National Goals for Promoting Health for People with Intellectual and Developmental Disabilities

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Abstract

Individuals with intellectual and developmental disabilities (IDD) face an uphill battle in optimizing their health. While there are many positive clinical and public health interventions to promote the health of this population, significant gaps remain. The Health Promotion strand from the National Goals Conference 2024 identified areas of emphasis at four different levels using the Social Ecological Model of Health: Individual, Interpersonal, Community, and Policy. Emphases include greater training of individuals with IDD, caregivers, and health care providers to address specific health needs; stabilizing funding to increase social connection and health insurance coverage; improving community infrastructure designs for better access; expand population data collection to include IDD identifiers; and incorporate the intersectionality of this population in all health promotion efforts.

Key Words: health promotion, intellectual and developmental disability, lifespan

Background

Health status, health promotion, and accessibility to optimize health-related well-being for those with an intellectual and developmental disability (IDD) lags far behind the rest of the population. People with IDD experience a higher burden of comorbid medical and psychiatric conditions (Ptomey et al., 2020; Centers for Disease Control and Prevention (CDC), 2020a,b), and is more likely to die prematurely from preventable causes (Landes et al., 2021; Lauer & McCallion, 2015). These factors, combined with a dearth of preventive measures and health promotion resources (Rimmer & Hsieh, 2016), lead to an increase in overall mortality for those with IDD. The intersectionality with any minority group, including ethnic, racial, gender, class, sexual orientation, age, and/or religion, can create worse outcomes (Xu et al., 2023; Lahti-Anderson et al., 2024).

Recommendations from entities such as the Office of the Surgeon General and the World Health Organization have been publicized to improve the health of those with IDD (Office of the Surgeon General, 2005; World Health Organization, 2022). However, while many public health, clinical, and community efforts have been implemented for this population (Friedman et al., 2020), multiple challenges remain to effective health promotion among this population. Given inherent constraints, people with IDD often struggle with issues such as health literacy (Alshammari et al., 2018; Geukes et al., 2019), ableism and self-management (Friedman et al., 2019), and caregiver support (Shady et al., 2024; Williamson et al., 2014). Problems of population scope, efficacy, and sustainability have limited program and initiative successes (Santos et al., 2022). And while often considered a homogenous group who all experience similar challenges, a wide continuum exists in ability and function across those with IDD (Bach, 2017), further hampering the success of "one size fits all" solutions.

The National Goals Conference, held in Louisville, Kentucky on June 8-9, 2024, explored existing efforts in care of people with IDD, identified ongoing challenges, and provided recommendations for future priorities. This article, adapted from the conference's nine-member group on Health Promotion, utilizes the Socio Ecological Model (SEM, McLeroy et al., 1988), focusing on individual, interpersonal relationship, community, and societal level needs to articulate prevailing gaps in health promotion efforts for those with IDD. The panel members included people with lived experience, healthcare providers, researchers, and policy experts.

Framework for Health Promotion National Goals Recommendations

The health promotion work group adopted a Social Ecological Model of Health (SEMH) when developing their recommendations. This model supports person-centered approaches to health promotion that recognizes that people live in and are influenced by the context of their families and communities (NASEM, 2021), as understanding this interplay is critical when considering health promotion efforts. The SEMH supported the social model of disability, in which disability occurs because of societal barriers, discrimination, and attitudes and is mismatch between a person's abilities and the environment or society around them. These physical, attitudinal, and social barriers often prevent people with disabilities from full participation in society (Haegele & Hodge, 2016), including in areas related to health, health promotion, and access to health care. Using the SEMH to address the barriers to achieving health equity faced by people with IDD can assist in developing a comprehensive approach to health promotion.

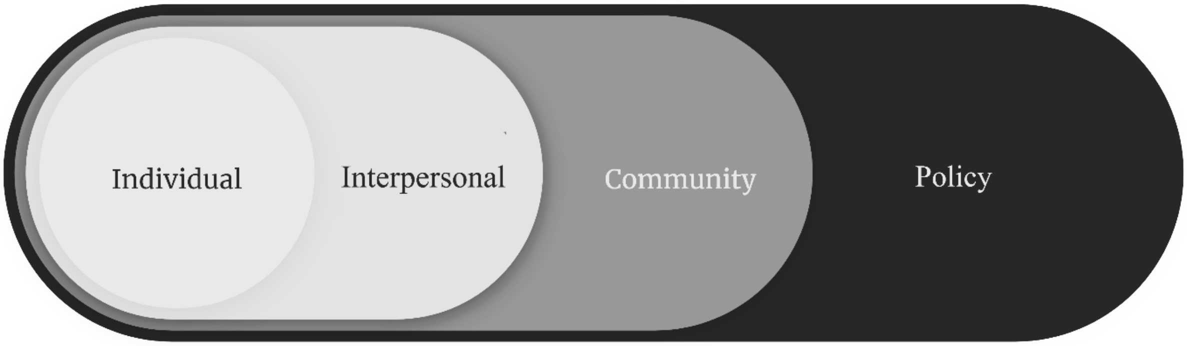
The SEMH (See Figure 1) has four levels (individual, interpersonal, community, and policy) that need to be addressed for effective health promotion (Kennedy et al., 2021). The individual level includes the knowledge, skills, and attitudes about health and health-related activities that an individual may have. Individual supports needed to undertake health promotion activities should also be considered.

The interpersonal level includes a person’s network which may include family, direct support professionals, friends, and others that interact with an individual on a regular basis. Some of these people may be involved in providing needed supports to engage in health promotion activities or helping people with IDD make decisions about their health.

The community-level describes organizations that include disability support-providers and organizations that serve the community as a whole. Ideally, community-based health promotion activities would be inclusive of the whole community and created using universal design principles.

The final level is policy. This can range from policies enacted by local governments (such as promoting accessible parks and recreation centers) to policies at the federal level, such as Medicaid funding, or the policies supporting data collected via national health surveys.

Figure 1: The Social Ecological Model of Health



Individual Level Goal Recommendations

Individual level goals focus on wide-ranging health education and training for those with IDD, families and friends, and support providers or caregivers. Difficulties around ableism, self-management, and health literacy underscore the challenges needing to be addressed. Improvements in direct clinical care, individual and community supports, and policy are necessary for health promotion at an individual level. Four areas of emphasis and recommendations for the individual level are articulated below.

Recommendation #1: Reduce Morbidity and Mortality Related to the "Fatal Five" and Chronic Health Conditions Through Improved Education of People with IDD, Family Members, and Support Providers

Five medical conditions constitute larger causes of significant morbidity and mortality for those with IDD than the general population: aspiration, dehydration, constipation, seizures, and sepsis (Landes et al., 2020). These conditions can occur unnoticed or underdiagnosed as it might take a while for specific symptoms to arise. Education should be integrated in every interaction possible, whether it involves clinicians, support providers, public health workers, case managers, or other people who regularly interact with this population. Prevention and early recognition of these conditions is imperative to improve the health and well-being of people with IDD.

Recommendation #2: Improve Health Literacy for Adults with IDD Using Health Coaching, Improved Knowledge Translation, and Health Education for People with IDD Across the Lifespan

Health literacy, or the degree to which people can find, understand, and use health-related information (Office of Disease Prevention and Health Promotion, n.d.), is a significant concern among the general population, but is even more pronounced among those with IDD (Alshammari et al., 2018). Significant solutions include ensuring ease of communication, individual engagement, and education on health-related matters aimed at modifying information to support individual understanding. The ultimate crux of the issue comes down to making health efforts more individually focused.

Addressing these challenges requires removing barriers to accessing care and public resources, as well as providing adequate training for clinical providers. Understanding how people with IDD communicate needs to be of greater emphasis in medical provider education. Communication training for providers on how to use more basic language, repetition of information, and use of the patient’s preferred language is essential. Instruction on how to better utilize publicly available information, such as government or other websites, and especially direction on what constitutes trusted health sources, will greatly impact an individual's understanding of their health.

Recommendation #3: Provide Training/Education to People with IDD, Family Members, and Support Providers to Increase Self-Determination/Supported Decision-Making

People with IDD deserve the right to make their own decisions when possible and to engage in supported decision-making. Self-determination has been shown to improve individuals' quality of life and physical health (Wehmeyer, 2020). Such allowances and support for this population are often underutilized, either due to ignorance by caregivers or clinicians, or the ease of addressing the needs without full individual input. Training individuals with IDD, family members and friends, and support providers is key to improving health-related decision-making in this population.

Given cognitive deficits and associated difficulties in communication, the capabilities of people with IDD are frequently underestimated. While competency is a legal concept about an individual's overall ability to manage different aspects of their lives, capability can be considered more specific to health-related decisions (Barstow et al., 2018). Greater understanding of supporting individuals in their capability of making health-related decisions, including clinically supported joint decision-making, is an important piece of optimizing the health of those with IDD.

Recommendation #4: Provide Improved Access and Training to People with IDD and Their Allies/Family Members to Plan for Transitions Across the Lifespan

Various social and physical changes in life are often difficult for people with IDD. Particularly transitions to adulthood, with its associated change in social supports, family dynamics, physical and personal changes, and changing legal requirements, can be confusing for people with IDD and family members. Early preparation for what adult transition entails is imperative for these individuals and their friends and family. Transition from pediatric to adult medical care has been studied extensively with recommendations for transition as a process and not just an event (Castillo & Kitsos, 2017), though addressing the other impacted areas of life should be included in such preparation. Medical and societal resources are often scarcer for adults with IDD than for children and adolescents, adding to the need for guidance and training at this time of life.

Transitions to later stages in life, with its associated decrease in physical and mental function, can be confusing and overwhelming. As various types of developmental disabilities progress more quickly than others, and in concert with the other causes of increased morbidity and mortality, the timing of transitions can be hard to anticipate. This underscores the need for ongoing information guidance as life progresses.

Interpersonal Level Goal Recommendations

Interpersonal goals include fostering a supportive and inclusive environment for people with IDD by developing physical and mental peer health education programs, addressing social isolation, enhancing support for family caregivers, and providing person-centered training for direct support providers on the health and wellness needs for those with IDD. Fostering these interpersonal goals may create a nurturing environment where people with IDD feel valued, supported, and included, directly impacting their health outcomes and overall quality of life.

Recommendation #1: Establish Peer Support Programs with Funding Mechanisms to Ensure Sustainability

Peer support programs have their informal roots as far back as the 18th century (Davidson et al., 2012). For people with mental health conditions, these programs have been recognized as effective in promoting both clinical and personal recovery (Smit et al., 2023). However, research on peer support programs for people with IDD has been more limited. A systematic review examining the social and behavioral outcomes of peer support interventions among students with IDD found that such interventions positively impacted social interactions and peer engagement (Bowman-Perrott et al., 2023). Regarding physical health outcomes, a 12-week peer support intervention led to significant improvements in physical activity, hydration knowledge, social support, and overall health behaviors among people with IDD (Marks et al., 2019).

Incorporating the lessons learned from mental health peer support into programs for people with IDD involves recognizing and addressing the communication barriers that both the individuals and their peer supporters may face. A program training peer supporters has shown significant improvements in these mentors' confidence in their communication abilities, adaptability, and supervision skills when supporting adults with IDD in post-secondary education programs (Cargiulo & Blaskowitz, 2022). Continued research and the development of comprehensive training curriculums for peer supporters may have a positive impact on both peer mentors and individuals with IDD.

Moreover, as of July 2024, forty-eight states and Washington, D.C. reimburse mental health peer support services, with forty-one states covering both mental health and substance use disorder (SUD) peer support (Peer Recovery Center of Excellence, 2024). The exclusion of peer support services for people with IDD in the current reimbursement model underscores the need for improved reimbursement systems to ensure the sustainability of these peer support models.

Recommendation #2: Decrease Social Isolation Through Addressing Stigma, Accessible Transportation, Social Skill-Building, and Connecting People with IDD to Social Opportunities

Children with IDD face higher levels of loneliness and social isolation compared to their peers. This increased isolation is associated with mental health concerns, behavioral and emotional developmental challenges, and learning difficulties (Kwan et al., 2020). For older adults with IDD, relationships are often limited to family, paid staff members, and others with IDD (Bigby & Knox, 2009). Examples of interventions to help combat social isolation in those with IDD include locating and connecting individuals with social opportunities, having available community activities, and supporting them in skill-building to socially engage with others in community settings (Giummarra et al., 2022). However, stigma remains a significant barrier to social inclusion for people with IDD across cultures, highlighting the need for research and strategies to promote greater acceptance within communities (Jansen-van Vuuren & Aldersey, 2020). Additionally, enhancing multidimensional accessibility via accessible transportation, information, and technology is crucial for decreasing social isolation in this population (Boland et al., 2023).

Recommendation #3: Improve Family Caregiver Supports

According to Larson et al. (2022), sixty-two percent of people with IDD who receive Medicaid-funded services live with their families. Family caregivers often face chronic fatigue, sleep disorders, musculoskeletal issues, severe pain, and mental health challenges related to their caregiving responsibilities (Gravdal Kvarme et al., 2016; Park & Chung, 2015). The 2023 Family and Individual Needs for Disability Supports (FINDS) survey found that family caregivers often require support in multiple areas, including stress management, work-life balance, financial assistance, employer support, and direct support professional care for their care recipients (Lahti Anderson & Pettingell, 2023). Medicaid-funded Home and Community-Based Services (HCBS) waivers empower states to provide essential support services to family caregivers, including counseling, training, and paid caregiving assistance (Friedman, 2023). Ongoing research, advocacy, and outreach should focus on enhancing HCBS supports and connecting family caregivers to these services, as well as advocating for policies that expand paid support for family caregivers.

Recommendation #4: Enhance Direct Support Professionals Training

Direct Support Professionals (DSPs) are vital for ensuring the health, wellness, and safety of individuals with IDD. Despite their importance, the dissemination and training of evidence-based practices to DSPs for supporting those with IDD often remain inconsistent and siloed, primarily due to a lack of resources (Hewitt et al., 2008). Professionalizing the DSP workforce can significantly enhance their education and training, equipping them with the necessary competencies to manage complex care tasks effectively. Additionally, this approach would foster the development of career progression ladders, offering opportunities for professional growth, improved compensation, and reduction of staffing shortages (Stone & Bryant, 2021).

Community Level Goal Recommendations

At the community level within the SEMH, it is key to examine connections between organizations, businesses, healthcare agencies, and community groups that influence health behavior. The community level of analysis is concerned with accessibility of resources, community-level policies, as well as social norms and cultural values that influence health promotion efforts (Kennedy et al., 2021). Health care and health promotion efforts need to be respectful, inclusive, and accessible for people with IDD (American Association for Intellectual and Developmental Disabilities [AAIDD], 2016; Institute for Exceptional Care, 2024; Pham et al., 2024).

Recommendation # 1: Promote Universal Design and Accessibility

Principles of universal design (UD) include equitable use, flexible use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, as well as size and space for approach and use (Centers for Disease Control and Prevention [CDC], 2020c). The most common examples of UD include no step entries, automatic doors, adjustable height chairs or tables in a healthcare facility, and elevators with braille floor buttons. However, UD also considers cognitive and social differences among people in accessing environments or materials related to health promotion. For example, exercise equipment in a community gym may not have "standardized" controls or be intuitive to use. People may experience cognitive challenges in using technology (such as websites or apps) for health promotion. Designers of materials, apps, websites, social media, and technology devices should consider all types of sensory, cognitive, and social factors that might facilitate or inhibit health behaviors and provide information in plain language (Squiers et al., 2023). A UD approach recognizes how needs may change over the life course, and thus underscore the importance of person-centered planning to promote engagement in health promotion (Craddock et al., 2023).

Recommendation #2: Improve Transportation Options

If people can't get around their community, they may become socially isolated which can impact personal, social, emotional, and financial well-being. In the United States (U.S.), transportation continues to be an intractable problem for people with and without disabilities. Friedman (2024) notes that 40% of counties in the U.S. do not have reliable accessible transportation. County-based accessible transit routes frequently stop at county lines or only go short distances, which may inhibit accessibility to health promotion or healthcare facilities. Accessibility goes beyond physical accessibility to include developing transportation options that do not require complex scheduling or problem solving. People from different programs (such as those serving people with mental illness, IDD, or older adults) may not use the same transit systems and local communities may be too small to establish unique transportation systems. On-demand ride shares (e.g., Uber, Lyft) are expensive and frequently do not accommodate wheelchairs. Transportation options should be universally designed and available to all members of the community at an affordable price.

Recommendation #3: Ensure that Care Partners Incorporate the Intersectionality and Voice of People with IDD

People with IDD benefit from health promotion efforts that consider risk factors as well as social determinants of health (SDOH) that address the conditions and environments in which people live, learn, play, worship, and age (Marquis et al., 2023; Williamson, et al., 2017). Public health organizations are increasingly recognizing the importance of societal factors and how they influence the health and wellbeing of people with disabilities in their communities (Friedman, 2021; World Health Organization [WHO], 2023). The social and community context is a critical component of SDOH that looks at social stigma or exclusion, networks for social support, as well as opportunities for social participation (Mohan & Roberts, 2022). Having something to "do" (e.g., work, volunteering, making gifts for others, having hobbies, being with friends) is seen as a determinant of health (Cardell, 2015).

Friedman (2024) notes that one of the greatest barriers to health equity in people with IDD is lack of knowledge about people with IDD and their needs. According to the Institute for Exceptional Care [IEC] (2024), disability-inclusive health care must gather health stories from people with IDD and provide profiles to inform community organizations and policy makers regarding the needs and wants of people with IDD. Pham et al. (2024) note that it is critical to understand which health outcomes are important to people with IDD and their caregivers/ partners. Additionally, it is important to recognize that people with and without disabilities hold multiple identities and roles that influence their well-being. Understanding the wants and needs of people with IDD will lead to more effective care models for person-centered health care and health promotion (Williamson, et al., 2017).

Recommendation #4: Enhance Training for Healthcare Providers and Support Staff

One of the greatest barriers to engagement in health promotion for people with IDD is health professionals lack of knowledge about the needs of this population, ultimately compromising quality of health care (Friedman, 2024; Williamson, et al., 2017). Many health professionals assume that people with IDD have a lower quality of life, are less likely to feel pain, are a burden, and have willful adverse behaviors. Because of these presumptions, practitioners limit the involvement of people with IDD in their own care and health promoting behaviors. People with IDD are capable of learning about their physical and mental health to obtain better healthcare outcomes when care providers support people with IDD to take an active role in their care (Williamson, et al., 2017).

While most organizations acknowledge the need for training of support staff and healthcare professionals, the debate is about the timing and the amount of training. At the support staff and para-professional level, a train-the-trainer approach can identify leaders to design and implement training programs to support direct care providers in the field. Early exposure to people with IDD should occur for people in clinical and medical residencies as well as technical training programs.

While there is little debate about the need for universal design and inclusive health care as a facilitator to health promotion at the community level, challenges persist regarding specific implementation strategies as well as resource allocation to support implementation. Given that multiple organizations are advocating for similar goals to give participants voice, person-centered planning, and allocating funds for health promotion and prevention efforts, collaboration across organizations, schools, and training programs on health promotion advocacy efforts might unify national goals and funding priorities.

Policy Level Recommendations

Recommendation #1: Ensure Adequate Medicaid Coverage for Health Promotion Activities

Many people with IDD have complex health care and other needs that require longer appointment times to adequately have their needs met (Johnston et al., 2022). Many also require specialist care, which is in short supply, leading to long wait times to receive needed care (Johnston et al., 2022). Medicaid and private insurance payments should be enhanced to cover longer visit times and to incentivize specialists and other healthcare providers to include people with IDD in their practice (Johnston et al., 2022; Pham et al., 2024). Medicaid coverage also needs to be expanded to include vision, dental care, and mental health equity, all areas identified as areas of need for people with IDD (Ward et al., 2019; Pham et al., 2024).

Recommendation #2: Ensure Public Health and Other Health Promotion Activities are Created Using Universal Design

People with IDD may experience limited health literacy skills and may need additional support to understand and use health information (Shady et al., 2022). This need was highlighted and magnified during the COVID-19 pandemic (Squiers et al., 2023). As a group, people with

IDD were disproportionately affected by the virus (e.g., Landes et al., 2020; Landes et al., 2021). However, despite efforts to release plain language information about COVID-19, information was often inaccessible to people with IDD (Squiers et al., 2023). The lack of clear health-related information extends to clinical practice and screening activities (Shady et al., 2023), highlighting the need for greater efforts in creating public health and other health information using universal design principles.

Universal design principles are highly compatible with the social model of disability and move beyond accessibility and accommodations with an emphasis on flexibility and usability for all to the fullest extent possible (Gossett et al., 2009). Policies of public health agencies and other organizations need to prioritize universal design principles in their planning, information dissemination, and other activities to ensure equity in access to people with IDD.

Recommendation #3: Include IDD Identifiers in Large National Health Datasets to Increase Knowledge About the Health Status of People with IDD

Effective policies and programs require sufficient data to guide decisions. The dearth of data about the health status and other health indicators for people with IDD has been identified as an area that needs to be addressed to support future decision-making that affects the most critical needs of this population (Krahn & Havercamp, 2019; Krahn et al., 2023; Bonardi et al., 2024; Pham et al., 2024). Efforts at the federal level to include the ability to identify people with IDD is being addressed through a cross-agency initiative (I/DD Counts; https://acl.gov/iddcounts). I/DD Counts is led by the Administration on Community Living (ACL) and includes the Assistant Secretary for Planning and Evaluation (ASPE), the CDC, the Centers for Medicare & Medicaid Services (CMS), and the National Institutes of Health (NIH). There have been inclusive efforts to identify the key factors that should be considered when designing data collection activities to ensure that the data collected is meaningful (Krahn et al., 2023; Pham et al., 2024). These efforts have involved people with IDD, their families or caregivers, healthcare providers, regulators, and researchers. These initiatives should be holistic and address multiple areas of health and wellbeing, including physical, mental, social, and sexual health, and pain management. Additionally, there should be access to high-quality, coordinated health care that treats people with IDD with respect (Krahn et al., 2023; Pham et al., 2024).

In addition, the unique needs of people with IDD should be considered when collecting data, including addressing stereotypes and discrimination, ensuring the validity of proxy responses, and understanding how SDOH may affect this population (Krahn et al., 2023). Two possible approaches to data collection include IDD identifiers in national health surveys to compare health outcomes for people with IDD to the general population, an effort which is already underway (Havercamp et al., 2019). Bonardi and colleagues (2019) propose harmonizing definitions of IDD across administrative data sets to understand health utilization and other outcomes for people with IDD.

Conclusion

The health inequities experienced by people with IDD can have a variety of causes and potential interventions. Addressing these health inequities using a social ecological model can assure that attempts to address these inequities are addressing the proximal cause. Health inequities and potential interventions can be found at the individual, interpersonal, community, and policy levels. It can be a powerful tool to address health inequities by identifying how factors at different levels (individual, interpersonal, community, and policy) contribute to disparities in health outcomes, and by guiding interventions that target these multiple layers.

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