

Do You See the Disability and the Injustice, or Do You See the Person Who is Deserving?

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Keywords: disability, choices, pandemic, education, change

Abstract

History has shown us that barriers can be diminished or overcome for individuals with disabilities when they are provided with inclusive choices. During the pandemic, everyone experienced a level of isolation and restrictions to their activities. A person with a disability may deal with feelings of isolation and likely feel restricted every day. Education can inspire change and motivate people to respond to the needs of others. Improving health equity for the vulnerable and disabled is an attainable goal.

Introduction

History has shown us that barriers can be diminished or overcome for individuals with disabilities when they are provided with inclusive choices. According to the Oxford Dictionary, the definition of inclusive is aiming to provide equal access to opportunities and resources for people who might otherwise be excluded or marginalized, such as those having physical or intellectual disabilities or belonging to minority groups.ⁱ Diminishing barriers can have a direct and positive impact on improving health equity and access to care and other resources. This definition is an adjective that can also mean global, all-embracing, unrestricted, vast, blanket, and far-reaching. To an individual with disabilities, being unrestricted or having far-reaching capabilities offers hope and potential for a better quality of life. The opposite of inclusive means limited, restricted, incomplete, or narrow. To a person with a disability, their outward limitations may be visible to all, but their inward thoughts may leave them feeling frustrated, restricted, or incomplete. The Office of Minority Health and Health Equity, a division of the Centers for Disease Control and Prevention (CDC), states, “For many the disability itself is not the main challenge; instead, it's the environments that they live, learn, work, and play that create the biggest difficulties.”ⁱⁱⁱ This article will examine four ways everyone can participate in meeting the challenge of assuring anyone with a disability either outwardly expressed or unseen to the naked eye feels included and has fair and deserving choices. The following recommendations are considered best practices in the field of healthcare.

Be Available

During the pandemic, everyone experienced a level of isolation and restrictions to their activities. A person with a disability may deal with feelings of isolation and likely feel restricted every day. There are many opportunities to volunteer our time, energy, and funds to local nonprofit organizations that will gladly connect us with individuals who may need assistance to go to

doctors' appointments, go shopping, or just enjoy time in nature. The Division of Human Development and Disability (DHDD), a division of the CDC, reports, "As of 2016, an estimated one in four adults in the United States reported a disability and face challenges to achieving optimal health and accessing high-quality health care."ⁱⁱⁱ Having less access to health care may increase symptoms of chronic illness and cause more anxiety and depression. Begin by finding an agency in your community and reach out to volunteer. Search for programs such as Making Opportunities for Volunteerism and Exploration (MOVE). A program like MOVE offers creative environments for adults with intellectual and developmental disabilities. They will have opportunities to express themselves through visual and performing arts.^{iv} Why not recruit some friends and family, get creative, volunteer, and help an adult in need fully engage in his/her choices of interests?

Support Caregivers

Education can inspire change and motivate people to respond to the needs of others. Healthcare providers can begin by screening caregivers during wellness checkups. They can take the opportunity to show support and educate their patients regarding their healthcare needs and offer information regarding local programs they can benefit from. When they do, caregivers will feel appreciated and be able to express their concerns. Caregiving can be stressful and may cause financial strains.

Disability & Health Promotion, a division of the CDC, states, "Educating yourself about disabilities or making sure your organization provides accessible educational materials for people with disabilities can make a difference. People with disabilities, their family members, first responders, and emergency planners must be prepared for emergencies or disasters."^v

We can show our support for caregivers by "helping them run errands, do chores or other tasks, negotiate times to check on them, help them to create and manage a care plan for the person they care for, and provide emotional and social support."^{vi} Communities may offer assistance through programs such as The Options program. The goal of programs like Options is to, "support families who care for family members at home by offering meaningful activities and social opportunities and assists persons with disabilities who are capable of living independently."^{vii} When we support caregivers, we help reduce their stress, give them needed breaks, and foster a sense of teamwork for them and the person they care for.

Protect Individuals with Disabilities

People with disabilities and single mothers with children are easily victimized. "Research shows that children with disabilities and their families have higher levels of disaster exposure, lower levels of disaster preparedness, and less recovery support due to longstanding discriminatory practices."^{viii} The recent pandemic, terrorism, and global warming may have had a greater impact on the disabled because of isolation, exposure to domestic violence, and the fear of the unknown. People with disabilities need assistance to create a disaster preparedness plan, gather essentials in case of an emergency, practice home drills, and have up-to-date emergency contact phone numbers available. Anyone in a supervisory or caregiver role, such as teachers and

healthcare providers, can be crucial in initiating these conversations with families of the disabled. Local fire departments, including volunteer fire departments, are staffed with caring, knowledgeable, and skilled people. We can benefit everyone, but especially the disabled, when we support their efforts to serve and protect our communities. If we see an injustice, we should take the initiative to assist anyone in need, especially young mothers with children, the elderly, and the disabled.

Make Career Goals to Assist and Advocate for the Disabled

Many people make career choices based on family dynamics, personal interests, or the economy, but choosing a career to care for others offers a sense of fulfillment and decreases the risk of depression and anxiety. “The need for caregivers is growing along with the aging of the US population. By 2030, an estimated 73 million in the United States will be 65 years or older.”^{ix} These statistics will include many disabled individuals. During their research, students involved in science, technology, engineering, and mathematics (STEM) education saw the healthcare relationship. C. Brook Bruthers states, “As fellows learned more about research, they saw the relationship to medicine and many integrated basic or clinical research into their career plans.”^x This is significant because during their discussions, these students developed “three central themes: the need to customize program goals for diverse participants, the pivotal role of the research mentor-student relationship, and the powerful impact of participating in a national scientific meeting.”^{xi} Reducing the national shortage of diverse healthcare providers is a high priority. A disabled individual may face physical challenges but may excel in STEM. We can encourage universities to widen out in their support of the disabled but also in support of students entering the healthcare field. Hospitals and clinics can increase the availability of student mentors and offer student loan assistance. Identify people who are compassionate and encourage them to consider becoming a doctor, a nurse, a therapist, a nutritionist, or a behavioral specialist. These occupational fields can have a powerful impact on improving health equity and access to care. Choosing a healthcare career will make a difference, give care to the deserving, and change lives.

Improving health equity for the vulnerable and disabled is an attainable goal. Erie Homes For Children & Adults states, “Each person with a disability should have the opportunity to make choices, to contribute to his or her daily lifestyle, to obtain the best education or training available, and to enjoy a home-like atmosphere with quality caregivers.”^{xii} When choosing a career, volunteering, or looking out for the vulnerable, make sure to think about how decisions we make show that we truly see the deserving person and not just the disability.

References

Alzheimer's Disease and Healthy Aging Program, Centers for Disease Control and Prevention. *Supporting Caregivers*. https://www.cdc.gov/aging/publications/features/supporting-caregivers.htm?s_cid=qr2022

Bruthers CB, Matyas ML. Undergraduates from underrepresented groups gain research skills and career aspirations through a summer research fellowship. *Adv Physiol Educ*. Abstract. 2020 Dec 1;44(4):525-539. <https://pubmed.ncbi.nlm.nih.gov/32880486/>

Disability and Health Promotion. Centers for Disease Control and Prevention. *Disability and Health Information for Partners*. <https://www.cdc.gov/ncbddd/disabilityandhealth/partners.html>

Erie Homes for Children and Adults. *Making Opportunities for Volunteerism and Exploration (MOVE)*. <https://ehca.org/programs/move/>

Erie Homes for Children and Adults. *About Options*. <https://ehca.org/programs/options/>

Erie Homes for Children and Adults. *Our vision*. <https://ehca.org/our-mission/>

Mann M, McMillan JE, Silver EJ, Stein REK. Children and Adolescents with Disabilities and Exposure to Disasters, Terrorism, and the COVID-19 Pandemic: a Scoping Review. Abstract. *Curr Psychiatry Rep*. 2021 Oct 13;23(12):80. <https://pubmed.ncbi.nlm.nih.gov/34643813/>

Office of Minority Health and Health Equity. Centers for Disease Control and Prevention *Disability Inclusion as a Cornerstone for Health Equity*. <https://www.cdc.gov/healthequity/features/disability-inclusion/index.html#print>

Oxford Dictionary of English. *Definition of inclusive*.

The Division of Human Development and Disability (DHDD). Centers for Disease Control and Prevention. *What is Health Equity?* <https://www.cdc.gov/ncbddd/humandevelopment/health-equity.html>

ⁱ Oxford Dictionary of English.

ⁱⁱ Office of Minority Health and Health Equity. CDC

ⁱⁱⁱ The Division of Human Development and Disability (DHDD). CDC

^{iv} Erie Homes for Children and Adults. MOVE.

^v Disability and Health Promotion. CDC

^{vi} Alzheimer's Disease and Healthy Aging Program. CDC

^{vii} Erie Homes for Children and Adults. About Options.

^{viii} Mann M, McMillan JE, Silver EJ, Stein REK.

^{ix} Alzheimer's Disease and Healthy Aging Program. CDC

^x Bruthers CB, Matyas ML.

^{xi} Bruthers CB, Matyas ML.

^{xii} Erie Homes for Children and Adults. Our vision.