

VIEWPOINT

Health Equity for Individuals With Intellectual and Developmental Disabilities

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COVID-19 highlighted the elevated health risks and systemic inequities experienced by people with intellectual and developmental disabilities (IDDs), the group with among the highest rates of infection and death during the pandemic.¹ However, the challenges and disparities affecting people with IDD such as Down syndrome, fragile X, cerebral palsy, and autism long predate COVID-19. Persons with IDDs have shorter average life expectancies, by 20 years for some conditions.² Although some differences reflect biological factors, many are related to modifiable disparities such as individuals experience within communities, social service delivery, and health systems. This Viewpoint outlines 3 systemic health inequities experienced by individuals with IDDs along with corresponding remedies: (1) stigma, exclusion, and devaluing the equal worth of persons with IDDs; (2) underrepresentation in population epidemiology and research; and (3) inadequate access to high-quality care and social services tailored to needs.

Stigma, Exclusion, and Devaluing the Equal Worth of Persons With IDDs

Stigma and exclusion of individuals with IDDs within medicine, social services, public health, and society have a long history that persists to this day. The practices of eugenics and institutionalization were state-sanctioned and used within the US throughout much of the 20th century to remove persons with IDDs from the population through forced sterilization and placement in institutions.³ These movements received widespread support at the time, including from leading medical and public health authorities.⁴

Although US society has since rejected eugenics and institutionalization of persons with IDD and has embraced inclusive measures exemplified by the Americans with Disabilities Act, perceptions quietly persist that individuals with IDDs are unwanted, unproductive, and unable to form healthy relationships, lead happy lives, or exercise meaningful autonomy. Such perceptions contribute to the lack of person-centered care and disrespect for autonomy widely experienced by patients with IDDs and their loved ones during encounters with clinicians and individuals who provide social services. Too often, persons with IDDs have been made invisible from benign or purposeful neglect.

Key actions could help promote the full acceptance and inclusion of persons with IDDs. First, the Centers for Medicare & Medicaid Services (CMS) and other state and federal programs must include individuals with IDDs and their loved ones and caregivers as equal partners in the design and operation of programs and policies to meet their needs.

Second, individuals with IDDs must be more fully included in ongoing efforts to remedy historic injustices

experienced by members of minority groups, as well as in efforts to promote diversity, equity, and inclusion (DEI), championed by local and national professional health care and social services organizations. Persons with IDDs, their loved ones, and caregivers must be equal partners with these organizations in DEI training to communicate their experiences and perspectives. In addition, medical, nursing, and social work schools must better prepare trainees to provide proficient, respectful, and culturally competent care to patients with IDDs. Moreover, leading health care, professional, and social services associations must develop policies to eliminate any potential bias and discrimination against persons with IDDs.

Underrepresentation

The true count of adults and children with IDDs is unknown. Large gaps in US public health surveillance produce systematic undercounts, especially for adults.

The clinical and policy community's implicit identification of IDDs as a pediatric concern creates related representation challenges. Although average life spans have increased substantially among persons with IDDs, most research and funding has focused on children and does not include follow-up of persons with IDDs into adulthood. This pattern reflects and reinforces the framing of people with IDDs as children or child-like³ and also may reflect public and policy-maker perceptions that adults with IDDs are less worthy of support than children. The clinical literature on Down syndrome, for example, includes regular contributions in pediatrics; clinical challenges for adults with Down syndrome, such as early-onset dementia, receive less attention.

No National Institutes of Health (NIH) agency is dedicated primarily to studying IDDs. Furthermore, the NIH does not recognize individuals with IDDs as a health disparity group, making such research ineligible for funding by the National Institute on Minority Health and Health Disparities (NIMHD).⁵

Several specific actions could help ameliorate these inequities. As recommended by the assistant secretary for planning and evaluation, national surveys should add items that specifically identify adults and children with IDDs, and the CMS should link data for such individuals in Medicaid and Medicare.⁶ These approaches should include sampling of Community Integrated Living Arrangements and related residential settings and should oversample the nearly 1 million people with IDDs in the US who live with caregivers older than 60 years.⁷

The NIH should officially recognize that people with IDDs are a distinct health disparity group, as unequivocally supported by the scientific evidence. Such recognition could open funding on policies and interventions to reduce these disparities as well as on intersectional

research on interactions between IDD and other minority statuses and disparities consistent with the mission of the NIMHD.

In addition, lawmakers should earmark some NIH and CMS funding for research on individuals with IDD. Congress recently directed the Patient-Centered Outcomes Research Institute to expand its mandate to fund more research on IDD.⁶

Inadequate Access to Quality Care and Social Services

Many factors hinder access to high-quality, patient-centered care that addresses health care and social-service needs for individuals with IDD. Many working-age adults with IDD lack conventional work histories, limiting access to private employer-based coverage, Social Security Disability Insurance, and Medicare. Most individuals with IDD are Medicaid enrollees and thus encounter the limitations of that program. Because of low reimbursement rates, many medical practices implicitly or explicitly limit caseloads and visit times for patients with Medicaid insurance. This is especially problematic for patients with IDD, who require longer visits to address complex issues and access to specialists in short supply.

Individuals with IDD often do not receive person-centered services tailored to their needs. Few clinicians and social service professionals are properly trained or experienced in delivering care to individuals with IDD. Health systems are similarly ill-designed to meet their needs, and primary and specialty care services are underprovided to patients with IDD.⁸ Ineffective treatment of conditions such as epilepsy that commonly co-occur with IDD produce preventable complications and worsening prognoses.

Individuals with IDD also experience long wait times to obtain home and community-based services; in some states, service recipients routinely wait more than a decade. These wait times are especially harmful for persons with IDD who live with older care-

givers, and for others whose loved ones struggle to provide needed supports owing to physical limitations or socioeconomic challenges. Complex enrollment processes, waiting lists, and administrative burdens such as onerous prior authorization requirements for receipt of covered services create additional disparities, because families with greater resources more readily navigate bureaucratic processes to obtain services.⁹

To help address these issues, policy makers could expand private insurance and Medicare access for adults aged 18 to 64 years with IDD by extending dependent coverage to parents of children with IDD past age 26 years and by relaxing Medicare Social Security Disability Insurance entitlement requirements for individuals with IDD who lack qualifying work histories.

State Medicaid programs also need to reduce long wait times for individuals with IDD seeking to access home and community-based services. States must also improve financing and payment systems to better support and incentivize care that addresses medical and social needs. Such systems could increase payment rates to clinicians for complex visits with patients with IDD and risk-adjust payment rates to managed care plans that insure such patients for their greater resource needs. Payment increases could be combined with simplified pathways for all families to access needed services and care and with stronger incentives for delivery of high-quality care to patients with IDD.

Conclusions

Persons with IDD have the right to proficient medical care and social services delivered in a dignified and respectful manner, free from stigma, exclusion, or discrimination. In many ways, US society has opened its heart, laws, and treasury to more fully embrace persons with IDD as equal citizens. Much more remains to be accomplished.

ARTICLE INFORMATION

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