

Collaborative health advocacy for health promotion for individuals with intellectual and developmental disabilities

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Intellectual and developmental disabilities (IDDs) are neurodevelopmental disorders beginning in childhood that most often present with cognitive limitations and/or impaired adaptive functioning (American Psychiatric Association, 2013). Individuals with IDD have unique needs and an increased risk of major health concerns that make access to health care services and health promotion essential (Anderson et al., 2013). There is an increased risk of primary health conditions in this population including epilepsy, decreased mobility, and/or sensory challenges, all of which can increase the risk of obesity or other secondary conditions, such as Type II diabetes (Havercamp & Scott, 2015; van Schrojenstein Lantman-de Valk & Walsh, 2008). Additionally, individuals with IDD have also been disproportionately affected by COVID-19. People with IDD are more likely to be exposed to the disease due to living in congregate settings, like group homes, and those living in congregate settings are more likely to have severe cases and poorer outcomes overall (Landes et al., 2021). Increased exposure may also be due to difficulty physically distancing from caregivers who provide direct support to individuals with IDD (Drum et al., 2020; Karla K. Ausderau et al., 2021). The combination of these factors and the increased risk of disease in this population further highlight the need for accessible health care and related services.

An individual's health, functioning, and quality of life outcomes are affected by the *social determinants of health*: conditions in the environments where people are born, live, learn, work, play, worship, and age (Office of Disease Prevention and Health Promotion [ODPHP], n.d.). Social determinants of health are organized into five domains: health care access and quality, social and community context, economic stability, neighborhood and built environment, and education access and quality (ODPHP, n.d.). Individuals with IDD experience well-documented barriers to health promotion and health care access across all domains of the social determinants of health, leading to poorer health outcomes overall (Williamson et al., 2017). Figure 1 presents a summary of identified barriers to health promotion for individuals with IDD. Occupational therapists (OTs), as holistic health care providers, can use their unique lens and perspective to promote health participation and improve health outcomes for people with IDD. This article will discuss collaborative health advocacy as an intervention approach and provide practical examples for integration into clinical practice to address participation and health advocacy.

Figure 1. Barriers to Health Care and Health Promotion for Individuals With Intellectual and Developmental Disabilities

Note. Figure presents research identifying barriers to health care access and health promotion for individuals with IDD organized by the domains of the social determinants of health. Numbered references: 1. Dassah et al., 2018; 2. Williamson et al., 2017; 3. Navas et al., 2019; 4. Krahn and Fox, 2014

Health Promotion Through Meaningful Collaboration Between OTs and Individuals With IDD

Health promoting activities are essential occupations for well-being (American Occupational Therapy Association [AOTA], 2020). Historically, individuals with IDD are excluded from participation in and determination of their own health care (Meade et al., 2015). Meaningful participation in health promotion has been shown to improve global health outcomes (McPherson et al., 2017). As experts in occupational engagement, OTs are uniquely qualified to address systemic barriers to participation through individualized practical interventions that can lead to larger systemic changes. Through the lens of participation and occupational justice, OTs and their clients with IDD can promote improved population-level health outcomes through participation and advocacy. It is essential for OTs to address and collaborate with individuals with IDD as well as other stakeholder groups to prioritize health promotion at a broader level to mediate the existing effect of systemic barriers on health outcomes in this population.

We define collaborative health advocacy as intentional advocacy, completed in partnership between health care professionals and clients, for health promotion opportunities and improved health outcomes. Collaborative health advocacy is an effective way for OTs to support substantive change with individual clients and in health care for people with IDD. Table 1 outlines intervention opportunities for OTs to address collaborative health advocacy at both individual and population levels.

Table 1. Practical Strategies for Occupational Therapists (OTs) and Collaborative Health Advocacy

Setting	Collaborative Advocacy Strategies
Self-determination in therapeutic journey	<p>Clients should be engaged throughout all parts of their care delivery to optimize autonomy in the therapeutic relationship. Examples may include:</p> <ul style="list-style-type: none"> • Setting collaborative health goals • Prioritizing treatment approaches that align with their personal beliefs and values • Identifying meaningful participation-based outcomes
Self-determination in health care settings	<p>Collaborative interventions can be implemented by an OT to address specific health care-related goals. Examples may include:</p> <ul style="list-style-type: none"> • Co-construction of a health narrative or social story about a client's individual health care needs and priorities • Role-playing health care provider interactions to practice advocacy skills <p>These collaborative intervention approaches can be modified and implemented in other therapeutic settings (e.g., work or school).</p>
Systems-level legislative advocacy	<p>Systems advocacy focuses on prioritizing advocacy work to promote improved outcomes for vulnerable groups at the systems or population level. Effective health-promoting legislative or policy change must consider the perspectives and inclusion of relevant stakeholders. Examples of systems advocacy OT interventions include:</p> <ul style="list-style-type: none"> • Leading or attending legislative or policy-based events, such as the American Occupational Therapy Association's Hill Day • Communicating with representatives about issues important to the profession and the health priorities of their clients • Serving on committees or boards that can support improved public health and influence policy change



	<ul style="list-style-type: none"> • Advocating for policies that improve health outcomes at the organizational level
Community-based partnerships	<p>OTs must collaborate with community organizations that serve or represent this population; partnership with these organizations provides opportunities to address population-level health outcomes. Examples of local and nationally based organizations available in many states that protect and promote health priorities include:</p> <ul style="list-style-type: none"> • Board for People with Developmental Disabilities • Special Olympics • The Arc • Easter Seals • United Cerebral Palsy • TASH: Disability Advocacy Organization
Research and scholarship for health advocacy	<p>One of the most critical concerns with health-based research for diverse groups is the translation of research into practice. Health-based research results that are disseminated beyond traditional academic pathways at an accessible reading level are more likely to be integrated into clinical practice and promote systems-level health-related change (Nicolaidis et al., 2015). Examples of health research translation interventions include:</p> <ul style="list-style-type: none"> • Promoting or encouraging attendance at a health summit where stakeholders can convene with other researchers to discuss relevant research priorities • Teaching clients how to critically engage with scientific research to improve their individual health outcomes • Valuing and promoting the importance of evidence-based clinical practice • Including stakeholders as key personnel to diversify perspectives and priorities in relevant research • Collaborating with stakeholders on research dissemination pathways and methods

Case Examples



OTs have an ethical and professional responsibility to address health promotion and participation across the social determinants of health domains, especially through

avenues for advocacy. As demonstrated in the *Occupational Therapy Practice Framework: Domain and Process* (4th ed.; AOTA, 2020), OTs have a role in advocating for the needs of their clients as well as empowering clients to advocate for themselves.

Two individuals with IDD were interviewed to describe their involvement in collaborative health advocacy capitalizing on their extensive experience pursuing health-promoting advocacy opportunities to improve health outcomes for themselves and their peers. In both examples, OTs worked with the individuals by helping them to perfect their health story—an advocacy tool to be used in future health care provider interactions. OTs are uniquely skilled to support individuals with IDD in identifying key content to include in their story and collaborating on avenues for advocacy-related discussion or dissemination, such as provider interactions or collaborative platforms. Through meaningful collaboration on targeted advocacy goals through platforms such as health stories, OTs may scaffold self-directed health promotion and community engagement for adults with IDD that lead to sustainable self-advocacy to initiate long-term systematic change. Implementing both individual and systems-level collaborative health advocacy interventions can have a catalytic impact on health outcomes for all.

Edward

Collaborating with an OT, Edward crafted a personal health narrative or health story about his experience. Edward uses his health story to advocate for affordable medication and medical equipment. He is also using his health story to develop post-pandemic support groups to address physical, mental, and emotional health for people with IDD. Edward's passion for helping others and the OT skillset to support self-determination has allowed for collaborative health advocacy that affects Edward and his community moving toward positive change. In his words, "it takes one person to help to change the world. If my story can help one hundred people or two, I know I made an impact. It is not about me."

Edward embodies the spirit of collaborative health advocacy and is passionate about collaboration with organizations that help others with disabilities. He is a Unified

collaboration with organizations that help others with disabilities. He is a Clinical Leadership Specialist through Special Olympics and facilitates courses and programs for other athletes and organizations to learn about leadership within the advocacy sector. Edward is pursuing opportunities in Washington, DC, to continue to advocate for systems-level health-related change, blending both systems and individual collaborative health advocacy opportunities. In his own life, Edward has had to be an advocate for his own dental health. After having considerable tooth pain and being denied consistently by his dentist for services due to his insurance provider, Edward reached out to state and national organizations that serve others with intellectual disabilities. Through these connections, he was able to find dental care from a provider that would take his insurance and treat him.

Cindy

Cindy has also spent time collaborating with OTs to continue to strive for health equity for people with disabilities. Recently, Cindy participated in a health research summit facilitated by OTs where she was able to collaborate with both clinicians and researchers to provide feedback on how to be more inclusive with health research practices and dissemination. Cindy believes that all providers should continually seek opportunities to help individuals from marginalized communities, including those with disabilities, to improve their health. "If we're in this world, we're meant to help each other," she said. Cindy has acted as a powerful health advocate in her own life, advocating for more inclusive and accessible care delivery through her own health challenges, such as breast cancer and chronic jaw difficulties. Like Edward, Cindy co-constructed a health story with an OT to use as an advocacy tool in health experiences such as the aforementioned one. She is the current executive director of a state-wide self-advocacy organization for people with disabilities and has held several different leadership roles on scientific research studies. Cindy has prioritized collaborative health advocacy and education after hearing from her friends and colleagues about similar negative experiences with health care providers and service denial due to disabilities. She said about self-advocates in collaborative health advocacy, "we shouldn't be doing all the advocacy ... we should be teaching people how to be advocates for themselves ... when someone learns how to speak for themselves in little

advocates for themselves ... when someone learns how to speak for themselves in those moments, they can stand up for themselves in big moments." Cindy has also taken her perspective on the importance of collaborative health advocacy to public events. She has delivered two keynote speeches at self-determination conferences for individuals with disabilities and spends time talking about health advocacy to medical students and physicians.

Conclusion

Collaborative health advocacy implemented by OTs can promote participation and access to related services improving health and well-being for people with IDD. By prioritizing self-determination skills in the clinical setting with individual clients through collaborative health advocacy, OTs can support clients in developing skills required for health-related advocacy outside of the clinic across multiple settings. Collaborative health advocacy that occurs both inside and outside the clinic can ultimately lead to improved health outcomes across this population. Systemic advocacy for people with IDD towards health promotion and improved health care service access and quality can impact population-level health outcomes and reduce health disparities.

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