National Goals on Health Equity's Recommendations for Disability Competent Healthcare

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Keywords: Healthcare Systems; Health Professionals Education and Training; Equity

Abstract

People with intellectual and developmental disabilities (IDD) face significant barriers in accessing quality healthcare, which contributes to disparities in health outcomes. In July 2024, a group of researchers convened at the American Association on Intellectual and Developmental Disabilities National Goals on Health Equity meeting to develop goals related to disability competent healthcare. These goals were reviewed with people with IDD to ensure they were appropriate, comprehensive, and reflective of diverse perspectives. Goals are focused on: 1) education and training, 2) funding and reimbursement, 3) data accuracy and integrity, and 4) environment. Each goal includes multiple recommendations to address barriers. Achieving these goals will improve the healthcare experiences, quality of health care, health outcomes, and overall well-being for people with IDD.

Key Words: health, competent, outcomes, quality, training, data, systems, funding

Background

The definition of intellectual and developmental disabilities (IDD) varies substantially from source to source, significantly impacting the accuracy of prevalence data and health outcomes research for people with IDD (Tassé et al., 2025). In addition to issues in data accuracy and integrity, research consistently demonstrates a cascade of inequities leading to poorer health outcomes for people with IDD (Krahn & Fox, 2014). People with IDD have higher rates of adverse health conditions and unmet needs coupled with poorer preventive care, health promotion practices, and broader challenges in accessing healthcare, which all contribute to disparities in health outcomes (Krahn & Fox, 2014). Adverse health outcomes for people with IDD range from decreased life expectancy and increased co-occurring and chronic conditions as compared to people without IDD (St. John et al., 2018) and health disparities are often amplified for individuals with IDD from communities that have faced systemic disparities (Gilela & Perkins, 2022). There are a number of policies, regulations, and guidelines that have been established to improve the quality of health care for people from underserved communities, including people with IDD, however, challenges with training and the lack of accountability in the American healthcare system prevent these from being adequately implemented (Iezzoni, McKee, et al., 2022; Iezzoni, Rao, et al., 2022; Ordway et al., 2021).

Developing the Goals

The American Association of Intellectual and Developmental Disabilities (AAIDD) invited individuals with IDD, content expert researchers, and healthcare providers to develop National Goals on Health Equity across nine strands. The disability competent health care strand initially included eight (8) members. The group came together in Louisville, Kentucky in June 2024 to develop goals related to disability competent healthcare. Members of the strand included a combination of academics with experience in the American healthcare system from across the United States. Over two days, the group discussed overall barriers to providing health care to people with IDD, identifying common themes across the group's knowledge and experiences. These themes were then used to generate goals and were presented to all attendees of the National Goals on Health Equity meeting. At that meeting, this subgroup decided to broaden the focus of our efforts to IDD Competent Healthcare Systems. The disability competent health care systems strand was the only group that did not initially include an individual with IDD. Recognizing this gap, the group involved individuals with IDD after the National Goals on Health Equity meeting. After joining the work group, individuals with IDD reviewed the identified goals to ensure they were appropriate, comprehensive, and reflective of diverse perspectives, and participated in meetings, reviewing materials, and editing this manuscript.

IDD Competent Healthcare Systems

The healthcare systems for people with IDD strand recommended goals in four areas: 1) education and training, 2) funding and reimbursement, 3) data accuracy and integrity, and 4) environment. In each of these areas, we have recommendations for research, practice, and/or policy.

Education and Training

People with disabilities, including those with IDD, experience persistent health disparities compared to those without disabilities (Bourne et al., 2021; National Institutes of Health, 2023; Stirling et al., 2021). Many people with IDD have complex healthcare needs and healthcare providers and/or settings are not always equipped to provide the care they require. As the life expectancy for people with IDD increases, they may also develop additional conditions including cancer or heart disease that require specialized care; however many healthcare providers are not trained to provide specialized care to people with IDD (Coppus, 2013; Lagu et al., 2022). Most medical and allied health professional accrediting bodies require education on healthcare for underserved populations, but do not explicitly require IDD-related content (Accreditation Council for Occupational Therapy Education, 2018; Accreditation Council for Pharmacy Education, 2015; Commission on Accreditation in Physical Therapy Education, 2017; Commission on Collegiate Nursing Education, 2018; Council for Accreditation of Counseling and Related Educational Programs, 2016; Council on Academic Accreditation in Audiology and Speech-Language Pathology, 2020; Liaison Committee on Medical Education, n.d.). As such, there is wide variation in IDD-related content between healthcare professional programs and graduate training programs. For example, there are limited opportunities for medical students to learn about IDD as part of their training curriculum (Lee et al., 2023). Currently, as of 2023, the only profession that requires graduates to be competent in assessing and managing the treatment of people with IDD is dentistry (Commission on Dental Accreditation., 2023). Given the lack of education about and exposure to IDD in formal health professional curricula, it is no surprise that healthcare providers report low confidence and low competence in treating people with IDD, and have negative attitudes about working with people with IDD (Bacherini et al., 2021; Sonalkar et al., 2020; Wilkinson et al., 2012; Iezzoni et al., 2021).

Given these training gaps, there is a significant need to embed IDD-specific content into health professionals' curricula and continuing education requirements (Chardavoyne et al., 2022). Some progress has been made in this area, for example, the National Inclusive Curriculum for Health Education (NICHE) was developed by the American Academy of Developmental Medicine and Dentistry (AADMD) and Special Olympics in 2009 to define and integrate the concepts of developmental medicine into the medical school curriculum of every medical school in the United States (AADMD, 2024). To date, thirty medical schools in the United States have participated in NICHE. Beyond this initiative, didactic lectures, educational interventions, home visits, and conversations with people with disabilities have been incorporated into various educational programs (Ankam et al., 2019; Cecchetti et al., 2021; Rotenberg et al., 2022; Sarmiento et al., 2016; Woodard et al., 2012). Additionally, many specific curricula have been developed with input from people with IDD for medical students and physicians, nurses, and other allied health professions (Vi et al., 2023). These curricula vary in length, duration, and pedagogical approaches ranging from simulation, role play, didactic experiences and case study application (Vi et al., 2023).

Many of these efforts resulted in immediate improvements in a variety of student outcomes, including attitudes, confidence in skills, and communication with people with disabilities (Berger et al., 2023; Siegel et al., 2023). However, most of these efforts have not included a longitudinal assessment of learned outcomes sustained over time (Rotenberg et al., 2022). Further, the assessment of education and training impacts have mostly been conducted in small cohorts of students rather than across medical and allied health professional students or among currently practicing health professionals. Additionally, there has been a decline in the number of clinical publications in peer-reviewed journals related to IDD, impacting the availability of evidence-based information for health professionals' clinical decision-making (Dharampuriya et al., 2023). Until IDD specific standardized and mandatory core competencies in healthcare provider education and training are adopted, the fragmented nature of education and training on disability will continue to impact health outcomes of people with IDD.

The Core Competencies on Disability for Health Care Education, created by the Alliance for Disability in Healthcare Education, were vetted for consensus among people with disabilities, health educators, and providers working with individuals with IDD (Alliance for Disability in Health Care Education, 2019). These competencies include: 1) understanding disability in the context of diversity, wellness, and social environments; 2) demonstrating professionalism, communication, and respect from the patient's perspective; 3) recognizing legal requirements; 4) collaborating within and outside disciplines for interprofessional care; 5) collecting and interpreting health information to create individualized care plans; and 6) engaging patients in coordinated care planning (Alliance for Disability in Health Care Education, 2019). These competencies, or similar ones, should be incorporated across all medical and allied health programs to improve education and outcomes for people with IDD.

Research goal: Evaluate the long-term impact of IDD training/education in medical and allied health students on awareness, practice, and health outcomes for people with IDD.

In collaboration with people with IDD, researchers should conduct longitudinal studies with cohorts of medical and allied health students who received training on IDD to assess their clinical practices and evaluate outcomes in care, overall health and well-being, and satisfaction with care over time among people with IDD. Researchers should include people with IDD from various underserved backgrounds, including race, ethnicity, gender, socioeconomic status, geographic location (urban, rural, and suburban) and linguistic differences in their research efforts. This includes the full research process from design of the study to publication of findings. Findings from these research efforts should be used to inform accrediting bodies, medical and allied health education programs, and continuing education entities to create and refine content about people with IDD, across all demographic groups, and health outcomes.

Policy goals: 1) IDD content is included in all medical and allied health educational standards for students and 2) All medical and allied health professionals are required to have

a minimum of 1 hour CME/CE/CEU per year on IDD for maintenance of certification and licensing.

To achieve this goal, professional organizations, advocacy groups, educators, and individuals with IDD and their supporters should continue to advocate for the importance of IDD-specific content being included in medical and allied health education programs and a requirement for healthcare provider continuing education. Specifically, advocates and allies should use the findings from the research directions described above to highlight the importance of requiring these changes for accrediting bodies, licensure boards, and certification bodies. Lastly, researchers need to monitor and evaluate the effectiveness of implementation of these standards across medical and allied health professional programs. Achievement of these goals will likely result in change that enhances the preparation of healthcare professionals when working with people with IDD and may ultimately lead to improved health outcomes for people with IDD.

Funding

The healthcare needs of people with IDD are often complex, requiring extended health care appointment times, and additional resources to ensure thorough assessments and comprehensive care. The current American healthcare system utilizes a model of short appointment duration across all patients in primary care and relies on reimbursement models that are based on services rather than time which can hinder the ability of healthcare providers to deliver adequate and appropriate care. These limitations are hypothesized to result in incomplete evaluations, limited opportunities for people with IDD to express their health concerns, and suboptimal health outcomes (Lagu et al., 2022; Oosterveld-Vlug et al., 2021). Notably, people with IDD frequently report difficulties communicating with healthcare providers, including challenges in processing, relaying, and retaining important health information (Lagu et al., 2022; Oosterveld-Vlug et al., 2021).

Emerging evidence suggests that extending appointment times or implementing reimbursement models that account for multiple visits may help address some of these inequities (Casson et al., 2018). Additionally, healthcare provider training tailored to best practices when working with people with IDD, such as preparing in advance for communication needs and collaborating effectively with supporters when appropriate, combined with reimbursement models that account for additional preparation time and interdisciplinary collaboration, can significantly enhance the quality of care delivered (Casson et al., 2018). Research focused on the relationship between appointment duration and health outcomes could yield valuable insights to inform policy and practice changes and funding models that better meet the needs of people with IDD.

Given the complexity of care required by many people with IDD, interprofessional team-based approaches have also been proposed as an effective solution to better care. These models aim to manage health conditions within outpatient settings incorporating multiple healthcare providers into one appointment timeframe (Bobbette et al., 2020). A scoping review of interprofessional care models (e.g., diverse interprofessional team compositions, varied care settings, variations in approach, using shared electronic medical records (EMR) and joint appointments) or providing individual services but within the same larger appointment time and space demonstrated evidence of reduced emergency department visits, inpatient admissions, hospital readmissions, and lengths of stay, alongside increased family satisfaction (Bobbette et al., 2020). Additionally, preliminary research suggests that involving supporters as integral members of interdisciplinary teams, if the individual with IDD consents and desires their involvement, can improve health outcomes for people with IDD (Casson et al., 2018; Zhang et al., 2023). These findings highlight the promise of interprofessional care for people with IDD and the need for further research to establish evidence-based best care practices to inform funding models.

Understanding the dynamics of team composition, roles, and models of care on health care outcomes and costs is essential to identifying the most impactful and efficient approaches to improving health and satisfaction outcomes for this population. Importantly, much of the research has focused on outcomes related to traditional health metrics, such as readmission rates, and emergency department utilization; however, research should also include patient-reported outcomes to measure satisfaction with care, perceived quality of communication, and patient perceptions of their health and whether their healthcare needs are addressed. Future research should focus on these factors to inform policy, practice recommendations, and funding.

Research Goal: To eliminate health disparities experienced by individuals with IDD, it is critical to examine current research and healthcare delivery systems to describe contributing factors such as time allocation and team composition. To inform funding models, research studies should be conducted in collaboration with people with IDD, including those from underserved backgrounds, to explore how healthcare delivery factors influence health outcomes. Findings can be used to develop and test hypothesized models of care and team compositions that improve health outcomes for this population. This evidence should then inform best practice and policy recommendations for funding models.

Practice and Policy Goal: Healthcare providers should receive equitable reimbursement that reflects the time spent and quality of care provided when caring for individuals with IDD. To achieve this, findings from the aforementioned research on best practice models and interprofessional team composition must be leveraged to advocate for systemic healthcare policy changes. Currently, Medicaid has complex eligibility requirements, and requires prior authorization for many tests, procedures, specialist visits and surgeries, in addition to having long waitlists to receive care from many providers, leading to delays or denials in reimbursement (Shady et al., 2024; Pham et al., 2024; Burns et al., 2023). Both Medicaid and Medicare have restrictive policies, limiting service provision and impacting health professionals' ability to spend adequate time with patients with IDD (Shady et al., 2024; Lagu et al., 2022; Pham et al., 2024). Private health insurance plans, although varying greatly, may limit coverage for certain evidence-based therapies and assessments for people with IDD (Shady et al., 2024). Medicaid, Medicare, and private health insurance plans all offer inadequate reimbursement for specialized services, specifically, if the payment does not reflect the time or expertise required to provide quality care to people with IDD (Shady et al., 2024; Pham et al., 2024).

Thus, American health organizations and professional associations can use findings from the research goal described above (i.e., explore how healthcare delivery factors influence health outcomes) to engage policymakers, insurers, healthcare systems and other stakeholders in advocating for changing reimbursement structures to enable healthcare providers to adopt and sustain best practices. Specifically, research findings can support the introduction or amendment of federal and state legislation and regulations advocating for improved eligibility, care standards, and reimbursement policies across Medicaid, Medicare, and private health insurers that align with better health outcomes. For instance, proposition of time-based compensation for extended appointments or incentivizing the adoption of interdisciplinary care models, which have been shown to improve health outcomes, can be powerful at the state and federal levels. By aligning payment with evidence-based care delivery, these changes can empower healthcare providers to address the complex needs of people with IDD more effectively, reduce health disparities, improve health outcomes for people with IDD, and reduce overall healthcare costs.

Data Accuracy and Integrity

Data collection about people with IDD in the United States has consistently been challenging due to inconsistent definitions, variations in identifying or determining disability status in education and healthcare systems and research studies, and inconsistent coding (i.e. code capture) in health records.

Despite intellectual disability and developmental disabilities often being grouped together, an individual can have one condition without having others (Schalock & Luckasson, 2015; Tassé et al., 2025). For example, a child could have one type of developmental disability (e.g., cerebral palsy, autism) and not have intellectual disability. The umbrella term IDD, however, generally refers to people with mental or physical impairments, or a combination, that originated at birth and are expected to continue indefinitely (The Arc King County, n.d.). Research projects on IDD may be broad or limited to only a few diagnoses (National Institute of Child Health and Human Development, 2021). Additionally, there are challenges with inconsistent coding in health records that prevent accurate capture of IDD diagnosis for research purposes. For example, one study found that a high proportion of those identified in a hospital health system as having an IDD were misidentified and had a condition not associated with ID (Bourke et al., 2017).

When specific diagnoses are not used to determine IDD-status, health care and education systems and studies often rely on questions to assess IDD-disability status, however there are no standardized and consistent questions to confirm IDD. Across the United States, varying approaches (e.g., condition-based eligibility, functional ability questions, etc.) are used to qualify individuals for educational, health, or other types of support under IDD (Congressional Research Service, 2020). Similarly, many national surveys will elicit patient- or caregiver-reported cognitive disability status where it may be difficult to differentiate between IDD and cognitive conditions developed later in life (e.g., dementia or traumatic brain injury) (Iezzoni, McKee, et al., 2022; Krahn & Fox, 2014; Tassé et al., 2025). Given these challenges, data from education systems or health records may often describe different populations.

Without universally accepted operational definitions and consistent processes to identify and determine IDD-status, data on IDD will continue to lack accuracy, specificity, and consistency (Karimi et al., 2024; Tassé et al., 2025). This is also true for understanding health outcomes for people with IDD from underserved backgrounds. Data accuracy about people with IDD is vital for understanding this population's health and for addressing health disparities, resource allocation, and ultimately, for improving healthcare for this population (Bonardi et al., 2019; Disability Equity Collaborative, n.d.).

Research goal: Develop a list of (International Classification of Diseases) ICD codes that encompass IDD for standardization of documentation and data analysis.

Efforts have been undertaken to raise awareness about the issue of adequate and accurate public health data surveillance for people with IDD. Developing and using an operationalized definition of IDD that will allow for standardization across different data systems and national health surveillance efforts is of great value for research and clinical work. The Administration for Community Living (ACL) is leading the 'IDD Counts' initiative to develop a tool to improve health surveillance for people with IDD. This effort includes self-advocates, advocacy organizations, researchers and multiple federal organizations (Tassé et al., 2025). ACL's ongoing effort in this area offers a promising avenue for collaboration among stakeholders to come together to develop standardized ICD codes that accurately represent the broad spectrum of IDD. These standardized codes will play a critical role in improving data accuracy, informing research, shaping policy, and enhancing clinical practice.

Practice goal: IDD is captured accurately in EMRs.

To achieve this goal, an operational definition of IDD, including ICD-10 codes that accurately represent the complexity of individuals with IDD, is necessary. Once definitions and codes are created collaboratively with people with IDD from underserved backgrounds, they should be tested, evaluated, then incorporated into EMR system templates, clinical workflows, and training materials so that healthcare professionals are well-equipped to accurately and consistently document their patients with IDD. Accurate documentation is associated with improved care coordination and quality of care for people with IDD, enhanced prevalence estimates, and improved resource allocation and policy development for people with IDD. Additionally, accurate coding should lead to commensurate reimbursement, addressing previously discussed funding goals.

Environment

There are numerous laws and regulations that should guide healthcare practices to ensure equitable care for people with IDD. However, persistent health disparities experienced by this population suggest that these regulations often fall short in real-world application.

Laws.

The Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and the Affordable Care Act (ACA) all provide protection from discrimination based on disability. Specifically, the ADA prohibits discrimination based on disability in both public and private healthcare settings (Americans with Disabilities Act of 1990, 1990). The ADA requires healthcare providers to offer reasonable accommodations to ensure equitable access, such as communication aids, modified facilities, and inclusive practices (ADA, 1990). Section 504 of the Rehabilitation Act mandates that federally funded programs, including healthcare providers, offer equitable access to services for individuals with disabilities (Rehabilitation Act of 1973, Section 504, 1973). Specifically, the Section 504 Final Rule, titled “Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance” passed in 2024, strengthens civil rights protections for people with disabilities, prohibiting discrimination in health programs, requiring accessible technology and diagnostic equipment in health programs, and prohibiting the use of assessments that discount the value of a life extension based on disability (Office for Civil Rights, 2024). The ACA also includes nondiscrimination provisions requiring healthcare organizations to provide accommodations to individuals with disabilities. Importantly, the updated Section 1557 rule under the ACA requires covered healthcare providers, insurers, grantees, and others to proactively inform patients that there are language assistance and accessibility services available at no additional cost to patients, which supports people with IDD from underserved backgrounds, specifically spoken languages, which also includes digital information (Health and Human Services Press Office, 2024).

Despite these policies, people with IDD frequently indicate challenges communicating with healthcare providers, and challenges with equitable access to services (Lagu et al., 2022; Oosterveld-Vlug et al., 2021). Although the ACA is audited by the Internal Revenue Service regularly, there are no mechanisms to audit and ensure accountability of enforcement of the ADA and Section 504 of the Rehabilitation Act, leaving many organizations reactive, addressing accessibility issues only when complaints arise (U.S. Department of Justice, n.d). Additionally, there are limited requirements for training related to these laws, leading to limited awareness of legal obligations among healthcare organizations and professionals (Iezzoni, McKee, et al., 2022; Iezzoni, Rao, et al., 2022; Ordway et al., 2021; Whaley et al., 2024). While some institutions provide regular ADA and ACA compliance training, the helpfulness of these programs in preparing healthcare providers to implement accessibility measures remains unclear. For example, while structural modifications (e.g., ramps, elevators) are emphasized, other critical areas like communication accessibility and healthcare provider training are often overlooked (Iezzoni, McKee, et al., 2022; Iezzoni, Rao, et al., 2022; Lagu et al., 2022; Oosterveld-Vlug et al., 2021; Ordway et al., 2021). There is also a lack of specificity regarding the needs of people with IDD, such as extended appointment times, communication supports, or multisensory environments, which directly relates to the need for research to better understand best practices for people with IDD (Bobbette et al., 2020; Breslin et al., 2020; Shea et al., 2024).

Healthcare Programs.

The Centers for Medicare and Medicaid Services (CMS) often serve as the primary insurer for people with IDD. The most recent Medicaid strategic plan emphasizes closing gaps in healthcare access, improving care quality, and addressing social determinants of health (SDOH) (Centers for Medicare & Medicaid Services, Health Services Advisory Group, 2024). Specific strategies include promoting culturally and linguistically appropriate services, expanding data collection to include diverse demographic information, incentivizing equitable care through programs like the Health Equity Index, and addressing health-related social needs (CMS, 2024). However, significant variation in Medicaid programs across states leads to inconsistent access to necessary supports. For instance, some states mandate continuing education requirements and regular annual training on disability and social determinants of health for healthcare providers.

These requirements help ensure that healthcare providers are equipped to meet the needs of people with IDD. Despite these training initiatives, the effectiveness and consistency of these programs vary widely across states, contributing to inequities in healthcare access and quality. For example, while some states prioritize community-based care and comprehensive service delivery, others face challenges such as limited healthcare provider networks or delayed services, particularly in rural areas. This variability in Medicaid programs across states further complicates efforts to provide consistent, equitable care for people with IDD (Amin et al., 2021; Yamaki et al., 2019).

Practice goal: All healthcare organizations and educational entities regularly audit their current policies and related practices to ensure optimal healthcare delivery for individuals with IDD.

American healthcare organizations need to conduct quality improvement projects, including forming multidisciplinary task forces with representation from healthcare providers, administrative staff, and people with IDD to review current processes, develop guidelines for audits, and ensure accessibility, inclusion, cultural responsiveness, and equity in healthcare delivery in alignment with ADA, Section 504 of the Rehabilitation Act, ACA, and CMS guidelines. Healthcare organizations, private and public insurers, and other systems should establish a centralized system to collect and analyze audit data nationwide. Reports can be published to establish baseline measures, track progress, and improve transparency. Further, healthcare organizations, insurers and other systems should consider implementing penalties for non-compliance and incentives for organizations that demonstrate significant improvements. The development and implementation of audits as well as the creation of (1) databases to report progress and enhance transparency and (2) systems to penalize and incentivize healthcare organizations will ensure accountability of vital policies and guidelines within healthcare organizations that will ultimately enhance health outcomes and quality of care for people with IDD.

Policy goal: Healthcare organizations know about and comply with relevant federal and state regulations that address equitable healthcare access for people with IDD.

To meet this goal, the previously described task forces can develop plain language educational tools to ensure that all individuals working within healthcare entities are informed about and trained in accessibility considerations to promote inclusion, cultural responsiveness, and equity in their care in accordance with ADA, Section 504, ACA, and CMS guidelines, among others. These tools should be evaluated for their effectiveness through quality improvement and research projects. This education should improve healthcare provider and staff competence in implementing necessary policies that will improve the healthcare experience, quality of care received, and ultimately, health outcomes for people with IDD.

Conclusion

People with IDD face significant barriers accessing quality healthcare, including issues related to healthcare professionals' education and training to provide care to people with IDD, funding and reimbursement related to team allocation, interdisciplinary team composition, equitable reimbursement for time spent, health improvements achieved, data accuracy and integrity of capturing IDD in health records and research, and successful implementation of relevant policies ensuring accessibility of healthcare for people with IDD (e.g., ADA, Section 504, ACA, and CMS guidelines). The IDD competent healthcare systems strand provided multiple recommendations across four areas: 1) education and training, 2) funding and reimbursement, 3) data accuracy and integrity, and 4) environment to address the barriers faced by people with IDD. Achievement of these goals will improve the healthcare experience, quality of care, health outcomes, and overall quality of life and well-being for people with IDD.

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