

Social Determinants of Health Strand:

Recommendations of the National Goals on Health Equity Working Meeting

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Abstract

There has been a shift in U.S. population health and wellness initiatives in the past decade from initiatives to describe health disparities to initiatives to understand and address underlying causes of those disparities within a framework of Social Determinants of Health (SDOH). People with intellectual and developmental disabilities (IDD), their caregivers, and advocates have much to contribute and to gain from this work. The National Goals on Health Equity meetings provided a unique platform and an opportunity to summarize the current state of knowledge, identify national SDOH recommendations in research, practice, and policy, and set the stage for the future directions in SDOH in the IDD field. This article presents an outline to improve the SDOHs by better including people with IDD. The recommendations identify major SDOH issues and solutions proposed by a group of disability researchers, policy specialists, advocates, health care providers, and service providers with the aim to set forth an agenda for national, state, and local SDOH action to address health disparities, improve health and well-being, and advance health equity with people with IDD.

Key terms: Social Determinants of Health; Intellectual and Development Disabilities; Health Equity; Housing; Transportation;

What do we know about Social Determinants of Health

Promoting the health of our nation requires community-based opportunities for all people to self-determine and lead healthy lives. Healthy People 2030 (HP2030; Office of Disease Prevention and Health Promotion, n.d.) charts a course toward this outcome using two priority areas—health literacy and social determinants of health (SDOH). In this article, we outline recommendations to expand and strengthen work in the SDOH area for the estimated 8.38 to 16 million people with intellectual and developmental disabilities (IDD) in the U.S.

In HP2030, SDOH's are defined as "...the conditions in the environment where people are born, live, learn, work, play, worship, and age that affect a wide range of health, function, and quality-of-life outcomes and risks" (HHS 2024). According to the CDC (2024), addressing SDOH's: 1) is essential to improving the health of subpopulations and communities that have poorer health than the general population or other communities—such as people with IDD who experience a range of health disparities (Emerson, 2021; Krahn & Fox, 2014); and 2) can have a bigger impact on health than efforts to address other health determinants such as genetic factors or access to healthcare services. From a disability rights perspective, addressing SDOH's is consistent with independent living principles and priorities and with the vast resources and knowledge of IDD advocates and professionals.

The HP2030 SDOH priority area and framework is being used to advance one of HP2030's five goals; this goal is to "...create social, physical, and economic environments that promote attaining full potential for health and well-being." The SDOH framework is helpful for identifying and intentionally addressing the factors that affect a wide range of health, functioning, participation and well-being outcomes and risks. However, the existing frameworks

fail to adequately include the systemic and structural conditions that disproportionately impact people with IDD and their families.

There have been different initiatives to integrate priorities and knowledge from the IDD field into the SDOH framework and actions (DiSipio & DeMarco, 2023; Hammel et al., 2008; Hotez & Shea, 2023; Mohan & Roberts, 2022; Rubin, 2016; Traci, Horner-Johnson, & Meshesha, 2024). For example, we are learning more about the experiences of SDOH among persons with IDD through surveys (National Core Indicators, 2024), syndromic surveillance (Friedman, 2020); environmental assessments (Friedman & Rizzolo, 2016; Greiman, Traci, & Leopold, 2021; Seekins, Traci, & Hicks, 2022; Traci et al., 2021) and research (Bonaccio et al., 2020; Jones et al., 2023; Ipsen & Hoard, 2024; Rydzewska et al., 2020; Santore & Myers, 2024; Sheppard-Jones et al., 2022). We are developing better SDOH screening and measurement tools (Hotez et al., 2023; Friedman, 2020; Lee, Anastasiadis, Hitti, & Connery, 2024; SDOH-PWIDD, 2024) with improved care coordination and linkage models (Bowers, Owen, & Heller, 2017; Gould et al., 2024; Ruiz et al., 2020) to organize planning processes for purposes such as whole-person care, long-term services and supports, youth-to-adulthood transitions, vocational rehabilitation, and emergency preparedness and recovery. And the IDD and rehabilitation sciences fields are producing and translating knowledge on SDOH initiatives and outcomes related to SDOH domains such employment, education, and housing (Angelelli et al., 2022; Baker, Lowrey, & Wennerlind, 2018; Fudge Schormans et al., 2024; Gilmour & Lam, 2024; Ikutegbe et al., 2023; McKinney, Williford, Abbeduto, & Schmitt, 2024; Morin, Cobigo, Rivard, & Lépine, 2010; Seekins, Traci, Cummings, Oreskovich, & Ravesloot, 2008; Traci, Hsieh, & Anderson, 2016; Ziedas, 2023).

Still, more needs to be done to strategically organize these initiatives within the SDOH framework, across domains and in related research to realize outcomes that will benefit people with disability, including people with IDD. There is important HP2039 work happening every day that could inform and improve the health and wellness work of the IDD field and community but it rarely happens because disability and IDD are not represented within the SDOH framework. For example, Ogletree and colleagues conducted a review of 675 NIH-funded, unique SDOH research studies conducted during the years 2019-2023. The review linked research to study participant characteristics and to HP2030 domains; however, the project did not identify if any research was relevant to people with disabilities or with IDD because the review concluded before *people with disabilities* became a NIH-designated health disparities population, and the analysis plan did not include disability search and linkage terms. Also, HP2030 has produced a resource, *Social Determinants of Health and Older Adults* (Office of Disease Prevention and Health Promotion, n.d.), and while it suggests a product that the IDD field and community could model and develop with a focus on SDOHs and people with IDD, it is concerning that the resource references ‘disability’ in a way that negatively stigmatizes the experience of disability and excludes the descriptions of SDOHs that help older adults adapt to functional limitations and to adopt a positive view of disability.

Leveraging the intent of Healthy People 2030 and the SDOH Priority Area, we have a call to action to advance health and well-being with people with IDD. People with IDD with positive SDOH conditions are more likely to lead healthy lives with their friends and family and to be active contributors in their communities. How we understand SDOH is important to describe, as it impacts how they are used in the context of “health equity.” The World Health Organization defines health equity “as the absence of unfair and avoidable or remediable

differences in health among population groups defined socially, economically, demographically or geographically” and states that “...pursuing health equity means striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions” (WHO, 2025). The aim of this article is to describe the methods and rationale that we used to develop SDOH recommendations, to describe the basis for those recommendations, and to address the implications of the SDOH recommendations for advancing health equity with people with IDD. As we work to integrate knowledge from the IDD field and community into SDOH work, we need to work and maintain the focus on reducing health disparities and inequities for people with IDD.

Developing the recommendations

During the National Goals on Health Equity working meeting held June 8-9, 2024 in Louisville, KY, a group of eight national leaders (including family members and advocates) met to discuss health equity and the social determinants for health. This group also met three times via videoconferencing after the in-person conference and worked together by email to summarize findings into an Issue Brief and the present article. A self-advocate was recruited to the group to contribute to these products.

The group collected and reviewed definitions of social determinants of health used in Healthy People 2030, the World Health Organization, and peer-reviewed literature. Members also discussed the history of work in the IDD field that has used life-span developmental theory, contextualism, the bio-psycho-social model of disability, and approaches to life course and whole-person planning to innovate supportive environments and programs that result in opportunities that drive health equity with persons with IDD. The group discussed the opportunity to integrate knowledge and tools from 50+ years of deinstitutionalization and community living environmental initiatives into the SDOH framework as well as concerns that

the current HP2030 SDOH work was organized without clear input from the IDD field and community. This article outlines our recommendations to guide SDOH research, practice, and policy efforts over the next 10 years.

General Recommendations

To strengthen and support efforts to meet SDOH objectives to create social, physical, and economic environments that promote people with IDD's achievement of their full potential for health and well-being, the following overarching recommendations are proposed:

- Offer guidance to the Office of Disease Prevention and Health Promotion on the use of plain language for HP2030 supplemental SDOH materials (Nygren, 2022) and how to represent the lived experiences of people with IDD in those materials. It would be helpful to develop education and training tools in plain language and with people with IDD. For example, “health” is a complex term for people with IDD, giving rise to questions regarding who decides and defines “health” particularly within systems of care that are incentive and structured to cure and treat.
- Expand the descriptions of the five SDOH domains (economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context) with input from people with IDD on how to represent the interconnected and cross-cutting disability justice issues (e.g., Sins Invalid, n.d.) including inter-dependence, self-determination (Horner-Johnson & Bailey, 2013), choice, dignity of risk, appropriateness of services and support, stigma (Ditchman et al., 2013), and bias (Antonopoulos, Sugden, & Saliba, 2023; Doerpinghaus et al., 2022). Currently, the HP2030 SDOH model places similar emphasis on all five domains, but individuals may not prioritize each domain similarly or equally. Additionally, IDD field and

community input could help address failings of the HP2030 model that does not represent larger systematic issues, or (if it does), it embeds these as subdomains (see: discrimination). Broadly speaking, we recommend modifying the SDOH graphic (derived from Healthy People 2030 model) with: 1) “outer rings” that attend to structural issues that inform and are informed by the five domains, including: stigma and -isms (including ableism), public policies (including funding structures), and interdependence/relationships; and 2) dotted lines to illustrate the interconnectedness of cross-cutting issues related to inclusion, accessibility, and advocacy (Andrews et al., 2023).

Recommendations for Policy

- Improve mechanisms for the application and enforcement of the Americans with Disabilities Act, particularly as they relate to accessibility within healthcare systems, schools, and public accommodations unrelated to healthcare delivery but still important to improving health and reducing health disparities.
- Promote cross-system collaboration to avoid policy silos when addressing SDOH domains and subdomains.
- Promote changes that reduce barriers and increase access to care and services, including removal of barriers to cross-payment, enhanced funding for preventative care and whole-person care, and removal of asset and means testing for benefit programs.
- Enhance service eligibility–determination processes, including adopting assessment measures that consider SDOHs and alternatives to the medicalization of disability.
- Support the National Institutes of Health’s designation of people with disabilities as a population with health disparities (NIH 2022, 2023).

Recommendations for Practice

- Adopt person-centered best practices for assessing disability and SDOH.
- Foster cross-sector partnerships that advance health improvements with people with IDD by achieving SDOH objectives.
- Crosstrain health and community providers to assess and intervene across SDOH domains.
- Encourage healthcare systems and professionals to implement policies that are equitable for people with disabilities (NCD, 2022).
- Support shifts in organizational practices that result in individuals with disabilities being employed in all sectors; for organization's SDOH-identified activities, establish advisory groups with diverse stakeholders that have clear guidelines on how to ensure that the activities will benefit people with IDD and require the use the ECHO model and similar approaches for continuous learning and improvement.

Conclusion

Addressing SDOHs has the potential to dramatically improve quality of life for people with IDD. The present recommendations outline attainable opportunities to strengthen and support efforts to meet SDOH objectives, particularly within the HP2030 framework, and reflect strategies to more fully engage people with IDD and IDD partners in the effort.

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