

Improving health of people with intellectual, developmental disabilities

Discrimination, exclusion harm care

Health care access improving for people with IDD, but gaps remain

LIKE MILLIONS OF AMERICANS, Iowa resident Mike Hoenig lined up to get vaccinated during the H1N1 influenza pandemic of 2009.

Other patients in line that day got a written handout explaining the shot's possible side effects. But it was useless to Hoenig, who is blind, and the nurse said she was too busy to explain it to him. Fortunately, a manager stepped in to help, but Hoenig said the experience is emblematic of how people with intellectual and developmental disabilities like himself are often treated in health settings.

"There's still a dearth of (health care) training related to disability," said Hoenig, MA, program coordinator at Iowa's University Center for Excellence in Developmental Disabilities.

While the U.S. has made considerable inroads to improve health access and outcomes among people with IDD, significant gaps and disparities remain. About 8 million Americans have such disabilities, which are typically present at birth and last throughout a person's lifetime. They can include both physical and mental impairments due to a range of condi-

tions, such as cerebral palsy, autism and Down syndrome.

Research shows people with IDD experience many disparate health outcomes, including fewer preventive screenings, more complica-

tions during pregnancy, lower life expectancy and a high risk of chronic diseases like diabetes. The population also has a long history of suffering discrimination and maltreatment in health care, including forced institutionalization.

It was only 25 years ago that the U.S. Supreme Court's landmark ruling in *Olmstead vs. L.C.* found that the unjustified segregation of people with disabilities constituted discrimination under the Americans with Disabilities Act. Last year, the National

Institutes of Health officially designated people with disabilities as a population with health disparities.

"The fight for people with IDD to live in the community and to live the lives they want to is one that's ongoing," said Darcy Milburn, MPH, director for Social Security and health care policy at The Arc, a national nonprofit that advocates for people with IDD. "Discrimination, stigma, exclusion are still rampant in our health care system."

Remedying the gaps and inequities takes action on many fronts, Milburn told *The Nation's Health*, including policy and systems change, more federal and state funding for home- and

community-based services, and better training for medical providers. And because people with IDD are, happily, living longer than ever before, the need for robust support systems will only grow, she said.

"There has been so much positive change," Milburn said. "But there's so much more that needs to be done."

Local work fosters inclusion, equity

Americans with IDD face a range of barriers to health care and health-promoting opportunities, from Medicaid waiting lists to building features that impair people's mobility. The challenges continue even after they get to the exam room.

In a study published in 2021 in *Health Affairs*, researchers surveyed

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To adequately meet the health care needs of people with IDD, more training is needed for health and medical professionals.

More medical, nursing schools address needs Programs train health students to care for people with IDD

WHEN JONATHAN GARDNER reported that he had a pain in his leg, doctors automatically assumed it was related to the fact that he has autism.

"After a lot of time going through the medical thing and pushback from the doctors...I eventually found out that I had cancer," Gardner told *The Nation's Health*.

It is a story he recounts often in front of health care students in New England as part of Operation House Call, a training program from The Arc of Massachusetts. The program educates students at schools of medicine and nursing about the health care experiences of people with intellectual and developmental disabilities. Students receive six hours of personal stories, coursework and home visits with families.

Training programs such as Operation House Call, which was codified into Massachusetts state law in 2023, are necessary to train the next generation of health care professionals to improve the quality of care for people with IDD, who number about 8 million in the U.S.

In a survey of 75 medical schools, just 52% had some

sort of disability awareness program, according to a 2017 study in the *American Journal of Physical Medicine and Rehabilitation*. A 2002 surgeon general report found medical schools spent an average of 11 minutes covering IDD over the course of four years.

A common excuse for IDD's absence in school curricula is that there is no room for it, said Ellen Banister, MA, a board of directors member of

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In their own words**

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8 million people in US have an IDD

It's time to expand equity, inclusion work to include people with IDD

IN MY OVER 20 years in public health, I've watched the field progress from a focus on disparities to a more upstream approach in creating health equity. More recently, there has been increasing recognition to ensuring that accessibility and belonging are a part of diversity, equity and inclusion work. However, even with this intentionality, there is a population that often remains overlooked — people with intellectual or developmental disabilities.

As many as 8 million people in the U.S. are estimated to have an IDD, such as Down syndrome, cerebral palsy or autism. Many people with IDD have health issues that are exacerbated by poor quality health care, a health system that is not designed to meet their needs, and a host of challenges related to housing, transportation, education and employment. As a result, this population experiences significant health disparities that are worse for those who are at the intersections of multiple identities, including race, ethnicity, gender and sexual orientation.

Unfortunately, most health care and public health professionals are not trained on the unique presentations and considerations of people with IDD. As a result of a lack of exposure, misconceptions exist that influence how people with IDD are treated.

After being awarded a grant from the Special Olympics, my colleagues and I in the APHA Center for Public Health Policy set out to learn more about the lived experiences of people with IDD, their caregivers, family members and advocates. Through a series of listening sessions, we heard repeatedly that people with IDD are infantilized and ignored by their providers. Many described encounters where their doctors only

spoke directly to their caregiver or support person, and not to them. We also learned that there are many legal and policy barriers to ensuring equity for people with IDD.

As a Black woman who has worked in the health disparities and equity spaces for decades, what struck me are the similarities in the challenges experienced by people with IDD and other marginalized groups: lack of access to quality health care, not being listened to by doctors, health communications that are hard to understand and fragmented services and systems. At the same time, people with

IDD also have a strong desire to be seen, heard and valued for their full selves and their many identities.

As public health professionals, we have the responsibility

to center the needs and priorities of people with IDD in our work. While there are nuances and considerations that are unique to the type of IDD, much of the learning and unlearning that the public health community has embraced through the lens of diversity, equity, inclusion, access and belonging can be extended to advancing health equity for people with IDD. We must honor and listen to the lived experiences of people with IDD and meaningfully engage the community in advocacy, program and policy efforts.

We also must acknowledge and learn from the many organizations that have been creating opportunities for people with IDD for decades. And we have to ensure that our commitment to equity and social justice extends to improving the health and well-being of people with IDD. ■

— Tia Williams

Williams, MPH, CNS, is director of APHA's Centers for Public Health Policy.

Mental health issues for people with IDD can be misunderstood

NEARLY 20% of U.S. adults are estimated to be living with a mental illness, according to Mental Health America. But for people with intellectual or developmental disabilities, that estimate increases to as high as 35%, with depression a common issue, research has found.

Despite the higher prevalence, family and caregivers often overlook mental health conditions in people with IDD, which can include the same conditions that occur in other people, such as anxiety disorders, obsessive behavior or bipolar disorder.

At the same time, people with IDD can also be misdiagnosed as having a mental health issue. For example, some people with IDD have problems with communication and experience frustration, which can be misconstrued as depression or chronic anxiety.

“Children of elementary or middle school age are sometimes diagnosed as suffering from a psychiatric condition, when they're actually suffering from communication elements or issues related more to neurodevelopmental disorder,” said Yaara Zisman-Ilani, PhD, MA, assistant professor of social and behavioral studies at Temple University College of Public Health.

The good news is that awareness is increasing. In recent years more attention has been given to mental health and IDD, including more therapeutic options.

In a study published in 2022, researchers found that people with IDD, including people with autism, who experience mild or moderate depression benefit from cognitive behavioral

therapy, without a need for drugs. But many clinicians use only pharmaceutical treatments, which are often ineffective and come

with side effects.

“Clinicians treating this population often rely on their own clinical experience when deciding on the treatment,” the researchers said. “This most often bypasses the psychotherapy treatment approach and resorts to psychopharmacology only.”

Another shift has been offering therapies that show anecdotal success at improving mood and behavior among patients with special needs. Among these are speech therapy, self-care, learning domestic chores and social skills, practicing mindfulness and meditation, and physical activity. The methods can improve both mobility and independence.

More emphasis is also being placed on communication between providers and patients with IDD in mental health treatment, Zisman-Ilani said.

“Every person with every condition in any intensity should have the right to be involved in decision-making about their care,” Zisman-Ilani told *The Nation's Health*. “Most of my work is with people with serious mental illness. This includes people with schizophrenia, people with major depression. Research shows that people with various health conditions can be involved in decision-making about their treatment.”

The American Psychiatric Association and the Substance Abuse and Mental Health Services Administration have endorsed shared decision-making between providers and patients on treatments.

For more information, visit www.psychiatry.org. ■

— Mark Barna



Photo by Edwin Tan, courtesy iStockphoto

In recent years, more attention has been given to mental health and IDD, including nontraditional therapeutic options.



Photo by Slovenia, courtesy iStockphoto

People with IDD can find it difficult to afford oral health treatment and access professionals qualified to give care.

More training needed to serve population Personal approach improves oral health care of people with IDD

LIKE MANY Americans, people with intellectual and developmental disabilities can miss out on regular dental care. But for people with IDD, a range of barriers worsens the problem, leading to poorer oral health among the population.

Research shows that people with IDD experience more tooth extractions and cavities, fewer fillings, greater gum inflammation and fewer preventive dental care visits than the general population.

Insurance coverage is one hurdle. Most people with IDD rely on Medicaid coverage for dental care, but in 12 states, the program does not cover dental care for adults. And even for the millions of people with IDD who have Medicaid coverage, patients can experience difficulties finding an oral health provider who will take them as a patient or accept Medicaid's lower reimbursement rates.

The need for oral health care for people with IDD is great. Oral health problems can result not only in chronic pain and interfere with eating, but also lead to heart disease and pregnancy complications, according to Farah Alam, DDS, director of special care dentistry at Rose F. Kennedy Children's Evaluation and Rehabilitation Center at Montefiore Medical Center.

Oral health providers can also spot early symptoms of conditions such as diabetes and cancer in the

mouth, helping to head off chronic illnesses.

Given the needs of patients, all dental and other oral health providers should receive training to serve people with IDD, Alam said.

But not everyone with IDD experiences the same oral health issues. Some people with autism who have heightened sensory experiences may dislike the feeling of brushing their teeth or allowing a physician to have access to their mouth, for example.

Others with IDD may take medications with side effects that contribute to tooth decay, and some may experience high anxiety, limiting their ability to stay still during checkups or cleanings.

In recent years, more dental and medical schools have opened specialized clinics to train students on treating people with disabilities, Alam said. At Montefiore Medical, health professionals are working with patients and caregivers to emphasize the importance of personalized care for people with IDD.

"You have to understand the individual that's sitting in your (dental) chair, understand their background — meaning what they're able to do and what they're not able to do — what their oral hygiene routine is, what their diet might be," Alam told *The Nation's Health*.

For more information, visit www.aadmd.org. ■

— Mark Barna

Living with IDD profile: T.J. Gordon

Advocating for health at the intersection of race and IDD

BEING A PERSON OF COLOR in America comes with its own set of challenges in relation to achieving health and racial equity.

Those challenges are no different for people of color with intellectual and developmental disabilities such as Timotheus "T.J." Gordon, Jr., MFA, MS, a research associate at the University of Illinois at Chicago's Institute on Disability and Human Development.

Gordon, who has autism, co-founded the Chicagoland Disabled People of Color Coalition in 2018.

How has your coalition fought for disability justice?

From a disability justice standpoint, we help provide information on important advocacy topics but create more webinars, town halls and discussion meetings. We fought for maintaining community and support and dignity during the pandemic and civil unrest as a result of how the nation addresses police violence.

It was a time of fear, uncertainty and a lot of misinformation going around. Not only on COVID-19, but a lot of fear because of the violence and the result of how the nation is handling police violence.

So part of the disability justice in our work during that time period was to bring the disability community together to talk about disability and race. That's rarely discussed.

I would like to give a shoutout to the University of Illinois at Chicago's Institute on Disability and Human Development, because they provided us a lot of tools and resources they already have on various disability topics.

And we as a coalition translated the information into information about disability topics such as the right to work, exploring healthy relationships, sexuality and gender identity, identifying as a disabled

person, finding accommodations

for work and school and so much more.

What can health workers do better to support people of color with IDD?

Health workers should listen and understand people of color with disabilities, especially people of color with intellectual and developmental disabilities, and treat our wants and what we have to say with respect and know that no matter how much you may not understand, our wants and needs are valid.

When it comes to the intersection of race and IDDs, what do workers need to know?

Having the respect to listen to people from various cultures and try to understand what the person needs — not only from a human perspective but also a disability and racial-cultural-ethics standpoint as well — will go a long way. And also while listening, create supports that are disability and iden-

tity affirmative.

Let's take diabetes, for example. How can health workers not only create interventions that are beneficial to the person, but also does not fat shame, does not shame a person's culture, does not shame the person with an IDD?

How has being a person with an IDD led you to the work you do today?

From a personal standpoint, I became a career researcher advocate because, honestly, I don't know what life for people with autism looks like after between 21 and 30.

My pie-in-the-sky goal as a researcher advocate is to create opportunities for people like myself, especially BIPOC people with autism, to not only live and enjoy the life they want to experience, pursue the passion they want to pursue, but also find and ask and advocate for health supports that will get them through not only teenage years, college/transitional age, but also mid-30s, 40s and 50s, and 50 and beyond.

What do you want people to know about IDD?

If you want your community to be stronger, respect and nurture and support the talents of people with IDD.

Yes, we may need more supports. We may need more connections. But if you give us a chance to thrive, we will succeed not only for ourselves but for our communities too. ■

— Natalie McGill

This interview was edited for length and style.



Photo courtesy T.J. Gordon

T.J. Gordon, at left with megaphone, encourages health and medical professionals to "respect and nurture and support the talents of people with IDD."

IDD training programs benefit medically underserved population

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the Alliance for Disability in Health Care Education. If it does come up, it usually refers to disability as an adverse health outcome.

“It really does not honor the idea that people with disabilities and people with intellectual and developmental disabilities can have a very high quality of life, can be healthy, can live full lives, can participate in the community,” Bannister told *The Nation’s Health*. “The thing that is going to cause the most problems for them is the attitudes toward them and the lack of support and accommodation.”

This has led students to seek out training beyond their schools through disability advocacy organizations such as The Arc. There they learn important lessons such as the fact that non-verbal communication is still communication, and that knowing a patient’s baseline behavior is crucial when figuring out if something is amiss. Sometimes the lesson is as simple as acknowledging the patient in the room.

During his experience with Operation House Call, Michael Zhu Chen, a Harvard Medical School student, learned that doctors often ignore a patient with IDD and speak directly to

their caregiver.

“Whether they’re verbal or non-verbal or whether they can respond to questions in a fast way, or whether they need more time, ultimately they’re human beings and human beings are people who should be respected, particularly if they are the patient who the appointment is for,” Chen told *The Nation’s Health*.

Establishing that level of comfort is crucial, according to Shane Janick, MPH, executive director of The Arc of Philadelphia. Through SpArc, The Arc of Philadelphia’s affiliated home community-based service provider, health professional students spend at least two hours with participants in an adult day program administering lifestyle questionnaires on health behaviors and observing a health screening.

Students can help patients navigate the screening and get follow-up care. For example, if a patient reports not being able to hear out of one ear, a student will use that as a prompt and remind them to bring it up the next time they see a doctor.

“We’re trying to build

up those self-advocacy skills about managing one’s own health care for those patients,” Janick told *The Nation’s Health*.

Janick tells students about a 2021 *Health Affairs* study that found only about 41% of physicians were confident about their ability to give the same quality of care to people with disabilities as to patients who do not have them.

The statistic concerns Julianna Tolotta, a Thomas Jefferson University medical student

“There’s nothing like working with people who have disabilities and learning skills firsthand.”

— Julianna Tolotta

who worked with fellow students at her school’s American Academy of Developmental Medicine and Dentistry chapter to

partner with SpArc in 2023.

“Jefferson does teach about disabilities, and they do their best to incorporate it into our academic curriculum, but there’s nothing like working with people who have disabilities and learning skills firsthand,” Tolotta told *The Nation’s Health*.

For schools that are looking to develop their own curriculum, the Alliance for Disability in Health Care Education promotes a framework based on six core competencies, which covers areas such as clinical care over the lifespan and interdisciplinary care teams.

Bannister teaches a University of Oklahoma Health Sciences course where students work with adults with IDD who pose as patients.

Throughout the course, students work to respect patients’ choices while working with classmates from different disciplines to create a care plan.

“People say it really makes them think about listening to the patient and talking to the patient,” said Bannister, academic programs coordinator for



Photo by Jovanmandic, courtesy iStockphoto

Thanks to programs such as those offered through The Arc, health students are learning how to care for people with IDD.

the university’s Center for Learning and Leadership. “We also have people saying that their attitudes shift after the simulation and they see how people with intellectual and developmental disabilities can make health care decisions, but they may need additional supports.”

While experiential learning is essential, the health care system does not make it easy for recent graduates to help people with IDD, said Vanessa Rastovic, JD, disability health policy director for Achieva’s Disability Health Care Initiative. Achieva provides services, advocacy and resources for people with disabilities in Pennsylvania.

Many people with IDD are covered by Medicaid, and physicians often find they receive low reimbursement for their care, she said.

“In Pennsylvania, I know we do have a lot of difficulties and problems and a backlog of credentialing public health professionals to take public insurance,” Rastovic told *The Nation’s Health*. “I’m sure that a lot of states have similar problems. So providers end up running headlong into a lot of bureaucratic red tape and low reimbursement rates. We’re just not doing a good job supporting the health care professionals who want to do this.”

Advocates are calling on the Health Resources and Services Administration to designate people with IDD as a “medically underserved population,” which Rastovic said would provide additional federal

health care dollars to not only reimburse health care providers, but also train them in care for patients with IDD.

“Downstream, it could do a lot to reduce waiting times and make more practices inclusive,” she said.

Maura Sullivan, Operation House Call’s program director, said she is encouraged by some recent progress, such as the Commission on Dental Accreditation requiring all dental schools to train students on treating patients with IDD as of 2020, and a National Institutes of Health designation of people with disabilities as a population with health disparities in 2023.

“We’re hoping to see that medical schools maybe follow that lead and put in some required education,” Sullivan told *The Nation’s Health*. “Most of the students I meet now, they haven’t had exposure.”

For Sullivan, a mother of two children with autism, it is imperative that all health professional students receive training and learn directly from people with IDD.

“When you have responsive medical doctors and nurses, you don’t feel alone,” Sullivan said. “And even if they don’t know exactly what’s going on with your kid, just knowing that they care, that they’re listening, that they want you to communicate, that makes such a difference.”

For more information, visit www.operationhousecall.com. ■

— Natalie McGill





Photo by Bevan Goldswain, courtesy iStockphoto

An international initiative is gauging how well health workers and systems serve people with IDD.

Special Olympics to issue global report Initiative to assess ability of health systems to serve people with IDD

A NEW SPECIAL Olympics global research initiative aims to both reveal and close health care system gaps to better serve people with intellectual and developmental disabilities.

Special Olympics recently launched its Rosemary Collaboratory initiative, which tasks research teams with evaluating IDD inclusivity in health care systems in eight countries: Chinese Taipei, India, Ireland, Nigeria, Pakistan, Paraguay, South Africa and the U.S. In America, the work has a focus on Pennsylvania, Washington state and Wisconsin.

IDD inclusivity is important because there are barriers at all levels for people with IDD, said Dimitri Christakis, MD, MPH, chief health officer for Special Olympics. Barriers range from physicians who never received training in medical school, to health care facilities that are not designed with patient sensory issues in mind.

“The reality is that people with IDD live 12 to 20 years less than people without IDD, so there are real consequences of getting inadequate health care or poor health care,” Christakis told *The Nation’s Health*.

Researchers will evaluate health systems using an assessment from the Missing Billion Initiative, an international effort to transform data and research on disability inclusion into advocacy and innovative programs to reduce health inequity.

Health systems will be scored on IDD inclusivity across multiple areas such as health care affordability, health professional training and health financing. The assessment will also determine if physicians are adequately reimbursed for treating patients with IDD.

Christakis said health financing is particularly important because health care providers are typically not reimbursed for care of people with IDD at the same rates as when caring for people without IDD, which could lead them to hesitate about taking them on as patients.

“You have to speak more slowly, you have to make sure they understand what you’re saying,” Christakis said. “You might have to make other accommodations. The reality is caring for someone with IDD is going to take longer than caring for someone without IDD. And that should be reflected in reimbursement.”

The initiative adjusted and added indicators to its existing system-level assessment on disability inclusion after consulting with IDD experts from countries such as South Africa, England and the U.S.

Findings from the initiative will be shared in a global report on the health of people with IDD that Special Olympics plans to launch in 2025. For more on the Rosemary Collaboratory, visit www.specialolympics.org. ■

— Natalie McGill

Living with IDD profile: Pauline Bosma

Bringing a voice to people with IDD in the LGBTQ+ community

PAULINE BOSMA is the founder and coordinator of the Rainbow Support Groups, a network for self-advocates who are members of both the intellectual and developmental disability community and LGBTQ+ community.

Bosma, who works for Massachusetts Advocates Standing Strong, identifies as a transgender woman who is labeled with an intellectual disability.

What inspired you to start the Rainbow Support Groups in 2004?

What convinced me to start them was my personal search for resources for people that identified as LGBTQ+ and also had IDD. I also started the Rainbow Support Groups to educate other people about LGBTQ+ people who have IDD.

We all need support and knowledge about what sexuality and gender is, and what they are in our lives. People with IDD are not given sexual education in schools. Most people with IDD learn about sexual education either from TV, movies or media in general.

Another reason why I did it was to give people a safe environment to talk about LGBTQ+ and IDD without being put down — to be able to have a voice on their own.

What part of your work are you most proud of?

I took a course on how to be a better leader through Leadership Series, and that made me the leader I am now.

But what I’m proud of over the past 20 years is that I have taught and talked to people all over the U.S. and other countries. I learned that people with disabilities don’t get the support and help they need when they identify as LGBTQ+ and IDD.

I’m proud that I didn’t

give up on my quest to support others. Some of the other things I’m proud of are the Rainbowguidebook.com that I created with two colleagues of mine, and I gave input on a curriculum called Awareness and Action, which helps people report abuse and provides peer-to-peer training.

What would you like to tell health care professionals so that they can do a better job supporting your community?

The biggest thing is when doctors talk to staff about the patient, and not the patient themselves. They should talk to the patient, ask them how they feel and what they want the doctors to do.

My primary doctor is very helpful and honest when I’m talking to her

“Be truthful and honest with us, regardless of our disabilities, because all of our disabilities are different. It’s important to recognize that we all should be respected equally.”

— Pauline Bosma

What can the overall community do to better support LGBTQ+ people with IDD?

Be kind, be caring and look us in the eye. And be truthful and honest with us, regardless of our disabilities, because all of our disabilities are different. It’s important to recognize that we all should be respected equally. ■

— Teddi Nicolaus

This interview was edited for length and style.



Photo courtesy Pauline Bosma

Pauline Bosma advocates to give people with IDD who are gender or sexual minorities an open environment where sexuality is part of the conversation.

Physicians say they feel less confident in caring for people with IDD

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about 700 practicing U.S. physicians, more than 82% of whom said that people with significant disability have worse quality of life than people without a disability. Only about 41% of the physicians said they were very confident in their ability to provide the same quality of care to patients with a disability.

Less than 57% of the physicians strongly agreed that they welcomed patients with disabilities into their practices.

“Some (clinicians) just truly don’t believe that some people with disabilities have a quality of life that’s worth continuing,” said Margaret Nygren, EdD, executive director and CEO of the American Association on Intellectual and Developmental Disabilities. “Sadly, it’s still prevalent in the medical field — shockingly so.”

Nygren said the biggest issues people with IDD face in taking care of their

health are access and attitudes. She noted that access is deeply intertwined with Medicaid, which provides over 75% of the funding for services for people with IDD.

When health interventions prioritize people with disabilities, better outcomes can follow, she said. For example, a 2021 report from the U.S. Department of Health and Human Services showed that prioritizing people with IDD for vaccination during the COVID-19 pandemic led to high immunization rates among that population.

A number of efforts are aimed at training health providers to better care for people with IDD and recognize their own biases. Hoenig, in Iowa, co-leads a program designed for medical and health professions students at the University of Iowa. The curriculum — now in use for almost 20 years — includes lectures during the first year of medical school and a chance to practice new skills in a staged clinical

encounter with people with IDD during the third year.

Hoenig said the training addresses many of his own health care experiences, such as poor communication and providers who assume people with IDD cannot make their own medical decisions.

When Hoenig was diagnosed with cancer about a decade ago, he wanted to bring a friend to his medical appointments for emotional support. But he was worried providers would assume the friend was there to speak for him, as had happened in the past. So he often went alone.

“Overall, what we hear most is that students realize that people with disabilities are people first and much more similar to them than they are different,” Hoenig said about the training.

The Iowa effort used to receive funding from the Centers for Disease Control and Prevention, which has supported a variety of projects aimed at closing health inequities among people with IDD.

“People with disabilities, including people with IDD, need public health programs for the same reasons anyone does — to be healthy, active and part of the community,” JoAnn Thierry, PhD, with CDC’s National Center on Birth Defects and Developmental Disabilities, told *The Nation’s Health*.

Many of CDC’s efforts focus on policy, systems and environmental changes that integrate the inclusion of people with IDD into community decision-making. Such changes can be more sustainable and impactful over the long term and reach more people, said Karma Edwards, MSPH, a public health consultant at the Center for Advancing Healthy Communities at the National Association of Chronic Disease Directors.

NACDD led a CDC-supported national pilot project — Reaching People with Disabilities through Healthy Communities — that funded five states and 10 communities to make inclusive changes at the local level. An overarching goal was “changing norms and culture around disability and inclusion,” Edwards said.



Photo by Alex Potemkin, courtesy iStockphoto

People with IDD can face problems accessing care and negative attitudes when interfacing with U.S. health systems.

Overall, the five-year pilot led to more than 600 inclusive policy, systems and environmental changes, according to Edwards. A majority were related to improving built environments to facilitate access to health-promoting public spaces, such as parks and playgrounds. Some specific examples include public wheelchair charging stations, inclusive maps and signage at parks, and auditory beacons at crosswalks.

“There’s a big difference between something that’s ADA-compliant and something that’s fully inclusive,” Edwards said.

Empowering people with IDD with skills to advocate for their own health is also key, said Celina Urquidez, MPH, education and training senior coordinator at the University of Arizona’s Sonoran Center for Excellence in Disabilities.

Last year, the center debuted “How to Speak Up for Your Health,” which includes more than two dozen videos featuring people with IDD discussing their personal experiences and tips for navigating health systems. The program also has a toolkit, available in English and Spanish, to help people with IDD prepare for medical visits.

“It’s not often we hear from people with disabilities about what’s really happening in health care settings, so it’s very powerful,” Urquidez said.

The center is also hoping to reach public health workers, Urquidez said. In March, it debuted a free, online continuing education course especially for

public health professionals that teaches skills needed to equitably serve and include people with IDD.

“We really want to get at the root of people’s experiences,” Urquidez said.

One root underpinning health for people with IDD is funding for Medicaid community- and home-based services, which enable people to stay as independent as possible. The services — which help with everyday activities such as bathing, preparing food and transportation — were designed as an alternative to institutional care, but are not actual mandates of the Medicaid program, said David Goldfarb, JD, director of long-term supports and services policy at The Arc.

The result, he said, is long waiting lists for services, low reimbursement rates for home health workers, and people going without needed care. As of 2023, according to the Kaiser Family Foundation, almost 700,000 Americans were on waiting lists for Medicaid home- and community-based services, which can cost hundreds of thousands of dollars out of pocket. People with IDD accounted for nearly three-quarters of those on the lists.

Goldfarb said more Medicaid dollars are critical to sustaining and improving health for people with IDD.

“The foundation of independence starts with these services,” he said.

For more information, visit www.thearc.org or <https://sonorancenter.arizona.edu>. ■

— Kim Krisberg

Medicaid reimbursement lags for workers Health advocacy can help improve access to care for people with IDD

PUBLIC HEALTH professionals know the value of advocacy and how it can transform health outcomes, especially for marginalized populations. Among those that can benefit from the work are people with intellectual and developmental disabilities. For several years, Congress has failed to provide adequate funding to meet the needs of the disability community, speakers at a legislative seminar in April in Washington, D.C., said. The failures are exacerbated by threats of government shutdown and budget cuts to programs that help people with disabilities.

Programs most impacted by funding inadequacies include those authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, the Individuals with Disabilities Education Act, the Assistive Technology Act, the Autism Cares Act and the Lifespan Respite Care Act. Advocates hope to change the pattern by advancing legislative priorities that improve funding and care for people with disabilities.

One particular area of concern is Medicaid. Many people with IDD are eligible for long-term services and support through the program. But direct service providers — who provide care and assistance for people with disabilities — say they cannot retain workers because of inadequate pay. The situation has become more dire since the end of the emergency phase of the COVID-

19 pandemic. Additional Medicaid funding made available during the pandemic's height ended last year, causing concern among direct service providers that the demand for care will not be met.

The Home and Community-Based Services Relief Act would provide dedicated Medicaid funds to states to stabilize home and local services for people who are disabled, including those with IDD, and retain and recruit care workers. Without the option of home and community care for people with IDD, some people are unnecessarily institutionalized, while others must rely on unpaid family care.

Another important bill is the Better Care, Better Jobs Act, which would expand home and community-based services for older adults, injured workers and people with disabilities while also increasing Medicaid reimbursement. The bill would improve access to quality care and lead to better pay and benefits for direct service professionals.

As people with IDD struggle under the same determinants of health that the public health workforce addresses, it is imperative that the population is included in conversations related to health equity. It is also important that their voice and experiences are at the center of decisions being made and policies being passed. ■

— Lawrence Haynes

Haynes, MA, is program manager for racial equity within APHA's Center for Public Health Policy.



Photo by SerrNovik, courtesy iStockphoto

Several bills in Congress would improve health care and Medicaid coverage for people with intellectual disabilities.

Living with IDD profile: University of Montana's Connie Lewis

Helping people with IDD gain confidence, find independence, communicate more effectively

CONNIE LEWIS works as an administrative assistant at the University of Montana's Rural Institute for Inclusive Communities. Lewis is actively engaged in the IDD community and serves as a member of APHA's IDD Advisory Board.

What do you enjoy doing in your personal time?

Gardening. I do cauliflower, broccoli, cabbage, carrots, beans and peas. I like to hand sew or crochet. I like to go out to the stores to see if there's something I might be interested in buying. I like to read. I'm reading a book that's called "Surviving Change."

What are some tasks you perform in your roles?

I work on the photocopier and I answer the phones. I can put packets together and mail them out. I sort our regular mail and put it in people's mailboxes so they can get their mail for the day. There are times when I clean the microwaves or the tabletops. I've helped out with some other projects across campus by signing people in. I also help with writing things in plain language.

I have a second job at Summit Independent Living. They help people with disabilities to become more independent. I'm a part of the peer group that gets to gather by Zoom once a month.

What are common misunderstandings about people with IDD?

I don't think that people understand me very well. Maybe it's the way that I say things to them. Or maybe they're not quite relating to what I am try-



Photo courtesy Connie Lewis

Lewis, left, works with Emily Coyle, a doctoral candidate in the School of Public Health and Community Health Sciences, to make plain language edits to a survey on wildfire smoke.

ing to get out.

I know that there are probably some folks out there who thought it

“Having things in plain language doesn't only help people with IDD or people with disabilities; it might help somebody else out who doesn't have a disability.”

— Connie Lewis

wasn't possible to get a driver's license. But I was able to get my driver's license a long time ago. This year I was able to get a new car.

How can spaces be welcoming to people

with IDD?

A welcoming place would be a nice, peaceful place. An unwelcoming would be a place with a lot of violence or things like that.

I've been to restaurants where the doors should be automatic for people to get in to make it more accessible. Staff members at different jobs should have training to know how to work with somebody with an IDD or a person with a disability. It's also important to have people with IDD as staff on the job.

I think that having

things in plain language doesn't only help people with IDD or people with disabilities; it might help somebody else out who doesn't have a disability.

What advice do you have for health care workers when working with people with IDD?

It is important if they have good questions if they need to ask a person like me or somebody else with IDD. I might not be sure what they need to know. They should try to understand the diversity that they're working with and understand what they're asking about.

Why is it important to include people with IDD in discussions about health care?

So people are able to advocate for themselves in health care and speak up for themselves. I think it helps people to become a little more independent instead of

being isolated. There are people out there who have been isolated before. It's nice to be out and trained to be independent. ■

— Sophia Meador

This interview was edited for length and style.



Photo courtesy Connie Lewis

Lewis, in her office at the University of Montana, is part of APHA's IDD Advisory Board.

Working toward equity and inclusion in health for all

ASHLEY GLEARS, who works at The Arc of the United States, advocates for the equity and inclusion of people with intellectual and developmental disabilities. Glears, who was diagnosed with mild cerebral palsy at birth, is part of the IDD community and serves on APHA's IDD Advisory Board.

What do you do at The Arc, and what initiatives does the organization have?

I'm the chapter associate and co-leader of the access, equity and inclusion team at The Arc of the United States. My role supports over 500 chapters

across our organization to ensure that each chapter operates in alignment with the overarching mission, core values, guiding principles and position statements of The Arc.

We have initiatives like education, transportation and criminal justice. We also have community integration opportunities for people with disabilities. We focus heavily on policy.

What are common health issues for people with IDD?

Communication difficulties pose significant challenges, making it harder for individuals with IDD to express their needs and understand medical information, leading to potential misdiagnosis.

Sensory impairments, epilepsy and mental health disorders are also prevalent among individuals with IDD. Some people with disabilities have a dual diagnosis. They might have mental health issues as well.

People might have cerebral palsy and anxiety, or cerebral palsy and depression. So there's overlap with health issues.

What are some additional barriers to health care?

The lack of equipment in the facilities to help the people with disabilities. Specifically, ramps or elevators. I just came from a facility yesterday where the door was super heavy, so I couldn't open it.

Transportation is so big. Limited transportation can make it hard for people with disabilities to move around because they rely on public transportation so much. I know

I do. This leads to financial constraints as well. It can make it difficult to travel to appointments, or anywhere in the community.

Stigma and discrimination within the health care system can lead to negative experiences for individuals with IDD. Inadequate training for health care providers on working with individuals with IDD further hinders access to quality health care.

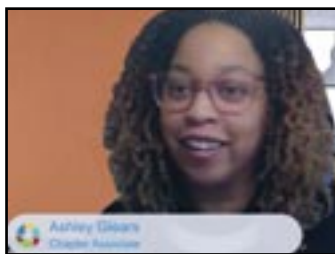
How can health care providers support the IDD community?

We could all raise awareness or go to educational trainings to understand people with disabilities as a whole. We could also support organizations that help people with disabilities as well by going to panels and public health week. That's a win-win for sure.

I want to emphasize the importance in really looking into the intersectionality of people. Recognizing that people have different identities like gender, sexuality and disability. Really understand the person to dismantle barriers for us all. That's how we create equity, access and inclusion, particularly health equity for all. ■

— Sophia Meador

This interview was edited for length and style.



Glears, who advocates for people with IDD, speaks during an APHA event in April.

More research, accurate diagnoses needed for IDD population

Dementia rates higher among people with Down syndrome, but condition may be missed in others

THE U.S. HEALTH CARE SYSTEM must do better at screening people with intellectual and developmental disabilities for dementia, especially as some members of the population are at higher risk.

Dementia is defined by a progressive loss of thinking, memory and decision-making skills, the most common form being Alzheimer's disease. Most research and professional education about IDD and dementia centers around people with Down syndrome, as that population is more likely to develop the condition, according to Kathleen Bishop, PhD, MS, a board member of the National Task Group on Intellectual Disabilities and Dementia Practices.

People with Down syndrome are born with a third copy, rather than a pair, of chromosome 21. The chromosome is responsible for the body's production of amyloid beta, a protein responsible for brain plaques that have been linked to Alzheimer's disease.

"People with Down syndrome have an increased production of (the protein) over a lifetime," Bishop told *The Nation's Health*. "It has been found even in teenagers and young adults and could be even earlier."

While dementia prevalence is higher in people with Down syndrome, the overall prevalence of dementia among older adults with IDD mirrors the general population's, according to the task group. Yet research is lacking on dementia rates for other forms of IDD, such as autism, Bishop said.

Getting an accurate diagnosis can be difficult for people with IDD, as most specialists who work with the population focus on children, said Kathryn Service, RN, MS, FNP-BC, a task group board member who facilitates an online support group for families living with someone who has an intellectual disability and dementia. Today, people with Down syndrome live well into their 60s — much longer than they did decades ago.

"With appropriate services, adults with intellectual disabilities affected by dementia can continue to live quality lives in community settings," according to the task group.

To encourage health workers to be more proactive about monitoring brain health in people with IDD, the Gerontological Society of America released a new toolkit this year.

"Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities" follows the society's "KAER" model, which stands for kickstarting brain health conversations, assessing for cognitive impairment, evaluating for dementia and referring to community resources.

"We don't have enough geriatricians and people who really understand the unique needs of older adults, nor do we have enough who understand the unique needs of people with intellectual and developmental disabilities," said Jen Pettis, MS, RN, CNE, the society's director of strategic

alliances. "We want to give you an actionable framework. Even if you're someone in primary care or in a busy clinic, you can use those tools and resources to drive improved care and improved outcomes for older adults."

The toolkit highlights the importance of educating support staff at residential facilities on dementia care, and linking families with resources

"With appropriate services, adults with intellectual disabilities affected by dementia can continue to live quality lives in community settings."

— National task group

such as state developmental disability agencies and local aging support groups after a diagnosis. The resources help with developing long-term

care plans that address a person's medications, future living arrangements, advance directives and help for aging caregivers as their loved one's dementia progresses.

It also recommends screenings, such as the task group's tool for Early Detection and Screening for Dementia. Caregivers can use it to give health care professionals a record of a patient's background information, such as medications, language, sleep patterns and mental health changes.

For more information, visit <https://gsaenrich.geron.org/brain-health>. ■

— Natalie McGill



Photo by Halfpoint, courtesy iStockphoto

People with Down syndrome are living longer, healthier and more active lives compared to decades ago.