Setting National Goals for Health Equity for Adults with Intellectual and Developmental Disabilities Across the Life Course

Lieke van Heumen[1], Lindsay DuBois[2], Meghan M. Burke[3], Sarah Swanson[4], Sarah Demissie[3],
Alex Cobb[3], Courtney Krueger[5]

[1] University of Illinois Chicago
[2] Human Services Research Institute
[3] Vanderbilt University
[4] University of Nebraska
[5] Special Olympics Illinois

Lieke van Heumen **(Corresponding)**

Author Note

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Abstract

Health inequities persist for adults with intellectual and developmental disabilities (IDD) across the life course, both compared to the general population and within the disability community (Hall & Kurth, 2019). At the 2024 National Goals on Health Equity working meeting a group of seven subject matter experts (SMEs), consisting of representatives from academia, government and non-profit organizations, worked together in the strand on issues of adulthood covering topics such as life transitions, reproductive health, and aging. The SMEs' discussion served to propose national goals to promote health equity among adults with IDD in the next decade. After the conclusion of the meeting, two of the SMEs involved self-advocate members of their inclusive research teams to further review and finalize five goals. These include: (1) *Changing Research to Close Health Gaps*, and transforming research to be more inclusive of people with IDD; (2) *Adapting Research for Changing Circumstances*, and exploring how research methods can capture the impact of systems-level changes on outcomes for people with IDD; (3) *Addressing Overlooked Research Areas*, and developing a research agenda in partnership with the IDD community; (4) *Measuring and Improving Service and Support Quality*, exploring experiences with services and using data to improve service delivery; and (5) *Promoting Equity and Dignity*, using research strategies to center the voices of historically marginalized people with IDD. In addition to detailed descriptions of these goals, this article presents an overview of health inequities among adults with IDD, and a description of themes of the group's discussion that informed the national goals.

Keywords: intellectual and developmental disabilities (IDD), health equity, social determinants of health, social ecological model, life course perspective, inclusive research

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Health inequities persist for adults with intellectual and developmental disabilities (IDD) across the life course, both compared to the general population and within the disability community (Hall & Kurth, 2019). On June 8th and 9th, 2024, AAIDD hosted the National Goals on Health Equity working meeting in Louisville, Kentucky. Disability experts from across the country collaborated in nine strands, covering broad topic areas to develop national goals to promote health equity among people with IDD during the next decade, and to create recommendations for achieving these goals. The strand on issues of adulthood focused on matters relevant to health equity among adults with IDD across the life course.

Background

While there is ample evidence of health inequities across research studies, it has been challenging to monitor and address these inequities at a population level. One reason is the lack of consistent data infrastructure to identify people with disabilities, in particular people with IDD (Dhopeshwarkar et al., 2022). Additional barriers include the lack of proper representation in data collection. For example, the prevalence rates of developmental disabilities published by different US federal agencies have varied from 3% to 17% (Tassé et. al., 2025). The allocation of funding for services and supports is impacted by disability prevalence rates which calls into question if funding is proportional to community need.

People with disabilities experience barriers to good health at the individual, community, and systems levels, and these barriers can be more pronounced for people with IDD. For example, individual-level barriers such as high levels of unemployment and underemployment (DuBois et al., 2024) and lack of access to quality healthcare (Krahn, 2019; Heslop et. al., 2014) lead to adverse outcomes for people with IDD. Community-level barriers such as lack of transportation (Bezyak et al., 2020) and physician attitudes (Agaronnik et al., 2020) contribute to inequities. Finally, system-level barriers such as ableist views based on the medical model of disability, including physicians' perceptions that people with disabilities experience a lower quality of life, can further contribute to health disparities (Iezzoni et al., 2021).

In addition to having higher rates of preventable health conditions such as cardiovascular disease, diabetes, and hypertension (Krahn, 2019), individuals with IDD also have a higher mortality rate. U.S. adults with intellectual disability without a comorbid developmental disability, die on average 10 to 15 years earlier than adults in the general population (Landes et. al., 2019). Health outcomes also vary among racial and ethnic groups with IDD. Latino and Black adults with IDD have worse health outcomes compared to White adults with IDD, and Latino and Black adults with IDD have worse health outcomes than nondisabled adults from the same racial and ethnic groups (Magaña, et. al., 2016). Finally, the COVID-19 pandemic disproportionately impacted the IDD community (Landes, 2022), and the impacts of long-COVID on health of people with IDD are still not well known.

Health disparities continue, even though the Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act of 2008 mandate equal access to health care services, (Lagu, et. al, 2022) and Section 504 of the Rehabilitation Act recently explicitly stipulates that people with disabilities be free from discrimination in healthcare settings receiving federal funds (OCR, 2025).

In 2023, after strong advocacy from the disability researchers and advocates (Reynolds, 2024), the National Institute on Minority Health and Health Disparities (NIMHD) designated people with disabilities as a population experiencing health disparities for research supported by the National Institutes of Health (Pérez-Stable & Valdez, 2023). This classification recognizes the poorer health outcomes experienced by people with disabilities. Advocacy remains crucial to prioritize research that expands our understanding of factors contributing to inequities, and strategies to remedy them. These realities and developments set the stage for the 2024 National Goals on Health Equity working meeting.

Methodology

A group of seven subject matter experts (SMEs), consisting of representatives from academia, government and non-profit organizations, worked together in the strand on issues of adulthood covering topics such as life transitions, reproductive health, and aging. To prepare for the discussion, the SMEs reflected on the 2015 national goals (Hahn et al., 2015), issues and challenges for adults with IDD, and advancing priorities in the field using the research literature. After two half-days of discussion guided by a set of questions provided to each of the strands, the group agreed upon five goals for the next decade to address the challenges faced by adults with IDD at both the systems and individual level. Two of the SMEs involved self-advocate members of their inclusive research teams to review the proposed national goals after the conclusion of the meeting. The goals were finalized with feedback from the self-advocates and further discussion among the SMEs.

Results

The discussion of the SMEs centered around five themes that informed the formulation of the national goals. These themes included 1) inclusive frameworks, 2) theoretical approaches, 3) overlooked research areas, 4) quality of services and supports, and 5) representation. Each of these themes is discussed in detail below.

Inclusive Frameworks for Health Equity Research with Adults with Intellectual and Developmental Disabilities

In recent years there has been a paradigm shift toward community-based and inclusive research approaches in research with people with IDD (O'Brien et al., 2022). For example, in the U.S, the National Institutes of Health, Patient Centered Outcomes Research Institute (PCORI), and other research financing institutions have embraced the concept of community engagement in research. Community Engaged Research (CEnR) is an umbrella term used to describe a range of activities and approaches (e.g, community-member engagement, patient engagement, public involvement, and participatory action research) in addressing issues directly affecting the population of study (Key, et. al, 2019).

Involving people with disabilities in research is important to fully understand the issues that matter to them and to identify strategies to remediate challenges they experience. While best practices for participatory and inclusive research with people with IDD are emerging (Kidney & McDonald, 2014; van Heumen et al., 2024), most research on health and IDD is not conducted in an inclusive way, led by people with IDD. Inclusive research conducted by teams that include people with IDD can help narrow inequities in health by better integrating their lived experiences. At the same time, because of institutional and system-level barriers to inclusive research, people with IDD often do not have opportunities to share their embodied knowledge with the research community, for example as authors of research articles (Strnadová & Walmsley, 2018). Additionally, most peer-reviewed research is not open access and behind a paywall and not available in plain language, limiting the ability of community members to access this important source of research knowledge (O'Brien et al., 2022; St. John et al., 2022). Further, people with IDD are often not eligible to be research investigators at universities due to institutional red tape (e.g., lack of institutional affiliations and onerous research ethics training processes) (O’Brien et al., 2022; Schwartz et al., 2025). Principal investigators often have advanced degrees, and such educational opportunities are still lacking for people with IDD (Becht at al., 2020). Despite progress in developing more inclusive research procedures, such as alternatives to research ethics training that are more accessible, the ultimate result of these systems is a lack of bi-directional knowledge sharing. This becomes a fundamental impediment to a stronger understanding of the experience of the heterogeneous population with IDD and the necessary solutions to improve their health outcomes. Researchers must carefully evaluate facilitators and barriers of inclusivity within research infrastructures, such as the challenges of involving and hiring researchers with intellectual disability, and develop new pathways for more inclusive research approaches (Krueger et al., 2024).

Despite recent increases in the use of participatory and inclusive research, significant challenges in effective knowledge translation remain. There is increased recognition that the translation of findings from researchers to community members is limited (Ketelaar et al., 2024). Recently various approaches and strategies to knowledge translation and implementation have been developed (Barwick et al., 2020). They focus on ensuring research results are communicated so they are accessible, equitable, and actionable for various audiences. The likelihood of developing resources that can facilitate meaningful interpretation of research with a variety of audiences is greatly enhanced by including those individuals as partners in the research itself; hence, knowledge translation is intrinsically connected to participatory and inclusive research methods. In fact, many frameworks for knowledge translation emphasize the need to plan products and research outputs at the beginning of a project, as opposed to the end when research has been concluded. Frameworks for knowledge translation effective with the IDD community are still scant, and academic researchers often lack understanding of methods that would facilitate knowledge sharing with the IDD community in particular (Spassiani et al., 2016).

Theoretical Approaches to Health Equity Research with Adults with Intellectual and Developmental Disabilities

One of the main challenges to positively impacting health outcomes for people with IDD is understanding the complex connections between individuals with disabilities, their environments (e.g., their social networks and service providers), and the institutions, communities, and policies that affect health. The social ecological model clarifies that multiple system level factors need to be examined to adequately identify all the supports necessary to improve health outcomes for individuals with disabilities, including people with IDD (Froehlich-Grobe et al, 2021). Individual health behaviors, such as nutrition and exercise, are important contributors to good health. Health outcomes are also impacted by health care decisions made for adults with IDD by guardians, which are not always aligned with the decisions a person may make for themselves (Arsenault, 2017). Community-level factors also impact people with disabilities. Access to affordable and accessible housing, participation in educational programs, and limited employment opportunities are examples of social determinants of health that act as barriers or facilitators to improved health outcomes (Froehlich-Grobe et al, 2021). Additionally, many states have different policies determining access to Home and Community-Based Services for people with IDD, with some states having long waitlists and others imposing limits on the amount of services people can receive (Friedman, 2023). Finally, the ongoing direct support professional workforce shortages further strain the resources available to people with IDD (Britton Laws et al., 2024)

Another important theoretical underpinning to health equity research with adults with IDD is the life course perspective. This perspective acknowledges that lives unfold over time and that events and conditions earlier in life impact outcomes across the life course (George, 2020). Particularly, unfavorable circumstances can accumulate to further disadvantage and impact health negatively later in life (Graham, 2005). A life course perspective to health equity research reveals processes that shape the evolution of health inequities across the life course and also offers opportunities for interventions that can positively alter individuals' life course trajectories. The argument has been made that life course research on health disparities has for example yet to effectively incorporate the impact of social welfare policies on long term health outcomes (Herd, 2016).

A life course perspective is still rarely applied in research to living with disability, but can also give important insight into how the support needs of adults with IDD vary and change across the life course (Heller, 2019). For example, adults with IDD often need more support with (instrumental) activities of daily living as they age (van Heumen & Heller, 2017). Additionally, at any point in time, people with IDD, as those without, can experience injury or illness that can require hospitalization and the need for additional support for some duration of time. These realities provide a challenge for health outcomes research, which often characterizes the rates of specific health outcomes at one point in time.

A helpful concept in applying the life course perspective to the needs of adults with IDD is that of life course transitions, consisting of changes in someone's state or role, such as leaving the parental home, marriage, becoming a parent and retiring (Elder, 1985). Adults with IDD tend to experience challenging life course transitions (van Heumen et al., 2025). For example, the transition from adolescence to adulthood presents unique challenges for this group, as typical milestones like finishing schooling, achieving financial independence, getting married, and having children may be out of reach without significant support (Floyd, Costigan & Piazza, 2009). In the case of marriage, many people with IDD are impacted by what is known as the 'marriage penalty', causing them to lose access to benefits upon marrying (Garbero, 2021). Transitions in later life also tend to cause challenges for adults with IDD, for example transitions in social networks with primary caregivers like parents passing away and being replaced by support from direct support professionals (van Heumen et al., 2025).

Future Research Agenda on Health Equity for Adults with Intellectual and Developmental Disabilities

A principle of future research about health equity for adults with IDD is to ensure that adults with IDD are driving the research agenda. Based on contemporary research in the field and statements from self-advocacy organizations, the SMEs identified a number of topics that have yet to receive sufficient attention and may be considered in future research. It should be noted that: (1) research topics should be driven by adults with IDD; (2) the presented list of topics is not exhaustive; and (3) unforeseen issues may arise in the future that necessitate different topics of study.

Decades of research have shown that adults with IDD are significantly more likely to acquire secondary health conditions compared to those without IDD, including depression (Macdonald et al., 2018; Emerson et al., 2020), obesity, cardiovascular morbidity, and Type 2 diabetes (Centers for Disease Control and Prevention, 2022). Research underpinned by the social ecological model can illustrate how such health inequities can be addressed by interventions at various system levels surrounding adults with IDD. For example, to prevent secondary health conditions, it is imperative to develop and test inclusive health and wellness programs for adults with IDD (Rimmer, 2022). However, as highlighted by The Arc of the United States with input from self-advocates, there is a significant underinvestment in public health and wellness programs among individuals with IDD (2024). An important direction for future research is to investigate how to promote equitable access to healthcare and wellness program interventions for people with IDD. Such research could include ways to make recreation programs and currently available health and wellness programs accessible to adults with IDD. Another example is the need to address poverty among adults with IDD, an often overlooked risk factor for health disparities. Socioeconomic position impacts health directly and indirectly, for example by causing stress, and limiting access to needed resources. Understanding the unique impacts of poverty on adults with IDD across the life course is an important part of a future research agenda to help eliminate health inequities (Anderson, 2013; Emerson et al., 2006).

Another relevant issue in this realm is access to life sustaining care, treatment needed to prolong a person's life. In their position statement, Self Advocates Becoming Empowered (SABE, 2024) call for all individuals with disabilities to receive access to life sustaining care. Unfortunately, research conducted during the COVID-19 pandemic documented that many adults with IDD were deprived of such access (e.g., ventilators), due to ableism (Piscitello et al., 2020; Scully, 2020). The combination of feedback from the disability community and burgeoning research, demonstrating existing disparities among adults with IDD, suggests that access to life sustaining care could be a relevant and needed issue for research. Research about this topic (as with all topics) should be centered on the experiences of adults with IDD. In several of the studies about triage guidelines for ventilators during the pandemic (e.g., Piscitello et al., 2020), a common theme was that individuals with disabilities were not helping to inform such policies. The expertise that lived experience brings needs to be reflected in research.

Using a life course perspective reveals a number of issues relevant to the health of adults with IDD. An important but often overlooked aspect of overall health of adults with IDD is sexual and reproductive health. Many adults with IDD experience barriers in access to sexual and reproductive healthcare and exercising their sexual and reproductive rights, particularly women (Pérez-Curiel et al., 2023). Additionally, as older adults with IDD have more health problems compared to other older adults (Haveman et al., 2010), understanding their aging experiences remains crucial to design supports and services that promote healthy aging and quality life (Hahn et al., 2015).

Future research should also examine the role of self-determination in healthcare decision-making across the life course. Research has documented that exercising self-determination should begin in early childhood (Palmer et al., 2013). However, individuals with disabilities, from childhood through adulthood, report that healthcare providers often do not listen to their experiences or respect their choices. Some individuals with disabilities report that healthcare providers only communicate with their support person (e.g., parents, Wilkinson et al., 2013; Doherty et al., 2020). These research findings are similar to the lived experiences of some people with disabilities on our authorship team who reported that doctors did not listen to their experiences, deferring only to hear from their parents during healthcare appointments. Research is needed to examine how to improve recognition from healthcare providers that self-determination begins in childhood.

A related direction for future research is to explore the values, preferences, and structures (e.g., the role of health insurance providers) that influence decision-making about health among individuals with disabilities across the life course. While there is substantial research examining how individuals without disabilities choose their healthcare providers (e.g., Kozikowski et al., 2022; Lin et al., 2024), there is little understanding about whether similar values, preferences, and structures are used by individuals with disabilities. By understanding how individuals with IDD choose healthcare providers, systems can be developed that facilitate healthcare access in alignment with their preferences. For example, in an interview study conducted by researchers with and without autism (Authors, under review), with autistic adults across the U.S., participants reported preferring finding autistic doctors to meet their health needs; others reported needing to prioritize transportation (i.e., whether they could travel to the healthcare office using public transit) in choosing healthcare providers.

Quality of Services and Supports to Adults with Intellectual and Developmental Disabilities

Medicaid Home and Community-Based Services (HCBS) waiver programs play a critical role in supporting the lives of adults with IDD. They are the most important funding mechanism for long-term services and supports (LTSS) for adults with IDD, and allow states to create and expand community living options as an alternative to institutional care (Friedman, 2023). Many of the services offered under HCBS waiver programs are connected to social determinants of health. Opportunities for supportive and inclusive environments for adults with IDD to live, work, and play are often dictated by their ability to access HCBS and the services that they are offered within these programs. For example, many HCBS waivers offer supported employment services for adults with IDD to gain the skills they need for competitive, integrated employment (Butterworth et al., 2024).

Over the past three decades, the proportion of HCBS spending in relation to total Medicaid LTSS expenditures has consistently grown (Murray et al. 2021) with the majority of adults with IDD known to state IDD agencies receiving Medicaid Waiver funded supports (71%) (RISP, 2024). Medicaid is a state-federal partnership, giving states wide discretion in terms of which services can be targeted for which populations. As a result, there are often significant differences in eligibility and services covered as part of HCBS both across and within states. Further, the Affordable Care Act provided the opportunity to expand eligibility for many states, and American Rescue Plan Act funding as part of COVID-19 allowed states to pursue flexibilities to minimize disruptions to HCBS. The continued shortages among direct support workers were exacerbated by the COVID-19 pandemic, and these shortages contribute to long waiting lists and challenges accessing needed supports for people with IDD. In fact, recent data suggests that more than one out of every three IDD provider agencies turned away referrals for services in 2023 due to staffing issues (NCI-IDD State of the Workforce, 2023).

Additionally, current research tends to focus on access to HCBS among the IDD community, rather than quality of services and the connections between access, quality, and long-term health outcomes. To better understand quality of services, and the connection with long-term health outcomes, it will be essential for researchers to work in partnership with the IDD community and advocacy organizations. Community-based organizations like Centers for Independent Living, State Independent Living Councils, Developmental Disability Councils, Protection & Advocacy organizations, and University Centers for Excellence in Developmental Disabilities are organizations whose missions focus on building capacity, developing leadership and supporting advocacy. Engaging these organizations is a way to bridge the knowledge-to-translation gap, increase the adoption of evidence-based practice, and collaborate to improve programming. These partnerships could also be key to developing appropriate research questions and methods to better study the quality of services and supports, and how quality is connected to health outcomes.

Representation in Health Equity Research with Adults with Intellectual and Developmental Disabilities

Most IDD research does not reflect the rich diversity of the population of the United States (Heller et al., 2008; Krahn, 2019). It bears repeating that research needs to reflect the population including those who are marginalized and, often, multiply marginalized. While the extant research often fails to achieve a representative sample, there is research suggesting that there are racial, ethnic, urbanicity, gender identity, and socioeconomic disparities with respect to health outcomes and health services among adults with IDD (e.g., Courtney-Long et al., 2017; Magaña et al., 2016). Additionally, individuals with multiple marginalized identities face barriers to accessing healthcare services (e.g., Lett, Dowshen, & Baker, 2020). For example, users of long term services and supports from communities of color have less access to high quality care and report a poorer quality of life compared to their White counterparts (Shippee et al., 2022). Research is needed to examine the role of intersectionality in the context of health equity among adults with IDD. Individuals with IDD who are marginalized need to be recruited as participants in research, consequently. In proceeding with this type of research, as with all health equity research, it is critical to center the voices of adults with IDD who live with multiple marginalized identities.

Discussion

The following national goals were formulated to promote health equity among adults with IDD in the next decade, and disseminated in an issue brief (citation removed for peer review):

(1) *Changing Research to Close Health Gaps*, and transforming research to be more inclusive of people with IDD.

We recommend changing the way we think about, fund, support, conduct, and share findings from research. This consists of promoting advocacy by the disability community in research, implementing more participatory and inclusive research practices, and promoting research opportunities to redress traditional power imbalances between researchers and communities of focus. This is relevant for determining research topics, conducting and analyzing research, and formulating recommendations for policy and practice. Ultimately, this transformative redesign of research can lead to more equitable engagement with the IDD community.

(2) *Adapting Research for Changing Circumstances*, and exploring how research methods can capture the impact of systems-level changes on outcomes for people with IDD.

Systems-level events or circumstances impact research. These include public health emergencies, geopolitical events, social justice movements, and technology advances. For example, during the COVID-19 pandemic, researchers changed the ways they gathered data, the focus of their research, and how they communicated findings. Ever-changing system-level developments can be hard to account for and capture in research, and often interact with individual characteristics (e.g., age, socio-economic status, race/ethnicity, and residence). Theoretical approaches (e.g., social ecological model, life course perspective) and research methods (e.g., hierarchical linear modeling, inclusive research, and longitudinal research) should be applied to better understand the impact of systems on outcomes for all people with IDD.

(3) *Addressing Overlooked Research Areas*, and developing a research agenda in partnership with the IDD community.

The field needs to develop a research agenda to address critically overlooked areas in research on the health needs of adults with IDD. Though mental and behavioral health issues have received significant attention (Robertson et al., 2015), other areas of importance to the health of people with IDD have not. These include but are not limited to sexual and reproductive health (Pérez-Curiel et al., 2023), poverty and its effects, and age-related risks and concerns. The development of priority areas for research must be driven by people with IDD.

(4) *Measuring and Improving Service and Support Quality*, exploring experiences with services and using data to improve service delivery.

IDD research should move beyond determining access to services and supports to enhanced individualized measurement of the quality of those services and supports. The quality of both formal and natural supports should be studied for people with IDD and their families across the life course. Although the availability of affordable supports and services remains a challenge for people with IDD, the extent to which services and supports improve quality of life by promoting community inclusion and self-determination also warrants significant attention. Analysis of robust, longitudinal data on the experiences of people with IDD and their families using supports and services should inform person-centered individualized models of service delivery.

(5) *Promoting Equity and Dignity*, using research strategies to center the voices of historically marginalized people with IDD.

To promote equity, belonging and dignity across the life course for all people with IDD, the needs and voices of people with IDD who have been historically marginalized need to be prioritized (Shogren et al., 2022). Of particular importance is the need to train a disability and culturally competent direct support and health care workforce to support health among the diverse population of people with IDD.

Conclusion

Across these five goals, a life course perspective is needed to positively intervene in the lives of people with IDD. Understanding how to best support transitions in adulthood can improve interventions to promote positive long-term health outcomes (Krahn & Fox, 2014). Promoting self-determination and quality support across the life course can provide opportunities for adults with IDD to shape their life course trajectories in a way that is meaningful to them. Finally, continued advocacy in a rapidly changing world is needed to secure disability rights and justice for the community of people with IDD, including their families and allies. Best summarized by [name removed for peer review], a self-advocacy researcher and co-author, “Research about health for people with disabilities should examine all aspects of their lives and their overall well-being”. Ultimately, a commitment to the implementation of these goals is the necessary next step.

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