

## **Health Inequities in the Intellectual and Developmental Disabilities Population**

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### **Abstract**

Health inequities are prevalent in the Intellectual and Developmental Disabilities population, and as this population grows, health inequities will grow. Policymakers and leaders have an opportunity to collaborate and partner with IDD providers to educate clinicians entering healthcare and provide training to the existing workforce. Empowering healthcare workers to be knowledgeable of best practices to implement for anyone, with or without a disability, will enable them to provide better quality care at a lower cost and achieve better-quality patient outcomes for those they care for. Best practices are an excellent start toward health equity for all. It is necessary to include people with disabilities in programs to prevent and manage chronic diseases and conditions.

### **Introduction**

Health inequities exist across the nation, resulting in multiple underserved populations. One significantly affected group is those with Intellectual and Developmental Disabilities (IDD). Individuals with IDD experience lower rates of preventative screenings and higher rates of obesity, diabetes, seizures, and cardiovascular disease; resulting in lower life expectancy. There are a number of contributing factors, including unconscious bias against people with disabilities, knowledge deficits of those treating IDD, physical access barriers, and inequities due to the unmet social determinants of health. Nevertheless, there is one area where health and human service policymakers and leaders can have an immediate impact on the growing population of people with IDD in the US; that is in educating the healthcare workforce on how to engage in best practices to meet the needs of people with intellectual and developmental disabilities: using best practices. Together, these sector leaders must agree upon and develop policy that supports consistent standards of care for the complex IDD population.

There are a number of explanations for these disparities and some of the contributing factors, including unconscious bias against people with disabilities, knowledge deficits of those treating IDD, physical access barriers, and inequities due to unmet social determinants of health.

As a Registered Nurse for 30 years and more than 25 years in Home Health, Hospice, and Palliative Care, it felt intuitive that my expertise in community health would translate into a new role as a VP of Integrated Health Services for a large non-profit residential program for people with IDD. The role involves oversight of clinical support, both nursing and behavioral health, for

over 300 people with severe and profound levels of intellectual and developmental disabilities. The goal of this role is to integrate the care received and reduce care gaps or disparities in care. However, it quickly became apparent how ill-prepared I was to manage this population, as are the health care systems within the region. IDD is a specialty, and major healthcare institutions have been serving this population with a knowledge deficit of this population's needs. IDD providers have a strong knowledge base for the needs of the IDD population and can work with policymakers and healthcare institutions to better serve this growing community-based population.

The number one priority now is finding ways to educate and integrate with other healthcare providers such as skilled nursing facilities, hospitals, physicians, nurse practitioners, physician assistants, nurses, physical, speech, and occupational therapists, dentists, and other clinicians in the area to reduce health inequities and implement best practices for people with IDD. Inequities continue to be identified, and according to the 2022 National Council on Disability's Health Equity Framework for People with Disabilities, "...comprehensive disability clinical-care curricula [should be required] in all US medical, nursing, and other healthcare professional schools."

Most clinicians will admit that they are not taught the skills to clinically and accurately diagnose, interact, and develop plans of care for people with IDD. They are trained to treat specific medical conditions such as aspiration pneumonia, bowel impaction, seizures, diabetes, obesity, swallowing disorders, and gastroesophageal reflux, to name a few. Most healthcare professionals are not trained in psychiatric conditions and how these conditions often have different presenting signs and symptoms in people with the IDD population. Individuals within the IDD population may present with behavioral issues and are unable to vocalize what is actually bothering them. This could lead to misdiagnosis and lack of treatment for a medical condition.

It is essential to educate clinicians about best practices and how to implement them with common presentations of treatable medical illness in people with IDD, medication management, and The Fatal Five conditions that are the top causes of preventable morbidity and mortality in people with IDD. The issues can differ in order of frequency depending on the population being represented. However, the five conditions most likely to result in death or health deterioration for persons with Intellectual and Developmental disabilities are:

- Aspiration
- Bowel Obstruction
- Dehydration
- Seizures
- Infection/Sepsis

It is necessary that policymakers, in collaboration with IDD providers, encourage local hospitals and clinicians' offices to provide training on caring for people with IDD to their clinical staff. Medical schools, nursing schools, and other health professional training programs should incorporate mandatory disability-competent training for their students. It is important to raise

awareness of this population as specialty care among clinicians, health system leaders, and communities about IDD-related resources and training options to better understand the IDD populace. There are organizations such as the American Academy of Developmental Medicine and Dentistry, the Developmental Disabilities Nurses Association, the Institute for Exceptional Care, and resources such as the Curriculum in IDD Healthcare that are working on increasing awareness for the IDD population. Ultimately, legislators and medical societies should offer and promote education in this area.

Knowledge, care coordination, and the idea of a nurse navigator to facilitate care needs are key. Empowering healthcare workers to be knowledgeable of best practices to implement for anyone, with or without a disability, will enable them to provide better quality care at a lower cost and achieve better-quality patient outcomes for those they care for. Best practices are an excellent start toward health equity for all. It is necessary to include people with disabilities in programs to prevent and manage chronic diseases and conditions. One of the recommended ways to address the health inequities that exist for people with disabilities is integration into community-based programs with nurse navigators coordinating individual care needs. However, to integrate effectively and successfully, it is important to be knowledgeable of disability culture, understand disability literacy, adhere to disability etiquette, and incorporate inclusion/accessibility challenges in the program.

People with disabilities are a diverse group. It doesn't matter whether they are born with a disability or acquire a disability because of injury or illness/chronic condition. An individual with a physical, developmental, cognitive, sensory, or emotional disability must have community integration and be able to fully participate in community programs and activities. As a result of deinstitutionalization, integrating people with disabilities into overall community-based programs requires advocating for inclusion and full accessibility. All activities should be inclusive and welcoming to people with disabilities, regardless of their disability or the accommodation that might be required. As the IDD community grows, let our knowledge and integration grow with it.