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An Ethical Approach to Health Equality

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Plain Language Summary

Over the last 50 years, the United States has changed how it helps people with intellectual and developmental disabilities (IDD). In the 1960s, people started fighting for the rights of those with disabilities. This led to important laws that gave people with IDD the right to go to school and live independently.

Everyone deserves the same chance to be healthy, including people with IDD, but people with IDD still face many challenges to staying healthy:

- It can be hard to find doctors who understand their needs.
- Many can't find safe and affordable housing.
- Less than 20% have regular jobs.
- Transportation is often hard to find.
- Some places they need to go are hard to get to.

There are two main ways to make things better:

1. Help each person with IDD set their own health goals and make their own choices about their health.
2. Include people with IDD in making rules about supports and in doing research about health.

People with IDD should help make decisions about things that affect their lives. To give people with IDD the same chance at being healthy as everyone else, problems need to be fixed both for individual people and within the whole system.

Introduction

The past half century in the United States has seen a shift in the public system of treatment for people with intellectual and developmental disabilities (IDD) from one that promoted institutionalization to one that focuses on supporting people in their communities. Although significant policy shifts toward recognizing individual rights, supporting autonomy, and inclusion of people with IDD have occurred, inequities persist that impact health. We adopt here a broad definition of "health equality" that encompasses the social determinants of health—the social, economic, and physical conditions in which people are born, grow, live, work, learn, play, worship, and age. It is a good thing to have equitable drivers of health for all members of society, including people with IDD.

Historical Movement Toward Health Equality

Advocacy. The civil rights movement of the 1960s helped develop a roadmap for disability rights, independent living, self-advocacy, and other advocacy movements to push for deinstitutionalization, access to education, community living, and equal rights. The disability justice movement of the 2000s furthered the principles of these earlier movements, highlighting the barriers of ableism and recognizing the intersectionality of people with IDD.

Defining Legislation. Bolstered by the efforts of advocates, federal laws—including several that emerged from landmark court decisions—have shaped the current landscape of systems supporting people with IDD. Notable legislation leading to greater access to services, education, and the community includes the Rehabilitation

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Act of 1973, the Developmental Disabilities and Bill of Rights Act of 1975, the Individuals with Disabilities Education Act of 1975, and the Americans with Disabilities Acts of 1990 and 2010.

Persistent Challenges to Health Equality

While the trajectory of advocacy and legislation has been toward more inclusion and equitable treatment of people with IDD, significant barriers to health equality persist. Compared with those without disability, people with IDD have lower access to those social, economic, and physical conditions that are known social determinants of good health, and they have poorer health outcomes across their lifespans.

Healthcare Access. A number of factors create barriers for people with IDD to accessing healthcare, including ableism, physical inaccessibility of treatment locations, transportation limitations, limitations in knowledge about disability among healthcare professionals, and communication barriers with healthcare professionals. In addition, typical insurance practices often serve to prevent people with disabilities from being able to see the doctors they need as long and/or as frequently as they need to have optimal health outcomes.

Community and Housing. A number of factors create barriers for people with IDD to living optimally healthy lives in their communities, such as the limited stock of safe, affordable, and accessible housing. In addition, ableism, transportation limitations, and physical inaccessibility of recreational and other social activities contribute to poor health outcomes.

Education. Completion of a greater number of years of formal education is strongly correlated with positive health outcomes across time in the general population. Until recently, a postsecondary educational experience was out of reach for people with IDD; however, the Higher Education Opportunity Act of 2008 and grant-funded Transition and Postsecondary Programs for Students with Intellectual Disability (TPSID) have broadened access to higher education for people with IDD. Though these developments are comparatively recent, the positive health outcomes associated with higher levels of education may yet be observed in people with IDD over time.

Employment. Fewer than 20% of people with IDD in the United States are employed in competitive integrated jobs. Having a job is critical for financial independence, and from a social determinant of health perspective, employment provides social networks and community, feelings of purpose and belonging, and opportunities for continued skill development.

Recommendations to Address Health Inequality

Having equitable drivers of health for all members of society is a good thing. We note that people with IDD are specifically included in the group "all members of society." Finally, the drivers of health—the social determinants—are the universe of social, economic, and physical conditions in which people exist and interact across their lifespan.

We recommend a capability approach as a theoretical framework for promoting health equality for and with individuals with IDD. This approach embodies two important concepts: (a) that a person who is free to make choices will try to achieve their own well-being and (b) that the ability to achieve well-being is affected by an individual's own capacities and by their opportunities, which depend on the social, economic, and physical situations in which they live., and physical situations in which they live.

1. People with IDD should be supported in making and setting personal health goals. Achievement of personal goals contributes to an individual's well-being.
2. Person-centered approaches to achievement of an individual's health goals should recognize the individual's relative strengths and weaknesses and the opportunities and limitations of their current environment. It is important to recognize the interconnectedness of a person's physical health, mental health, and environment and to

ensure that the person with the IDD is at the center of any decision that could impact their health and well-being.

We recommend the authentic engagement and integration of people with IDD in research, policy, and practice to remove systemic barriers to health equality. When people with IDD are authentically engaged, they are present to not only provide feedback but to meaningfully contribute to the development, implementation, and evaluation processes associated with research, policy, and practice activities.

Conclusion

An ethical approach to health equality for people with IDD should ensure people with IDD are included in decisions that impact their lives. In addition, moving from current practice of utilitarian approaches to a capabilities ethical framework will proactively support health equality.

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