Getting People with Intellectual and Developmental Disabilities What They Need

A Plain-Language Introduction for Public Health Workers

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AMERICAN PUBLIC HEALTH ASSOCIATION
For science. For action. For health.

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PART 1

Background

Glossary

Ableism

Discrimination or unfair treatment of people because they have disabilities. It's the idea that being non-disabled is better or more "normal."

Accessible

Something is accessible when everyone, including people with disabilities, can use or understand it easily.

Cognitively accessible

Something is cognitively accessible when it is easy to understand and easy to use, especially for people who think or learn in different ways.

Developmental disability

A type of disability that starts before the age of 22 and makes it harder to do everyday activities, like talking, walking, learning, or taking care of themselves.

Health equity

Everyone has a fair and equal chance to be as healthy as possible, no matter who they are or where they live.

Intellectual disability

A type of disability that makes it harder for a person to learn, understand, or do everyday things. It usually begins before the age of 22.

Physically accessible

When a space or place is easy for people with mobility challenges, like those who use wheelchairs or walkers, to get around and use.

Psychotropic medications

Medicines that affect a person's mind, emotions, or behavior. They are often used to treat mental health conditions.

Intellectual Disability is Important for Public Health

"The lives of people with IDD are important, our experiences matter, our quality-of-life matters."

-Person with IDD[1]

For over 20 years, public health leaders have called for better support for people with intellectual and developmental disabilities (IDD). Even the top doctor in the U.S., the surgeon general, has tried to teach public health workers what people with IDD need.[1] Still, people with IDD get left out when we talk about "health equity." Health equity means making sure everyone has what they need to be healthy and the opportunity to have a good life. People with IDD can be any age, race, ethnicity, gender, sexuality, nationality, or background.[2]

When people with IDD get the support they need, everyone's lives improve. The best way to do this is to include people with IDD in planning public health programs. When we talk about public health, we mean any program that helps us live a good life, like public transportation, education, good jobs, an affordable place to live, clean air and water, and good doctors and medicines. People who work on these programs can improve everyone's lives if they listen to people with IDD.

Language Matters

Person-first language (e.g., person with disabilities) is one way to reduce shame or stigma around disability, changing the story from someone's disability being their identity to the disability being just one part of them.

Identity-first language (e.g., disabled person) is one way to say that disability can be an important part of a person's identity, and that disability is something to be proud of.

Some people like person-first language better, and other people like identity-first language better. [3-4] The best way to know which version to use is to ask the person with a disability which version they like better. Or, you can listen to see which version they use.

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]*

In 2019, 7.4 million people in the United States had intellectual and/or developmental disabilities.[6] That's enough people to fill about 123 football stadiums. An intellectual disability means someone has trouble understanding and doing some things, starting before age 22.[7] Someone with a developmental disability has a disability their whole life that starts before they turn 22 and makes at least three big life activities harder, like talking, walking, learning, or taking care of themselves.[8] Common types of IDD are autism, cerebral palsy, Down syndrome, and Fragile X syndrome. Having one type of IDD often means a person might have another disability too. For example, someone with Down syndrome might also have muscular dystrophy, or someone with Fragile X could also have autism.[9-12]

Some people with IDD need machines to talk or learn new things. Others use walkers or wheelchairs to move around. Many people with IDD communicate with words, but others use sign language, typing, gestures, sounds, and/or tools like tablets. Most people with IDD can show what they want and need somehow.

For over 100 years, families and officials sent people with IDD to live in institutions instead of with their families.[13] Today, most live in the community, even if they need more support. They are our neighbors, friends, and family. They have jobs, go to school, speak up for themselves and others and are an important part of our communities. More than half of people with IDD who get government help —about 58 out of every 100—live with their families. A small number, 12 out of every 100, live in their own homes. Others live in different places: 16 out of 100 live in group homes, 5 out of 100 stay in host homes or foster care, and 9 out of 100 live in government-run and non-government institutions separate from people without IDD.[14] When it comes to working in the community, it varies by state. In some states, only 8 out of 100 people with IDD can get jobs. In others, almost half—about 41 out of 100—do.[15]

Many people don't understand that people with IDD, even those with lower IQ scores, keep learning and growing as they get older. A lot of people think that people with IDD have a 'mental age' of young children and stop learning past that mental age.[16] Some adults with IDD may need more time for hard ideas or help with money, but they're not children. We all learn and grow as we get older, no matter our IQ.

Many of the struggles that people with IDD face come from wrong ideas about what they can do. These wrong ideas and feelings about people with IDD —called "ableism,"— are one of the many things that make it harder for them to get the support they need to live healthy, happy lives.

What is Ableism?

Ableism is when people have unfair or wrong ideas about disability. This could look like someone assuming people with disabilities are less important than people without disabilities, can't do things or have sad lives. It can also appear as ideas that seem "positive" but still hurt, like assuming all people with IDD act sweet, happy, and simple, calling people with disabilities "inspirations," or pitying them without knowing them. Ableism is part of most of us, and it can be hard to see. Many people don't know they are ableist.[17]

Ableism is part of our community systems (like schools and hospitals) and structures, (like laws and government), making life harder for people with disabilities. For instance, when medicine or medical services run short, doctors sometimes follow rules that prioritize others over people with disabilities or delay their treatment, based on ableist ideas that their lives hold less worth.[18,19]

An example of this is a trend that doctors will withhold saving care (called a "do not resuscitate" order) to people with IDD without their permission or the permission of their families because they do not value the lives of people with IDD as much as they do people without IDD.[17]

PART 2

What problems do people with IDD have in getting what they need to be healthy?

What Problems do People with IDD Have in Getting What They Need to Be Healthy?

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]

Due to ableism in community systems and in laws and policies people with IDD have more health problems compared to people without disabilities and with other disabilities. For example, they often have physical health problems that aren't part of their disability. One of the most common issues for people with IDD is epilepsy and seizures.[20] They're also more likely to have heart disease, high blood pressure, bone disease, type 2 diabetes, thyroid problems, asthma, obesity, and dental cavities.[21] People with cerebral palsy are more likely to have long-term kidney disease, spine pressure, strokes, liver disease and pressure ulcers.[22] Many with Fragile X syndrome have nose and stomach problems.[23] Also, autistic people tend to have sleep problems and issues regulating hormones.[24]

People with IDD who face unfair treatment for reasons beyond their IDD have even poorer health. People of color with IDD have worse health and die younger than white people with IDD.[25] For example, Black people with IDD are more likely to have diabetes, high blood pressure and asthma than white people with IDD.[26] Black and Latino autistic kids are more likely to be obese than white autistic children.[27] Women with IDD have worse health-related quality of life than men with IDD.[28] People in the LGBTQ+ community with IDD also have worse physical health and struggle more to get the right doctors or medicines.[29]

Even though people with IDD are living longer than they used to, they still get health problems younger and die earlier than people without disabilities. For example, people with Down syndrome die up to 20 years earlier than those without it.[30] In addition, people with IDD are eight times more likely to die from COVID-19 than people without IDD.[31]

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]

People with IDD are more likely to have mental and behavioral disabilities than people without IDD. Between 1 in 3 and 1 in 2 people with IDD have these conditions.[32] In the LGBTQ+ community, people with IDD experience more depression, anxiety and stress. This happens because of ableism, which leads to disabled people not being able to get the care they need, for instance not being able to see the doctor.[33] People with IDD are more likely to have "challenging" or "maladaptive" behavior, like actions where they might hurt themselves or others.[34] It's important to say that what people call "challenging" depends on who you ask. For example, because of racism, folks may see people of color with IDD as behaving worse than white people with IDD. Also, doctors might assume they have mental or behavioral disabilities they don't have, or that they have more disabilities than they do.[35] Adding to this, people often see a person with IDD's "challenging" behavior as a flaw. But usually, something they need causes it. For example, their environment might be bad, they might feel pain, they might be sick without medicine, or someone might be hurting them or ignoring their needs.[36] Doctors and family members often don't understand why these behaviors happen. So, they're more likely to suggest medicines that affect their brains. Finally, doctors and family members are more likely to send people with IDD with these types of health problems to live in institutions. There, people with IDD have less personal freedom than in the community.[37]

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*[38]

Many people think that people with IDD can't or don't want to have sex. This wrong idea means that people with IDD often miss out on sex education. They're also less likely to be taught how to have or not have kids. For example, doctors might assume people with IDD can't or don't have sex or aren't at risk for reproductive health problems. For this reason, they're less likely to check women with IDD for cancer in their cervix (pap smears) and breasts (mammograms) than women without disabilities and women with other disabilities.[39] Women with IDD, especially Black and Hispanic women, have more issues related to pregnancy.[40] In fact, they're much more likely to get really sick or die from pregnancy than women without IDD.[41] After a surgery to stop having kids (called a hysterectomy), women with IDD also have more health issues than women without IDD.[42]

Understanding Sexuality

We don't pay enough attention to what people with IDD want and need when it comes to sex or having kids. This is one reason why sexual abuse is common among people with IDD.[43] Sexual abuse occurs when someone touches or speaks to them sexually without their consent. It's also a reason why doctors or caregivers force some people with IDD to get surgeries or take pills so they can't have babies, even if they don't want to.[44]

Many states also won't let people with IDD get married. Additionally, authorities or caregivers often don't let people with IDD take care of their children just because they have a disability.[45] Doctors, nurses, teachers, and other caregivers often make decisions about who people with IDD might be attracted to (sexuality), and how they express it. They base these decisions on what they want, not what the person with IDD wants.[46]

People with IDD want better sex education so they can make healthy choices about their sexual relationships. They also want to decide for themselves if they want to have sex or have kids. LGBTQ+ people with IDD need more chances to be open about who they like and who they are; many people assume people with IDD aren't transgender, gay, or queer, but that's wrong.[47] In fact, people with IDD are just as likely to be LGBTQ+ as people without disabilities. Autistic people, though, are more likely to be LGBTQ+ than non-autistic people.[48] LGBTQ+ people with IDD often have trouble fitting in with the IDD community and with other LGBTQ+ people. This can lead to poor treatment and feeling bad about what makes them different, so they might try to hide who they are.[49]

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*[50]

People with IDD don't get the health care they need as much as people without disabilities. Most government money that pays for their health care comes from Medicaid. In 2019, about one million people with IDD had Medicaid for health insurance, and 600,000 had Medicare, with a lot of overlap between the two.[51] Some people with IDD have private insurance too, but we don't know how many. Also, some people with IDD who have Medicaid or Medicare weren't counted in official totals. In 2023, 500,000 people with IDD were waiting to receive Medicaid.[52]

Many people with IDD can't see doctors when they need to. People of color, women, and LGBTQ+ people with IDD struggle more to see doctors and get the support they need compared to white, straight men with IDD. This makes it harder for them to stay healthy.[53] A law called the Americans with Disabilities Act (ADA) says doctors' offices have to be accessible for everyone. But almost 3 out of 4 adults with disabilities say they didn't get what they needed to have a good doctor or hospital visit.[54] This can mean doctors used equipment that didn't work for them, like exam tables that don't move or tools that don't work for people with IDD. Offices can often be loud and bright, and doctors might use words that the patient can't understand or talk too fast.

A big reason people with IDD don't get good health care is that many doctors and nurses don't understand their disabilities enough to treat them well.[55] Many doctors and nurses assume people with IDD have a hard life, are more difficult, burden others and are less likely to feel pain. Because of this, doctors and nurses are more likely to feel frustrated and uncomfortable when working with people with IDD. This leads them to miss health problems or guess the wrong illness, known as diagnostic overshadowing.[56] These assumptions make it harder for patients to make decisions about their own health, too. But if doctors and nurses are taught better and people with IDD get help to share their needs and experiences, treatments work better.[57]

Family members and caregivers often struggle to support people with IDD when they don't know enough about health or health care. This can be especially hard for immigrant families and those who don't speak English.[58] People with IDD want to learn more about their health and bodies. They want to understand physical and mental health, the health issues they're more likely to face, how their lives differ from people without disabilities, and what changes as they get older. Doctors, nurses, family, and caregivers need to find respectful, clear ways to give people with IDD the information they need to make health decisions.

PART 3

How do social causes of health problems affect people with IDD?

How Do Social Causes of Health Problems Affect People with IDD?

The World Health Organization states people with disabilities face more health problems than people without disabilities. The disability itself isn't the problem. The issue comes from the unfair way we treat people with disabilities. In public health, we see this pattern with many groups: people of color, women, low-income people, LGBTQ+ people, and people with disabilities, to name a few. When groups don't have as much money, education, support, or fair treatment as other groups, their health suffers more. To fix these health differences between groups, we need to tackle the causes that lead to some people having more health problems than others. We call these "social determinants of health." By helping specific groups who are not getting what they need to stay healthy, we move toward "health equity." People with IDD deal with way more health issues than others. A great way to shrink that gap is to focus on the unfair ways we treat people with IDD, and the money, education, support, and fair treatment they need to be healthy.

Long-Term Services and Supports

"I wouldn't be where I am today without the staff that help me."
-Person with IDD[1]

Many people with IDD need Long-Term Services and Supports (LTSS) to get the care they require. These services can be expensive, but the government can help pay for them through the Medicaid health insurance program. Medicaid's Home- and Community-Based Services (HCBS) are a great way for the U.S. government to support people with IDD. The program lets states take care of each person who needs help in the way that works best for them, without having to move away from their homes and communities.[59] These services don't just help when someone is sick —they stop people from getting sick in the first place. For example, HCBS programs help people with IDD with personal care, getting and keeping jobs, transportation, technology for communication or movement, and support family caregivers.[60]

A rule called the HCBS Settings Rule tells program staff to work with each person to give them the support they want and live how they choose to.[61] Years ago, the government used to spend more money on separate institutions for people with IDD. Now, it spends much more money on HCBS programs so people with IDD can live in their communities. This is because people with IDD prefer this because they stay healthier and happier—and it costs the government less too.[62] In 2021, the government set aside $43 billion for HCBS to help 860,000 people with IDD.[63]

Medicaid HCBS can make life better for people with IDD. But in 2023, 500,000 people with IDD were waiting to get these services.[64] That's enough people to fill about 8 football stadiums. Without HCBS, some might need to move to an institution to get the care they need. There are also not enough workers to provide those services, and the workers who are there come and go. This makes life harder for people with IDD who use those services to stay healthy and can make it more likely for them to get hurt or sick.[65]

Medicaid also has a problem called an "institutional bias." The federal government requires states to pay for care in institutions, but paying for home or community care is optional. On top of that, Medicaid pays for rent, bills, and food in institutions, but not in HCBS. This forces some people to live in institutions if they can't afford community-based housing while on HCBS.[66]

Finding a Good Place to Live

> *"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]

Living in the community is often harder for people with IDD, partly because of problems with Medicaid. Also, housing in the U.S. that suits the needs of people with IDD costs a lot. Only 1 in 20 homes in the U.S. works well for people with disabilities and finding them is getting harder.[67] People with IDD are more likely to be very poor than people without IDD. Because of this, many can't afford expensive housing and good options are scarce. This means they are less likely to find a good place to live than others.[68] In general, they are more likely to live in homes that are unsafe or cost more than they can afford.[69-70] Since finding good homes is tough for people with IDD, they are more likely to end up in an institution, prison, or become homeless.

Many people with IDD, especially those who need a lot of support, don't choose where they live. Instead, family members or others often decide for them. Most people with IDD want to live alone or with their families, but many live with strangers in group homes or institutions. This happens because there's not enough government funding and community support for them to stay in their own communities. For a long time, society sent people to live in institutions far from their families. Changing the way support systems work can take time. This change is important, as living with strangers in group homes or institutions makes people with IDD more likely to get sick, feel unhappy, or be abused.[71]

Being a Part of the Community

> *"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*[72]

More people with IDD live in the communities now than ever before. When they do, they're healthier, even if they need a lot of help.[73] Ableism—unfair and wrong ideas about people with disabilities—pushes people with IDD out of communities, both physically and socially. For example, a person with IDD living at home might not have many friends or things to do because the community doesn't include them.[74] This loneliness can be unhealthy and can make it harder to be happy.[75] In schools and jobs, people with IDD get separated out from others, or other times they can't find a job at all. It's also harder for people with IDD to make and keep friends when affordable transportation is missing, and people act unkind or don't understand their disability.[76]

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[1]***

People with IDD have trouble finding good, affordable transportation. The U.S. doesn't have very good public transportation in general: almost half of U.S. counties don't have any public transportation.[77] People with IDD face two main issues: transportation is often not physically or cognitively accessible. Physically accessible transportation is easy to use for people with mobility challenges, like those who use wheelchairs. This includes things like having elevators and sidewalks. Cognitively accessible transportation is easy to understand. This includes having simple schedules, signs, rules and updates.

Accessible, affordable transportation improves life for people with IDD. It also helps them be more independent, make their own decisions, and have friends.[78] When people with IDD can't use transportation to get around, they're lonelier and less connected to their communities. They also rely more on other people and have a harder time getting to jobs or school.[79] Additionally, when flying, airlines often lose or damage people's wheelchairs, making it much harder to travel and be independent.[80]

Special transportation for people with disabilities exists but you have to schedule it hours or days in advance. Many people don't qualify for it, though. States have transportation for people on Medicaid, but only to get to doctor's appointments, not for other needs.[81] Some states provide transportation through home-and-community-based services, but it's not mandatory. Sometimes the only other option is taking taxis or rideshares like Uber or Lyft. These often cost too much or have drivers who discriminate against people with disabilities.

Technology Makes Life Easier and Healthier for People with IDD

"Assistive technology" is what we call tools designed to help people with disabilities. For example, these tools can help people hear, communicate, move around, find and learn new information, and try new activities. In the U.S., about one-third of people with IDD don't have some kind of assistive technology they need. This is because it is expensive and can be hard to find.[82] People with IDD often have a harder time getting the technology they need.[83]

Not Having Enough Money

"They [policy makers] don't know what it means to live like we do in regard to how we spend our money."
-Ashley Wolfe, person with IDD[1]

People with disabilities usually have much less money than people without disabilities. We don't know exactly how many people with IDD don't have enough money, but 1 in 2 people with disabilities in the U.S. barely have enough money to live on.[84]

Having a disability can be expensive. People may need to pay for more medicines or doctors' visits, assistive technology, changes to make their house or car accessible, and transportation in general.

Medicaid and other government programs that help those who don't have a lot of money are important for people with IDD. But these programs often make people stay poor to get help. This makes it hard for people with IDD to get the support and money they need.

It's also hard for people with IDD to have and control their own money. This happens because "representative payees," like parents or caregivers, often handle their money for them.[85] There's also a "marriage penalty." This means that if people with IDD get married, they lose their Social Security benefits, which they need to live.[86] So, many can't afford to marry.

It's also harder for people with IDD to find a good job that pays them well, making it harder for them to earn enough money.[87]

Jobs

"No one is too disabled to live and work in the community."
-Nicole LeBlanc, autistic self-advocate[88]

People with IDD want to work in typical jobs with people without disabilities. Yet, they're pushed into separate jobs only for people with IDD, or they don't work at all. In fact, only about 1 in 6 people with IDD work in typical workplaces, compared to about 2 in 5 people with other disabilities and about 3 in 4 nondisabled people.[89] Asian, Black, Hispanic, and Pacific Islander people with IDD are even less likely to work in normal workplaces.[90] People with IDD often work in separate jobs where they do the same thing over and over, such as sorting parts.

Many people with IDD also join day programs where they don't work; but some day programs are much better than others. Day programs may be part of the community or separate from it. Some people with IDD also participate in pre-work programs. These are meant to help them learn skills to get a job. But these skills don't usually help them get normal jobs and often push them into lower-paid jobs.[91]

When people with IDD get jobs that match what they want and are good at, they can work any jobs that anyone else would..[92] People with IDD would rather work in workplaces that have both disabled and non-disabled workers, especially compared to separate jobs or programs where they don't get paid. When they work a normal job, they tend to enjoy life more.[93]

Because of unfair and untrue beliefs about people with disabilities, especially those with IDD, the law lets employers pay people with disabilities less than the minimum wage. Section 14(c) of the Fair Labor Standards Act allows employers with special certificates to pay people with disabilities much less than the minimum wage. They can pay as low as less than a dollar per hour, even if they do the same job as people without disabilities.[94] Research shows that making less than the minimum wage is unfair for people with disabilities. Ableism and racism make this problem even worse. Still, it's legal to pay people with disabilities less than the minimum wage.[95]

Also because of the law, companies can get more government money and work opportunities for hiring people with disabilities. Meanwhile, they pay these workers less than they deserve. Some of those companies openly tell the government to keep the law the same because it helps them make money.[96]

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 is very important for people with IDD to get jobs and have more choices in life. The Individuals with Disabilities Education Act (IDEA) promises free, appropriate, public education to people with IDD. Under IDEA, children with disabilities get individualized education plans (IEPs). These plans set goals for the student and prepare for any changes or extra help they need to do well.

Laws like IDEA try to ensure people with IDD get good education. But many schools still separate children and youth with IDD from regular classrooms, and they miss out on the educational help they need. This causes kids with IDD to fall behind in school and beyond.[97] Often, families of children with IDD have to ask many times before their kids get the help they need. Many parents don't understand how laws like IDEA give their kids rights to a good education that works for them. Parents who don't live in cities, don't know much about U.S. laws, or don't speak English as their first language struggle more to get their children the support they need for a good education. This can be because they don't have the information or money they need, or because people judge them unfairly.[98]

Many people with IDD go through a "transition cliff" after high school. This means the services and support they got in school stop suddenly. As part of IEPs, schools must help students with IDD get ready to leave high school. They do this by teaching them independent living skills, job skills, or getting them ready for college.[99] These services help people with IDD live better lives after high school, but some programs are much better than others. Many students get low-quality transition support that doesn't consider what they need, or don't get any transition support at all.[100] There are also very few accessible college programs designed for people with IDD.

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*[101]

It's very important for government workers to remember people with IDD when planning for emergencies, like a pandemic. A pandemic is a disease outbreak that spreads across many countries or continents, making a lot of people sick. People with IDD can suffer a lot during pandemics and disease outbreaks when a lot of people get sick, especially when safety rules and plans don't consider their needs.

This was a problem during the COVID-19 pandemic. People with IDD were more likely to get sick and die from COVID-19 than people without IDD. Public health plans didn't protect them enough.[102] For example, when public health workers tracked who was getting sick, they didn't track how many people had disabilities or what types of disabilities. They also didn't share COVID-19 information in ways that people with IDD could understand. Mask rules and re-opening plans did not consider the extra risks to people with IDD.[103] Plus, people who worked with people with IDD got COVID-19 vaccines before people with IDD did.[104]

We don't know exactly how many people with IDD die in emergencies. But we do know that people with disabilities in general are four times more likely to die in natural disasters, like a hurricane, flood, or disease outbreak, than people without disabilities.[105] People with IDD are also more likely to develop long-term illnesses or disabilities after disasters.[106] Plus, people with disabilities, including people with IDD, are more likely to have to move because of a natural disaster and have a harder time adjusting afterward.[107] This is because of unfair judgement from others, lack of needed support or services, not enough money, and living in lower quality homes and neighborhoods. In fact, the U.S. National Council on Disability has said government workers around the world that plan for disasters "systematically ignore" people with disabilities.[108]

Some people with IDD are especially dependent on electricity to stay healthy and safe. They might use assistive technology, medical equipment, refrigerated medicine, or need heating or cooling to be safe. This means that losing electricity or heating/cooling can put them in danger.

The systems we use for getting everyone out of an area quickly (evacuation), like public transport and highways, aren't made for people with IDD. Also, some first responders and emergency workers don't know how to talk to or support people with IDD.[109] People with IDD are rarely included in planning disaster responses, even though including them could make responses better for everyone.[110]

PART 4

Helpful strategies and resources to support people with IDD

Helpful Strategies and Resources to Support People with IDD

People with IDD face many challenges to staying healthy, but they can still live good lives in the community with relationships, jobs, and responsibilities. Their disabilities don't cause these challenges; a lack of support does. The World Health Organization says that helping people with disabilities stay healthy can't be a "siloed activity" that just one group does. Instead, everyone must work together.[111] The public health community plays an important part in getting people with IDD what they need to be healthy and happy. We've included below some government rules, resources, and recommendations to support good health and fair treatment for people with IDD.

Support Public Policies Designed to Improve Opportunities for People with IDD.

There are several government policies that could improve life for people with IDD. People in the IDD self-advocacy movement and others who support it have suggested these policies:

- Grow community-based and long-term services and support. Ask the government to pass federal policies that give states money for better home and community-based services. Also, keep and hire more support workers through better pay.
- Promise fair pay and job opportunities. Stop policies that let employers pay people with IDD less than others for the same work. Support movements like Employment First, which help states create more job opportunities for people with IDD in regular workplaces. This means focusing on jobs where they work alongside others and get paid fairly, instead of separate jobs or unpaid activities.
- **Pass Technology First policies.** Technology First is a movement that helps people with IDD access technology to be healthier, happier, and more independent. States that join promise to make technology more accessible.
- **Change Social Security benefit rules.** Many of the problems people with IDD face are because they don't have enough money for the support they need. The #DemolishDisabledPoverty movement is raising awareness about this and pushing for changes to Social Security rules. They want people on Social Security to get more help and keep their benefits, even if they have some money saved.
- **Pass legislation for supported decision-making.** People with IDD with guardianship/conservatorship (when someone else has control over their life decisions), have worse health and quality of life outcomes. In many states, they also can't get married or vote. Supported decision-making is a different type of guardianship that gives people with IDD more control, while still offering support. By asking for legislation in your state to allow supported decisionmaking as a legal option, you can help people with IDD have more control over their lives.

These policies can help make life better for people with IDD. But, because IDD affects so many parts of life, even policies that are not specifically about people with IDD or disability should consider the needs of people with IDD. For example, when making housing rules, it's important to ask yourself if that housing will be accessible for people with IDD. Leaders should ask people with IDD for their input and include them when creating public health programs and rules.

More and Better Training and Education About People with IDD for Health Care and Public Health Workers

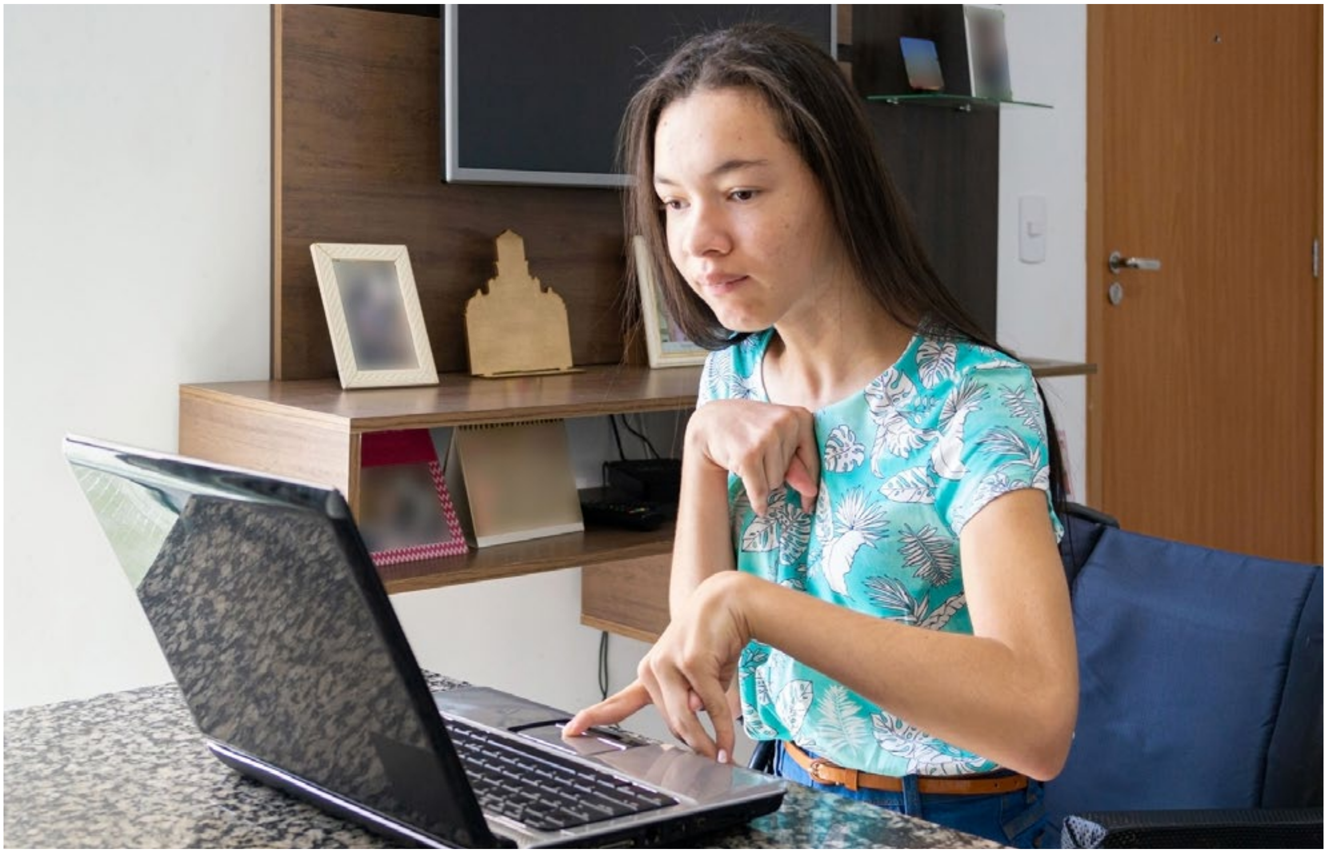
Public health workers can design better programs that are accessible and helpful to people with IDD when they understand their lives and what matters to them. When public health workers learn more about IDD, they make better choices, connect better with people with IDD, and improve their lives. Below, we recommend educational resources about key public health areas that impact people's lives:

- The Special Olympics Inclusive Health Fundamentals Curriculum introduces the concept of providing high quality, inclusive care to people with intellectual and developmental disabilities (IDD) for healthcare students and professionals.
- The Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers has resources and tips for doctors and nurses taking care of people with IDD.
- The World Health Organization's QualityRights Initiative is a training for professionals. It teaches them how to help people with IDD and other disabilities and starts by focusing on human rights.
- 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 workers to improve people with IDD's health.
- Havercamp et al. outline skills that professionals should include in education and trainings about disability and health care.
- Owen et al. describe ways to include people with disabilities and their needs when planning for emergencies. Also, *Disaster Justice: A Guidebook for People of Color with Disabilities* has recommendations for keeping people of color with disabilities safe during disasters.
- 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. It does this through training, help accessing information, and policy recommendations.

Organizations Can Work on Diversity, Equity, Inclusion, Accessibility, and Belonging (DEIAB) by Learning More About Ableism and Disability Justice

Learning about IDD is important, but it's not enough on its own. Unfair and wrong ideas about people with disabilities (ableism) impact our government systems, public health programs, and face-to-face interactions. That's why public health workers need to keep going to trainings, reading about IDD, and thinking about how they can make a difference. Here are some materials to learn more about ableism and new ways to think about disability. You can use them to create better public health policies and programs.

- Michelle R. Nario-Redmond's book *Ableism: The Causes and Consequences of Disability Prejudice* describes many ways ableism is harmful.
- The Disability Visibility Project has stories from people with a range of disabilities written in their own words, through articles, interviews, and a book.
- The Disability Social History Project explains important moments in disability rights, culture, and news history.
- Self Advocates Becoming Empowered and the Autistic Self Advocacy Network are the biggest national IDD self-advocacy organizations. Part of being a good ally is learning more about what is important to the IDD community and supporting those movements.
- Autistic advocate Lydia X. Z. Brown has a website explaining ableist language you should avoid using.
- Learn about the ten principles of disability justice and use them in your work.



- *Inventing the Feeble Mind: A History of Mental Retardation in the United States* by James Trent tells the history of how US society has viewed and treated people with IDD. This history helps us understand how we view and treat people with IDD in public health and other areas today.

Programs that Improve Health for People with IDD

People with IDD have more health problems compared to people without disabilities. Interventions that are designed to help people with IDD can improve their health. These programs should match the culture (cultural appropriateness), especially for people with IDD who are also people of color, LGBTQ+, immigrants, or speak languages other than English. Also, whenever they can, programs should be co-led by people with IDD. One model that works well is when a person with IDD trains the trainer on how to keep it inclusive. Here are some programs and interventions to educate people with IDD and their families about health:

- Parents Taking Action (PTA) is a type of intervention that uses community health workers to improve outcomes of Latino autistic children. It now also includes support for Chinese immigrant families, Black families, and at-risk low-resource households.
- HealthMatters™ is a health promotion program for people with IDD that works.
- The Administration on Community Living's The Link Center has trainings and 1-on-1 mental health help for people with IDD.
- The Sexuality Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD) project has resources, guides, and tools about sexuality for public health workers, 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.

Make Sure That Public Health Programs, Communications, and Events are Accessible for/to Everyone

The word "accessibility" means that everyone, including people with IDD, should be able to use something. But, many people with IDD can't use some technology or systems, even if they are labelled "accessible." This can make it hard for people with IDD to get good health care, good jobs and homes, and be a part of their communities. All public health programs, communications, and events must be accessible for people with IDD. Without this, people with IDD can't benefit from public health initiatives. These resources describe good basic rules to support accessibility for everyone:

- The Centers for Medicare and Medicaid Services (CMS) goes over how to improve physical accessibility in health care spaces in its report.
- Plain language means writing in easy-to-read words, and makes it easier for everyone, especially people with IDD, to understand. The *Self Advocacy Resource and Technical Assistance Center* explains how to use plain language, and also has accessible resources for people with IDD about health.
- The *Access is Love* reading list has a collection of resources from disability justice advocates on ways to support accessibility and inclusion.

- Regional ADA Centers have training, resources and free individual help for anyone who wants to improve accessibility.
- Universal design is a way to design spaces that are accessible for everyone, no matter what needs they have. These guidelines can be used to design homes, offices, community spaces and other locations.

Collect Data about People with IDD and Their Needs, Including Research About Different Types of People with IDD, Led by People with IDD

We don't have enough data and research about people with IDD. This is especially true for people with IDD who are also people of color, in the queer, gay or trans communities, immigrants, and other social minorities. Researchers need to include these groups in more studies. When studies include these groups, they tend to think of the person's disability as the most important thing about them. They treat their race, ethnicity, gender, or sexual orientation as less important.[112] Also, most health research about people with IDD only counts those who are connected to the government's disability service system. But this misses most people with IDD—7 out of 10—who don't get these services. These people likely have different needs and experiences because they don't get disability services, so collecting their information is very important.[112]

Because of ableism, research studies have not usually listened to people with IDD themselves to understand what they need. Instead, researchers ask their support staff or family members. This still happens today, with some studies about people with IDD not being done *with* people with IDD. People with IDD are good sources of information, especially about themselves. To be truly inclusive, researchers should collect data in ways that are accessible and empowering to people with IDD. A type of research called "participatory action research" can be especially helpful. It's more accessible and lets people with IDD have more power over the research goals and process. In addition, more research projects should include people with IDD as co-researchers, meaning they help lead the research process.

PART 5

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