

## What People with Intellectual and Developmental Disabilities Need to Be Healthy

### Introduction

This Issue Brief has recommendations to expand and strengthen opportunities for people with intellectual and developmental disabilities (IDD) in the United States to lead healthy lives. These recommendations focus on the social determinants of health (SDOH) priority area of *Healthy People 2030* (HP2030; Office of Disease Prevention and Health Promotion, n.d.) and may be applied to other areas that address health. SDOHs are defined in HP2030 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” (Office of Disease Prevention and Health Promotion, n.d.).

According to the Centers for Disease Control and Prevention ([CDC], 2024), addressing SDOHs

- is essential to improving the health of subpopulations and some communities that have poorer health than the general population or other communities—such as people with IDD, who experience a range of health conditions more often and with greater severity than other groups—and
- can have a bigger impact on health than other efforts aimed at mitigating genetic factors or increasing access to healthcare services.

From a disability-rights perspective, addressing SDOHs is consistent with the principles and priorities of community and independent living. 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. Still, much work is needed to ensure that the focus of SDOH remains on

### Plain Language Summary

Social determinants of health (SDOH) - the conditions where people live, learn, work, and play that affect their health - can help people with intellectual and developmental disabilities (IDD) live healthier lives.

People with IDD often have more health problems than others. Improving their living conditions can help more than just medical care alone. When people with IDD have good living conditions, they can live better lives in their communities.

Below are recommendations around SDOH:

1. In general, use simple language in health material that tells people with IDD what they can do to be healthy. Include people with IDD when making health materials for people with IDD.
2. For research, collect better data about people with IDD, include people with IDD in research projects, and study what works to improve their health.
3. For policy, enforce disability rights laws. work across different government systems, remove barriers to care and services, and recognize people with disabilities face health inequalities.
4. For practice, use person-centered planning, build partnerships between health and community groups, train providers to understand all aspects of health, and make sure people with IDD can go to school, get jobs, and have choices in activities to result in healthy outcomes.

Improving living conditions for people with IDD can greatly improve their quality of life. These recommendations show ways to include people with IDD in making these improvements.

reducing health disparities and inequities for people with IDD.

### **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 and how to represent the lived experiences of people with IDD in those materials.
- 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 issues of stigma, bias, interdependence, self-determination, choice, dignity of risk, and appropriateness of services and supports.

### **Recommendations for Research**

- Improve public-health and SDOH-surveillance data and its use by including IDD partners and self-advocates in cross-system collaborations to (a) standardize disability demographic and SDOH indicators in existing measures and (b) promote best practices in accessible data collection, storage, and retrieval.
- Promote an intersectional approach to SDOH research related to disability and provide supports for people with IDD to participate in such research.
- Identify and evaluate the implementation and outcomes of SDOH-related interventions intended to benefit people with IDD and investigate the extent to which the health benefits of interventions rest on restricted

personal choice and dignity, which may be unsustainable across the life course.

- Require SDOH-related research to include dissemination and implementation activities designed to reduce delay in the application of finding to policy and practice.

### **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.

### **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.

The views and opinions expressed in this document were generated by independent teams at the National Goals Conference on Health Equity held June 8-9, 2024 in Louisville, KY, and do not necessarily reflect the official policy or position of any of the planning partners.

- Encourage healthcare systems and professionals to implement policies that are equitable for people with disabilities.
- 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 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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### **References**

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