

# National Leadership Consortium **Bulletin**

Leading the Way  
Toward Health Equity

**NATIONAL  
LEADERSHIP  
CONSORTIUM**



ON DEVELOPMENTAL DISABILITIES

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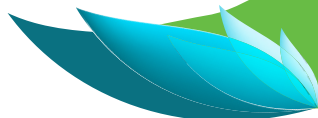
## About the Bulletin

The National Leadership Consortium Bulletin is a free, web-based publication dedicated to providing relevant, trustworthy, and thought-provoking information to leaders, practitioners, and people with disabilities and their families involved in the field of developmental disabilities support services. The Bulletin will serve as a bridge between scientific journals and day-to-day leadership, exploring timely research and policy issues in the leadership and disabilities fields with the aim of promoting organizational change and assisting leaders to support people with disabilities to experience inclusive, valuable, and meaningful lives.

## About the National Leadership Consortium

### Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.



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# Introduction: Leading the Way Toward Health Equity

This issue of the Bulletin, Leading the Way Toward Health Equity, comes as we start off a new year. As such, what better topic to explore than health and healthcare. It seems each year millions of people vow to ‘be healthier’ in the new year. To each that may mean something different but often it is accompanied by the knowledge that they have access to educated and helpful medical professionals and effective services and supports to achieve this goal. When we look at the research, we find that for people with intellectual and developmental disabilities, this is not often the case.

“People with intellectual disabilities report difficulty finding appropriately trained and willing healthcare providers.” Far too often, the medical system becomes a barrier to health and well-being. It can hold people back from achieving personal goals and living a full life. Systemic, societal, and attitudinal barriers and barriers related to other disparity groups can lead to a lack of health equity for people with intellectual and developmental disabilities. In this Issue, contributors explore the many complex facets of barriers to health equity and highlight some of the bright spots related to innovations and initiatives aimed at combating this inequity.

To understand how we got to where we are now, we need to first look to the past. Dr. Rick Rader and Steve Eidelman explore the history of health for people with intellectual and developmental disabilities and the rise and fall of the Medical model. They share how the Medical Model came to be and why it is so critical that we keep moving away from that model towards an Inclusive Health Model. To move to a more equitable health system, we need to first understand what leads to health disparities. Cory Gilden shares research on what contributes to these health disparities and what service providers can do to help, including better education and understanding what most impacts health outcomes.

One very recent and widespread challenge in healthcare access and equity relates to COVID. During the pandemic and still, people with intellectual and developmental disabilities face challenges accessing health services and even once accessed, challenges in diagnosis and treatment. Nicole LeBlanc shares her, and others, experience in this and provides strategies for improving quality healthcare for all. Upon considering the slow rate of improvement in the quality of healthcare for people with intellectual and developmental disabilities, it may be worth considering a new model. David Ervin, Executive Director at Makom, highlights how an interdisciplinary team at his organization is doing just that. This work aims to consider new ways of delivering healthcare and improving health outcomes.

Research shows us that there are key factors that impact our health called social determinants of health. Carli Friedman expands on research she has conducted to outline why understanding and focusing on social determinants of health may lead to opportunities to improve health outcomes for people with intellectual and developmental disabilities. Looking beyond the person to other determinants of health can also lead to consideration of mental health. Jeanne Farr of NADD shares a bit about the impacts of dual diagnosis on health outcomes and support, and how NADD and other national organizations are working to towards more ethical and effective mental health supports for those who need them. Lastly, James Meadours offers his thoughts and experiences around improving care for sexual assault survivors with developmental disabilities and how survivors of sexual violence and advocates with disabilities should be and are leading efforts in support and overcoming trauma.

As you read through this latest issue, we hope you better understand the movements and models that brought us to where we are now, the current quality of healthcare for many people with intellectual and developmental disabilities, and the many ways that we can work to improve access to and quality of healthcare, supports, and services.

*Kristen Loomis Greenidge*

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# The Rise and Fall of the Medical Model and its Transformation to the Inclusive Health Model

*By Rick Rader and Steven Eidelman*

*This article uses language that deviates from this publication's standard of using APA inclusive language guidelines. While the language in the article is used to illustrate the evolution of perceptions about and labels for disabilities and is historically accurate, it may be unintentionally offensive or triggering.*

- The Inclusive Health Model focuses on the inclusion of all, including people with intellectual and developmental disabilities, in health, medical, and dental policies, procedures, research, trainings, and services.
- The Inclusive Health Model is an evolution of the Social Model and the Medical Model.
- Throughout time, understanding of disabilities and societal and medical views of disability and people with intellectual and developmental disabilities changed, starting from a place of wanting to understand, to wanting to treat and 'fix', to recognizing that proper healthcare can be a powerful tool towards self-determination and inclusion.

During the Age of Antiquity and the Middle Ages (late 5<sup>th</sup> to the late 15<sup>th</sup> centuries) people with disabilities were a highly visible presence in everyday life. There were many old English terms to describe them: the "lepre," the "blynde," the "dumbe," "the deaf," the "natural fool," the "creple," the "lame," and the "lunatic."

In the past, when parents gave birth to children with disabilities they were naturally puzzled. They desperately wanted to know (as do parents today) the "why," the "how," and the "needs" to care for them and to protect them. In search of the answers to these puzzles, they didn't ask the politicians, the lawyers, the generals, the musicians, the alchemists, the poets, or the merchants. They went to the physicians. And the physicians did what they did (and continue to do) — they observed them, they described them, they studied them, they discussed them, they treated them, and they cared for them. Medicine at the time offered little as a science. Treatments included potions, incantations, bleeding, cupping, and leeching. Centuries before the idea that diseases were caused by pathogens, the theories included the belief that diseases and disabilities were caused by demons, sin, bad smells, astrology, stagnant water, and an imbalance of liquids in the body.

Throughout history, people with disabilities, especially people with intellectual and developmental disabilities (IDD), were devalued by society. They were mistreated, neglected, stigmatized, isolated, and harmed. In order for society to justify their inhumane treatment, they were assigned "social roles" which depicted them as subhuman. They were identified and labeled as "menaces," "burdens," "pitiful," "defective," "holy innocents," and "uneducable." The stigma served as a license for their mistreatment. The general exclusion of people with IDD from mainstream society often meant that many physicians had little or no experience working with people with IDD in their medical training.

Clinicians created and promoted the use of specific descriptive terms and labels. Depending on the level of disability, they were classified as "morons," "idiots," "imbeciles," "feeble-minded" and "mentally deficient." At that time, the terms were not considered derogatory, defamatory, or insulting; they were based on measured capacity, limitations, and functionality. These terms were not intended to be disparaging or belittling; the intention was to inform other clinicians as to the baseline of individuals they were treating or referring. The terms had a "shelf-life" of about 20 years until pop

culture hijacked the terms and used them in negative contexts towards people who did not have an intellectual disability but might have been socially awkward, unattractive, physically impaired, or even shy, modest, or diffident. Society, and not physicians, contributed to the negative perceptions of people with cognitive challenges.

The impact of terminology and the transformation of the acceptance of people with intellectual and developmental disabilities can be illustrated through the evolution of the American Association on Intellectual and Developmental Disabilities (AAIDD), one of the country's most respected and influential organizations dedicated to promoting the total inclusion of this population. AAIDD was founded in 1876 and its first president was the French physician Édouard Séguin, MD, regarded by many as the father of special education in U.S. The original name of the organization was the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons. Throughout its history, the name changed in 1906: American Association for the Study of the Feeble-minded, 1933: American Association on Mental Deficiency, 1987: American Association on Mental Retardation, and finally, in 2007: American Association on Intellectual and Developmental Disabilities; and remains named that ... for now. The name changes were not cosmetic but rather reflected society's view of people with IDD.

It is also noteworthy that for many decades the presidents of the association were all medical professionals. This reflected both the willingness and influence of the medical profession and the early need to establish a basic clinical understanding of the complex needs of people with IDD. Mainstream society, including education, training, and inclusion did not play a significant role until a new age of social acceptance changed our thinking after an additional 75 years.

The so-called '[Medical Model](#)' has been described as "viewing disability as a defect within the individual. Disability is an aberration compared to typical traits and characteristics. To have a high quality of life, these defects must be cured, fixed, or eliminated." The Medical Model saw the person as a 'patient,' and saw 'disability' as a defect. There is no doubt that the Medical Model was, in part, responsible for increasing the longevity of people with intellectual and developmental disabilities as it compelled the introduction of many health and medical interventions for people with disabilities. In addition to societal changes inspired by advocacy and advancing perceptions, extended lifespans created the need, the opportunity, and the imperative to begin to view people with IDD beyond the clinical perspective and to appreciate them as individuals with unrealized and unattained potential.

The newer '[Social Model](#)' viewed disability "as the inability to participate fully in home and community life. The Social Model distinguishes between disabilities and impairments. Disabilities are restrictions imposed by society. Impairments are the effects of any given condition. The solution, according to this model, lies not in fixing the person, but in changing our society. Medical care should focus on enhancing our daily function in society."

By taking the best tenets of medical care and optimizing opportunities for the full inclusion of the individual in their community setting, we have seen the genesis of the 'Inclusive Health Model.' This has resulted in its recognition as the current 'best practice.' It is a blueprint that has been shown by research and experience to produce optimal results and that is established or proposed as a standard suitable for widespread adoption.

The 'Inclusive Health Model' grew out of the 'biopsychosocial' model of healthcare; a belief and appreciation that illness, health, and disability are the result of an interaction between biological, psychological, and social factors. There is an understanding that to achieve one's personal goals there needs to be a platform of health and wellness. People need stamina, a positive outlook, confidence, self-esteem, and the ability to process sensory surroundings to reach their fullest potential across the



lifespan. The '[Inclusive Health Model](#)' views 'wellness' as the vehicle to achieve all the aspirational endeavors that people have dreamed they could achieve. The 'Inclusive Health Model' is a tribute to the tireless efforts of countless physicians, educators, researchers, advocates, reformers, visionaries, families, and change agents who strived for self-determination, inclusion, autonomy, and independence.

We call for increased training and support of physicians about intellectual and developmental disabilities. Physicians and dentists, among other health professionals, are a vital component of inclusion of people with IDD and their families into life, for everyone, in our communities. We have come far and have farther to go. The medical community needs to be a part of the journey. We are a long way from the days of a medical model. The National Council on Disability, in a [July 2021 letter](#) to the Accreditation Council on Graduate Medical Education wrote, "There is robust literature from the United States Surgeon General, the Center for Disease Control and Prevention, the National Institutes of Health, the National Academies of Science, Engineering and Medicine, and leading healthcare institutions and researchers, that acknowledges and confirms the statistically significant sub-optimal treatment for this vulnerable patient population in the healthcare sector. While there is a myriad of contributing factors involved in the health disparities in patients with disabilities (*e.g.*, access, stigma, reimbursement, transportation, economics, and environment), one of the main identified factors is the lack of physician training in the assessment, management, and treatment of patients with disabilities. This lack of training is a noted deficit in both graduate medical education as well as post-graduate clinical training in residency and fellowship programs..." Hard to imagine anything clearer than this.

And the [leadership in the dental profession](#) is on board as well, saying, "The American Dental Association is taking steps to help dentists better care for patients with intellectual and developmental disabilities, including by collaborating with the American Academy of Developmental Medicine & Dentistry (AADMD) and the American Medical Association."

The 'Medical Model' is in the rear-view mirror and going forward, inclusion in our communities must embrace inclusive physical health and oral healthcare.

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# Health Equity: A New Approach by Makom

By David Ervin

- People with intellectual and/or developmental disabilities (IDD) often cannot get culturally responsive, relevant healthcare that can lead to better health.
- Over the past several decades, there has been slow progress in developing healthcare options for people with IDD.
- A new approach to a healthcare delivery system in the Washington, D.C. metro area promises to improve health equity for people with IDD.

In 2002, then-United States Surgeon General, Dr. David Satcher observed in [a report on health disparities](#) that even as our system of healthcare for people with intellectual and/or developmental disabilities (IDD) has evolved, our attention to their health has lessened. He went on to note that the “glaring deficiencies” must be addressed and that people with IDD, their families, and others who support them “[live and struggle every day with the wide spectrum of issues that affect the health of these individuals.](#)”

In 2015, the Research and Training Center on Community Living at the University of Minnesota, the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago, the Rehabilitation Research and Training Center on Advancing Employment for Individuals With Intellectual and Developmental Disabilities at the University of Massachusetts-Boston, the American Association on Intellectual and Developmental Disabilities (AAIDD), the Association of University Centers on Disability (AUCD), and The Arc of the United States hosted the *National Goals in Research, Practice, and Policy Conference* to bring stakeholders together and create national goals. From the Health and Wellness strand of that conference, [recommendations were published](#) to spur “[considerable work \[that\] remains to ensure the best health outcomes for people with IDD and their supports.](#)”



Beginning in 2020 and over the two years that followed, the world endured the deadly COVID-19 pandemic. No community of people was more significantly impacted by COVID-19 than people with IDD, with substantially higher disproportionate morbidity and mortality rates from COVID-19 infection. The pandemic, and its impact on people with IDD, is a stark reminder that we have significant work still to do to address health and healthcare that is accessible and culturally relevant to people with IDD. While there has been important progress made since Dr. Satcher’s 2002 report, there remains much to do.

In May 2022, to address the health and healthcare needs of people with IDD in and around the District of Columbia metropolitan area and Virginia, Makom, a Home and Community Based Services (HCBS) provider in Rockville, Maryland, convened the first-of-its-kind for the region Health Equity Summit in May of 2022. The summit gathered 21 local, regional and national health policy experts, healthcare providers, and practitioners with experience delivering healthcare to people with IDD, self-advocates

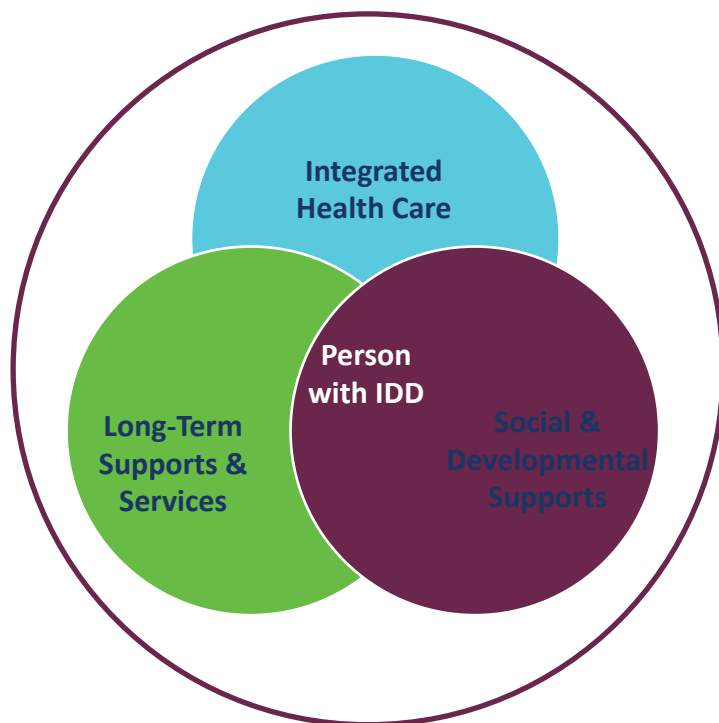
(including Nicole LeBlanc, who offers us a glimpse into her experience of the healthcare system during the COVID-19 pandemic in “Challenges Faced by Adults with Autism and Other Disabilities When Navigating the Healthcare System During a Pandemic,” also in this issue of the Bulletin), family members, and others, over two days with two purposes: 1) Conceptualize a healthcare delivery system that provides comprehensive healthcare (including integrated dental care, mental and behavioral health, and specialty care) and wellness to people with IDD, and is a national center of excellence in clinical training for health profession students and other practitioners in developmental medicine and dentistry, and 2) Design a workplan to build such a system. (Information in greater detail on the summit can be found in the *Proceedings of the Inaugural Health Equity Summit: Developing a Model of Healthcare for People with Intellectual and/or Developmental Disabilities in the Washington, DC Metropolitan Region* [Part 1](#) and [Part 2](#).)



Since the summit, Makom has continued in its role as the project’s convener. The healthcare system conceptualized through the summit is ostensibly a healthcare collaborative clinic in which multiple stakeholders — physicians, dentists and other health professionals, hospitals, academic medicine and dentistry, research institutions, and government — come together in common cause and purpose to identify gaps in healthcare for people with IDD and develop solutions to improve their care. The clinic is designed on a [series of formal partnerships among a number of entities](#), with partners sharing information on a common electronic medical record, identifying gaps in performance, and developing solutions to improve care to deliver better outcomes, improving processes, and share financial risk and reward. To date, a number of essential partnerships have been formally created in support of developing the envisioned clinic.

Partnerships confirmed or in progress include Georgetown University School of Medicine, University of Maryland School of Dentistry, the Kennedy Krieger Institute/Maryland Center for Developmental Disabilities (Maryland’s University Center of Excellence in Developmental Disabilities, or UCEDD), the Maryland Developmental Disabilities Council, and more. Among critical partnerships being explored and mapped currently are major providers in academic medicine, research institutions, and state and federal government entities in the public health insurance space. Ultimately, it is expected that this robust collaborative clinic will operate under a single governance structure that defines partners’ roles and contributions, as well as outlines how major system decisions will be handled.

The clinic is envisioned as an interprofessional collaborative, [medical home model](#). Makom has proposed a managed care capitation- and value-based reimbursement platform for the model to the Maryland Department of Health to leverage care management resources to integrate systems of care (i.e., healthcare, HCBS/long term services and supports, and natural supports that comprise each person's social capital—see the figure, below). At this writing, the clinic is expected to be operational by Summer 2025.



There is no debating the longstanding, disproportionately poorer health status experienced by people with IDD. And, more than 22 years after Dr. Satcher laid glaring deficiencies in access to and the quality of healthcare for people with IDD, too few sustainable models of accessible, culturally relevant healthcare have been developed. In the Washington, DC metropolitan area area, there are none. Informed by the convening of a novel community planning Health Equity Summit, Makom is leading the development of a clinic to address this need. People with IDD deserve nothing less.

**David A. Ervin, BSC, MA, FAAIDD**, is CEO for Makom, with more than 36 years professional experience working alongside people with intellectual and/or developmental disabilities. He is a 'pracademician,' with research interests in health and healthcare and people with IDD and is extensively published. He is regarded as a content expert in organization development and transformation, and in developmental health and healthcare. Contact David at [dervin@makomlife.org](mailto:dervin@makomlife.org).



# Challenges Faced by Adults with Autism and Other Disabilities When Navigating the Healthcare System During a Pandemic

*By Nicole Leblanc*

- Getting good healthcare, like getting tested and treated for COVID-19, is often harder for people with IDD.
- Long COVID is more likely to happen in people with autism, neurodiverse people, and other people with IDD who may experience worse COVID-19 symptoms than other people.
- Some ways to improve quality healthcare for people with IDD are to train doctors and Direct Support Professionals to better help people with IDD, and to support preventative healthcare, such as gym memberships and healthy lifestyles.

People with Autism Spectrum Disorder (ASD) and other developmental disabilities face numerous access and attitudinal barriers in navigating the U.S. healthcare system. The insurance reimbursement system is not set up to accommodate the extra support needs in caring for this population. Over the last three years I have seen how the COVID-19 pandemic has exposed how ableist and negative attitudes lead to less than desirable outcomes. In the area of accessibility, the pandemic exposed the need to make online websites more accessible. For instance, while telehealth is nice, convenient, and saves time and money in transit cost for patients, we still have a way to go in making easy, user-friendly platforms. Another example of this is that many of the vaccine registration platforms need to be more accessible or user friendly. The recent COVID-19 pandemic has highlighted issues many people with disabilities face when trying to get medical care.

The tests and doctor visits that are necessary when COVID-19 is suspected can be really difficult for someone with ASD. COVID-19 tests are not user friendly or easy to administer without staff support. This is a major challenge for the many of us in the autism world who don't get Home and Community Based Services (HCBS) support. In addition, getting doctors to accommodate our need for them to help administer these tests can be very difficult especially when they ask interrogating questions. In my experience, it is especially annoying when doctors blame XYZ complaints on anxiety or your disability and say things like, "It's all in your head."

COVID-19 in people with disabilities can show up differently than in people without, which can make it harder to diagnose and treat. It can show up as worsening ASD behaviors, anxiety, post-traumatic stress disorder (PTSD) symptoms. People with ASD, especially those of us who have been the most masked-up from the beginning when it comes to viral infection, may not always register on a COVID-19 test or always show the most obvious symptoms of this virus. As someone who has now had COVID-19 twice, I never had the more typical symptoms like a sore throat, fever, pink eye, shortness of breath, or nasal congestion. In ASD, COVID-19 dating back from summer 2021 to now can present as worsening [anxiety](#), [insomnia](#), [panic attacks](#), tremors and intense shaking, bleeding gums, intense muscle tension throughout lower body, diarrhea, TMJ jaw pain, and bloating. This pandemic has ended the era where everything is clear when it comes to random winter ailments that we are used to. COVID-19 is way worse than any flu, strep throat, walking pneumonia, common cold, postnasal drip, or chicken poxes. It's equal to being hit by a truck, the viral equivalent of cancer, given the mental and physical toll it takes.

As this pandemic has progressed, research is showing us that people with ASD, Attention Deficit Hyperactivity Disorder (ADHD), Anxiety, Vitamin D, and B12 deficiency are some of the populations that are most at risk of post/long-COVID complications from this virus. For instance, [a study published in MedRxIV](#) talks about the likelihood of experiencing health issues characterized by central sensitization and that “‘Long-COVID’ syndrome might also be explained by a heightened response to internal physiological stimuli, much like in myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS).” They also suggest that the more autistic traits a person has, the higher the risk of symptoms lasting 12 or more weeks. Many scientists believe COVID-19 is an [autoimmune virus](#) in which the immune system overreacts, causing the body to attack itself. More often than not, autoimmune issues are not active until they are triggered by a virus, especially a new one like COVID-19. Cortisol levels also play a big role in long COVID risk. Many people with ASD, especially those with ADHD, have an intense response to stress. Stress is not something people with ASD handle well. Many of us with ASD are also more sensitive to trauma compared to the neurotypical world. The trauma from COVID-19 can also cause suboptimal thyroid and post-traumatic stress disorder (PTSD). [One study](#) showed that the more autistic traits a person has the more likely they are to get PTSD from COVID-19.



In 2021-2023 I was diagnosed with PTSD, gut dysbiosis/leaky gut, and sub-optimal thyroid. Things like leaky gut and sub-optimal thyroid, are not recognized in western medicine. All the tests I underwent in 2021 showed vitamin D, B12 deficiency, high inflammatory bowel disease (IBD), markers for Crohn’s disease, and inconclusive for autoimmunity. No one at the time could say whether it was from COVID, but as more studies came out and one took lab results and typed in COVID-19, the connection between them was pretty obvious. To deal with these ailments and get back on my feet, I have undertaken a [functional medicine](#) protocol where functional medicine doctors and my nutritionists, who I see regularly, put me on an anti-inflammatory diet and tried various things like thyroid support, adrenal rescue, omega 3, COQ10, increased Vitamin D, B12, neuro-magnesium, BPC157, T3 Rx, levothyroxine, digestive enzymes, adrenal rescue, and HPA axis to regulate the stress-induced ‘fight or flight’ response. One of the major diet changes I made was eliminating high sugar fruits, and eating mostly organic produce, meat, lentils, protein shake, and cooking all veggies. Before the pandemic I could eat raw food without major issues, but since I’ve had COVID I have had to switch to eating mostly only cooked foods. Cooked veggies reduce bloating because they break down the fiber and cooked foods can also change the gut microbiome in positive ways to make it healthier. Other things that are very beneficial in dealing with COVID-19-related trauma are touch therapy to get regular myofascial release, massages, zero balancing, chiropractic adjustment and acupuncture to help regulate your nervous system, get out of ‘fight or flight,’ reduce bloating, pain, reduce trauma and improve overall function. Every time I lay on the table and my practitioners work on me, it settles my nervous system to create inner peace and better health in general.

It is important to note that the cost of most of these functional medicine treatments is out of pocket. For anyone on Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI), it can be deducted as an IRWE-Impairment Related Work Expense. You can also deduct it from your taxes at the end of the year. Many of my practitioners bill on a sliding scale, which is helpful. Medicaid, which is my primary insurance, covers the health nutrition and doctor appointments that are all done via telehealth, and labwork done at the center I go to.

Here are some ideas to reduce health disparities for people with disabilities who are trying to access healthcare:

- 1 Pay doctors higher rates for the time and effort needed to accommodate the needs of people with ASD and other developmental disabilities.
- 2 Require all healthcare providers to get training on disability health, wellness, and accessibility core competencies taught by people with disabilities and allies.
- 3 Train Direct Support Professionals on health promotion and healthy lifestyles.
- 4 Offer nutrition classes through disability providers.
- 5 Increase access to gym memberships to support people with disabilities to achieve better fitness, mental health, and reduce obesity.
- 6 Functional medicine supplements and touch therapy like zero balancing, massage, reiki, and acupuncture should be covered by Medicare, Medicaid, and all insurances.
- 7 Focus on reducing the unemployment rate among the IDD and Autism communities and increase dignified work opportunities for all adults.
- 8 Use tools like shot blocker, buzzy tool, and noise canceling headphones to reduce fear around needles for vaccines and blood tests.
- 9 Increase visiting nursing programs for nurses to visit our homes to support us with at home medical tests.
- 10 Assign everyone with ASD or IDD a care coordinator regardless of whether or not they get HCBS.
- 11 Increase access to HCBS supports by ending waitlists, eliminating IQ limits, and being at risk of ICF placement as a criterion for eligibility.
- 12 Develop specialty clinics like [“ALL Brains Belong VT”](#) to deal with long and post COVID complications in the IDD and Autism communities.

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# Improving Access to Care for Sexual Assault Survivors with Developmental Disabilities

## *An Interview with Civil Rights and Sexual Assault Prevention Activist James Meadours*

*By Kristen Loomis Greenidge and Amanda Rich*

- People with disabilities have an increased risk of experiencing sexual violence.
- Those who work in the disability service system need more knowledge and skills to support trauma survivors.
- First responders including SANE nurses, victims' advocates, and police officers need more knowledge and skills to support survivors with disabilities.
- Efforts to improve the services for people who have experienced sexual violence should be led by survivors of sexual violence and advocates with disabilities.

### Becoming an Activist

James's journey to becoming a nationally recognized disability rights and sexual assault prevention activist began in the 1980s. When asked how he became an advocate, he said, *"It's kind of hard to get through because the story started a long time ago when I was at a local group home. That's where I learned about advocacy. That's where my learning to make change started. Our laws were a problem. I never would have thought that from 1989 to today I would be seen as a leader of two different movements, across my life and career."*

*At the time I was living in a 12-bed group home. I also was at a sheltered workshop program making a sub-minimum wage. I was making something like 50 cents an hour. In 1990 I decided to go to the first ever self-advocacy conference in Oklahoma. I was so eager to get out of the workshop program. After that conference, my friend helped me find a job coach. That was with an agency that helped to equip me with what I needed and find opportunities to get out. I took the first job I'd seen because I was so desperate. The concept of looking for a job I actually liked just wasn't there for me at the time. I just wanted to get out of the sheltered workshop. And that was the start of my career. That's where this all started from, and I have been doing it ever since."*

James is a national leader in the self-advocacy movement. He currently serves as the President for the [Texas Advocates](#), a state-wide disability advocacy organization. He also is a widely respected speaker, expert, and activist on sexual violence prevention advocacy. He serves as a citizen member of the [President's Committee for People with Intellectual Disabilities \(PCPID\)](#).

James shared how his work as a sexual violence prevention activist began. He said, *"The other movement I am involved with is the sexual assault advocacy movement. Long ago I was a target of sexual crimes. The last time I was assaulted I put my foot down and decided to get the help I needed to recover from my sexual assault. From then on, I wanted to take on that issue. After the last assault, I wanted to tell the whole world about this issue. I had a wonderful experience with an incredible person*



that helped me get started. She was a 'Sexual Assault Nurse Examiner.' They are called [SANE nurses](#). I never called anyone Mister or Missus until I met Ms. Wanda. She is a person I respect. Ms. Wanda told me, 'James, before you can help others you need to recover from your own sexual assault experiences.' It took me a few years to heal and then I started to get more involved and start work on this important issue. Because I felt like there were not many voices like mine out there. The [Me Too. Movement](#) helped me see that I needed to focus more of my life on this issue. There were not many voices of survivors with disabilities and not many voices of male survivors with and without disabilities. When Joe Shapiro from NPR [interviewed me](#), that boosted my recognition as a sexual assault survivor and disability rights advocate."

## The Barriers to Support That Sexual Assault Survivors with Disabilities Face

James described several challenges survivors with disabilities face in getting needed care and support to heal from experiences of sexual violence. He said that sometimes survivors with disabilities face challenges of not being believed and being blamed or shamed for their experiences of other people hurting them. He shared, "Simply getting people to believe them and to avoid playing the blame game is hard. If you are playing the blame game, it makes the person feel guilty or blame themselves for what happened to them when it is not their fault. That is a challenge because we try to teach people to live in the community to be responsible and independent, but the flip side of the coin is that family members, case workers, or program coordinators can be overprotective of them and yet still say things like, 'Why did you let that person into your apartment?' It's not the person's fault. It's the perpetrator's fault. That's what they need to remember."



James also described a lack of recognition of and support for male survivors and survivors with disabilities. He said, "I felt like there was a lack of support for male survivors like me. People think we don't have a lot of male survivors out there, but we do have male survivors. It's hard sometimes. I feel like I'm ignored because I carry the male perspective. I try to see the big picture for male survivors with and without disabilities. I am an advocate for all people. Not just for people with disabilities."

There is also a challenge of family members and the care system trying to protect people with disabilities from harm by isolating them. That isolation, he says, both violates their rights and makes them less safe. He said, "Often people with disabilities get protected and have a dome put around them. They may not have relationships with anyone else because of an overprotective family member, or the system like a case worker or a program coordinator. They can't see that they need to have other relationships to live a good life and to be safe."

James also shared that a big barrier to support is that often those who work in the disability support service system do not have knowledge of the issue of sexual violence and how to help people heal from trauma, and those who work with survivors of sexual violence often have little experience with or knowledge of the needs of people with intellectual and developmental disabilities.

## How the System of Care and Support for Survivors with Disabilities can be Improved

James shared several ideas for how the system of support can be improved for survivors with disabilities. This included ongoing training for first responders and victim advocates on working with people with disabilities and ongoing training and support for disability service providers on trauma and sexual violence. He said, *“I think the service system needs to have a program maybe funded by new legislation that trains workers on how to help people recover from their own traumatic experiences. I know we have case managers and program coordinators, but someone needs to have experience to help people who have experienced trauma. Also, some of the first responders and other people they count on to ask for help may never had the experience of helping a person with a disability before.”*



*“This is especially important during the forensic examination. I was really scared at the time because I did not know what was happening or what would happen during the examination. I was lucky that Ms. Wanda took it one step at a time, describing what was going to happen, and what they were going to do next. That was great, but not everyone has someone like Ms. Wanda. She was a great help. She also helped the law enforcement folks know what I needed. She told them that I don’t need a guy who is hurried. We need someone who is very gentle, and calm, who can help a person who is scared to talk about it. We need people who can show compassion and not guilt people. We need all people to know not to blame the person who got hurt. Because that can make it very hard for people to be able to recover.”*

James said that this training should be mandatory and ongoing just like CPR and First Aid and must involve the voices of peer advocates. *“One of the things that would be great is to have a peer advocate to do training and do continued training for program coordinators, protective services, and case managers. We need to stay in the room when we provide that training for them. We are the experts in this experience. Even people with disabilities who are not necessarily survivors but are very passionate and knowledgeable could work. We need to train people in power. It should be a requirement, just like we have CPR and First Aid and other business requirements. More ongoing training on how to help a person who was hurt with peer advocates because I feel like that is missing.”*

Lastly, James described ensuring there are more consistent, responsive, and resilient systems to investigate and intervene in cases of violence and abuse. He said, *“Whether it be in Texas, Arizona, or any other state, we need to be there when a person has to file an incident report of being sexually assaulted and ensure someone takes it seriously. I have a friend who is living with another friend, and someone called protective services. It wasn’t related to sexual assault, and everyone was safe, but they came and did an investigation. On the flip side of that, another person I know, her son got sexually assaulted at a group home during a major ice storm. She tried to reach out to protective services and protective services did not help her. That was very disturbing. Sometimes protective services investigates when people are not in danger but then don’t help when someone is in danger and is sexually assaulted. It’s kind of disturbing. We need to train and increase the amount protective service workers and program coordinators and people in the system on how to be sensitive and responsive about this issue.”*

## Practicing Hope

Sexual assault prevention advocacy work as someone with lived experience can be heavy and hard. James shared that seeing others open and find healing and seeing care providers move away from over-protection and towards compassion, listening, and support is powerful. He said, *“To hear our voices is powerful. When we hear the voices of people who have had these experiences it helps other people with disabilities open and share their own experiences. That helps people heal. I want to challenge groups to be more willing to help that person and avoid that overprotective service side of things because that doesn’t help anyone. Sometimes people’s minds open and change.”*

### Resources on Supporting Survivors of Sexual Violence with Disabilities

[ACL Preventing and Addressing Sexual Assault of People with I/DD](#)

[The Arc Talking About Sexual Violence](#)

[National Sexual Violence Resource Center Victim Centered Approaches](#)

[RAINN Sexual Abuse of People with Disabilities](#)

[CDC Sexual Violence and Intimate Partner Violence Among People with Disabilities](#)

**James Meadours** is the Advocacy and Outreach Lead for Strategic Education Solutions, serves on the President’s Committee on Intellectual Disabilities, and was the past President of Texas Advocates. He is also a former SAFE (Stop Abuse For Everyone) Program Advisory Committee member and is a national advocate for healing from sexual assault and the rights of people with intellectual disabilities. Contact James at [jamesmeadours@strategicsolutions.com](mailto:jamesmeadours@strategicsolutions.com).



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**Amanda J. Rich** is the owner and CEO of [Open Road Inclusive Community Consulting](#), and the managing editor of the National Leadership Consortium Bulletin. Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at [openroadicc@gmail.com](mailto:openroadicc@gmail.com).



# Health Care Alone Isn't Enough: Improving Health by Focusing on Social Determinants of Health

*By Carli Friedman*

- Social determinants of health are things that make our health better or worse. For example, having friends helps our health but being lonely hurts our health.
- People with disabilities have worse health than people without disabilities because they don't receive the supports they need or want.
- To improve people with disabilities' health we need to provide better healthcare and reduce support staff turnover, increase community integration, and improve person-centered services.

## What Does the Research Say?

While health care is important, there are actually a lot of different factors that contribute to our health. In fact, a whopping [90% of our health](#) is determined by non-medical causes, called social determinants of health. Social determinants of health are conditions in the environments we live, work, play, and grow that contribute to our health and quality of life. For example, poverty, environmental and neighborhood conditions, housing, transportation, discrimination, education, employment, relationships, and technology are all social determinants of health, which either promote or hinder our health.

Unfortunately, many people with disabilities face disparities in these very areas compared to nondisabled people. For example, people with disabilities are more likely to be [housing insecure](#), [food insecure](#), and [financially insecure](#), and are less likely to be [employed](#) and have [relationships](#) compared to people without disabilities. So, people with disabilities' health disparities are not only caused by unmet healthcare needs and inaccessible and discriminatory healthcare systems, but also further exacerbated by disparities in these other social determinant areas. For example, in my research, I've found that the fewer social determinant-related outcomes people with intellectual and developmental disabilities (IDD) have present in their lives, the more likely they are to visit the [emergency department](#).

## What Does it Mean for Our Field?

What the existing research about social determinants of health means for our field is twofold. First, it means we have a lot of work to do to promote health equity for people with disabilities. Not only do people with disabilities face many inequities as mentioned above, but also conditions in the field can contribute to further disparities, including those related to social determinants of health. For example, for decades there has been a vast direct support professional (DSP) turnover issue in our field, with a significant portion of DSPs turning over annually. When people with IDD experience DSP turnover, they have significantly worse [health outcomes](#) and [quality of life](#). Essentially, the quality and continuity of the DSP workforce is a social determinant of health of people who receive services. Until we can remedy the DSP turnover 'crisis,' and other systemic factors like it, people with disabilities' health will continue to suffer.

Second – and this is good news – it also means a lot of things we already focus on as markers of quality in Long-Term Services and Supports (LTSS), such as employment supports, transportation, and relationships, will also help promote the health of people with disabilities. It may be more natural to work on social determinants of health than people realize! For example, the HCBS Final Settings Rule requires person-centeredness and choice, along with more requirements for states and organizations (as described in more depth in the previous National Leadership Consortium [Bulletin](#)). Research has found that if the [HCBS Settings Rule](#) is implemented with fidelity, it will also result in improved health among people with disabilities. For example, when people with IDD have [more choices](#), they have 35% fewer injuries. In addition, when they [participate in the life of the community](#), they have 90% fewer emergency department visits. By making services more person-centered, our field will naturally also address social determinants.

## What Does it Mean for My Organization?

While many people with disabilities face disparities in outcomes compared to people without disabilities, the good news is [individualized, organizational supports](#) can be immensely impactful in promoting social determinants of health! For example, when organizations implement [ongoing staff development](#), people with IDD are significantly less likely to be injured, visit the emergency department, and experience abuse and neglect. In addition, when organizations train their staff to promote [dignity and respect](#), behavioral events exhibited by people with IDD decrease by 61%.

I've developed the [Social Determinants of Health Index](#) to help organizations examine which areas they need to focus on. An individual person's score on the *Index* can tell organizations where that person would benefit from additional supports in order to promote their outcomes. In addition, *Index* scores can be aggregated across the entire organization to indicate where an organization is excelling, and which outcomes organizations should prioritize moving forward.

Another good place to start is by paying attention to disparities in social determinant-related outcomes. Women, people of color, people with personality/psychotic disorder, people with physical disabilities, people with seizure disorders, and people who live in intermediate care facilities (ICFs) have [fewer positive social determinant-related outcomes present](#). As such, organizations should be intentional about targeting additional support to these groups to improve their outcomes. By paying attention to people's social determinants and increasing individualized, person-centered supports, we will improve people with disabilities' health outcomes and, by extension, promote health equity!

**Carli Friedman** is the Director of Research for The Council on Quality and Leadership (CQL). She holds a PhD in Disability Studies from the University of Illinois at Chicago. Carli is passionate about research on quality of life outcomes, community integration, and ableism. Contact Carli at [cfriedman@thecouncil.org](mailto:cfriedman@thecouncil.org).



# Reducing Health Disparities for People with Disabilities

By Cory Gilden

- People with disabilities are at risk of being less healthy than other people because doctors may not know how to help them and because they have less access to doctors and healthcare.
- It is important for service providers and law makers to read national research about differences in healthcare for people with disabilities so they can learn how to help people who need it the most.
- People who provide services to people with disabilities can educate themselves, the people they support, doctors, and law makers to help promote good health practices.

## What Does the Research Say?

People with disabilities experience [health and health care disparities](#), or “[preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations](#),” due in large part to historic and persistent systemic oppression across the United States that limits their participation and inclusion in general society. There are [multiple contributing factors to health inequity](#) between people with disabilities and others, including more adverse social determinants of health<sup>1</sup> and negative or ableist attitudes that lead to less knowledge about or access to healthy lifestyles, lack of

There are [multiple contributing factors to health inequity](#) between people with disabilities and others, including more adverse social determinants of health<sup>1</sup> and negative or ableist attitudes that lead to less knowledge about or access to healthy lifestyles, lack of preventative, routine, and emergency health care, less effective and timely treatment, more [chronic conditions](#), and even [early death](#).

preventative, routine, and emergency health care, less effective and timely treatment, more [chronic conditions](#), and even [early death](#). For example, [a recent study of practicing physicians](#) across the U.S. found that ableist perceptions and lack of training about people with disabilities are common, with 82.4% of doctors saying that people with significant disability have worse quality of life than nondisabled people and only 40.7% of doctors being very confident about their ability to provide the same quality of care to patients with disabilities. Only 56.6% of physicians in the study strongly agreed that they welcomed patients with disabilities into their practices. When medical practitioners are not willing or equipped to treat patients with disabilities, health disparities expand.



<sup>1</sup> To learn more about the impact of the social determinants of health experienced by people with disabilities, see the article by Carli Friedman, “Health Care Alone Isn’t Enough: Improving Health by Focusing on Social Determinants of Health,” also in this issue of the Bulletin.

The health disparities of people with disabilities are so prevalent now that the National Institute on Minority Health and Health Disparities (NIMHD), part of the National Institute of Health, [officially designated](#) people with disabilities as a “population with health disparities” this past September. The designation brings with it more [funding for research](#) and an [update to the National Institute of Health’s mission statement](#) to ensure the prioritization of the health of people with disabilities.

## What Does It Mean for Our Field?

Because of the designation of being a “population with health disparities,” data from sources like the National Core Indicators (National Core Indicators®-Intellectual and Developmental Disabilities, NCI®-IDD), the [Behavioral Risk Factor Surveillance System](#) from the Disability and Health Data System of the Centers for Disease Control and Prevention (CDC), and other ways of tracking access and use of healthcare become even more important in policy conversations in the future.

The [NCI®-IDD Health Report for 2021-22](#) shows that while on average most of the nearly 13,000 people with disabilities surveyed across the nation have a primary care doctor or practitioner (90%) and consider themselves in “excellent” (17%), “very good” (31%), or “good” (39%) health, there are still many areas for improvement. For example, in Nevada, only 64% of people surveyed had a primary care doctor, which is well below the national average. More specialized care averages were also well below ideal, with 27% of women 21 and older reporting they have never had a Pap test and only 32% of people ages 45-75 reporting they’ve had a colonoscopy in the past 10 years, both of which are common cancer screenings for the general population.

The [Disability and Health Data System of the CDC](#) is another source that provides state-level disability data, monitoring approximately 30 health indicators, such as smoking, heart disease, and receiving the flu vaccine. According to the Disability and Health Data System, adults with disabilities in [more than half of U.S. states](#) are at or below that national average of the adult population in those states meeting the physical activity guidelines. Knowing this information can prompt funding for national [campaigns](#), [programs](#), and [guidelines](#) that educate people on the benefits of physical activity and encourage engagement in more, which can lead to better overall health and less disease.

Ongoing data collection and reporting about health indicators for people with disabilities is critical to state epidemiologists, researchers, policymakers, public health professionals, and service providers to plan for more inclusive communities that offer programs and services needed to improve the health of adults with disabilities. Keeping track of high and low indicators can help target interventions and highlight areas of need for the people with disabilities who receive services.

## What Can I Do? What Does It Mean for Me?

There are many steps leaders of disabilities organizations can take to fight stigma and contribute to health equity, from within the organization, within the community, with the people you support, and on a systemic level. Some examples include:

### Educate Yourself and Your Employees:

Become more knowledgeable about [health equity](#) through sharing resources with your employees, hosting trainings to educate employees about health disparities and how to combat them, and becoming a [Disability A.L.L.Y.](#), a program promoted by the National Center on Birth Defects and Developmental Disabilities, where A=Acknowledge and respect individual experiences and abilities, L=Learn about different disability types, L=Leverage your influence to promote accessibility and inclusion, and Y=Yield the floor to people with disabilities to help identify and eliminate barriers. The campaign provides sharable posts for social media that can expand education efforts to your online community.

## Educate Health Professionals:

To combat unmet healthcare needs and discriminatory health care systems in the community, share [resources from the National Center on Birth Defects and Developmental Disabilities](#) and the [American Association on Health and Disability](#) with health professionals. Educating health professionals about how to [communicate with and about people with disabilities](#) can also help prevent stigma and promote positive interactions.

## Promote Healthy Living:

The [National Center on Health, Physical Activity and Disability](#) has many resources to promote healthy lifestyles for people with disabilities, including an [Inclusive Worksite Wellness Toolkit](#) complete with guides, e-learning course, posters, and challenges, that can be used to promote inclusive practices and choices related to promoting healthy lifestyles at your organization. There are also resources for public health professionals, health care providers, educators, caregivers, and fitness professionals to encourage healthy living.

## Advocate:

In a [recent study](#), 18.1% of practicing physicians surveyed strongly agreed that the health care system often treats patients with disabilities unfairly. [Advocate for policy changes](#) to promote health equity and changing systemic factors that lead to social disadvantage, such as expanding access to health coverage, extending Medicaid buy-in programs, expanding access to Home and Community Based Services, expanding the scope of covered services, supporting integrated care programs, and advocating for research to inform future policy.

**Cory Gilden** is the Research and Evaluation Manager of the National Leadership Consortium. Cory holds a Ph.D. in Urban Affairs and Public Policy and works with local and national organizations conducting research and advocating for people with disabilities and their families. Contact Cory at [cgilden@natleadership.org](mailto:cgilden@natleadership.org).



# Innovative Initiatives Q&A: NADD's Community of Practice for People with IDD and Mental Health Conditions

*Jeanne Farr, CEO of NADD,  
answers questions about the organization and their work*

- NADD's mission is to promote leadership in the expansion of knowledge, training, policy, and advocacy for mental health practices that promote a quality life for individuals with dual diagnosis (IDD/MI) in their communities.
- Many people with IDD also experience mental health conditions and there are unique challenges and barriers in accessing mental health support.
- In recent years, there have been many organizations, initiatives, and resources developed and created to work towards more ethical and effective mental health supports for those who need them.

## Why was the National Association for the Dually Diagnosed (NADD) founded? What is the organization's mission and what does it do?

In the late 1970's and early 1980's, [NADD](#) founder Dr. Robert Fletcher and his close colleagues grew increasingly concerned that there were no resources to address the mental health needs of people with intellectual/developmental disabilities (IDD).

NADD's mission is to promote leadership in the expansion of knowledge, training, policy, and advocacy for mental health practices that promote a quality life for individuals with dual diagnosis (IDD/MI) in their communities.

NADD was founded in 1983 in response to that concern and the growing need for a forum to educate the professional community regarding the realities and unique needs of those with dual diagnoses — both IDD and mental health conditions. The purpose in establishing NADD was to address the absence of research, information, and access to effective services for people experiencing co-occurring IDD and behavioral health needs. NADD's mission is to promote leadership in the expansion of knowledge, training, policy, and advocacy for mental health practices that promote a quality life for individuals with dual diagnosis (IDD/MI) in their communities. Through all our work, we promote an integrated whole person approach to care through the [bio-psycho-social-spiritual approach](#). Through this lens, practitioners seek the input of those being supported and strive to understand their culture and all aspects of that person.



## How common is it for people with IDD to experience mental health conditions?

It is widely known that people with IDD have higher incidences of mental health conditions than people without IDD. People with IDD are two-to-three times more likely to also have a mental illness than the general population. While the exact prevalence is unknown, most professionals accept that roughly 50-60% of people with intellectual disabilities also experience mental health challenges. The reasons that the exact prevalence is not clear includes a lack of consistency in diagnostic definitions and assessment instruments, small sample sizes, lack of non-IDD control sample in studies, and consideration for functioning level and type of disability.

## What are some of the unique challenges or barriers people with IDD and their communities face in accessing effective and ethical mental health support?

There are many challenges faced by people with IDD in securing effective and ethical treatment and support, including:

- **Diagnostic Overshadowing** is an issue faced by people seeking assessment and treatment. Diagnostic overshadowing is where there is a negative bias impacting a clinician's judgement whereby a symptom may be misattributed to an existing condition (IDD) rather than a separate and unrelated (mental health) condition.
- **The Impact of Trauma** cannot be overstated. We are growing to understand that everything we do in our work as professionals must be through the lens of assuming trauma: not just considering, but assuming that most, if not all, people with IDD who are receiving care have experienced trauma and that how trauma impacts a life is very personal and unique.
- **Communication Style** can pose barriers in that a person may have ways of communicating that may not be understood by the people working with them, leading to all sorts of potential misunderstandings.
- **Multiple diagnoses** experienced by a person may not be recognized. There could be unrecognized mental health or physical health conditions impacting their life.
- **Medication-related issues** may also need to be addressed. While medication, when utilized with a professional who is trained to work with people with IDD and mental health conditions, can be very effective, that is not always the case. Individuals may be prescribed medication incorrectly or may be experiencing an adverse mixture of medications and/or side effects of medication, negatively impacting their health and well-being.

## What do you think has changed in the past few decades in the experience of people with IDD/MI in accessing quality care and support services?

The greatest change in the last few decades is that the voices of people with lived experience and families are increasingly a driving force for advocacy, ethical and effective treatment, and support. National initiatives have been established and are dedicated amplifying the voices of families and individuals. One of those is the [\*Supporting Families Across The Lifespan - A Community of Practice\*](#).

The Community of Practice (CoP) for Supporting Families of Individuals with Intellectual & Developmental Disabilities involves working with states to build capacity across and within states to create policies, practices, and systems to better assist and support families that include a member with IDD across the lifespan.

There is the growing understanding and acknowledgment that people with disabilities are not one-dimensional but are complex like everyone else. There is a growing body of research, education and practice that equips professionals to better understand the cultural, biological, social, environmental, psychological, spiritual aspects of a person and the increasing commitment to work with people through a trauma-assumed lens.

## In your work with NADD, what gives you the most hope for a better future?

While there is an enormous amount of work to be done and significant challenges to face, there are so many things to be very, very excited about! Many research projects are currently underway across the country to advance our knowledge and improve treatment and support for people with a dual diagnosis, collaboration and partnerships are the norm and there is a solid and united commitment across the country and across all sectors within this field of work and study to learn, to grow resources and to do better, and individual and family voices are loud and clear and commanding!

These last 10 years in particular have seen the building and flourishing of initiatives that focus on intellectual disabilities and mental health. Some of these include:

- In 2018, SAMHSA convened the first gathering of its kind to work with national leaders in exploring how to address the systemic issues relating to dual diagnosis policy and treatment.
- The Community of Practice (CoP) for Supporting Families of Individuals with Intellectual & Developmental Disabilities has evolved to positively impact policy, care and treatment across the country.
- Capacity Building Institutes in individual states like Pennsylvania and national initiatives, such as the NASDDDS (National Association of State Directors of Developmental Disabilities Services) Capacity Building Institute for Individuals with IDD and Mental Health Support Needs (CBI).

Perhaps the most exciting initiative happening now is the development of the Administration for Community Living (ACL) funded [Link Center](#), which can be seen as a culmination of decades of advocacy and is a wonderful example of the commitment at the highest level of our government to work together to better address the mental health needs of individuals with intellectual disability.

Through a five-year cooperative agreement with ACL, The Link Center is led by three national associations whose state and professional members are essential to systems change in this arena – the National Association of State Directors of Developmental Disabilities Services ([NASDDDS](#)), the National Association of State Mental Health Program Directors ([NASMHPD](#)), and the National Association for the Dually Diagnosed ([NADD](#)). Additional partners include the Autistic Self Advocacy Network ([ASAN](#)), [CommunicationFIRST](#), Green Mountain Self-Advocates ([GMSA](#)), [the National Center for START Services](#), [the Nisonger Center](#), [the Sonoran Center for Excellence in Disabilities](#), and the National Association of State Head Injury Administrators ([NASHIA](#)). This project is governed by a steering committee of 12 people with lived experience. Over their five-year terms, committee members will meet quarterly, and more often if needed, to advise on priorities and provide their perspectives on the center’s work. They will, in collaboration with NASDDDS, NASMHPD, NADD, and ACL, shape the center’s efforts to identify and share resources that better meet the needs of individuals with IDD and mental health conditions, recognizing that everyone is unique and has different needs and preferences.

## What else would you like people to know about the experience of people with IDD/MI and their families?

We are all family members. We all want the same basic things for our loved ones. We all face challenges, and we all seek to be included, truly seen and understood for who we are. In working with people, always look beyond the diagnoses into the heart and spirit of the person. No matter the severity or complexity of how someone may present how they feel, assume capability and look and listen deeply and with an open heart and mind. All of us are part of the wonderful tapestry of humanity and we all deserve to be honored for who we are.

To find out more about the Community of Practice for Supporting Families and Individuals with Intellectual & Developmental Disabilities, visit:

<https://www.nasddds.org/projects/community-of-practice-supporting-families-throughout-the-lifespan/>

**Jeanne Farr** is the CEO of NADD and holds a master’s degree in intercultural relations, has been in nonprofit executive leadership positions in organizations focusing on services or supports for people with intellectual/developmental disabilities for over 35 years and is passionate about working in ways that foster partnerships and collaboration. Contact Jeanne at [jfarr@thenadd.org](mailto:jfarr@thenadd.org).



# Useful Tools and Resources to Support Health Equity for People with IDD

Health and well-being involve [many dimensions](#). It can be hard to know where to start to help to support health equity. The following tools and resources aim to better support the health and well-being of people with IDD, their families, and support staff:

| Resource                                                                                                                                 | Published By                                                          | Types of Information |                |                         |                  | Description & Potential Uses                                                                                                                                                                                                                                                                                         |
|------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|----------------------|----------------|-------------------------|------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                                          |                                                                       | General Information  | Tips and Tools | Plain Language Material | Online Trainings |                                                                                                                                                                                                                                                                                                                      |
| <a href="#">Mental Health and Developmental Disabilities National Training Center Training and Resources</a>                             | Mental Health and Developmental Disabilities National Training Center | X                    | X              | X                       | X                | The MHDD Training Center is a treasure trove of accessible modules, resources, podcasts, and stories to help support staff, family caregivers and people who use services better understand mental health challenges and access care for people with developmental disabilities.                                     |
| <a href="#">Partnering to Transform Health Outcomes for People with Intellectual and Developmental Disabilities (PATH-PWIDD) Project</a> | IDD Health Equity                                                     | X                    | X              |                         |                  | IDD Health Equity is a partnership project between advocates, the health care workforce, policy experts, and academics to create interprofessional learning opportunities to ensure the healthcare workforce can better serve people with IDD. Its website has videos, policy information, and tools for evaluation. |
| <a href="#">Understanding Disability in American Indian &amp; Alaska Native Communities Toolkit Guide</a>                                | National Indian Council on Aging & National Council on Disability     | X                    | X              |                         |                  | This practical tool kit was designed to help people better understand and serve the health needs of American Indian and Native Alaskan people with disabilities.                                                                                                                                                     |
| <a href="#">Health Equity</a>                                                                                                            | Temple University Institute on Disabilities                           | X                    | X              | X                       | X                | This website provides information on training on topics related to health equity, healthy sexuality, food justice, access to care and public health emergencies like Covid                                                                                                                                           |

| Resource                                                                                                                   | Published By                                                              | Types of Information |                |                         |                  | Description & Potential Uses                                                                                                                                                                                                                                               |
|----------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|----------------------|----------------|-------------------------|------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                            |                                                                           | General Information  | Tips and Tools | Plain Language Material | Online Trainings |                                                                                                                                                                                                                                                                            |
| <a href="#">Disability and Health Emergency Preparedness Tools and Resources</a>                                           | Centers for Disease Control and Prevention                                | X                    | X              | X                       |                  | This site has toolkits published by various states to help people with disabilities, caregivers, emergency managers and first responders, better prepare for and meet the needs of people with disabilities during public health emergencies and other types of disasters. |
| <a href="#">Developmental Disabilities &amp; Oral Health</a>                                                               | National Institute of Dental and Craniofacial Research                    | X                    | X              |                         |                  | This website has useful tools, videos and helpful tips for caregivers and providers on meeting the oral health needs of people with developmental disabilities.                                                                                                            |
| <a href="#">Sexual Health Toolkit for Parents Of Youth with IDD</a>                                                        | U.S. Department of Health & Human Services Family & Youth Services Bureau | X                    | X              |                         |                  | This toolkit provides practical tips and resources for caregivers in discussing sexual health with adolescents with disabilities. Some of the content is useful for adults as well.                                                                                        |
| <a href="#">Victims Who Have Disabilities: Victim-Centered Approaches</a>                                                  | National Sexual Violence Resource Center                                  | X                    | X              |                         |                  | This toolkit provides information on violence prevention, trauma and tips to support survivors with disabilities.                                                                                                                                                          |
| <a href="#">The Impact on Trauma on Youth With Intellectual and Developmental Disabilities: A Fact Sheet for Providers</a> | The National Child Traumatic Stress Network and NADD                      | X                    | X              |                         |                  | This is a useful fact sheet for service providers the needs of survivors with disabilities, tips for accessing care and creating a trauma informed organization.                                                                                                           |

# What We're Reading, Viewing, and Listening To

## **Title:** [Healthy People 2023](#)

### **Author:**

Office of Disease Prevention and Health Promotion, Office of the Assistant Secretary for Health, Office of the Secretary, U.S. Department of Health and Human Services (2023)

### **Description:**

Health People 2023 provides freely accessible data sets to improve the health and well-being of people in the United States in the next decade.

## **Title:** [Sexual Health Equity for Individuals with Intellectual and Developmental Disabilities](#)

### **Author:**

Oregon Health & Science University, University Centers for Excellence in Developmental Disabilities

### **Description:**

This site provides many video links and print resources for supporting sexual health equity for people with IDD. It is a useful tool for providers, advocates, and family members.

## **Title:** [Promoting Access and Equity: A Historical Perspective of Healthcare Access for People with Disabilities](#)

### **Author:**

Jason Rotoli, Anika Backster, Cori Poffenberger and Wendy Coates (2022)

### **Description:**

This article provides a clear overview of the role of the perception of providers and social determinants of health, on health outcomes of people with disabilities. The article also describes important legislation that has helped to improve healthcare access for people with disabilities in the United States.

## **Title:** [Navigating Health Care with a Disability: Our Stories, a Focus on People with Disabilities](#)

### **Author:**

Centers for Medicaid Services (2019)

### **Description:**

These videos are testimonials of people with disabilities on their experience accessing health care. It highlights best practices for support and medical providers.

## **Title:** [Seen and Heard: IDD Community: South by Southwest Edu 2023](#)

### **Author:**

James Meadours (2023)

### **Description:**

In this compelling interview, James Meadours explains how telling your story can be a path towards healing and can change communities.

**Title: Just Say Know!:**  
**Understanding and Reducing the Risk of Sexual Victimization**

***Author:***

**Dave Hingsburger (1995)**

***Description:***

Although this book is now over 25 years old, the insight provided is still highly relevant. With the inspiring, compassionate, and deeply human way that only Dave Hingsburger could write, he paints a clear picture of the role support systems play and both increasing and reducing risk factors for sexual violence.

**Title: MHDD Equity, Diversity, & Inclusion Digital Storytelling Series:**  
**Melissa's Story**

***Author:***

**MHDD National Training Center (2021)**

***Description:***

In this storytelling series, Melissa Malcome King describes her experiences navigating the world including work, school, and the health care system as a person with developmental disabilities and mental health conditions. She describes what effective advocacy involves and she helps herself and others navigate some of the unique challenges faced by people with developmental disabilities and mental health challenges.

## Upcoming Events

### The Leadership Institute

This intensive leadership development program is designed for seasoned and emerging leaders. Applicants may work in areas of executive leadership, management, or program leadership in organizations that provide, advocate for, or fund support for people with intellectual and developmental disabilities and their families. The focus of the Leadership Institute is on supporting participants to determine and set organizational direction to move their organization to a high-performance model and build a lifetime network of peers and leaders to sustain career growth.

#### Spring 2024

The **Spring Leadership Institute** will be held May 5th – 10th in-person in Minneapolis, MN at the Institute on Community Integration. Applications are open now. [Click here](#) for more information or to apply. This Institute is open to all Disability Sector Leaders. If you are a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover tuition and some travel and hotel costs!

#### Summer 2024

The **Summer Leadership Institute** will be held July 14<sup>th</sup> – 19<sup>th</sup> in-person in Newark, DE. Applications are open now. [Click here](#) for more information or to apply. This Institute is open to all Disability Sector Leaders. If you are a leader who works for a state department of developmental disabilities within the United States, a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover tuition and some travel and hotel costs!

#### Fall 2024

The **Fall Leadership Institute** will be held September 22<sup>nd</sup> – 27<sup>th</sup> in-person in Stockton, CA. Applications are open now. [Click here](#) for more information or to apply. This Institute is open to all Disability Sector Leaders. If you are a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover tuition and some travel and hotel costs!

## Upcoming Workshops and Other Trainings

### Winter 2024

[Being Intentional: Feedback as a Supportive Tool for Encouraging Development](#) workshop is a four-session virtual workshop open to leaders at all levels that will be held on February 28-29 & March 6-7, 2024 on Zoom. In this workshop, leaders will discover the keys to giving great feedback, including how and when to share, and tips for receiving feedback. [Click here for more information or to register.](#)

Interested in bringing a National Leadership Consortium Workshop to your team or organization in-person or virtually? Check out more information, including our list of Workshops, [here](#)!

### Coaching for Emerging and Established Disabilities Sector Executives and Directors

The National Leadership Consortium now offers targeted coaching for established and emerging executive leaders like you! Leadership Coaches will support you in strengthening skills, setting a clear direction for your organization, and overcoming personal, interpersonal, organizational, and systems challenges that get in the way of fulfilling the missions and visions of your organization. [Click here](#) for more information!



**Contact Us:** <https://natleadership.org/bulletin> • [bulletin@natleadership.org](mailto:bulletin@natleadership.org)

*If you have any trouble accessing the referenced material, please email Amanda J. Rich at [openroadicc@gmail.com](mailto:openroadicc@gmail.com).*