally administered publication insurance program for people aged 65 and older and certain people under 65 with disabilities] eligibility (31%) (Rubenstein et al., 2024).

Particularly important for people with IDD, *Medicaid waiver programs* allow states to deviate from statutory requirements related to eligibility, financing, or service delivery, with common waivers including *1115 research and innovation waivers* and *1915(c) home and community-based services (HCBS)* waivers. *1115 waivers* can fund experimental, pilot, or demonstration projects, such as extending postpartum Medicaid coverage, while *1915(c) waivers* provide long-term services and supports in home or community settings instead of institutional care, benefiting people with IDD. More than 250 active 1915(c) waivers exist across nearly every state, with some targeting specific populations, like individuals with autism (CMS, n.d.-b).

In addition to insurers, public healthcare service financing is supported by *federal and state grant programs*. These grants typically go to state agencies or other organizations, which provide healthcare services directly or by contracting with providers. Examples of grant programs include substance use and mental health block grants from the Substance Abuse and Mental Health Services Administration, which fund prevention and treatment services not covered by insurance, and the Health Center Program (330 grant), which funds community and federally qualified health centers to provide health services and address issues like transportation and food insecurity.

The wide range of payers and payment models with differing (and sometimes conflicting) eligibility criteria and coverage makes delivery of effective, coordinated care difficult. This is especially true for people with IDD, who are more likely to have multiple types of insurance coverage and to use services that are paid from different funding streams (Keisler-Starkey & Bunch, 2024; Rubenstein et al., 2024). Even within Medicaid, the most common payer for people with IDD, people may struggle to access high-quality healthcare as fewer physicians may accept Medicaid because of low reimbursement rates (Alexander & Schnell, 2024) or because of years-long waitlists for Medicaid HCBS composed mostly of people with IDD (Burns et al., 2024).

Some attempts have been made to address the fragmented financing system and incentivize care coordination, including innovative delivery models and blending, braiding, or sequencing funds to provide a range of services (Butler et al., 2020). Implementation of these models, though, often does not account for the impacts on people with IDD making it difficult to assess their ability to address healthcare disparities for this population. Further, any cuts to public financing of healthcare services will have disproportionate impacts on individuals with IDD.

Target Areas for Research, Policy, and Practice

- *Expand research on the financing of healthcare services of people with IDD*. Conduct research to better understand the current status of healthcare financing for people with IDD.

- *Study innovative funding models*. Test new funding models for impacts on care coordination and health outcomes among people with IDD.
- *Provide equitable reimbursement for IDD healthcare providers*. Address under-reimbursement for IDD services, especially for more diverse and medically complex people, to ensure equitable compensation for providers working with complex needs.

Recommendation 4: Evaluate Healthcare Delivery Models to Better Understand Impact

State Medicaid programs are increasingly using managed care and a wide array of other service delivery and payment models to achieve better outcomes and lower costs. The Affordable Care Act (ACA) ushered in a new wave of innovations to better integrate financing and delivery of care across providers, enhance care coordination, and incentivize outcomes (i.e., often broadly referred to as value-based purchasing) (Friedman & Rizzolo, 2021; Medicaid Innovation Accelerator Program, 2019).

Development of innovative service and delivery models for people with IDD has been slow but is growing. Promising examples of Patient-Centered Medical Homes (PCMHs) for people with IDD (Aguayo et al., 2024; Ervin et al., 2014; Kastner & Walsh, 2012; Lind & Archibald, 2013; National Academies, n.d.) have been highlighted. PCMH is a physician-led model where a multi-disciplinary care team is provided an additional per member per month payment to manage and coordinate care holistically manage an individual's ongoing care, sometimes including behavioral health and other supports (Lind & Archibald, 2013).

The Centers for Medicare and Medicaid Services (CMS) awarded two major Health Care Innovation Awards to test medical home models for people with IDD. Mixed methods evaluation of these programs indicated positive outcomes, including improved quality and timeliness of care, self-management of chronic conditions, medication safety, and decreased hospitalizations and ED visits (Ruiz et al., 2020). However, most of these programs are very small in scale, and the extent to which people with IDD are receiving care from PCMHs is unknown.

Another promising model is the ACA Health Home, which is a Medicaid State Plan Option included in the ACA that provides states with enhanced federal funding (i.e., 90% federal match for a limited time) to improve care coordination for targeted groups, including people with IDD, who have or at risk of developing multiple chronic conditions (CMS, n.d.-a). As of December 2024, 33 Medicaid ACA Health Homes were approved in 19 states (CMS, 2024). Among these, 8 programs in 7 states were targeting people with IDD.

Accountable Care Organization (ACO) initiatives have been more predominant within Medicare. However, Medicaid ACOs have been established in 14 states (C. Lewis, et al., 2022). ACOs are groups of doctors, hospitals, and providers who share responsibility for a defined population's health care and outcomes. If they meet quality standards and save costs, they can share in the savings (CMS, n.d.). In Colorado, one ACO tested the effectiveness of a Cross-Systems Care Integration model and found positive impacts on reducing chronic conditions. This innovative model expanded traditional care coordination to include community-based LTSS coordination and the involvement of family, friends, and other naturally occurring social supports (Wilson et al., 2020).

Most Medicaid beneficiaries with disabilities, including many people with IDD, already receive their health care through some form of Medicaid Managed Care. Medicaid managed care involves state Medicaid agencies contracting with managed care organizations (MCOs) to deliver Medicaid services, including behavioral health, for a set per-member per-month payment (CMS, n.d.-c). In FY 2022, 54.1% of Medicaid beneficiaries who qualify based on disability were in "comprehensive" managed care (Medicaid and CHIP Payment and Access Commission

[MACPAC], 2024), and 46.9% were in "limited benefit" managed care arrangements. States can exclude certain benefits from "comprehensive" managed care, such as behavioral health services, oral health services, or non-emergency transportation.

Specific data on enrollment of people with IDD within managed care arrangements is limited. Moreover, the literature on care coordination models and the experiences and outcomes of people with IDD in managed care is sparse. Generalizability across states is limited, and the experiences of people and families are often mixed. These studies suggest the importance of design and implementation features within managed care programs, such as continuity of care, unmet needs, and person and family-centered care coordination (Bowers et al., 2019; Gibbons et al., 2016; Owen et al., 2016, 2020a, 2020b).

Over the past two decades, state adoption of Managed Long-Term Services and Supports (MLTSS) has grown exponentially. MLTSS refers to the delivery of long-term services and supports (LTSS) through capitated Medicaid managed care programs (CMS, n.d. -d). Within these programs, Managed Care Organizations (MCOs) integrate health care and LTSS to improve care coordination across the systems and outcomes.

Approximately half of the states now have MLTSS programs, up from only eight in 2004 (E. Lewis, et al., 2018; Dobson, 2024). However, most states have carved out people with IDD from MLTSS programs. Only ten states include people with IDD in their MLTSS programs or have specific MLTSS programs for people with IDD (MACPAC, 2018; S. Lewis, et al. 2018). The growth of MLTSS for people with IDD has been slower for several reasons, including organized and engaged IDD stakeholder resistance and mistrust, lack of MCO experience serving people with IDD, and reduced potential for cost savings through rebalancing (Barth et al., 2020). Key elements in the design of successful MLTSS programs for people with IDD include adequate time for transition, continuous stakeholder engagement, clearly identified goals, adequate network development and infrastructure, contracting and alignment of payment incentives, and effective state monitoring and oversight (Caldwell & Patterson, 2013; Dobson et al., n.d.; MACPAC, 2018).

There is very little research on the outcomes of MLTSS programs and the experiences of participants and families. Broadly, there is some evidence that programs may have contributed to greater rebalancing of LTSS spending, reduced HCBS waiver waiting lists for services, and improved health and quality of life outcomes (Dobson et al., 2021; Wysocki et al., 2020). However, findings are mixed, and few states have conducted formal evaluations. Moreover, given the wide variations in design and implementation of MLTSS programs, it is challenging to make sweeping generalizations about MLTSS across states. To our knowledge, no peer-reviewed studies have specifically evaluated outcomes for people with IDD. Qualitative studies of the experiences of families of people with IDD in MLTSS programs have indicated mixed experiences, particularly with family engagement in care coordination (Williamson et al., 2018).

Targeted Focus Areas for Research, Policy, and Practice

- *Improve data collection*. Improved data on the enrollment of people with IDD in innovative service delivery and payment models is needed to better understand participation and outcomes.

- *Research and evaluate service models.* As states implement innovative service delivery and payment models, research is needed to evaluate the experiences and outcomes for people with IDD and their families, focusing on health, community living, and system-level impacts.

- *Expand research on person-centered care coordination*. Research should identify promising practices, particularly from the perspective of people using services and their family members, in delivering person- and family-centered care coordination, integrating medical, behavioral, LTSS, and social supports, with evidence-based models needing to be scaled up.

Recommendation 5: Leverage Emerging Innovations and Technologies in Healthcare

Over the past decade, and particularly in the last five years, the integration of digital technologies has rapidly expanded within healthcare systems, creating new opportunities to improve health outcomes and facilitate care for people with IDD. Small pilot studies and larger trials have examined a broad range of interventions, such as telehealth and telemedicine platforms, mobile applications, personal digital assistants, virtual reality, and exergaming. While evidence suggests that digital health solutions can improve access, enhance self-management, and reduce barriers to care for people with IDD, methodological variability across studies has led to inconsistent outcomes and underscores the need for further research (Devitt et al., 2024; Selick et al., 2021).

Telehealth and telemedicine interventions constitute the most frequently studied digital health approach for people with IDD (Carnett et al., 2020; Delves et al., 2022; Devitt et al., 2024; Kim et al., 2024). Many of these programs target improved access to care, reflecting the distinct challenges people with IDD face when seeking specialized clinical services. Several investigations report substantial increases in telehealth uptake, including 56% more telemedicine encounters for adults with IDD compared to adults without IDD (Kim et al., 2024). Another analysis showed a 40% rise in technology-based healthcare visits during the COVID-19 pandemic (McCausland et al., 2022). Telehealth facilitates access to more distant or specialized providers at more convenient times (Delves et al., 2022). Hyde et al. (2020) observed that enrollment in remote behavioral interventions grew from 3 to 30 participants. In specific clinical contexts, the addition of telehealth consults contributed to shorter waiting periods for diagnostic evaluations and treatments (Valentine et al., 2021). Nonetheless, some studies encountered technological literacy challenges, small sample sizes, or difficulties measuring long-term sustainability (Kalb et al., 2023; Park et al., 2024; Selick et al., 2021).

Mobile applications and personal digital assistants (PDAs) have been used to increase oral health self-care, with one study reporting improvement in 40% of participants who remained in the program (O'Hara et al., 2008). Similarly, educational messaging platforms and reminder systems improved medication adherence in people with IDD and hypertension and demonstrated more than $1,000 in savings per member (Chen et al., 2024).

Studies also highlight positive user engagement with intelligent personal assistants (IPAs). For instance, Smith et al. (2020) found that 79% of users with mild to moderate IDD reported enjoying the devices, while 80% felt the technology helped them to accomplish more tasks independently. Such findings demonstrate the potential of these tools to bolster everyday functioning and autonomy. However, low device usage among some participants and technical hurdles (e.g., keeping PDAs charged and user training needs) remain limiting factors (O'Hara et al., 2008; Smith et al., 2020).

Virtual reality (VR) and video game-based interventions have increasingly been explored to encourage physical activity and build cognitive or behavioral skills in people with IDD (Corey et al., 2024; Torra Moreno et al., 2021). Exergaming platforms, which blend exercise with gaming elements, are posited to improve fitness outcomes and engagement by making physical activity more motivating (Corey et al., 2024). VR-based interventions show promise for skill development, including improvements in working memory, language skills, social skills, and behavioral skills, and can be adapted to user needs by customizing difficulty levels and providing immediate feedback (Torra Moreno et al., 2021). Despite the promise of VR and gaming approaches, more robust data are needed to establish standardized outcome measures and evaluate the accessibility of these tools across diverse IDD populations.

Speech-to-text and speech recognition technologies have long been used to support people with disabilities across various contexts. These technologies can improve participation and independence in educational, daily living, and communication tasks for people with speech impairments, motor disabilities, and visual impairments (Balaji & Sadashivappa, 2015; Berner & Alves, 2021; Semary et al., 2024). Automatic Speech Recognition (ASR) systems have been developed for specific conditions like cerebral palsy and apraxia (Ambewadikar & Baheti, 2020; Roundtree, 2022). Innovative interfaces, including mouth-mounted devices and biosignal sensors, are being explored to enhance speech recognition capabilities (Lee et al., 2021; Malavasi et al., 2017).

Recent advancements in artificial intelligence (AI) speech recognition are transforming accessibility for people with disabilities. Applications like Voiceitt use a large database of non-standard speech patterns and personalized voice training (Voiceitt, n.d.). Other large-scale collaborative data collection efforts through the Speech Accessibility Project (Hasegawa-Johnson et al., 2024) and targeted efforts like Google's Project Understood (*FCB | Project Understood*, n.d.) are making significant impacts by leveraging partnerships between industry, academic, and community partners. These developments, supported by research and industry collaboration, may help to increase the accessibility of a broader range of AI tools to improve healthcare access and delivery. However, challenges remain in ensuring fairness and accessibility in AI-driven speech recognition systems for people with disabilities (Guo et al., 2020). Future research should focus on developing more inclusive algorithms, conducting user-centered studies, and improving recognition accuracy for diverse populations and real-world applications.

Target Areas for Research, Policy, and Practice

- *Study the impact of existing technologies on people with IDD.* Although telehealth and other digital solutions have shown promise in improving healthcare access, more systematic research is needed to assess their long-term clinical and social impacts on people with IDD and to refine these tools for diverse user needs.

- *Include people with IDD in research and development for new technologies.* Actively involving people with IDD in the design and testing phases fosters greater usability, relevance, and ownership of technology.

- *Expand telehealth services by addressing technological and literacy barriers.* User-friendly interfaces, ongoing technical support, and inclusive policy frameworks will help to address digital skill gaps and logistical challenges for people with IDD.

- *Promote digital literacy programs for patients and caregivers.* Implementing targeted education and training initiatives can bridge knowledge gaps, enhance technology adoption, and improve health outcomes for people with IDD.

Conclusion

Healthcare financing and delivery play a significant role in creating disparities in outcomes for people with IDD. Complex and ever-changing insurance programs, insufficient funding of care, siloed services, and workforce shortages all contribute to inequitable access to healthcare, which in turn results in health outcome disparities. To address disparities, reform is necessary both within and outside finance and delivery systems as a comprehensive approach that is informed by people with lived experience of IDD and their families.

Across our recommendations, we see a clear need for improved and integrated data systems to better understand and enhance how healthcare financing and delivery systems support people with IDD. In particular, standardized quality metrics are critical for tracking and improving care across healthcare systems to ensure better outcomes. Within the fragmented healthcare financing landscape for people with IDD, we must address how to better reimburse complex, person-centered care and explore innovative funding models to ensure equitable access and support. A key part of expanding access includes increasing the availability and use of emerging technologies. Broadening telehealth services, improving digital literacy, and involving people with IDD in the design of healthcare technologies are essential steps to improve healthcare access and outcomes. Finally, and most importantly, the motto 'nothing about us without us' has never been more vital. People with IDD and their families must be engaged as leaders in their healthcare financing and delivery innovation. Whether identifying meaningful measures, co-researching financing models, or testing emerging technologies to improve care, people with IDD and their families have the most at stake and must be central to the solutions.

Challenges exist that may hinder the implementation of the recommendations discussed here. First, proposed Medicaid instability and other federal and state funding streams have created uncertainties in how aligned the future of healthcare funding may be to existing models and data. While changes may allow for the implementation of innovative models, overall funding is potentially facing cuts, along with cuts to federal research. While better use of technology for informing and using finance and delivery systems is a recommendation, it also poses a challenge when considering the security of the data collected and the privacy and safety of those using the technology. As with any new technology, ensuring that it does not further exacerbate disparities with inaccessibility is vital.

This call for reform in healthcare financing and delivery systems comes during a time of uncertainty and immense innovation. As a field, we must prepare for potential changes while continuing to innovate. We have opportunities to rethink assumptions about the ways in which these systems function and study where improvements may be made, including ways in which we may increase the relevance and person centeredness of finance and delivery systems to promote health equity for people with ID.

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