National Goals on Health Equality

Issue Brief

May 2025

Issues Across Adulthood

Lieke van Heumen, Kathryn Burke, and Lindsay DuBois
with contributions by Courtney Krueger, Meghan Burke, Sarah Swanson, Ravita Maharaj, Jennifer Johnson, Alex Cobb, and Sarah Demissie

Introduction

Research on the unmet mental health needs of Health inequities persist across the life course for adults with intellectual and developmental disabilities (IDD) as compared with both members of the general population and others within the disability community (Hall & Kurth, 2019). This issue brief outlines five goals for the next decade to address challenges for adults with IDD at both the systems and the individual level.

Changing Research to Close Health Gaps

Inclusive research, or research conducted by teams of people with and without IDD, can help narrow inequities in health by better integrating the lived experience of people with IDD into research topics, methods, analysis, and recommendations for policy and practice. While recent research projects have developed curricula, toolkits, and reports describing best practices for participatory research with people with IDD (Kidney & McDonald, 2014; van Heumen et al., 2024), most research on health and IDD does not utilize inclusive research methods. We recommend changing the way we think about, fund, support, conduct, and share findings from research. This represents both a bottom-up (i.e., advocacy, participatory and inclusive research) and a top-down approach (e.g., changing funder requirements, promoting research opportunities to redress traditional power imbalances between researchers and communities of focus). Ultimately, this transformative redesign of research could lead to more equitable engagement with the IDD community.

Plain Language Summary

People with intellectual and developmental disabilities (IDD) often don’t get the same quality healthcare as everyone else. Researchers want to fix this problem over the next 10 years with five goals:

Change How Research Is Done
Researchers should work together with people who have IDD so they will better understand what people with IDD really need and want.

Keep Up With Big Changes
Researchers need to study how big changes in the world—like COVID-19 and new technology—affect people with IDD.

Study Important Topics That Get Ignored
Some health issues that people with IDD have don't get enough attention and need more research—for example, sexual health, getting older, and dealing with poverty.

Make Sure Services Are Actually Helping
We need to check with people with IDD to make sure that the services provided to them are of good quality and really help them live the way they want to.

Make Things Fair For Everyone
Some people with IDD who come from groups that haven’t been treated fairly in the past have a harder time than others getting good healthcare.

We need to make sure everyone can get health information they can understand, get help understanding medical information, and have access to health professionals who understand how to work with people with disabilities. For people with IDD to live healthier lives, they must be part of making things better.

Suggested citation*:* American Association on Intellectual and Developmental Disabilities. (2025). *Issues across adulthood* [Issue Brief]. Author.

Adapting Research for Changing Circumstances

Public health emergencies, geopolitical events, social-justice movements, and technological advances are examples of systems-level events or circumstances that can impact research. For example, during the COVID-19 pandemic, researchers changed the ways they gathered data, the focuses of their research, and how they communicated their findings. Dynamic systems can be hard to account for and capture in research; therefore, we call for the use of research methods that will help us better understand the impacts of systems on outcomes for people with IDD (e.g., hierarchical linear modeling, inclusive research, longitudinal research). Further, the experiences of people with IDD accessing services and supports can vary significantly based on factors such as age, socioeconomic status, race and ethnicity, gender, and sexual orientation. Thus, it is essential for research to fully examine experiences across the life course and how systems influence them.

Addressing Overlooked Research Areas

As we seek to evolve systems-level approaches to research on the health needs of adults with IDD, it is critical for the field to develop a research agenda to address critically overlooked areas. While mental and behavioral health receive significant attention in research (Robertson et al., 2015), other areas remain understudied. 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 (e.g., falls, dementia). Importantly, the development of priority areas for research must be driven by people with IDD.

Measuring and Improving Service and Support Quality

Another essential step is to move beyond research on access to services and supports to engage in enhanced measurement of the *quality* of those services and supports. This will require thorough and individualized assessment of the quality of person-driven supports and services, including formal and natural supports, for people with IDD and their families across the life course. The availability of consistent, affordable supports and services remains an issue within the field, particularly in light of the direct support professional workforce crisis (Britton Laws et al., 2024). However, the extent to which services and supports facilitate 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 needs to be carried out to improve person-centered, individualized models of service delivery.

Promoting Equality and Dignity

Finally, to facilitate equality, belonging, and dignity across the life course for all people with IDD, deliberate strategies need to be developed to center and address the needs and voices of people with IDD who have been historically marginalized (Shogren, 2022). Examples of such strategies in research, practice, and policy include providing accessible health information, enhancing health and data literacy skills among people with IDD and their families and allies, and training a disability- and culturally competent healthcare workforce.

Conclusion

Across the five goals outlined here, a life-course perspective is needed to positively intervene in the lives of people with IDD. This perspective provides insight into how circumstances, opportunities, and constraints across the life course impact long-term health outcomes for adults with IDD. Ensuring equitable participation in research can yield better knowledge to support transitions in adulthood and can improve interventions to promote positive long-term health outcomes (Krahn & Fox, 2014). Finally, continued advocacy in a rapidly changing world is needed to secure disability rights and justice for people with IDD, their families, and allies.

Acknowledgments

The members of the Issues of Adulthood strand are gratefully acknowledged for their contributions to the work of the National Goals Conference and its products: Kathryn Burke, Meghan Burke, Lindsay Dubois, Jennifer Johnson, Ravita Maharaj, Sarah Swanson, and Lieke van Heumen.

References

Britton Laws, C., Hewitt, A., Boamah, D. A., Hiersteiner, D., Kramme, J.E.D., & Reagan, J. (2024). Direct support professionals: Diversity, disparities, and deepening crisis. *Intellectual and Developmental Disabilities, 62*(3), 174–185. https://doi.org/10.1352/1934-9556-62.3.174

Hall, J. P., & Kurth, N. K. (2019). A comparison of health disparities among Americans with intellectual disability and/or autism spectrum disorder and Americans with other disabilities. *Inclusion, 7*(3), 160–168. https://doi.org/10.1352/2326-6988-7.3.160

Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, *29*(7), 1013–1030. https://doi.org/10.1080/09687599.2014.902357

Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities, 27*(5), 431–446. https://doi.org/10.1111/jar.12067

Pérez-Curiel, P., Vicente, E., Morán, M. L., Gómez, L. E. (2023). The right to sexuality, reproductive health, and found a family for people with intellectual disability: A systematic review. *International Journal of Environmental Research and Public Health, 20*(2), Article 1587. https://doi.org/10.3390/ijerph20021587

Robertson, J., Hatton, C., Baines, S., & Emerson, E. (2015). Systematic reviews of the health or health care of people with intellectual disabilities: A systematic review to identify gaps in the evidence base. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 455–523. https://doi.org/10.1111/jar.12149

Shogren, K. A. (2022). Presidential address, 2022—Dismantling systemic barriers: Re-envisioning equity and inclusion. *Intellectual and Developmental Disabilities, 60*(6), 520–529. https://doi.org/10.1352/1934-9556-60.6.520

van Heumen, L., Krueger, C., & Mihaila, I. (2024). The development of a co-researcher training with and for people with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 37*(3), e13200. https://doi.org/10.1111/jar.13200