

Uncomfortable Conversations



What will the future look like for people with developmental disabilities? **Let's talk!**

Experts nationwide share their insights and advice

Brought to you by the National Association of Councils on Developmental Disabilities

It's Time to Have Uncomfortable Conversations

Leading the Way in Working for Change

The act of creating positive change through dialogue and policymaking has always been the way of Councils on Developmental Disabilities (DD Councils). Since the inception in federal statute in 1970, DD Councils have worked to change or improve policies, find solutions to problems, and bring the voices of people with lived experience to the forefront for the common goal of creating communities that can support people with Intellectual and Developmental Disabilities to live their best life in the community.

As communities across the country are now coming back from the pandemic, DD Councils are once again at the forefront leading the way through dialogue, discourse and public policy change. But as we begin the process of stepping back out of our homes and get

back to work, school, recreation and social activities, we know we have a critical moment—a brief time in which we have an opportunity to ask our selves important question and engage in what are sometimes “uncomfortable conversations.”

Uncomfortable conversations happen at the Council table, in meetings with state legislators, and with community leaders, individuals with I/DD, family members, allies and caregivers. Over the last 50 years, DD Councils have led the way in building inclusive communities. We have identified gaps and barriers to full inclusion and have innovated solutions to change what is wrong.

The COVID-19 pandemic changed everything about how we engage in community, and we saw some regression in community living because

of the necessity to stay in, stay healthy and stay safe. But now is the time for DD Councils to once again step forward in the way they do best, to take a pause and say, “Should we continue what we are doing, or can some things be done differently?”

When we engage in uncomfortable conversations, and when we encourage uncomfortable conversations rather than fear them, we open up good dialogue and opportunities to think about new solutions and ideas.

NACDD has developed this publication to help you lead the way in starting uncomfortable conversations. By providing information from a variety of Councils across the country showing how they have created change, and ideas on how to start the dialogue, we are hoping to equip you with support to lead the change in your communities.

“Over the last 50 years, DD Councils have led the way in building inclusive communities.”



State council members and representatives from across the country come together during NACDD conferences to share experiences and work for solutions.

PHOTOS COURTESY OF NACDD

Access to Health Care

After a history of mistrust and inequitable healthcare, we must do more to provide primary care that supports the whole person



BY THEA MARIE ROOD

In 1996, the last large institution in Maine closed, but when people with developmental disabilities were released into the community, they avoided any interaction with physicians.

Why?

“It was thought people with developmental disabilities didn’t feel pain as others do. If you bit someone, you had your teeth pulled out. Some people were forcibly sterilized,” explains Nancy Cronin, executive director of the Maine Developmental Disabilities Council.

To compound the matter, doctors didn’t—and don’t—have experience with this population. Cronin tells stories of patients at emergency rooms who can’t communicate and their caregiver is not allowed to go into the examining room with them. Data compiled from millions of records by ECRI, a nonprofit focused on improving safety in health care, shows such patients in ambulatory settings are frequently categorized as “violent,” “aggressive” or “non-compliant.”

But Cronin sees it differently.

“When I see a note that a patient is hitting someone, grabbing something, what I see is this person can’t communicate and is terrified,” she says. And her go-to advice: “When behavior changes, rule out pain first.”

Cronin says the inability of patients and health care providers to trust each other is literally a matter of life and death.

“How many people died from things that could be easily cured?” she asks.

“A person with a sore throat needs to be seen, but the patient has to be comfortable and the doctor has to be comfortable.”

This crisis intensified during COVID: People with disabilities died in large numbers because they were distrustful of the vaccines, didn’t have access to health care or

couldn’t communicate their symptoms. So Cronin began—in partnership with the Maine Primary Care Association—a series of “uncomfortable conversations” with doctors called Safe Table.

“At our first event, (the doctors) didn’t really say much and we thought it didn’t hit home,” says Christopher Pezzullo, D.O., who is PCA’s chief clinical officer. “But they talked to us afterward and told us it was so important.”

Cronin says they are still in the education phase, but she was both encouraged and touched by a doctor’s comment after a Safe Table event.

“We have to realize these are our patients too,” she recalls the physician saying. “To start including this population in your practice—that’s what will make the difference.

It was magical, really powerful.”

“How many people died from things that could be easily cured?”

Nancy Cronin

Executive director, Maine Developmental Disabilities Council



WHAT’S NEXT?

The partnership between the Maine Developmental Disabilities Council and the Maine Primary Care Association started an important discussion, as well as concrete results.



Physician Practice Readiness Form

This two-page reference helps doctors give the best care to adult patients with developmental disabilities, including ways to prepare their exam rooms and staff.

<https://mepca.org/wp-content/uploads/2021/05/IDD-Readiness-form-MePCA1.pdf>

Agency for Healthcare, Research and Quality

Part of the federal Department of Health and Human Services, AHRQ invited the Maine group to present its work and put its case study on the AHRQ website.

Physician training

All future training in Maine, ranging from diabetes to heart disease, will now include a segment on treating patients with these conditions and developmental disabilities. The Maine partnership plans to create a template tool that can be used nationwide at medical schools.

Technical support

Eventually, the group plans to offer real-time support for physicians as they work with patients with developmental disabilities in their day-to-day practices.

Creating Opportunities for Community Living is our Focus

Research points to the benefits of leading an independent life

BY JILL SPEAR

Colleen Wieck sees many benefits of independent living. “People who are developmentally disabled have the benefit of participating in the community, not merely being present,” says Wieck, executive director for the Minnesota Governor’s Council on Developmental Disabilities (or Minnesota Developmental Disabilities Council, MNDDC). “They have more opportunities for education, employment

and relationships.”

Housing is a key part of community living, a positive alternative to institutionalization. MNDDC supports people in their efforts to live as independently and happily as possible. That includes such efforts as the state’s eight Centers for Independent Living, which annually serve more than 6,000 Minnesotans.

“There are decades of research that show people have a better quality of life in a community setting compared to an institutional setting,” Wieck says.

However, Minnesota is still only one of 14 states nationwide that has ended the practice of institutionalization, which has a history of abuse and neglect.

Community living — which is the result of court decisions, advocacy from parents and the efforts of the MNDDC — benefits everyone, according to Wieck. People with disabilities help to build a healthier, more inclusive community. Important voices are heard that would otherwise be lost.

Gail Larsen, a 75-year-old Minnesotan, has benefited from community living, and so has her community. After a fall as a toddler, she developed traumatic brain injury, and was glad to stay home with her family at a time when institutions were still functioning.

As an adult, she’s been married, held down jobs, and is currently renting a three-bedroom trailer by herself. Next, Larsen is moving into assisted living to be around more people. “I’m trying to move forward,” she says.

“There are decades of research that show people have a better quality of life in a community setting.”

Colleen Wieck

Executive director, Minnesota Governor’s Council on Developmental Disabilities



A first step to building inclusive communities, an inclusive classroom allows children to learn and grow together.

PHOTO COURTESY OF NACDD

OPENING THE DOOR TO HOUSING



According to Mary Kay Kennedy, executive director of **Advocating Change Together (ACT)**, the first step to affordable housing isn’t the help of an advocate or parent. It’s self-advocacy, considered vital to creating a new life. The **ACT Olmstead Academy in Minnesota** helps individuals build the strength and skills to pursue independent living.

The Disability Equality Training Series, another approach for self-advocate learning, promotes community inclusion and self-determination. One of the sessions in this series, “**Living the Way WE Want – Housing Choice**” gives participants the ability to speak up and take action on housing options. The session concludes with a “**Tour of Homes.**”

In addition to Minnesota, other states working with DD Councils to provide affordable housing or a transition out of institutional settings include **Alabama, Colorado, Michigan, Tennessee, Virginia and Mississippi**, whose **Home of Your Own** project helped more than 500 people obtain home ownership.

Jobs and Career Paths are Possible!



He found meaning and satisfaction in work — when given a chance

BY GAIL ALLYN SHORT

For Kevin Wright, getting a job with the Washington, D.C., Developmental Disabilities Council (DDC) has been an important step toward his dream of living independently.

And though Wright, an employment and advocacy strategies fellow, lives with a learning disability and speech impediment, the 29-year-old D.C. resident says he is getting to do what he once thought was impossible: public speaking and training.

“I’m working with people who are doing amazing work every day,” Wright says, “and knowing that I can be a part of that conversation with them and that I also get to do some great work, meaningful work, every day, makes me feel not so different and that I really belong.”

Wright’s journey to employment started after he graduated from Mitchell College in New London, Conn., in 2015. Though he did not have a job at the time, Wright was determined to stay busy until he did, looking for as many volunteer and networking opportunities as he could find with organizations such as the Rehabilitation Services Administration (RSA).

“I asked my RSA counselor if I could partake in RSA events by volunteering to sign people in to the events,” he recalls. RSA agreed.

While volunteering in the community, Wright also took certification classes in Microsoft Word and PowerPoint at the Community College Preparatory Academy in D.C. Meanwhile, his counselor kept him abreast of online job postings for which he could apply.

In 2016, the DDC offered Wright a six-month paid internship with its Aspiring Professionals Internship Program.

When the internship ended, DDC hired him as a contractor for five years. Then DDC hired Wright again for a new position as an employment and advocacy strategies fellow in the DDS Lead for America Fellowship.

In this role, Wright makes presentations at national conferences, conducts training sessions and mentors others. Wright says that when the fellowship ends, he will look forward to the next chapter in his life.

“I’m working with people who are doing amazing work every day, and knowing that I can be a part of that (effort) ... makes me feel not so different and that I really belong.”

Kevin Wright
Employment and advocacy strategies fellow,
Washington, D.C., Developmental
Disabilities Council

“My dream path is that I want to become a public speaker and mentor young adults,” says Wright. “I feel like it’s important for me to give back to my community, especially to the young adult age group.”

And he says he is grateful for his job and his wages, which allows him to make a meaningful contribution to his family’s household.

“I still live with my parents, but I always said to myself that I wanted to find work so I could help pay some of the bills,” Wright explains. “By having this work, I’m making a step into adulthood because, in a way, this is preparing me to live on my own. I’ll know what to do, what not to do and how to better manage my money.”

To learn more about Employment First, call the Tennessee Department of Intellectual and Developmental Disabilities at 615-532-6530 or visit Employment First at <https://bit.ly/3M9Jfii>.

SHELTERED WORKSHOPS VS. EMPLOYMENT FIRST

The U.S. Bureau of Labor Statistics says just **17.9%** of people with disabilities were employed in 2020 compared to **19.3%** the previous year.

“For a lot of people, a good life includes employment, having a job where they feel like their gifts and skills are used and appreciated,” says Emma Shouse, public information specialist with the Tennessee Council on Developmental Disabilities.

But many Americans with developmental disabilities work in sheltered workshops, separate from the regular workforce.

Conversely, the Employment First initiative supports people with disabilities working in integrated settings. Here’s the difference in Tennessee:

In a sheltered workshop, employees:

- o Labor **separately** from nondisabled workers.
- o Generally perform repetitive tasks.
- o Are paid **below** the \$7.25 minimum wage.

Under Employment First, employees:

- o Work in **integrated** settings.
- o Have opportunities to learn new skills.
- o Enjoy **equal** pay for equal work.

Building confidence—and a feeling of belonging—is a process. Learn how to put together the pieces of life's puzzles.

PHOTO COURTESY OF NACDD

Set Your Life Course

People with disabilities can live the life they want



BY GAIL ALLYN SHORT

On weekday mornings, Bryshawn Jemison, 26, of Nashville rises at 4:30 a.m., gets dressed and catches a bus to a local gym where he works out. He then catches the 5:25 a.m. bus to his job at Vanderbilt University's Campus Dining.

At work, Jemison stocks shelves. He cleans and he organizes supplies. And every two weeks, his job coach stops by just to see how he is doing.

Though Jemison lives with a learning disability, he has his own apartment and gets help from aides who drop in to help him with routine chores.

"I love hanging out with friends," he says. "I like working out, going to games and talking on the phone."

Helping individuals with disabilities like Jemison's to map out the life they want is achievable, says Emma Shouse, public information specialist with the Tennessee Council on Developmental Disabilities.

"What makes a good life for people with disabilities is what makes a good life for all of us, which is having friends and family who love and care about us, and having the resources and money to do the things that we want to do," says Shouse, whose own brother, Evan, 26, lives with autism.

"It's having a feeling of belonging in our community," she says.

Helping individuals define their "good life" is the purpose of a tool called the LifeCourse Framework.

The LifeCourse Framework is "a set of guiding values, ideas and tools" that encourages dialogue and helps individuals with disabilities and their families to solve problems and discover what that person wants out of life—whether it is

living on their own with help from aides, getting a job or just going swimming.

The tool is useful, says Shouse, because although many persons with developmental disabilities receive some Medicaid services like vocational rehabilitation or accessible transportation, only 25% receive formal services. The vast majority are supported by their families.

LifeCourse helps families find solutions outside of the Medicaid disability support services, she says.

"You don't need a special disability service if going swimming is what they're passionate about," she says. "They may just need a neighbor to drive them to the rec center."

Shouse led Tennessee's "LifeCourse Community of Practice" for five years, and says that when her own family used the LifeCourse tools, they discovered that Evan wanted to visit a nearby river more often.

"That wasn't on our radar," she recalls. "It never occurred to us to say, 'Hey, support staff, why don't you guys make sure you go once a month to the river? That would make him really happy.'"

Meanwhile, Jemison says living on his own makes him happy.

"It makes me feel good and independent," he says. "It makes me feel awesome and great."

"What makes a good life for people with disabilities is what makes a good life for all of us. ... It's having a feeling of belonging in our community."

Emma Shouse
Public information specialist, Tennessee
Council on Developmental Disabilities

WHAT ARE HCBS WAIVERS?

HCBS stands for Home and Community-Based Services. HCBS waivers—also known as Section 1915 waivers—are long-term Medicaid supports that make it possible for people to live at home and in their communities who otherwise would need placement in a nursing home or some other institutional setting.

What are some examples?

The federal government waives some Medicaid requirements to let states decide which HCBS services to offer to certain groups of citizens. Services can include: access to **home health aides**; help with **personal care; case management**; aides to help with **household chores, meal preparation** and **transportation**; and **day and residential care**, just to name a few.

Who qualifies for HCBS waivers?

States can decide which groups of individuals qualify for HCBS waivers and set the criteria for service. But examples of people who might qualify include people with **intellectual or developmental disabilities** or **traumatic brain injuries** or anyone who might otherwise be placed into an institutional setting.

Families can find the free LifeCourse tools at www.lifecoursetools.com.

Self-advocate Ketrina Hazell has taken steps to ensure she has control over her own future with a Supported Decision-Making agreement.

PHOTO COURTESY OF KETRINA HAZELL

Alternatives to Guardianship Exist

Individuals with disabilities can retain their rights with Supported Decision-Making



BY ANNE STOKES

Cerebral palsy has not kept Ketrina Hazell from making a name for herself. The self-advocate was crowned Ms. Wheelchair New York 2018, co-founded the Voices of Power advocacy group, recently earned her associate degree and created a mentor program to help students with disabilities transition from high school to college.

Yet despite her capabilities, her parents were inundated by well-meaning case managers and medical professionals advising them to start the legal guardianship process around her 18th birthday. Luckily for Hazell, her parents were hesitant to take away their daughter's legal rights.

"It's like someone is assigned to be your voice, even if you can speak," she says of guardianship. "All I needed was someone to support me in making decisions."

Hazell found her solution when she attended a workshop put on by Supported Decision-Making New York (SDMNY). The program aims to educate individuals with disabilities as well as their families about alternative and less restrictive options to guardianship.

"This is what I really wanted, to create a support system instead of guardianship," she says. "The difference is the supporters aren't there to make the decisions for me, they're there to support me in making those decisions. They're not making them for me, I'm able to communicate with them and say, 'I want to make this decision in terms of medical (care), do you think that's a good idea?'"

Instead of an individual having no legal right to make life decisions, as would be the case under guardianship, supported decision-making involves an individual in creating their own plan with the help of chosen supporters in important areas like housing, finance, medical care, relationships, education and more. In 2018, Hazell created her own Supported Decision-Making

Agreement and today serves as a SDMNY advisory council member.

While not a legal document, Supported Decision-Making Agreements are a valuable tool that can be shared with medical providers, schools and more. Hazell says one of her advocacy goals is to have agreements like hers legally recognized.

"I want other people to know this is another option besides guardianship,"

she says. "I want policy makers to know that everyone's disability is not a one-size-fits-all approach. Just because a person has a disability doesn't mean they're not capable of using their voice."

"Just because a person has a disability doesn't mean they're not capable of using their voice."

Ketrina Hazell

Self-advocate and SDMNY advisory council member

GUARDIANSHIP VS. SUPPORTED DECISION-MAKING

For individuals who aren't capable of making their own life choices, guardianship may be the right choice. But for the many people who are capable, supported decision-making is a less restrictive option.

What is guardianship?

Guardianship **removes a person's rights to make their own life decisions** and gives that power to another. A guardian can make decisions in all aspects of their ward's life, including housing, health care, education, employment, finances and even personal relationships.

What is supported decision-making?

Supported decision-making **enables individuals with disabilities to make their own choices** with the guidance and advice of trusted friends and family designated as supporters. Supporters do not make decisions; rather they help evaluate options, provide information, or communicate with medical staff, educators, landlords or any other third parties.

For more information on Supported Decision-Making agreements, visit sdmny.org.

Sometimes a transportation issue comes down to where to park. Volunteers repaint parking spots reserved for people with disabilities.

PHOTO COURTESY OF NACDD



Making it Easier to Get Around

Transportation access is key to work and personal freedom

BY JILL SPEAR

BRIDGING THE DIGITAL DIVIDE

For years, people with disabilities have used the internet at rates below the rest of the population. This is largely due to the obstacles inherent in web software and hardware. A Pew Research study found that “62% of adults with a disability say they own a desktop or laptop computer compared with 81% of those without a disability.”

However, a 2010 law was enacted to address this inequality. The 21st Century Communications and Video Accessibility Act was passed by Congress to enable easier access to broadband, mobile and digital technology for people with disabilities.

Now, more assistive technologies to further enhance access are available, including:

- o **Subtitle Viewer** for online movies and videos
- o **RogerVoice** to capture phone conversations
- o **NonVisual Desktop Access** for people with low-visibility issues
- o **VoiceOver** with braille
- o **Accessibility Keyboard** for motor disabilities
- o **FaceTime Sign** for hearing disabilities

Tracee Garner uses a wheelchair and often relies on public transportation. “Navigating the transit system is a big deal,” she says.

The problems with transit in Sterling, Virginia, where she lives, have been numerous. “I work full time in another city,” she says, “and it’s really hard to get around without your own transportation.”

Rain, long trips on the bus and a lack of sidewalks to bus stops are among the barriers she and others constantly faced. Garner adds that it often takes a whole day to finish her errands.

Fortunately, the Virginia Developmental Disabilities Council awarded a grant aimed at improving transportation to the disAbility Law Center of Virginia. Steven Traubert was the project lead, working with self-advocates to create a video describing the barriers to health-care facilities that people with disabilities face. In addition, Traubert and his team developed a transportation toolkit that contained forms and an online survey for people to identify obstacles to public transportation.

Traubert says they considered the difficulties faced by individuals who use rides that come to their homes rather than public transit. Typically, they have to wait two hours for the ride, which itself takes two hours, followed by a two-hour ride home. “We thought, ‘What if people with disabilities could just get on a bus like everyone else?’ Then, we thought, ‘maybe the bus stops aren’t accessible,’” which Garner and other people with disabilities confirmed.

The grant was awarded in 2017, and the work was completed in 2018. Four localities in Virginia were selected for the project, which covered about 37% of the state’s population.

“We thought, ‘What if people with disabilities could just get on a bus like everyone else?’”

Steven Traubert

Advocate, disAbility Law Center of Virginia

Traubert and his team soon learned that many obstacles had to be fixed, from lack of crosswalks and curbs to cracked sidewalks and lack of visibility for people with vision issues.

Along with making transportation easier for residents, the project provided an economic benefit. The need for private rides, paid for by the city, was eliminated, saving both funds for the community and wasted hours for individuals. It was a win for everyone.

“When we finished, we were contacted by two other communities who were interested in the project,” Traubert adds.

Legislative outreach is often one on one. During Wisconsin's "Take Your Legislator to Work Day," Kate Rekoske explains expiration dates to Rep. Knodl in the pharmacy where she works.

PHOTO COURTESY OF NACDD

At the Ballot Box

Learn how and why a Georgia advocate is willing to make an 'awkward situation more awkward' on Election Day



BY THEA MARIE ROOD

Every American has the right to vote privately and independently. In fact, the Georgia Secretary of State—during an Independent Living Day event at the Capitol—unveiled three voting machines that were touted as being accessible to anyone with a physical or developmental disability.

The problem?

"None of them worked," says Danny Housley, the assistive technology case manager at Shepherd Center in Atlanta. "We were told, 'Oh, these are just demo machines—they'll work by the election.'"

But the reality is they didn't.

At the primary, for example, Housley, who is blind, waited more than four hours. At the general election, he waited "awhile," and the January senate runoff was a "nightmare."

"There were two different machines and one had a headset but didn't have a controller and the other had the controller but not the headset. And apparently you couldn't switch one out of the other," he recalls. "We were told we'd have access to someone who could have immediate tech support, but a poll worker was on hold on two cellphones, and when she finally got a technician, he didn't know the answer."

When these glitches occur, Housley describes pressure from poll workers to read him the ballot and mark down his answers. "If you can and are comfortable," says Housley, "make an awkward situation more awkward. (Tell poll workers), 'You're not reading it to me—I want to do it myself—and I'm going to sit right here until you get a machine that works.'"

In fact, his voting advice is simple: Know your rights. Have some advocacy phone numbers to call. And dig your feet in if you have to. "Do not be steamrolled," he advises. "Do not let

your rights be trampled on."

Housley advocates for people with disabilities, but he also has a soft approach to the people at his polling place, who he admits know him by now and have a bit of an "Oh, God" reaction when he walks in the door. "On the flip side, the poll workers handling the machines need better training. And (they need training around) what does it mean to interact with someone with disabilities?...It's always going to be a struggle—it's just a question of how intense is the struggle going to be."

"You're not reading it to me—I want to do it myself—and I'm going to sit right here until you get a machine that works."

Danny Housley
Assistive technology case manager,
Shepherd Center

Learn more at NACDD's voting website for people with disabilities, www.onevotenow.org.

VOTING ISSUES

Danny Housley sits on the executive board of the National Federation for the Blind and gives feedback to the Georgia Secretary of State on voting accessibility.

According to Housley, obstacles to casting your ballot include:

- o **Physical barriers:** These can range from broken sidewalks or inaccessible entrances for people in power chairs to voting machines—set up in haste—that aren't working properly.
- o **Transportation:** Especially in rural settings, polling places can be as far as 5 miles away—a real concern for people who don't drive. Many states have also done away with "Souls to the Polls," which allowed people to travel via church bus or carpool after services on Sundays.
- o **Too long a wait:** Especially during COVID, people can become anxious and leave their polling place, whether it's due to a long line or waiting for a tech to fix a machine.
- o **Misinformation:** People may wrongly assume mail-in ballots or accessible voting machines are no longer available.

Kevin Nuñez has advocated for improved working conditions and increased pay for direct support professionals statewide in New Jersey.

PHOTO COURTESY OF KEVIN NUÑEZ

Direct Support Professionals (DSPs) Are Essential

DSPs deserve a living wage

THE NEED FOR A LIVING WAGE

Across the country, wages for direct support professionals (DSPs) fail to meet the national cost of living, making it difficult to hire and retain skilled workers.

Low wages

- The median wage for a DSP is **\$12 an hour**, substantially lower than **\$16.14**, the national cost of living hourly wage needed to support a family of four.
- Such low wages put DSPs on the same income level as fast-food and retail workers, positions that require significantly **less** responsibility, training and skill.
- In New Jersey, **48%** of DSPs rely on public assistance.

High turnover rates

- The national average turnover rate for DSPs in 2019 was **42.8%**, although rates reached 64.8% in some states.
- Vacancy rates averaged **11.2%** nationally, but reached as high as **20.5%** in some states for part-time positions.
- The demand for DSPs is estimated to increase by **48%** in the next decade.

BY ANNE STOKES

What would you do for less than a living wage? Administer medications? Work around-the-clock hours? Provide behavioral intervention in potentially dangerous situations? For direct support professionals (DSPs), these are just some on-the-job expectations.

Kevin Nuñez knows first hand how important DSPs can be for individuals with disabilities. Nuñez, who serves as vice chair of the New Jersey Council on Developmental Disabilities, was born with cerebral palsy. He relies on family and DSPs to help with everyday tasks like getting in and out of his wheelchair and personal hygiene. Without such support, he says, “Honestly, we would be lost.”

“You’re essentially helping someone live their life. The assumption is that it’s glorified babysitting, but in reality it’s not,” he says. “Depending on the individual, you are their voice; you are more than just a physical elevator to get them in and out of bed. In some cases, you are by default their mother, their father, their brother. Without an effective DSP, an individual has no life.”

Despite their importance, DSPs face low pay, lack opportunities for advancement, and not surprisingly have a high turnover rate, which negatively affects individuals with disabilities and their continuum of care. Often, DSPs are their client’s main source of emotional support as well.

“It takes time for the DSP to get to know an individual, for the individual to trust them with some of the more intimate tasks,” Nuñez says. “A living wage and benefits in general could really entice the right caregiver to stay more than hopefully six months because what people don’t realize is a lot

of our caregivers, or DSPs, work two or three jobs just to make ends meet.”

In addition to his advocacy work with the New Jersey Council on Developmental Disabilities, Nuñez also serves on New Jersey’s Coalition for a DSP Living Wage. The coalition successfully advocated for a statewide wage increase, ensuring all DSPs receive a \$1.25 wage increase over the next several years. Nuñez says the goal is to improve conditions throughout the industry and help DSPs make a career out of caregiving, rather than a short-term job.

“They need to be seen as valued members of the health care workforce,” he says. “They make a world of difference.”

“Without an effective DSP, an individual has no life.”

Kevin Nuñez
Vice-Chair, New Jersey Council on
Developmental Disabilities

Working for Change, One Conversation at a Time

NACDD executive director sees opportunities by creating dialogue

Donna Meltzer, executive director of the National Association of Councils on Developmental Disabilities, sees the need for thoughtful conversations nationwide—especially open dialogue that can lead to positive change, even when the conversation is uncomfortable.

NACDD wants to empower Councils to start those conversations. “At the national level, we work for change,” Meltzer says. “We do this in concert with our State Councils on Developmental Disabilities.”

“We know that conversations can be difficult and often there is push-back from people when new ideas are presented because these new ideas can challenge their authority, feel like they are losing control, or the ideas may sound costly and unwieldy. But we created this publication to provide each Council with a start for their own narrative.

“If a Council is struggling to get a new idea moving for employment, perhaps by knowing which other states have done it successfully can help move their idea forward with proof of concept that the idea can work.”



Creating Change Doesn't Happen Overnight

Some questions for discussion with your Council around the topics we have presented in this publication:

- Do we fully understand the change we want to make?
- Are all populations/people at the table and sharing their thoughts and ideas?
- Have we tried to make this change before? If we tried before but didn't succeed, why not? Were we missing key data points? Were we not being sensitive to all perspectives or not listening actively to all people? Was there resistance from other stakeholders or policymakers?
- If we succeeded before but the pandemic has changed things again (or opened new opportunities), should we try again?
- What are the reasons why we want or need this change? Can we list three to four reasons?
- What might we have to give up or lose in order to achieve our goal?
- Are we prepared for success? What does success look like?
- If we don't make this change now, then what?

“Uncomfortable conversations are just the start. We want to create good dialogue.”

Donna Meltzer
Executive director, NACDD

Find the Developmental Disability Council near you at www.nacdd.org/councils/.

Conversation Starters for Your State

Find the data you need to stay informed

Having data—especially state-specific data—can be very helpful in breaking the ice for a conversation. The more you know about your state demographics and trends in state legislation in a particular area, the better prepared you will be to engage in meaningful dialogue. Below are data sets and other resources to help make conversations specific to your state.

Access to Health Care

Compared to people without disabilities, people with disabilities have less access to health care. DD Councils can search and compare national and state level disability data on approximately 30 health indicators, such as smoking, heart disease, and receiving the flu vaccine using the Disability and Health Data System. These data can help with advocacy for inclusive communities, programs and services needed to improve the health of adults with disabilities.

Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability. Find Disability and Health Data System (DHDS) data at <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>.

Job and Career Paths are Possible

The Disability Employment TA (Technical Assistance) Center's Resource Clearinghouse offers a trove of resources on disability employment for Administration on Disabilities (AoD) programs and other stakeholders. You can search an extensive database for resources on dozens of employment issues such as 14(c), employment first, career pathways, inclusion and equity, job coaching, self-determination and so much more.

Resource Clearinghouse, Disability Employment TA Center; aoddabilityemploymenttacenter.com/resource-clearinghouse/.

To find which employers hold 14(c) certificates in your state, go to this Department of Labor website: www.dol.gov/agencies/whd/workers-with-disabilities/section-14c/certificate-holders.

Creating Opportunities for Community Living is our Focus

Get an overview of affordable housing needs at the state level. Learn about the most critical housing needs in communities across the country. Connect with National Low Income Housing Coalition partners to expand housing resources in your state.

"Housing Needs by State," National Low Income Housing Coalition; nlihc.org/housing-needs-by-state.

Set Your Life Course

Find out which Medicaid waivers the Centers for Medicare and Medicaid Services (CMS) has authorized in your state using the Medicaid State Waivers database for 1915(b), section 1915(c), and section 1115 authorities.

"State Waivers List," Medicaid, Centers for Medicare and Medicaid Services; <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>.

Alternatives to Guardianship Exist!

Each state maintains its own guardianship laws. The Law and Aging Commission of the American Bar Association maintains a website of recent developments in supported decision-making. It also has a model law for states to consider when moving from traditional guardianship to supported decision making model.

"Guardianship and Conservatorship," American Bar Association; www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/.

Making it Easier to Get Around

The National Conference of State Legislatures maintains an Accessible Transportation State Legislative Update that tracks how legislatures continue to adopt laws and programs that assess accessibility practices and provide mobility options.

"Accessible Transportation State Legislative Update," National Conference of State Legislatures; www.ncsl.org/research/transportation/accessible-transportation-state-legislative-update.aspx.

At the Ballot Box

Check out an interactive map that tracks state election laws and policies and learn more about creating better ways to protect our access to the ballot box by going to the Democracy Maps website.

"Democracy Maps," Movement Advancement Project; www.mapresearch.org/democracy-maps/ratings_by_state.

Direct Support Professionals (DSPs) are the Key to Success!

Family caregiving is also an important part of natural supports for people with I/DD. Read the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council report to learn more about the current state of family caregiving and 26 recommendations for how the federal government, states, tribes, territories and communities can support family caregivers.

"RAISE Family Caregivers Act Initial Report to Congress, Administration for Community Living; acl.gov/RAISE/report.

Get Toolkits and other Resources

Find information and links to resources created by NACDD's member councils on such topics as:

Cultural and Linguistic Competency	Health Care
Education	Housing
Emergency Preparedness	Inclusive Child Care
Estate and Trust Planning	Support Services and Service Brokers
Faith-based Communities	Transportation

Go to: <https://www.nacdd.org/resources>

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