Addressing Intellectual and Developmental Disabilities as a Health Equity Imperative

A Primer for Public Health Professionals

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> *"The lives of people with IDD are important, our experiences matter, our quality-of-life matters."*
>
> *-Person with IDD[1]*

For more than two decades, there have been calls, including from the United States Surgeon General, to improve health equity for people with intellectual and developmental disabilities (IDD).[1] Despite this, and growing awareness that accessibility and belonging must be centered in diversity, equity and inclusion efforts, people with IDD are often left out of broader health equity efforts. People of all ages, races, ethnicities, genders, sexualities, nationalities and backgrounds have IDD.[2] As such, attending to the inequities people with IDD face will advance equity for everyone. Promoting health equity for this community requires intentionally incorporating their input in research, public policies, and intervention initiatives. The most effective way to do this is to include people with IDD in designing public health programs and processes. Public health professionals play a critical role in ensuring that the voices, experiences and priorities of people with IDD are centered in all efforts to advance health equity and reduce health disparities.

Language Matters

Person-first language (e.g., person with disabilities) arose from a desire to reduce stigma by emphasizing the personhood of people with disabilities, who have historically been dehumanized and thought to be only their disabilities.

Identity-first language (e.g., disabled person) is a reclaiming of disability that recognizes disability as an integral part of a person's identity. Identity-first language pushes back against stigma by promoting the idea that disability is a form of diversity and pride, rather than something negative that should be avoided.

People with more stigmatized disabilities, such as people with IDD or people with psychiatric disabilities, tend to prefer person-first language.[3] However, autistic people and people with other disabilities generally prefer identity-first language.[4] While these are general guidelines, one should always use the language the person prefers. In addition, language that tries to avoid saying disability (e.g., 'people with abilities,' or 'special needs') and/or implies disability is inherently bad (e.g., 'people struggling with mental illness') should be avoided.

Who are People with Intellectual and Developmental Disabilities?

> *“If you mention developmental disabilities they quickly assume that people [with IDD] don’t have the capacity to understand or know what’s happening in their lives, or somebody has to help them, or somebody has to explain it. And that’s not the case. Sometimes that kind of thinking gets you riled up. We are always needing to explain to people that people [with IDD] are capable.”*
>
> *-Person with IDD[5]*

As of 2019, 7.4 million people in the U.S. had intellectual and/or developmental disabilities.[6] An intellectual disability is defined as limitations in intellectual functioning as well as adaptive behavior, that occur before 22 years old.[7] A developmental disability is defined as a life-long disability that occurs before the age of 22 and results in at least three functional limitations related to major life activities (e.g., self-care, communication, mobility, learning).[8] Common forms of IDD include autism, cerebral palsy, Down syndrome, and Fragile X syndrome. For many people with IDD, having one form of IDD makes them more likely to have another disability, including another form of IDD. For example, there are relationships between Down syndrome and muscular dystrophy, Fragile X syndrome and autism, cerebral palsy and psychiatric disabilities, intellectual disability and visual and hearing impairments, and autism and attention deficit disorder (ADD)/ attention deficit hyperactivity disorder (ADHD).[9,10,11,12]

While some forms of IDD result in a need for cognitive support (e.g., adaptation of educational material), others can also result in a need for mobility support (e.g., wheelchairs).

Many people with IDD communicate with verbal or spoken language, but others may communicate using sign language, typing, communication devices and assistive technology (e.g., communication boards, iPads, or Dynavox with language programs), or through gestures or vocalizations. Regardless of method, all people with IDD communicate in some way or another, and all have wants, needs and preferences.

From the 1800s through the 1960s, people with IDD were commonly institutionalized.[13] Today, most people with IDD, even those with higher support needs, live and thrive in the community, People with IDD are our neighbors, friends, and family members, have jobs providing essential services, attend our schools, advocate for improved lives for themselves and others and are a vital part of our communities. Recent figures show that 58% of people with IDD who receive funded support live with their family members while 12% live in their own homes; people with IDD also live in group homes (16%), host homes/family foster care (5%), and segregated public and private institutions (9%).[14] Community-based employment rates of people with IDD range by state from 8% to 41%.[15]

A common misconception about people with IDD, especially those with lower IQ scores, is that they have a 'mental age' of young children and stop learning or developing past that mental age.[15] While people with IDD may require more time processing complex or abstract information, or may need support with tasks like money management, adults with IDD are not children, and we all learn and grow as we age, regardless of what our IQ number is.

Many of the barriers people with IDD face stem from false ideas about people with IDD and what they are capable of. These predominant stereotypes and attitudes – ableism – result in systems and structures that are not inclusive and accessible, which hinder health and quality of life for people with IDD.

What is Ableism?

Ableism is prejudice, stereotypes, and discrimination about disability, including the assumption that people with disabilities are inferior to people without disabilities. Ableism can manifest as negative beliefs, such as that people with disabilities are incapable, disability is bad and sad, or people with disabilities' lives are tragic. It can also appear as seemingly 'positive' attitudes, which are still harmful, such as portrayals of all people with IDD as angelic, sweet, and happy, framing people with disabilities as inspirational, or having pity for people with disabilities because of false assumptions of how bad their lives must be. While ableism is extremely prevalent, ableism most commonly operates implicitly, with people unaware they are biased.[16] Ableism permeates our society, systems, and structures, oppressing people with disabilities. For example, medical rationing protocols frequently discriminate against people with disabilities based on ableist assumptions about their quality of life.[17] Similarly, it is not uncommon for people with IDD to have do not resuscitate (DNR) orders instituted by medical professionals without their or their family members' consent due to the devaluating of people with IDD's lives.[18]

How Are People with IDD Impacted by Health Disparities and Health Inequities?

PHYSICAL HEALTH

> *"It's good to know what things to be prepared for as people age—your health changes as you age, and helping people be prepared for those changes [is important]."*
>
> *-Person with IDD[1]*

People with IDD face several health inequities compared to both people without disabilities* and people with other disabilities. For example, people with IDD frequently have additional physical health comorbidities. One of the most common comorbidities for people with IDD, across many IDD types, is epilepsy and other seizure disorders.[19] People with IDD are also more likely to have cardiovascular disease, hypertension, arthritis, osteoporosis, type 2 diabetes, thyroid dysfunction, asthma, obesity, and dental caries.[20] Specifically, people with cerebral palsy are more likely to have chronic kidney disease, myelopathy, stroke risk, liver disease and pressure ulcers.[21] More unique comorbidities among people with Fragile X syndrome include sinusitis and gastrointestinal problems.[22] Additionally, autistic people more commonly have sleep and endocrine disorders.[23]

People with IDD who have additional marginalized identities face further disparities. People of color with IDD have poorer health, including mortality, than white people with IDD.[24] For example, Black people with IDD are more likely to have diabetes, hypertension and asthma than white people with IDD.[25] Black and Latino autistic children are more likely to be obese than white autistic children.[26] Moreover, women with IDD have poorer health-related quality of life than men with IDD.[27] LBGTQ+ people with IDD also report poorer physical health and more unmet needs.[28]

Despite living longer than ever before, people with IDD often have age-related health conditions earlier and more frequently and have higher mortality rates than people without disabilities. For example, people with Down syndrome die up to 20 years earlier than people without Down syndrome.[29] In addition, people with IDD are eight times more likely to die from COVID-19 than people without IDD.[30]

MENTAL AND BEHAVIORAL HEALTH

> *"Overuse of psychotropic medications—we are among the most vulnerable people, but docs rush to psychotropics that have side-effects."*
>
> *-Person with IDD[1]*

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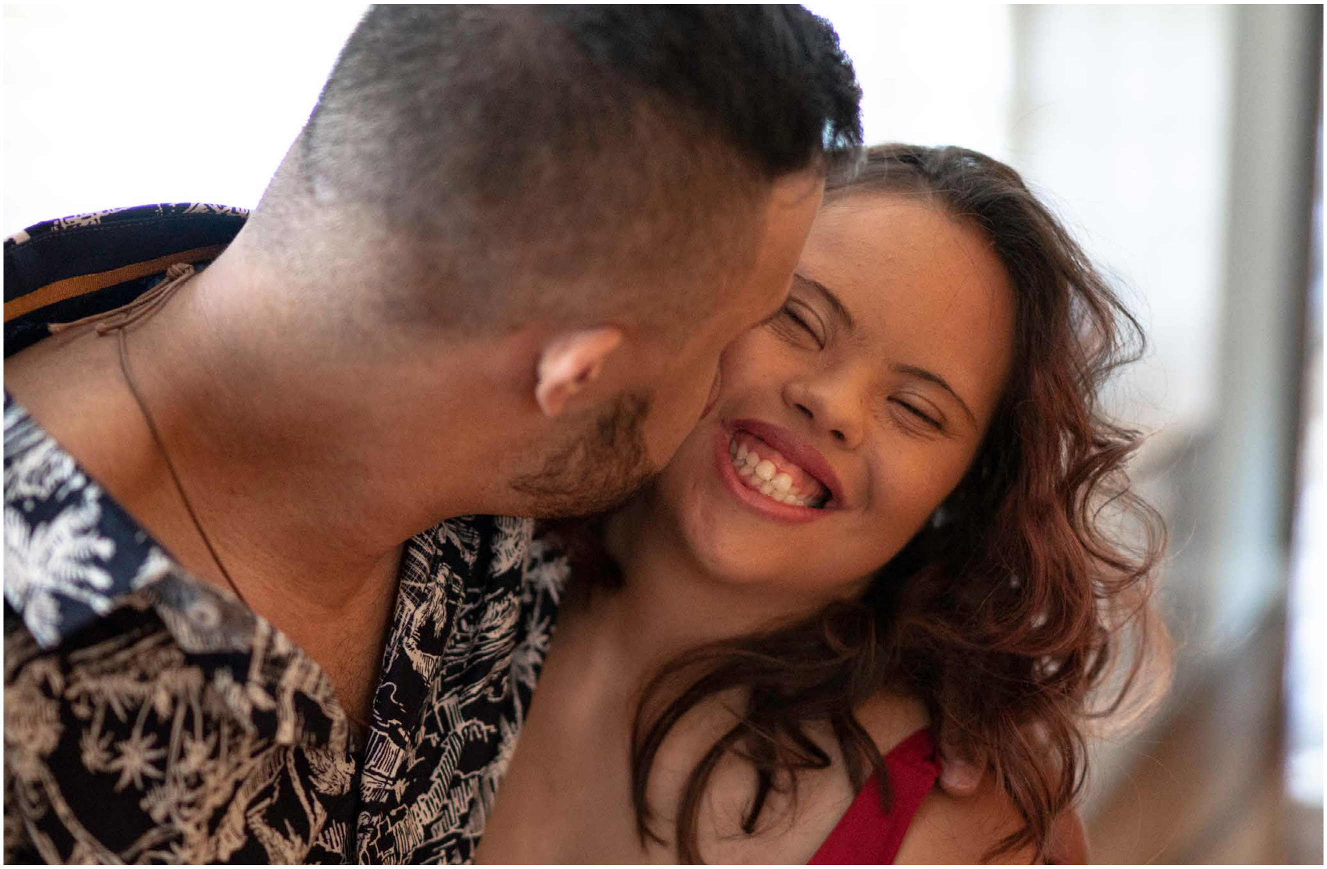
* *In some places we use the word "disability" broadly if data is not available specifically for IDD.*

People with IDD have higher rates of mental and behavioral disabilities than people without IDD, with an estimated 40% of people with IDD having these conditions.[31] LBGTQ+ people with IDD, in particular, are more likely to experience depression, anxiety and stress, in large part due to stigma, discrimination, and unmet needs.[32] In addition, people with IDD more commonly have "challenging" behavior, which is maladaptive behavior that can cause harm to themselves or others.[33] It is important to note that what is considered "challenging" is subjective. For example, due to racism, the behavior of people of color with IDD is frequently believed to be worse, and they are often overdiagnosed and misdiagnosed with psychiatric disabilities.[34] Moreover, while people with IDD's "challenging" behavior is often portrayed as a flaw or defect, the cause is frequently environmental, related to pain, untreated medical conditions, lack of life satisfaction, or abuse and neglect, which occurs at higher rates in this community.[35] Due to a lack of understanding of the root causes of some of the behaviors of people with IDD, instead of examining environmental causes, people with IDD who have mental and behavioral health conditions are more likely to be prescribed psychotropic medications, frequently without official mental health diagnoses; they are also more likely to be institutionalized.[36]

SEXUAL AND REPRODUCTIVE HEALTH, AND IDENTITY

> ***"The biggest issue is professionals just do not see a future for people with IDD. We had one doctor tell us to sterilize her [our daughter] when she was 6. They just have such low expectations for people with IDD, it's a problem."***
>
> ***-Family member of a person with IDD[37]***



It is often falsely assumed that people with IDD are not capable of or interested in sexual relationships. As a result, people with IDD receive little to no sex education and receive reproductive health care less frequently. For example, in large part because of physician misconceptions about people with IDD's sexuality and reproductive health risks, women with IDD are less likely to receive pap tests and mammograms than women without disabilities and women with other disabilities.[38] Women with IDD, especially Black and Hispanic women, have worse pregnancy outcomes.[39] Women with IDD have significantly higher rates of severe maternal mortality and morbidity compared to women without IDD.[40] Women with IDD are also more likely to have complications after hysterectomies than women without IDD.[41]

People with IDD have called for more comprehensive sexual and reproductive education so they can make empowered and informed choices, more opportunities for sexual expression, and for the removal of gatekeepers. LGBTQ+ people with IDD in particular need greater opportunities to live openly and express their identities, as people with IDD are often assumed to be cisgender and heterosexual.[46] Yet, people with IDD are not only LGBTQ+ in similar rates as people without disabilities, but autistic people are actually more likely to be LGBTQ+ than non-autistic people.[47] LGBTQ+ people with IDD often face exclusion not only from the IDD community but also from the larger LGBTQ+ community, leading to increased harassment, internalized stigma, and pressure to conform and hide their identities.[48]

HEALTH CARE ACCESS, QUALITY, AND EDUCATION

> ***"I go to the doctor, and he has a hard time looking at me. My staff is usually in the room with me, and he looks at my staff and talks to my staff, instead of looking at me and talking to me."***
>
> ***-Person with IDD[49]***

Avoidable and unjust health inequities often cause people with IDD to experience more health disparities than people without disabilities. Medicaid is the primary funder of IDD health care spending. In 2019, approximately

Sexuality in Context

A lack of attention to the sexual and reproductive wants and needs of people with IDD contributes to high rates of sexual abuse of this population.[42] These attitudes have also led to historical and current day eugenics wherein people with IDD have been sterilized without their consent, coerced into abortions, and forced to take birth control.[43]

Many states also prohibit people with IDD from marrying, and people with IDD's parental rights are frequently terminated simply because they have a disability.[44] Even when less drastic measures are taken, professionals, service providers, and support staff often serve as gatekeepers to people with IDD's sexuality and sexual expression, imposing their own values upon people with IDD.[45]

one-million people with IDD received Medicaid, and 600,000 received Medicare (74% of which were also receiving Medicaid, called dual eligible).[50] While some people with IDD also have private insurance, due to a lack of data collection and research, private pay rates are unknown; in addition, it is estimated that Medicaid and Medicare figures may be undercounting eligible or enrolled people with IDD. Moreover, half a million people with IDD are waiting to receive Medicaid in their homes and communities as of 2023.[51]

Many people with IDD have unmet health care needs because of barriers to access. People of color, women, and LGBTQ+ people with IDD have less access to health care services and supports than white, heterosexual, men with IDD, which contributes to inequitable health outcomes.[52] In addition, despite the Americans with Disabilities Act (ADA) legally requiring accessibility and accommodations in health care settings, 72% of adults with disabilities report not receiving the accommodations they need in health care settings.[53] Inaccessible diagnostic equipment, a lack of adjustable exam tables, noise, overstimulation, a lack of cognitive accessibility, and more can make health care visits inaccessible for people with IDD.

One of the largest barriers to health equity for this population is health professionals' lack of knowledge about people with IDD and their needs, which significantly hinders the quality of health care people with IDD receive.[54] Many health professionals assume people with IDD have a lower quality of life, are more difficult, are a burden and are less likely to feel pain. As a result, they may be more likely to feel frustrated, stressed, and uncomfortable when working with people with IDD, and overlook and misattribute their health symptoms, also known as diagnostic overshadowing.[55] These assumptions and misconceptions can deny people with IDD opportunities to play an active role in their own health. Yet, when people with IDD have the support to share their needs and experiences, health interventions are more likely to be effective and professionals are better equipped to address people with IDD's health needs.[56]

Lack of education about health and health care also hinders the families and support staff of people with IDD especially immigrant and non-English speaking families.[57] People with IDD want to learn more about their own health and bodies, including both physical and mental health, health risks, how disability may impact their lives, and how their needs change over their lives, particularly in ways that are respectful, inclusive and accessible.

What Role Do Social Determinants of Health Play in People with IDD's Health Equity?

The World Health Organization recognizes that "many of the differences in health outcomes between persons with disabilities and those without cannot be explained by the underlying health condition or impairment and are associated with avoidable, unjust or unfair factors." Indeed, social determinants of health have a profound impact on health and quality of life of people with IDD. The U.S. Office of Disease Prevention and Health Promotion defines social determinants of health as "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks." Health equity for people with IDD necessitates attention to these social determinants.

LONG-TERM SERVICES AND SUPPORTS

> *" I wouldn't be where I am today without the staff that help me."*
>
> *-Person with IDD*[37]

Medicaid Home- and Community-Based Services (HCBS) are the largest funding source for Long-Term Services and Supports (LTSS) for people with IDD and serve as a critical safety net for this population. Medicaid HCBS allows states to create customized service plans to support people who need assistance, while allowing them to live in their homes and communities.[58] Unlike acute care, which may be more episodic, Medicaid HCBS are wrap-around services, designed to support the social determinants of health more broadly. For example, within their HCBS programs, states commonly provide people with IDD with personal care support, employment and day services, transportation, assistive technology, community integration services, support for family caregivers, and more.[59] There are even regulations called the HCBS Settings Rule[60] which promote outcomes and person-centered practices, to help ensure people are living quality lives of their choosing. The amount of funding spent on HCBS for people with IDD has far surpassed the amount of funding for institutions for people with IDD. This is due to people with IDD's preferences for community living, improved outcomes associated with community living, people's rights to community integration and cost-effectiveness of community living over institutional care.[61] In 2021, $43 billion was projected for HCBS for 860,000 people with IDD.[62]

While Medicaid HCBS plays a vital role in people with IDD's health and quality of life, as of 2023, 500,000 people with IDD were waiting to receive HCBS.[63] Without these services, many are left relying on aging caregivers or risking institutionalization. There is also a significant shortage of direct support professionals to provide HCBS, as well as frequent turnover, which results in less community integration for people with IDD and puts their health, safety and quality of life at risk.[64] In addition, Medicaid has what is called an "institutional bias," where states are required to fund institutional care, while home or community care is an optional benefit. Moreover, Medicaid funding cannot be used for room and board in HCBS, but it can in institutions, which means some people may need to live in institutions if they cannot afford community-based housing while on HCBS.[65]

HOUSING

> *“ If I had a dream home, I would want it to be accessible so I could be able to do the stuff on my own and be able to reach everything.”*
>
> *-Person with IDD[37]*

In addition to Medicaid’s limitations, community living for people with IDD is also threatened by a lack of affordable and accessible housing in the U.S. Estimates suggest less than 5% of housing in the U.S. is accessible for people with disabilities, and these shortages are expected to increase.[66] As a result of this, and higher poverty among people with IDD, people with IDD are more likely to be housing insecure.[67] Compared to people without disabilities, people with disabilities live in poorer quality housing, poorer quality neighborhoods and are more likely to be unhoused.[68] People with disabilities are also significantly more likely to be what the U.S. Department of Housing and Urban Development calls "worst case needs" when it comes to housing, living in inadequate housing conditions, as well as paying more than half of their income for rent.[69] Housing insecurity among people with IDD puts them at risk for institutionalization, incarceration and becoming unhoused.

In addition, many people with IDD, especially those with higher support needs, are not given choices about where they live, as family members or others often make choices on their behalf, and available options are limited. Most people with IDD want to live on their own or with their families, but many live in congregate settings, such as group homes and institutions. This is due to inadequate infrastructure to support community living, as well as a system that has historically favored and is structured around congregate care. These very same congregate settings are associated with more negative health outcomes for people with IDD.[70]

COMMUNITY INTEGRATION AND SOCIAL WELL-BEING

> *“ People with disabilities deserve to live in the community without being segregated. When we are included, people see what we have to offer.”*
>
> *-Max Barrows, autistic self-advocate*[71]

More people with IDD live in the community than ever before. Living and participating in the community is associated with better outcomes, even for people with IDD with higher support needs.[72] Ableism also contributes to the segregation of people with IDD, oftentimes due to inaccessible environments and attitudinal barriers from people without disabilities. For example, while living physically in the community, many people with IDD face social isolation and loneliness – they are not meaningfully included in their communities.[73]

This isolation and loneliness negatively impact people’s health and quality of life.[74] The isolation people with IDD experience, as well as segregation in school, increased unemployment, ableist attitudes, and a lack of transportation, also serve as barriers to people with IDD forming and maintaining friendships and other relationships.[75]

TRANSPORTATION

> *“We do field trips [at my group home] but not all of us. Because we only have one van, and that van is not working right now. They said they can’t get us another vehicle to where all of us could fit in it.”*
>
> *-Person with IDD*[37]

Lack of accessible transportation is a common problem for people with IDD. In the U.S., there is a lack of public transportation, with 40% of counties without transportation, especially in rural areas.[78] Transportation may be both physically inaccessible for people with IDD, such as a lack of elevators and sidewalks, or cognitively inaccessible, such as requiring them to understand complex schedules and last minute problem-solving.

Affordable and accessible transportation improves health and quality of life for people with IDD, it also increases their independence, self-determination and social well-being.[79] Conversely, a lack of available and accessible transportation increases the isolation and loneliness of people with IDD, hinders community integration, limits employment and education, and makes people with IDD more reliant on others.[80] For

Technology Improves People with IDD’s Health, Quality of Life, and Inclusion

Assistive technology is a term used to describe an umbrella of devices specifically aimed at improving the functioning of people with disabilities. For example, it can help people with mobility, communication, accessing information, hearing, or skill building. Approximately one-third of people with IDD in the US have unmet needs for assistive technology, largely due to access and affordability barriers.[76] In addition to assistive technology, people with IDD are less likely to have access to other forms of technology, such as smartphones, computers, and internet due to financial and accessibility barriers.[77]

example, airlines frequently lose and damage people's wheelchairs, which threatens their mobility and independence.[81]

While specialized disability transportation can be more accessible, it is inflexible and inefficient, often requiring scheduling hours to days in advance. While states provide non-emergency medical transportation for Medicaid beneficiaries, it can only be used for medical services, not for other reasons people with IDD need transportation.[82] States can provide transportation for non-medical purposes in their HCBS programs, which is helpful, but this is up to the discretion of the state to implement. Other options, such as taxis and rideshares, have a history of being discriminatory towards people with disabilities and may also be cost prohibitive.

POVERTY AND FINANCIAL INSECURITY

> *"They [policy makers] don't know what it means to live like we do in regards to how we spend our money."*
>
> *-Ashley Wolfe, person with IDD*[71]

People with disabilities have significantly less economic security than people without disabilities. While the exact prevalence for people with IDD is unknown, approximately 50% of people with disabilities live in or near poverty in the U.S.[83] Disability is also associated with additional costs, such as the need for medical expenses, assistive technology, accessibility and housing modifications and

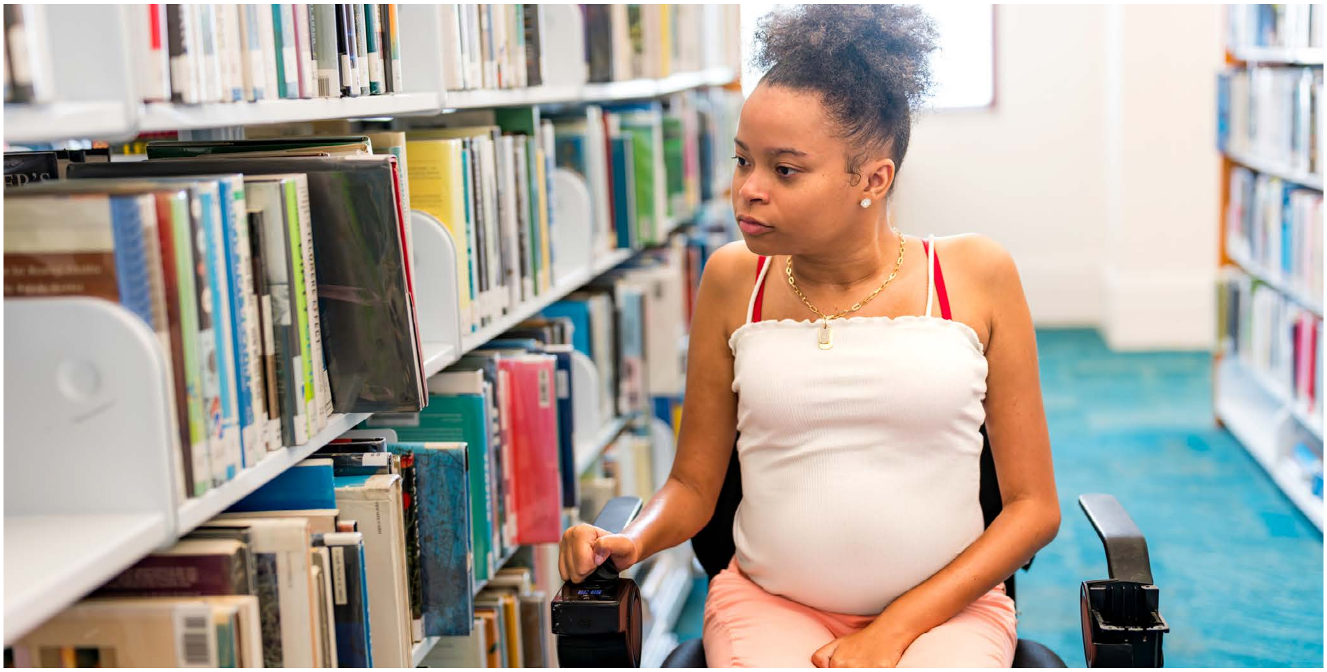
transportation costs. Poverty requirements to qualify for Medicaid and other public benefits also contribute to people with IDD's financial insecurity. So too does the limited access some people with IDD have to their own money because of representative payees, who manage their money on their behalf.[84] There is also a "marriage penalty" where people with IDD who get married lose their Social Security benefits which they need to live, leaving people unable to get married.[85] People with IDD also experience higher unemployment and underemployment, as well as a subminimum wage, further increasing financial insecurity.[86]

EMPLOYMENT

> ***"No one is too disabled to live and work in the community."***
>
> ***-Nicole LeBlanc, autistic self-advocate[87]***

Despite the interest and ability to work in competitive, integrated settings with people without disabilities, many people with IDD are funneled into segregated work or non-work settings. In fact, only 16% of people with IDD work in integrated employment settings, compared to 40% of people with other disabilities and 74% of nondisabled people.[88] Asian, Black, Hispanic, and Pacific Islander people with IDD are even less likely to work in integrated employment settings.[89] People with IDD often work in segregated settings where they do repetitive piecemeal tasks, such as sorting parts. Many people with IDD also participate in non-work day programs, but those day programs vary greatly. Day programs may be integrated into the community or segregated. Some people with IDD also participate in prevocational programs, which in theory aim to improve their employment skills; however, these skills rarely translate to integrated employment settings and actually result in lower wage job placements.[90] However, when jobs are appropriately matched with people with IDD's wants and skills, people with IDD are able to successfully work in integrated employment settings.[91] People with IDD prefer integrated employment, especially compared to segregated employment or non-work activities, and integrated employment is associated with higher quality of life.[92]

As a result of ableist stereotypes about the productivity of people with disabilities, especially those with IDD, it is legal to pay people with disabilities subminimum wage. Section 14(c) of the Fair Labor Standards Act, which makes paying subminimum wage legal with special certificates, allows companies to pay people with disabilities cents an hour, even for doing the same exact job as people without disabilities.[93] While research and government investigations have found subminimum wage results in unequal standards for people with and without disabilities, and that both ableism and racism play a role in the use of subminimum wage, no progress has been made to end this practice.[94] In addition, companies who benefit simultaneously from subsidies, contracts, and/or donations for hiring people with disabilities and by underpaying those staff with disabilities continue to lobby for subminimum wages.[95]



EDUCATION

> *“It keeps me up at night, the whole you’re a child until age 22, but you’re an adult for much longer than that, but the opportunities and openings for adults are much fewer and farther between, and what do you do?”*
>
> *-Family member of a child with IDD*[37]

Education plays a key role in the employment and outcomes of people with IDD. The Individuals with Disabilities Education Act (IDEA) guarantees people with IDD free, appropriate, public education. As part of IDEA, children with disabilities receive individualized education plans (IEP) which should set goals for the student and plan for accommodations to help them succeed.

While laws like IDEA aim to promote the education of people with IDD, many children and youth with IDD remain in segregated classrooms and still do not receive the educational resources they need, resulting in gaps in learning both in school and after school.[96] Families of children with IDD often must advocate to ensure their children with IDD receive the services and supports they need. However, many families do not understand the rights their child is entitled to in education. Families in rural areas and culturally and linguistically diverse families face additional barriers to this advocacy, both in terms of a lack of resources and discrimination.[97]

Many people with IDD also face a "transition cliff" after secondary school, where the services and support they were receiving in school abruptly stop without other services to make up the gaps. As part of IEPs, schools are required to help prepare students with IDD for transition after secondary school, with activities such as training on independent living or vocational skills or helping them prepare for college.[98] While these transition services help improve people with IDD’s outcomes, implementation varies. Many students receive lower quality transition supports, including ones that do not incorporate the needs and wants of the individual child, or receive no transition supports at all.[99] There is also a significant lack of accessible college programs designed with the needs of people with IDD in mind.

EMERGENCIES, DISASTERS, AND PANDEMICS

> *“ When we are left out of [COVID-19] relief packages like this, Congress is telling us they don’t care whether we live or die.”*
>
> *-Julia Bascom, autistic self-advocate[100]*

When public policies and emergency planning do not consider the needs of people with IDD, the results can be disastrous. People with IDD can be particularly vulnerable during pandemics and disease outbreaks, especially when public health initiatives are not responsive to their needs, as demonstrated during the COVID-19 pandemic. Despite being more vulnerable to morbidity and mortality from COVID-19, people with IDD’s needs were not considered during the pandemic.[101] For example, there were no infection tracking efforts related to disability, COVID-19 information was inaccessible, and masking and reopening policies did not consider the higher risks to people with IDD.[102] Additionally, staff who worked with people with IDD were prioritized for vaccines before people with IDD themselves.[103]

While death rates for people with IDD specifically are unknown, people with disabilities in general are four times more likely to die in natural disasters than people without disabilities.[104] People with IDD are also more likely to acquire additional chronic conditions or disabilities after disasters.[105] People with disabilities, including people with IDD, are also more likely to experience displacement from natural disasters, and are more vulnerable to the after-effects of these emergencies.[106] This is due to a combination of discrimination, access barriers, increased financial insecurity, living in lower quality housing and neighborhoods, and, according to the U.S. National Council on Disability, being “systematically ignored” by government disaster planning efforts.[107] Some people with IDD are reliant on electricity for their health and safety (e.g., assistive technology, medical equipment, refrigerated medications, temperature regulation) and loss of electricity or heating/cooling may put their lives at risk. Not only is infrastructure, such as those used for evacuations, not designed with people with IDD in mind, but first responders and emergency management personnel often do not have experience with or training about interacting with people with IDD.[108] Government and disaster management planners have also often failed to include people with IDD and their needs in policies and planning.[109]

Promising Strategies and Resources for Promoting Health Equity

While people with IDD face many health inequities, they can and do have fulfilling lives in the community with relationships, jobs and valued social roles. It is not their disabilities that cause their disparities, but the inequities they experience. As such, the World Health Organization notes health equity for people with disabilities cannot be a "siloed activity," but rather requires comprehensive, integrated approaches across sectors.[110] The public health community plays a vital role in promoting health equity of people with IDD. We've included promising policies, resources, and recommendations to help promote health equity for people with IDD.

ADVOCATE FOR PUBLIC POLICIES AIMED AT IMPROVING ACCESS AND OPPORTUNITIES FOR PEOPLE WITH IDD

There are several policy initiatives that could significantly improve the health equity of people with IDD. Priorities of the IDD self-advocacy movement and its allies include:

- **Expanding Community-Based and Long-Term Services and Supports.** Support federal policies to mandate funding to states to expand and stabilize home and community-based services for people with disabilities and retain and recruit support workers through better pay and benefits for direct service professionals.
- **Ensuring pay and employment equity.** Remove policies that allow employers to pay people with IDD lower wages. Support efforts such as Employment First, an initiative where states commit to a statewide systems change in order to advance integrated, competitive employment for people with IDD, especially prioritizing it over other forms of employment or non-work.
- **Implementing Technology First**, which is a movement to increase people with IDD's access to technology in recognition of the impact technology has on their independence and outcomes. Technology First states commit to changing their policies and practices to expand technology availability and access.
- **Updating SSI Benefits and Asset Limits.** Many of the barriers people with IDD face relate to increased poverty and financial insecurity among this population. Through the #DemolishDisabledPoverty movement, the disability community has been calling attention to this issue as well as advocating for changes to Social Security Income to increase benefits and update asset limits.
- **Enacting Legislation for Supported Decision-making.** People with IDD with guardianship/conservatorship have diminished health and quality of life outcomes, and, in many states, are not able to get married or vote. Supported decision-making is an alternative, less restrictive form of guardianship that maximizes people with IDD's control, while still offering support. By enacting legislation in your state to allow supported decision-making as a legal option, people with IDD will have more control over their own lives.

While the above areas are specific initiatives that can be taken, given the cross-cutting nature of IDD, all policy efforts, even those that are not explicitly about people with IDD or disability, should consider the needs of people with IDD. For example, if working on a broad housing policy or initiative, it is important to consider if it will be accessible for people with IDD. People with IDD should also be actively consulted and involved in public health program and policy development.

EXPAND TRAINING AND EDUCATION FOR HEALTH CARE AND PUBLIC HEALTH PROFESSIONALS ABOUT PEOPLE WITH IDD

With a better understanding of people with IDD's lived experiences and multifaceted identities, public health professionals will do a better job of building a culture that is inclusive and accessible and addresses health inequities. Ongoing learning is necessary for increased understanding, more informed decision-making, and relationship building with a population whose lives are affected by public health immensely. Below we recommend educational resources about the key public health areas which impact people's lives but often do not know much about people with IDD.

- The Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers includes resources, risk assessments, and recommendations for providers to improve the quality of their care when working with people with IDD.
- The World Health Organization's QualityRights Initiative is a comprehensive training and resource guide for professionals that takes a rights-based approach to supporting and serving people with IDD and other disabilities.
- The Partnering to Transform Health Outcomes with Persons with Intellectual and Developmental Disabilities (PATH-PWIDD) project has a collection of resources and educational materials for health care professionals to improve people with IDD's health.
- Havercamp et al. outline competencies that should be incorporated in education and training initiatives about disability and health care.

- Owen et al. describe core capacity-building work necessary to increase disability inclusion and equity in emergency preparedness. In addition, Disaster Justice: A Guidebook for People of Color with Disabilities includes recommendations about disaster justice for BIPOC with disabilities.
- The National Center on Criminal Justice and Disability® (NCCJD®) brings together the disability and criminal justice communities to improve people with IDD's experiences with the criminal justice system, including through training, technical assistance and policy initiatives.

BUILD ORGANIZATIONAL CAPACITY FOR DIVERSITY, EQUITY, INCLUSION, ACCESSIBILITY, AND BELONGING (DEIAB) BY LEARNING MORE ABOUT ABLEISM AND DISABILITY JUSTICE

While learning about IDD is important, it alone is not enough. Given how ableism impacts systems, structures, and perceptions of IDD, and informs public health decision-making, growing our awareness about ableism and disability justice through anthologies, trainings, professional development, and self-reflection is critical. Here are starting points to learn more about ableism and more nuanced views of disability more broadly, which can then be used to inform public health policies and practices.

- Michelle R. Nario-Redmond's book Ableism: The Causes and Consequences of Disability Prejudice describes the many ways ableism operates and is harmful.
- The Disability Visibility Project includes first-person stories from people with a range of disabilities, through articles, interviews, and a book.
- The Disability Social History Project highlights important moments in disability rights, culture, and media
- Self Advocates Becoming Empowered and the Autistic Self Advocacy Network are the most prominent national IDD self-advocacy organizations. Part of being a good ally is learning more about the priorities of the IDD community and following suit.
- Autistic advocate Lydia X. Z. Brown covers ableist language to avoid on their website.
- Inventing the Feeble Mind: A History of Mental Retardation in the United States by James Trent traces the history of how people with IDD have been perceived and treated in the US. This is an important foundation as this legacy continues to shape how we see and treat people with IDD today in public health and beyond.

IMPLEMENT PROGRAMS TO IMPROVE HEALTH OUTCOMES OF PEOPLE WITH IDD

People with IDD face more health disparities compared to people without disabilities. Targeted interventions can help promote health outcomes of people with IDD. Programs should be culturally relative, especially for communities of color, LGBTQ+, immigrants, and linguistically diverse people with IDD. In addition, whenever possible, programs and interventions should be co-led by people with IDD; a train-the-trainer model can also be beneficial. Some established programs and interventions to promote the health of people with IDD by educating them and their families about health include:

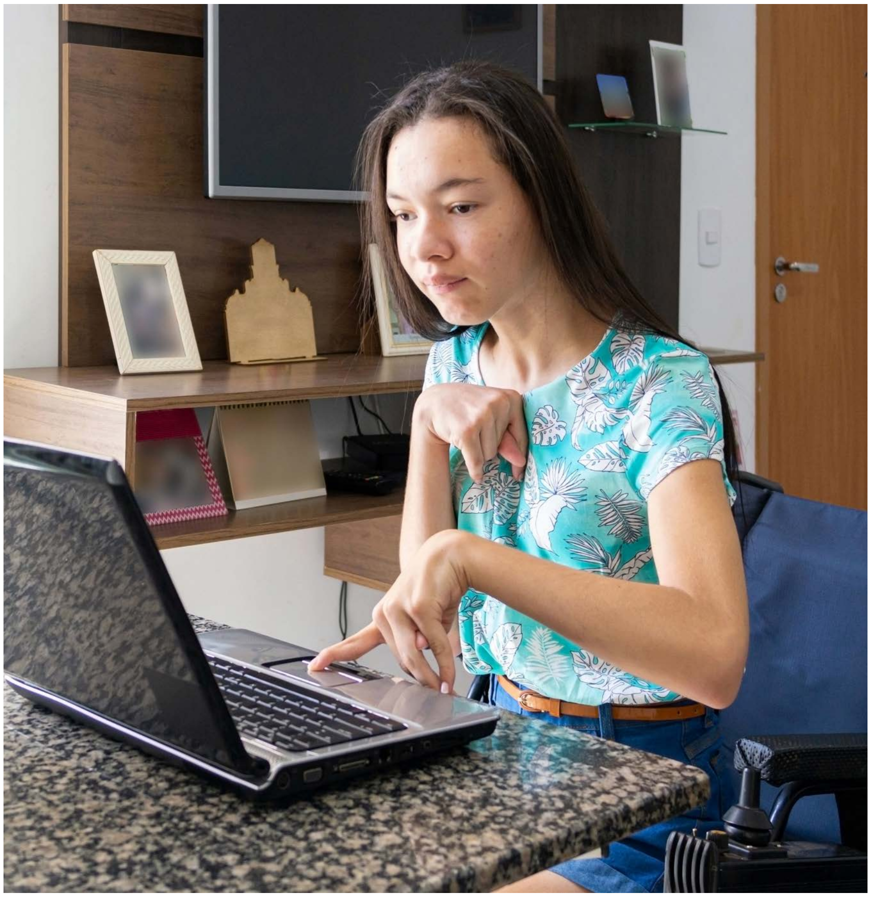
- Parents Taking Action (PTA) is an intervention model that incorporates community health workers to improve outcomes of Latino autistic children. It has also been adapted for Chinese immigrant families, Black families, and at-risk low-resource households.
- HealthMatters™ is an evidence-based health promotion program for people with IDD.

- The Administration on Community Living's The Link Center provides training and technical assistance about best practices in mental health of people with IDD.
- The Sexuality Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD) project has resources, guides, and tools about sexuality for professionals, people with IDD, and their families. The National Council on Independent Living also has a series of accessible sex education videos for people with IDD.

ENSURE THAT PUBLIC HEALTH PROGRAMS, COMMUNICATIONS, AND EVENTS ARE ACCESSIBLE FOR/ TO EVERYONE

While accessibility promotes access for people with IDD, when not addressed, it can serve as a major barrier to health care, employment and community integration. All public health programs, communications, and events must be accessible for people with IDD. Without accessibility, people with IDD will not be able to benefit from public health initiatives. The following resources describe best practices in maximizing accessibility for everyone:

- The Centers for Medicare and Medicaid Services (CMS) provides guidance on improving physical accessibility in health care spaces in its report and online training module *Modernizing Health Care to Improve Physical Accessibility*.
- Plain language is simplified, easy-read language designed to make it easier for everyone, especially people with IDD, to understand. The *Self Advocacy Resource and Technical Assistance Center* provides guidance on how to use plain language, as well as providing accessible resources for people with IDD about health.
- The Access is Love reading list includes a collection of resources from disability justice advocates on best practices in promoting accessibility and inclusion.
- Regional ADA Centers provide training, resources and free technical assistance about improving accessibility.
- Universal design is a way to design spaces to promote maximum access for everyone, while accommodating varying access needs. These principles can be applied to homes, offices, community spaces and many other locations.



PRIORITIZE DATA COLLECTION ABOUT PEOPLE WITH IDD AND THEIR NEEDS, INCLUDING INTERSECTIONAL, INCLUSIVE, AND CO-PRODUCED RESEARCH

Given the lack of data and research about people with IDD, especially about BIPOC, LGBTQ+ people, immigrants, and other social minorities with IDD, and the need to significantly improve health equity, more research needs to be conducted actively recruiting, monitoring, and including this population. Research has also problematically tended to focus on disability first as the primary identity, and then race, ethnicity, gender, or sexual orientation as a secondary add-on.[111] In addition, most health research about people with IDD has only included people with IDD already connected to the disability service system; however, this ignores 70% of people with IDD who are not connected, and they likely have different needs and experiences as a result.[112]

Historically, due to ableism, people with IDD have not been considered as legitimate producers of knowledge; they have been systematically excluded from research as a result, with proxies used in their place (e.g., support staff, family members). This legacy continues today with some research about people with IDD not being conducted with people with IDD. People with IDD are not only credible research subjects, they are also experts on their own lives. To maximize inclusion, data collection efforts, research measures, and methodologies must be thoughtfully implemented to promote accessibility and empowerment of people with IDD. For example, participatory action research can be especially fruitful as it can be more accessible while also downplaying power disparities. In addition, more research projects should include people with IDD as co-researchers, having them actively drive the research process.

References

1. Krahn G, Cargill-Willis K, Bersani L, Moore T, Johnson J. Recruiting the voices of persons with intellectual and developmental disabilities in policy development: Priorities for health equity data. *Intellectual and Developmental Disabilities.* 2023;61(5):368-384. doi:10.1352/1934-9556-61.5.368

2. Anderson LL, Larson SA, MapelLentz S, Hall-Lande J. A systematic review of US studies on the prevalence of intellectual or developmental disabilities since 2000. *Intellectual and Developmental Disabilities.* 2019;57(5):421-438. doi:10.1352/1934-9556-57.5.421

3. Self Advocates Becoming Empowered. *People first language: The basics.* 2014. https://www.sabeusa.org/wp-content/uploads/2014/01/People-First-Language-Manual.pdf

4. Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism.* 2023;27(2):565-570. doi:10.1177/13623613221130845

5. Caldwell J. Disability identity of leaders in the self-advocacy movement. *Intellectual and developmental disabilities.* 2011;49(5):315-326. doi:10.1352/1934-9556-49.5.315

6. Larson SA, Neidorf J, Pettingell S, Sowers M. *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019.* 2022. https://ici-s.umn.edu/files/y_7tYyJDmn/risp_2019_v6_ar.pdf?preferredLocale=en-US

7. American Association on Intellectual and Developmental Disabilities. Defining criteria for intellectual disability. https://www.aaidd.org/intellectual-disability/definition

8. The Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402, (2000).

9. McGrath RJ, Stransky ML, Cooley WC, Moeschler JB. National profile of children with Down syndrome: disease burden, access to care, and family impact. *The Journal of Pediatrics.* 2011;159(4):535-540. e2. doi:10.1016/j.jpeds.2011.04.019

10. Nazareth T, Li N, Marynchenko M, et al. Burden of illness among patients with fragile X syndrome (FXS): A Medicaid perspective. *Current Medical Research and Opinion.* 2016;32(3):405-416. doi:10.1185/03007995.2015.1119678

11. Ryan JM, Albairami F, Hamilton T, et al. Prevalence and incidence of chronic conditions among adults with cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology.* 2023;65(9):1174-1189. doi:10.1111/dmcn.15526

12. Khachadourian V, Mahjani B, Sandin S, et al. Comorbidities in autism spectrum disorder and their etiologies. *Translational Psychiatry.* 2023;13(1):71. doi:10.1038/s41398-023-02374-w

13. Trent JWJ. *Inventing the feeble mind: A history of mental retardation in the United States.* University of California Press; 1994.

14. Larson SA, Neidorf J, Pettingell S, Sowers M. Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019. 2022. https://ici-s.umn.edu/files/y_7tYyJDmn/risp_2019_v6_ar.pdf?preferredLocale=en-US

15. National Core Indicators. 2021-22 data at a glance. 2023. https://idd.nationalcoreindicators.org/wp-content/uploads/2023/05/0519_NCIIDD_Visusummary-A.pdf

16. Friedman C. Mapping ableism: A two-dimensional model of explicit and implicit disability attitudes. *Canadian Journal of Disability Studies.* 2019;8(3):95-120. doi:10.15353/cjds.v8i3

17. Andrews EE, Ayers KB, Brown KS, Dunn DS, Pilarski CR. No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. American Psychologist. 2021;76(3):451-461. doi:10.1037/amp0000709

18. Taggart L, Mulhall P, Kelly R, Trip H, Sullivan B, Wallén EF. Preventing, mitigating, and managing future pandemics for people with an intellectual and developmental disability-Learnings from COVID-19: A scoping review. Journal of Policy and Practice in Intellectual Disabilities. 2022;19(1):4-34. doi:10.1111/jppi.12408

19. Liao P, Vajdic C, Trollor J, Reppermund S. Prevalence and incidence of physical health conditions in people with intellectual disability–a systematic review. PloS one. 2021;16(8):e0256294. doi:10.1371/journal.pone.0256294

20. Liao P, Vajdic C, Trollor J, Reppermund S. Prevalence and incidence of physical health conditions in people with intellectual disability–a systematic review. PloS one. 2021;16(8):e0256294. doi:10.1371/journal.pone.0256294

21. Ryan JM, Allen E, Gormley J, Hurvitz EA, Peterson MD. The risk, burden, and management of non-communicable diseases in cerebral palsy: a scoping review. Developmental Medicine & Child Neurology. 2018;60(8):753-764. doi:10.1111/dmcn.13737

22. Nazareth T, Li N, Marynchenko M, et al. Burden of illness among patients with fragile X syndrome (FXS): A Medicaid perspective. Current Medical Research and Opinion. 2016;32(3):405-416.

23. Al-Beltagi M. Autism medical comorbidities. *World journal of clinical pediatrics.* 2021;10(3):15. doi:10.5409/wjcp.v10.i3.15

24. Magaña S, Parish S, Morales MA, Li H, Fujiura G. Racial and ethnic health disparities among people with intellectual and developmental disabilities. Intellectual and Developmental Disabilities. 2016;54(3):161-172. doi:10.1352/1934-9556-54.3.161

25. Xu Y, Morales MA, Magaña S, Hsieh K. Racial and ethnic disparities in chronic disease outcomes among adults with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities.* 2023:Advanced online publication. doi:10.1007/s10882-023-09923-7

26. Magaña S, Eliasziw M, Bowling A, Must A. Racial and ethnic disparities in obesity and contributions of social determinants of health among boys with autism spectrum disorder. *Frontiers in Pediatrics.* 2023;11doi:10.3389/fped.2023.1198073

27. Braden BB, Pagni BA, Monahan L, et al. Quality of life in adults with autism spectrum disorder: Influence of age, sex, and a controlled, randomized mindfulness-based stress reduction pilot intervention. *Quality of Life Research.* 2022;31(5):1427-1440. doi:10.1007/s11136-021-03013-x

28. Wallisch A, Boyd BA, Hall JP, et al. Health care disparities among autistic LGBTQ+ people. Autism in Adulthood. 2023;5(2):165-174. doi:10.1089/aut.2022.0006

29. World Health Organization. *Global report on health equity for persons with disabilities.* World Health Organization; 2022. https://www.who.int/publications/i/item/9789240063600

30. Ibid.

31. Charlot LR, Hodge SM, Holland AL, Frazier JA. Psychiatric diagnostic dilemmas among people with intellectual and developmental disabilities. *Journal of Intellectual Disability Research.* 2022;66(10):805-816. doi:10.1111/jir.12972

32. Koffer Miller KH, Cooper DS, Song W, Shea LL. Self-reported service needs and barriers reported by autistic adults: Differences by gender identity. *Research in Autism Spectrum Disorders.* 2022;92:101916. doi:10.1016/j.rasd.2022.101916

33. Poppes P, Van der Putten A, Vlaskamp C. Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities. *Research in Developmental Disabilities.* 2010;31(6):1269-1275. doi:10.1016/j.ridd.2010.07.017

34. Williamson HJ, Chico-Jarillo TM, Sasse S, et al. A scoping review of health research with racially/ethnically minoritized adults with intellectual and developmental disabilities. *Developmental Disabilities Network Journal.* 2023;3(2)

35. De Winter C, Jansen A, Evenhuis H. Physical conditions and challenging behaviour in people with intellectual disability: A systematic review. *Journal of Intellectual Disability Research.* 2011;55(7):675-698. doi:10.1111/j.1365-2788.2011.01390.x

36. Lulinski A, Heller T. Community capacity to provide mental/behavioral health services for people with IDD transitioning from state-operated developmental centers. *Intellectual and Developmental Disabilities.* 2021;59(3):224-238. doi:10.1352/1934-9556-59.3.224

37. Friedman, C. There's no place like home: A national study of how people with intellectual and/or developmental disabilities and their families choose where to live. The Arc of the United States & The Council on Quality and Leadership.2020. https://futureplanning.thearc.org/assets/CFP_Housing_Survey_Technical_Report-80e6eb718c816d07a15a9972df06a6e73b1393d5b56ae145acc058fce243cd93.pdf.

38. Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. Disability and Health Journal. 2015;8(2):165-172. doi:10.1016/j.dhjo.2014.11.002

39. Akobirshoev I, Mitra M, Parish S, Moore Simas T, Dembo R, Ncube C. Racial and ethnic disparities in birth outcomes and labour and delivery-related charges among women with intellectual and developmental disabilities. Journal of Intellectual Disability Research. 2019;63(4):313-326. doi:10.1111/jir.12577

40. Mitra M, Akobirshoev I, Valentine A, Brown HK, Simas TAM. Severe maternal morbidity and maternal mortality in women with intellectual and developmental disabilities. American Journal of Preventive Medicine. 2021;61(6):872-881. doi:10.1016/j.amepre.2021.05.041

41. Amir N, Mitra M, Leung K, Simas TAM. Complications following hysterectomy in women with intellectual and developmental disabilities. Disability and Health Journal. 2022;15(1):101213. doi:10.1016/j.dhjo.2021.101213

42. World Health Organization. Global report on health equity for persons with disabilities. World Health Organization; 2022. https://www.who.int/publications/i/item/9789240063600

43. Ibid.

44. Powell RM. Safeguarding the rights of parents with intellectual disabilities in child welfare cases: The convergence of social science and law. CUNY Law Review. 2016;20(1):127-149.

45. Friedman C, Arnold CK, Owen AL, Sandman L. "Remember our voices are our tools:" Sexual self-advocacy as defined by people with intellectual and developmental disabilities. Sexuality & Disability. 2014;32(4):515-532. doi:10.1007/s11195-014-9377-1

46. Dinwoodie R, Greenhill B. Developing a psychological understanding of the lived experiences of young lesbian, gay, bisexual and/or trans (LGBT+) people labelled with intellectual disability (ID). In: Toft A, Franklin A, eds. Young, Disabled and LGBT+. Routledge; 2020:48-72.

47. McQuaid GA, Gendy J, Lee NR, Wallace GL. Sexual minority identities in autistic adults: Diversity and associations with mental health symptoms and subjective quality of life. Autism in Adulthood. 2023;5(2):139-153. doi:10.1089/aut.2021.0088

48. Dinwoodie R, Greenhill B. Developing a psychological understanding of the lived experiences of young lesbian, gay, bisexual and/or trans (LGBT+) people labelled with intellectual disability (ID). In: Toft A, Franklin A, eds. Young, Disabled and LGBT+. Routledge; 2020:48-72.

49. Friedman, C., Arnold, C.K., Owen, A.L., Sandman, L. Remember our voices are our tools: Sexual self-advocacy as defined by people with intellectual and developmental disabilities. Sexuality & Disability. 2014;32(4):515-532. doi:10.1007/s11195-014-9377-1.

50. Rubenstein E, Tewolde S, Levine AA, et al. Medicare, Medicaid, and dual enrollment for adults with intellectual and developmental disabilities. Health Services Research. 2024;doi:10.1111/1475-6773.14287

51. The Henry J. Kaiser Family Foundation. Medicaid HCBS waiver waiting list enrollment, by target population and whether states screen for eligibility (2023). https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?

52. Wallisch A, Boyd BA, Hall JP, et al. Health care disparities among autistic LGBTQ+ people. Autism in Adulthood. 2023;5(2):165-174. doi:10.1089/aut.2022.0006

53. Friedman C, VanPuymbrouck L. Experiences of discrimination in healthcare: A survey of disabled people's perspectives. Manuscript submitted for publication. 2024

54. Williamson HJ, Contreras GM, Rodriguez ES, Smith JM, Perkins EA. Health care access for adults with intellectual and developmental disabilities: A scoping review. OTJR: Occupation, Participation and Health. 2017;37(4):227-236. doi:10.1177/1539449217714148

55. Werner S, Yalon-Chamovitz S, Rinde MT, Heymann AD. Principles of effective communication with patients who have intellectual disability among primary care physicians. Patient education and counseling.

56. Friedman C, Rizzolo MC, Spassiani N. Self-management of health by people intellectual and developmental disabilities. Journal of Applied Research in Intellectual Disabilities. 2018;32(3):600-609. doi:10.1111/jar.12554

57. Xu Y, Zeng W, Wang Y, Magana S. Barriers to service access for immigrant families of children with developmental disabilities: A scoping review. Intellectual and Developmental Disabilities. 2022;60(5):382-404. doi:10.1352/1934-9556-60.5.382

58. U.S. Department of Health and Human Services. Understanding Medicaid home and community services: A primer. 2000. https://aspe.hhs.gov/report/understanding-medicaid-home-and-community-services-primer-2010-edition

59. Friedman C. Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities. Intellectual and Developmental Disabilities. 2023;61(4):269-279. doi:10.1352/1934-9556-61.4.269

60. Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2947 (January 10, 2014) (to be codified at 42 C. F. R. pts. 430, 431, 435, 436, 440, 441, 447).

61. Friedman C. Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities. Intellectual and Developmental Disabilities. 2023;61(4):269-279. doi:10.1352/1934-9556-61.4.269

62. Ibid.

63. The Henry J. Kaiser Family Foundation. Medicaid HCBS waiver waiting list enrollment, by target population and whether states screen for eligibility (2023). https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

64. Friedman C. The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. Inclusion. 2021;9(1):63-73. doi:10.1352/2326-6988-9.1.63

65. Paode P. Housing for adults with autism and/or intellectual and developmental disabilities: Shortcomings of federal programs. 2020.

66. McCormick L, Schwartz A, Passerini C. Housing for people with disabilities: A review of state Olmstead and HUD consolidated plans. Journal of Planning Education and Research. 2023;41(1):20-34. doi:10.1177/0739456X19844567

67. Friedman C. Housing insecurity of Medicaid beneficiaries with cognitive disabilities during the COVID-19 pandemic. Disability and Health Journal. 2023;16(1):101375. doi:10.1016/j.dhjo.2022.101375

68. Glendening ZS, McCauley E, Shinn M, Brown SR. Long-term housing subsidies and SSI/SSDI income: Creating health-promoting contexts for families experiencing housing instability with disabilities. Disability and Health Journal. 2018;11(2):214-220. doi:10.1016/j.dhjo.2017.08.006

69. Souza MT, Collinson R, Martin M, Steffen B, Vandenbroucke DA, Yao Y-GD. Worst case housing needs of people with disabilities: Supplemental findings of the worst case housing needs 2009: Report to congress. 2011. https://www.huduser.gov/portal//Publications/pdf/WorstCaseDisabilities03_2011.pdf

70. Friedman C. The influence of residence type on personal outcomes. Intellectual and Developmental Disabilities. 2019;57(2):112-126. doi:10.1352/1934-9556-57.2.112

71. Larson, S.A., Butterworth, J., Winsor, J., Tanis, S., Lulinksi, A., Smith, J. 30 years of Community Living for individuals with intellectual and/or developmental disabilities (1987-2017). 2021. https://www.thinkwork.org/sites/default/files/files/PNS_Book_FINAL_07-12-21.pdf.

72. Friedman C. The relationship between participating in the community, significant support needs, and emergency department utilization. Journal of Developmental and Physical Disabilities. 2022;34(3):417-428. doi:

73. Friedman C. There's no place like home: A national study of how people with intellectual and/or developmental disabilities and their families choose where to live. The Arc of the United States, & CQL | The Council on Quality and Leadership; 2020. https://futureplanning.thearc.org/assets/CFP_Housing_Survey_Technical_Report-80e6eb718c816d07a15a9972df06a6e73b1393d5b56ae145acc058fce243cd93.pdf

74. Emerson E, Madden R, Graham H, Llewellyn G, Hatton C, Robertson J. The health of disabled people and the social determinants of health. Public Health. 2011;125(3):145-147. doi:10.1016/j.puhe.2010.11.003

75. Fulford C, Cobigo V. Friendships and intimate relationships among people with intellectual disabilities: A thematic synthesis. Journal of Applied Research in Intellectual Disabilities. 2016;31(1):e18-e35. doi: 10.1111/jar.12312

76. Devi CR, Sarkar R. Assistive technology for educating persons with intellectual disability. European Journal of Special Education Research. 2019;4(3)doi:10.5281/zenodo.3246839

77. Perrin A, Atske S. Americans with disabilities less likely than those without to own some digital devices. Pew Research Center. https://www.pewresearch.org/fact-tank/2021/09/10/americans-with-disabilities-less-likely-than-those-without-to-own-some-digital-devices/

78. Williams G, Thatcher R. Supporting the development of cost-effective paratransit services: The United States' Section 5310 program. Presented at: TRANSED; 2012; New Delhi, India.

79. Tilly L. Afraid to leave the house: Issues leading to social exclusion and loneliness for people with a learning disability. Tizard Learning Disability Review. 2019;24(4):168-175. doi:10.1108/TLDR-02-2019-0005

80. Wormald AD, McCallion P, McCarron M. The antecedents of loneliness in older people with an intellectual disability. Research in Developmental Disabilities. 2019;85:116-130. doi:10.1016/j.ridd.2018.11.009

81. Secretary Buttigieg announces proposed rule to ensure passengers who use wheelchairs can fly with dignity Februrary 29, 2024. https://www.transportation.gov/briefing-room/secretary-buttigieg-announces-proposed-rule-ensure-passengers-who-use-wheelchairs-can

82. The Centers for Medicare and Medicaid Services. Medicaid non-emergency medical transportation booklet for providers. 2016. https://www.cms.gov/medicare-medicaid-coordination/fraud-prevention/medicaid-integrity-education/downloads/nemt-booklet.pdf

83. World Health Organization. Global report on health equity for persons with disabilities. World Health Organization; 2022. https://www.who.int/publications/i/item/9789240063600

84. Social Security Administration. A guide for representative payees. 2022. https://www.ssa.gov/pubs/EN-05-10076.pdf

85. Mahoney E. Millions of disabled Americans could lose federal benefits if they get married. NPR. https://www.npr.org/2022/02/13/1080464176/disabled-americans-cant-marry-able-bodied-partners-without-losing-federal-benefi

86. Friedman C. Ableism, racism, and subminimum wage in the united states. Disability Studies Quarterly. 2019;39(4)doi:10.18061/dsq.v39i4.6604

87. Larson SA, Butterworth J, Winsor J, Tanis S, Lulinski A, Smith J. 30 years of Community Living for individuals with intellectual and/or developmental disabilities (1987- 2017). 2021.

88. Winsor J, Butterworth J, Migliore A, et al. StateData: The national report on employment services and outcomes through 2021. Institute for Community Inclusion; 2023.

89. Shepard J, Migliore A, Butterworth J, Winsor J. Employment and economic outcomes by race, ethnicity, and gender for individuals with and without disabilities, 2017. 2020.

90. Nazarov ZE, Golden TP, Schrader Sv. Prevocational services and supported employment wages. Journal of Vocational Rehabilitation. 2012;37(2):119. doi:10.3233/JVR-2012-0605

91. Butterworth J, Hall A, Hoff D, Migliore A. State and international efforts to reform or eliminate the use of sub-minimum wage for persons with disabilities. University of Massachusetts Boston: Institute for Community Inclusion; 2007:1-148.

92. Migliore A, Grossi T, Mank D, Rogan P. Why do adults with intellectual disabilities work in sheltered workshops? Journal of Vocational Rehabilitation. 2008;28(1):29-40.

93. Whittaker WG. Treatment of workers with disabilities under section 14 (c) of the Fair Labor Standards Act (RL30674). 2005. https://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1211&context=key_workplace

94. Friedman C. Ableism, racism, and subminimum wage in the united states. Disability Studies Quarterly. 2019;39(4)doi:10.18061/dsq.v39i4.6604

95. Whittaker WG. Treatment of workers with disabilities under section 14 (c) of the Fair Labor Standards Act (RL30674). 2005. https://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1211&context=key_workplace

96. Buren MK, Rios K, Burke MM. Advocacy experiences among rural parents of children with disabilities. Rural Special Education Quarterly. 2022;41(1):12-24. doi:10.1177/87568705211049337

97. Burke MM, Goldman SE. Special education advocacy among culturally and linguistically diverse families. Journal of Research in Special Educational Needs. 2018;18:3-14. doi:10.1111/1471-3802.12413

98. Mello MP, Burke MM, Taylor JL, Urbano R, Hodapp RM. Characteristics of students with disabilities who do and do not receive transition services. The Journal of Special Education. 2021;54(4):251-259. doi:10.1177/0022466920925437

99. Ibid.

100. Contrera J. People with disabilities desperately need the vaccine. But states disagree on when they'll get it. The Washington Post. https://www.washingtonpost.com/dc-md-va/2021/01/13/disabled-coronavirus-vaccine-states/

101. Chakravarty A, Lincoln M. The coronavirus still doesn't care about your feelings. The Nation. October 13. https://www.thenation.com/article/society/covid-pandemic-panic-calm-advice/

102. Boyle CA, Fox MH, Havercamp SM, Zubler J. The public health response to the COVID-19 pandemic for people with disabilities. Disability and Health Journal. 2020;13(3):100943. doi:10.1016/j.dhjo.2020.100943

103. American Academy of Developmental Medicine & Dentistry. Joint position statement on equity for people with intellectual and developmental disabilities regarding COVID-19 vaccine allocation and safety. 2020. https://www.aadmd.org/s/Covid19Vaccine-IDD-Statement-atxj.pdf

104. National Council on Disability. The impacts of extreme weather events on people with disabilities. 2023. https://www.ncd.gov/assets/uploads/reports/2023/ncd-extreme-weather-2023.pdf

105. Stough LM, Sharp AN, Resch JA, Decker C, Wilker N. Barriers to the long-term recovery of individuals with disabilities following a disaster. Disasters. 2016;40(3):387-410. doi:10.1111/disa.12161

106. National Council on Disability. The impacts of extreme weather events on people with disabilities. 2023. https://www.ncd.gov/assets/uploads/reports/2023/ncd-extreme-weather-2023.pdf

107. Ibid.

108. Owen A, Griffen A, Augustin D, Wolf-Fordham S. Prepared4ALL: Increasing disability inclusion and equity in local emergency planning. Collaborations: A Journal of Community-Based Research and Practice. 2023;6(1):1-15. doi:10.33596/coll.112

109. National Council on Disability. The impacts of extreme weather events on people with disabilities. 2023. https://www.ncd.gov/assets/uploads/reports/2023/ncd-extreme-weather-2023.pdf

110. World Health Organization. Global report on health equity for persons with disabilities. World Health Organization; 2022. https://www.who.int/publications/i/item/9789240063600

111. Williamson HJ, Chico-Jarillo TM, Sasse S, et al. A scoping review of health research with racially/ethnically minoritized adults with intellectual and developmental disabilities. Developmental Disabilities Network Journal. 2023;3(2)

112. Ibid.

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