

One of Us: Combating Stigma Against People with Intellectual and Developmental Disabilities

August 30, 2021



The COVID-19 pandemic exposed inequalities in all walks of American life, bringing to the forefront long-overdue conversations about health disparities among various marginalized populations, including individuals with intellectual and developmental disabilities (I/DDs). Even before the pandemic, however, individuals with I/DDs—including attention-deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, learning disabilities, seizures, developmental delays, and intellectual impairment (Bagcchi, 2020; Turner-Musa et al., 2020)—experienced pronounced health disparities (Scior et al., 2016), such as increased rates of cardiovascular disease, diabetes, epilepsy, and psychiatric conditions and decreased life expectancy relative to the general population (Krahn & Fox, 2014; Young-Southward et al., 2017). Perhaps unsurprisingly, during the pandemic, they experienced more severe illness, greater risk of hospitalization, and almost twice the case fatality rates (Turk et al., 2020). And yet despite these staggering findings, individuals with I/DDs were often excluded from receiving priority vaccinations. As I noted in a [commentary](#) and [opinion piece](#) published earlier this year, stigma—adverse social judgments about a person or group (Weiss et al., 2006, p. 280)—was partially to blame.



Author Emily Hotez (right) and her sister Rachel (left) reading together as children

As a developmental psychologist and the sister of an autistic adult, I have witnessed firsthand the effects of stigma on the health of people with I/DDs. Health care stigma, including physician misinformation and bias, is a significant driver of negative health outcomes. Indeed, I have been privy to countless stories of doctors who have expressed preconceived biases, discomfort, or outdated knowledge about autism, and, as a result, deemed my sister too complex, dangerous, or challenging to treat. For example, more often than not, my sister's dentist appointments would culminate in referrals to other dentists who were purportedly more equipped to address her anxiety and sensory challenges in the chair. But stigma originates well before individuals with I/DDs step foot in their doctors' offices. It can be traced back to a lifetime of experiences and accumulates to create health disparities (Krahn & Fox, 2014). The pandemic magnified these disparities, and it is now more important than ever to understand how stigma permeates throughout the life course for individuals with I/DDs, how it contributes to poor health outcomes, and what we can do to combat and prevent it.

Physician misinformation and bias are major facilitators of stigma and key mechanisms underlying health disparities.

Understanding stigma

Stigma begins when people identify differences—often based on stereotypes and prejudices—and link people to undesirable characteristics. The labeling separates the stigmatized group—“them”—from “us,” resulting in discrimination (Link & Phelan, 2006; Sheehan et al., 2017). I’ve seen this process play out for my sister, from peers at school who avoided her to strangers who unleashed anger, threats, or verbal abuse. Although these are examples of overt stigma, stigma can also be more insidious, not only experienced but anticipated or, at worst, internalized, resulting in shame or self-loathing (Chaudoir et al., 2013). Countless marginalized groups experience stigma, and many individuals experience amplified intersectional stigma because they belong to more than one marginalized group (Turan et al., 2019).

Health in People With Intellectual and Developmental Disabilities

- Having an I/DD is a statistically significant predictor of poor general health (Young-Southward et al., 2017).
- People with I/DDs experience decreased life expectancy and greater rates of co-occurring conditions (Scheepers et al., 2005).
- People with I/DDs are more likely to experience increased rates of sensory impairment, epilepsy, psychiatric disorders, limited mobility, and gastrointestinal disorders than those without I/DDs (Traci et al., 2002).
- Individuals with I/DDs are more likely to develop common health conditions such as high cholesterol, hypertension, and cardiovascular disease and are more likely to experience multiple chronic conditions (Bodde & Seo, 2009; Draheim, 2006; Krahn et al., 2006; Reichard & Stolzle, 2011; Reichard et al., 2011; Tyler et al., 2010).

Stigma—in all of its many forms—is directly damaging to health. Perceived or experienced discrimination produces heightened stress responses (Murphy et al., 2007; Pascoe & Smart Richman, 2009), and over time, chronic exposure accumulates and creates physical wear and tear (Ganzel et al., 2010). It also puts people at higher risk for maladaptive coping behaviors, including substance use and disordered eating (Simone et al., 2019; Wang et al., 2018). Stigma is further associated with reduced psychological well-being (Ali et al., 2012; Dagnan & Waring, 2004), including increased vulnerability to emotional and interpersonal challenges (Jahoda et al., 2010). Finally, stigma may prevent people from accessing appropriate services, which further compounds health disparities (Ali et al., 2012).

The experience of stigma among individuals with I/DDs

Stigma against the I/DD population begins in childhood, increases with age, and is perpetuated through limited exposure to individuals with I/DDs. For instance, by age 9, children without I/DDs have distinctly negative perspectives of children with I/DDs, and that negativity is greater among older children and those with less contact with the I/DD population (Bellanca & Pote, 2013). Middle school students without I/DDs report that they have limited contact with peers with I/DDs, believe that they are unable to participate in academic classes, and do not want to interact socially with them (Siperstein et

al., 2007). Stigma continues to proliferate throughout adolescence. For instance, 13-year-olds with I/DDs are significantly more likely than their peers without I/DDs to report being bullied (Christensen et al., 2012). High school students with I/DDs report experiencing overt stigma, including name-calling, ridicule, and exclusion (Cooney et al., 2006). Thus, there appears to be a snowball effect throughout adolescence, whereby more implicit and subtle forms of stigma that originate in childhood become more explicit and pronounced.

Stigma continues to accumulate in adulthood

A nationally representative study revealed more negative stereotypes, greater social distance, and greater withdrawal behaviors toward people with I/DD compared to people with physical disabilities. In this study, adults read vignettes about “Joseph,” were told that he had either an I/DD or a physical disability, and responded to a series of questions. When participants were told that Joseph had an I/DD (instead of a physical disability), they were more likely to report, for example, that they would maintain social distance from him in a coffee shop or worry about him being aggressive toward them. Indeed, people continue to distance themselves from the I/DD community in adulthood, which contributes to lower acceptance, higher perceived dangerousness, and other negative perspectives (Werner, 2015). For example, the general adult population overestimates the extent to which individuals with attention-deficit/hyperactivity disorder have hyperactivity, impulsivity, and impairments at work or school, which has clear negative implications for their vocational and educational trajectories (Godfrey et al., 2020). The effects of stigma may be felt most deeply among certain subgroups. For example, older adults with I/DDs report more stigmatizing experiences relative to younger adults, and individuals with moderate I/DDs are more likely to report being made fun of and being treated like children relative to those with mild I/DDs (Ali et al., 2016). In effect, lifelong stigma continues to accumulate for members of the I/DD population, and they are well-aware of its presence.

Compounding lifelong experiences of stigma

Physician misinformation and bias are major facilitators of stigma and key mechanisms underlying health disparities (Malik-Soni et al., 2021). Health care professionals report stress, lack of confidence, fear, and anxiety in providing care for patients with I/DDs, as well as a tendency to treat those patients differently (Pelleboer-Gunnink et al., 2017). Bias and preconceptions about the I/DD community are also rampant. For example, pediatric providers describe working with their patients with I/DDs as a “minefield” (Como et al., 2020). A recent review of more than 40 studies revealed that direct-support professionals, social workers, and therapists are often skeptical about community inclusion for people with high support needs, which in turn affects the quality of care they receive (Pelleboer-Gunnink et al., 2019). Low I/DD knowledge among health care providers is potentially most damaging for vulnerable groups, including those with limited support networks (Nicolaidis et al., 2015).

The effects of stigma on I/DD population health

As noted, stigma broadly contributes to chronic stress and maladaptive coping behaviors and impedes service access and utilization. In addition, individuals with I/DDs experience distinct health impediments due to variability in the extent to which their I/DDs are discernible to the general public, making stigma particularly potent for this group. In anticipation of or in response to experiences of

stigma, individuals with I/DDs strategically use concealment, whereby they choose not to share their disability (Botha et al., 2020). Camouflaging—using strategies to compensate for or hide traits associated with I/DD—is also common, particularly among those who experience more stigma (Hull et al., 2020; Perry et al., 2021). Qualitative research has revealed that, over time, camouflaging creates considerable stress and fatigue and exacerbates chronic stress (Hull et al., 2017).

Individuals whose I/DDs are easier to conceal from the public have just as many, if not more, health challenges. For example, they report greater social isolation and less social support—factors that have profound impacts on psychological and physical health—relative to individuals with more visible conditions (Hatzenbuehler et al., 2009). Stigma associated with high-functioning autism, for instance, may be worse than that associated with more visible conditions, because individuals with high-functioning autism are more likely to be blamed or personally attacked for divergent behaviors (Gray, 2002). Thus, all individuals with I/DDs—not only those with the highest support needs—experience poor health outcomes due to stigma.

Exacerbating issues of visibility, the fear of being labeled may cause individuals to delay or avoid seeking treatment altogether (Link & Phelan, 2006). The fact that anticipated or experienced stigma discourages service utilization and help-seeking is particularly detrimental for the I/DD population, given their distinct service needs (Havercamp & Scott, 2015; Ward et al., 2010). Thus, the health effects of stigma are uniquely and profoundly experienced among individuals with I/DDs.

Previous attempts to address stigma

Anti-stigma interventions—including interventions that are interpersonal, educational, or structural in nature—are widespread but often fall short. For example, interpersonal interventions that promote direct or indirect contact with people with I/DDs—such as by having participants watch movies or vignettes with characters with I/DDs—are common. These approaches, however, often lack nuance, primarily targeting explicit attitudes about individuals with I/DDs (e.g., opinions on whether children with I/DDs should be included in mainstream classrooms or levels of self-reported comfort with individuals with I/DDs). This strategy is problematic because it does not address implicit attitudes. Whereas explicit attitudes tend to improve with age, implicit attitudes tend to remain negative (Aubé et al., 2021). Although these interventions purport short-term improvements in attitudes toward individuals with I/DDs, it has yet to be seen whether these changes lead to long-term, lasting changes in both explicit and implicit attitudes, let alone actions or behaviors (Walker & Scior, 2013).

Anti-stigma interventions also include educational interventions to challenge misconceptions and stereotypes. Medical schools, for example, are beginning to develop core competencies for trainees relating to the care of patients with disabilities, including understanding patients' experiences and cultivating skills in providing patient-centered care (Iezzoni & Long-Bellil, 2012). But these educational approaches tend to be retroactive, implemented long after trainees have internalized preconceptions, misinformation, and biases. In addition, they typically focus on stigma pertaining to individual health conditions or identities in isolation. This tendency to ignore intersectionality has encouraged a siloed approach to health-related stigmas, impeding comparisons across stigmatized conditions and subsequent innovations to improve health outcomes (Stangl et al., 2019). Further, programming is often biased toward individuals with the most prevalent conditions, which excludes many less prevalent subgroups

(e.g., autistic girls and women, like my sister; Staniland & Byrne, 2013).

Finally, anti-stigma interventions include structural interventions, which focus on large-scale institutional stigma, often through legislative action or mass-media campaigns. These approaches have the potential to impact stigma beyond traditional educational approaches. For example, among college students, exposure to one episode of a fictional drama depicting autism, compared to watching a lecture, resulted in more accurate knowledge of autism, more positive and fewer negative characteristics associated with autism, and a greater desire to learn more about autism (Stern & Barnes, 2019). However, although structural interventions hold promise in combating stigma, they have not been leveraged to full capacity.

The lack of evidence-based methods for addressing stigma is due to many flaws in the existing research. First, individuals with I/DDs have been excluded from research, particularly through studies that unnecessarily deem them ineligible to participate. Indeed, a recent review of 300 randomized clinical trials published in high-impact medical journals found that people with I/DDs were represented in only 2% of trials and could have been included in others with minor methodological tweaks (Feldman et al., 2014). Thus, we know little about their experiences, perspectives, and priorities when it comes to stigma and health disparities. Second, the vast majority of these approaches have not been robustly evaluated using rigorous research methodology. In the few instances when a rigorous randomized trial was conducted, fewer than half reported measures of practical significance (i.e., effect sizes), and those varied widely in magnitude and were typically small (Rao et al., 2019). Finally, program outcomes are often not meaningful. Most available I/DD attitudinal scales and measurement tools are outdated or otherwise insufficient, focusing exclusively on measuring explicit attitudes at the expense of other types of stigma (Werner et al., 2012).

Combating stigma at its core

Educators, professionals, and researchers can meaningfully address stigma by intervening in education across the life course, health care practices, and research.

First and foremost, we need to implement neurodiversity-oriented approaches that promote positive perceptions of the I/DD community before stigmatizing attitudes even develop. For instance, Dr. Nava Siltan has developed [Realabilities](#), a multimedia educational curriculum that portrays children with I/DDs in a positive light and promotes education about specific I/DDs. Interventions like this are proactive and can foster positive perspectives of the I/DD population before negative perspectives develop. Approaches that focus on cultivating meaningful social interactions with the I/DD community, as well as promoting education and advocacy capacities for all children, could build on this progress. Efforts need to target both explicit and implicit attitudes by promoting active reflection on implicit attitudes (Aubé et al., 2021). They should also target diverse I/DD conditions. Teachers, school psychologists, administrators, and educational institutions should support these efforts (Salinger, 2020). And stigma must also be addressed in medical training. To effectively capture the complexities underlying stigma, training and educational approaches need to consider intersectionality and how those with multiple stigmatized identities experience more pronounced health disparities. Informal educational approaches should focus on creating informed and accurate media depictions of individuals with I/DDs.

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Addressing stigma in health care should not stop at the end of medical school. Health care institutions need to promote a culture of neurodiversity—that is, an organizational culture focused on accessibility, patient empowerment, self-advocacy, and self-determination in care (Sabatello, 2018; While & Clark, 2010). A culture of neurodiversity may be more commonly understood by physicians as precision medicine. Precision medicine, sometimes called personalized medicine, seeks to replace the “one-size-fits-all” approach with more customized preventative and therapeutic options that take individual genetic, environmental, and lifestyle variability into account.

Stigma in education, research, and practice

Stigma in education and practice is perpetuated through stigma in research, which we can address in several ways. Most importantly, we need research that is inclusive of individuals with I/DDs. Beyond simply including individuals with I/DDs as research participants, it is essential to collaborate with individuals with I/DDs in all aspects of the research process. Research has often focused on stigma faced by family members of individuals with I/DDs (Mitter et al., 2019; Werner & Shulman, 2013), leaving individuals with I/DDs themselves out of the conversation. My colleagues and I at the [Autism Intervention Research Network on Physical Health](#) created an Autistic Researcher Review Board—composed of autistic scholars from the United States, Canada, and the United Kingdom—to ensure that all research supported within the network aligns with the priorities of autistic individuals. Continuing to advance these types of research collaborations will promote a comprehensive understanding of individuals with I/DDs, which will, in turn, enhance education and practice.

These approaches must be accompanied by research that captures meaningful outcome variables. There is a need to develop innovative measures of stigma that reflect practical applications in the real world. For example, we should avoid assessing “contact” with the I/DD community with a yes/no checkbox and consider the closeness of relationships with individuals with I/DDs (Blundell et al., 2016). Finally, there is a need for researchers to implement robust research designs, including longitudinal studies with large samples that can generate more conclusive findings. With more inclusive eligibility and recruitment criteria, researchers will be more equipped to recruit robust samples. Through engagement with the I/DD population, they will gain a better understanding of how to retain participants with I/DDs in longitudinal research.

Because education, practice, and research are interdependent, enacting meaningful change at one level is likely to lead to meaningful changes at other levels. Thus, addressing stigma across sectors that intervene at different points in the life course can have cascading effects on health disparities for individuals with I/DDs. The COVID-19 pandemic has exposed the effect of stigma on the health of individuals with I/DDs; we can’t afford to waste this opportunity to attack that stigma head-on.

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