

The Power of Inclusion

The Nebraska Council on
Developmental Disabilities
helps everyone
have a voice.





Maximum Impact

The Nebraska Council on Developmental Disabilities leads changes on a systemic level

BY MATT CRAGGS

For nearly 50 years, the Nebraska Council on Developmental Disabilities has been a leading voice for change for people with disabilities and their families.

“Governor Exon, on March 11, 1971, established the council,” said Kristen Larsen, Executive Director, NCDD. “It goes back to the Developmental Disabilities Assistance and Bill of Rights Act of 1970. Within that act, the federal definition of intellectual and developmental disability was established.”

The law also created four sister programs, now found in every state — State Councils on Developmental Disabilities; University Centers for Excellence in Developmental Disabilities Education, Research, and Service; Protection & Advocacy Systems; and Projects of National Significance.

As described in the DD Act of 2000, the collaborative goal of the programs is to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.”

By law, 60 percent of state council membership must be individuals with developmental disabilities or their family members, and the remaining 40 percent are sourced from relevant state and advocacy agencies.

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Kristen Larsen
Executive Director, Nebraska Council on
Developmental Disabilities

“When you have this rich collection of input from self-advocates and family members, the developmental disability community is positively impacted,” Larsen said.

The Council engages in advocacy and systemic change activities, such as conducting research, reviewing proposed legislation, and providing funding that addresses gaps and improves services statewide.

In addition to advocacy and leadership training seminars plus efforts to expand and enhance respite and dementia care, the NCDD also recently provided funding for the initial development of Nebraska’s Olmstead Plan.

“The Plan is named after the 1999 U.S. Supreme Court decision,” Larsen said, referring to *Olmstead v. L.C.* “The court ruled that states should work to undo unnecessary segregation of people with disabilities and assure that they receive services in the most integrated setting for their needs.”

For Larsen, whose adult son has autism, it’s a personal cause.

“If I’d had my son many years ago, I would have been told by the doctor, ‘You don’t have to worry about raising him, you can just send him to the state institution.’”

Instead of segregating and marginalizing people with disabilities, Larsen hopes the Council can continue to help promote a truly integrated community.

“Challenging communities to recognize a person’s strengths and commonalities rather than focusing on a person’s disability or label encourages inclusion,” Larsen said. “There’s diversity in all of us — that’s what makes our communities richer.”

Self-Advocates

Services and supports can help people with disabilities in everyday life, but self-advocacy is the driving force behind a life of the individual’s choosing.

“Promoting self-advocacy is a foundational component to helping people with disabilities experience meaningful lives,” said Kristen Larsen, Executive Director of the Nebraska Council on Developmental Disabilities.

Self-advocacy can take many shapes — choosing jobs, housing, friends or activities — but ultimately comes down to individuals having the attitude and skills to direct the next step in their lives.

However, when there’s an emphasis on self-advocacy from an early age, Larsen believes people with disabilities can thrive.

“They’re learning skills and becoming active citizens in their community,” Larsen said. “When they’re doing that well, they’re helping others around them be a little more mindful about the decisions they make every day.”

Toby (left) and Boaz McDonald (right) at Buffalo Hills Elementary School.
PHOTO BY TODD RUNDSTROM



Learning By Example

Being in the same classroom as other children makes a difference for Toby and Boaz McDonald

BY JENNIFER XUE

Suzanne McDonald is the mother of five children. Two of her sons, Toby Jr. and Boaz, were adopted and have Down syndrome.

McDonald has always provided her children with the same love, care and attention. So she never questioned that Toby and Boaz should be included in the same activities and schooling that all other children have access

“Since they both have been fully included in their classes, I can’t even begin to list all of the appropriate behaviors and life skills they have learned.”

Suzanne McDonald
Mother and education advocate

to. However, when the family moved into a new school district, she realized not everyone thought the same way.

“At his first school, Toby was fully included in a class with typical peers for preschool and kindergarten,” said McDonald. “The new school district had a life skills classroom where they put *any* child with *any* disability. This infuriated me.”

That’s when McDonald decided to become an advocate for inclusive education: She enrolled in the Inclusive Education Lay Advocacy Program through Disability Rights Nebraska.

McDonald said when Toby was separated from the rest of his class, he was seen as a student with a disability first.

“Instead of being a kindergartner with Down syndrome, he was seen as a child with Down syndrome who happened to be at the kindergarten level,” she said. “Even the kids knew it.”

Eventually, the McDonalds changed school districts again and are now happily attending Buffalo Hills Elementary in Kearney, where both her sons are included in regular classroom settings.

McDonald sees the progress they’re making now by imitating their peers. “Since they both have been fully included in their classes, I can’t even begin to list all of the appropriate behaviors and life skills they have learned,” McDonald said.

Including people with disabilities in everyday society and giving them access to the same resources as everyone else is a basic civil right, McDonald said. Whether in the classroom or on the athletic field, that simply means connecting with her sons’ teachers and coaches and discussing how to best meet their needs.

Today, Toby plays flag football on a YMCA team alongside his peers. In a team setting, he’s learned the most important lesson McDonald has witnessed so far — that he’s a valuable member, just like everybody else.

“Inclusion doesn’t just benefit the child with the disability,” McDonald said. “It helps their peers know the value of every life and helps them learn how to interact with individuals who are different from them. It’s a total win-win!”

Knowing Where to Turn

Fourteen percent of public school students in the 2017-2018 school year had a developmental disability and received educational assistance, according to the National Center for Education Statistics.

Getting the right help for a student with special needs can be daunting for parents, but fortunately there are programs and organizations in Nebraska dedicated to empowering students with inclusion, advocacy and education.

▶ **PTI Nebraska (Parent Training and Information)**

Provides statewide educational resources and access to parent/professional staff for parents of children with disabilities.

pti-nebraska.org
402-346-0525 or 800-284-8520

▶ **Answers4Families**

Offers support and resources for families of individuals with special needs.

answers4families.org
402-472-0844 or 800-746-8420

▶ **Disability Rights Nebraska**

Helps train advocates for inclusive education for people with disabilities.

disabilityrightsnebraska.org
402-474-3183 or 800-422-6691

A Global Messenger

Jason Gieschen takes his message across the state, the country and the world

BY MATT CRAGGS



Jason Gieschen as a global messenger.
PHOTO COURTESY OF JASON GIESCHEN

For people with intellectual and developmental disabilities, finding the right services and supports can make all the difference, fostering a lifetime of confidence and advocacy.

“When I was in high school,” Jason Gieschen said, “I got in trouble and had to go to the principal’s office. He said, ‘I would like to see if you’re interested in doing Special Olympics.’ I’d never heard of Special Olympics. But I said I’d give it a try and I fell in love with it.”

Gieschen, who has Asperger’s syndrome, a condition on the autism spectrum, began a career of athleticism and advocacy by bowling. He also competed in swimming, equestrian, basketball, golf, track and field and unified bowling and golf.

In 2009, he began training as a powerlifter. Gieschen’s focus was on squats, bench press and deadlift — with a personal record of 302 pounds.

“I’m a lot stronger now,” Gieschen said. “I was always a strong kid, but I’m a lot stronger now.”

While training to compete in the 2015 Special Olympics World Games in Los Angeles, Gieschen was invited to become a Sargent Shriver International Global Messenger, one of only 12 people chosen out of more than five million Special Olympics athletes.

Gieschen traveled the world, speaking to groups at the 2017 Special Olympics World Games in Austria and the Centers for Disease Control and Prevention in Atlanta, Georgia.

“I tell them my story,” he said, “what Special Olympics is about, what it provides for people with intellectual disabilities, and how much fun their athletes can have.”

Gieschen built his confidence in speaking to large groups and, when his four-year term recently ended, Gieschen continued his public advocacy work as a Special Olympics Health Messenger, a health and wellness leader, role model and educator.

“People who have an intellectual disability live 10 to 15 years less than people without an intellectual disability,” Gieschen said, citing the lack of access to good healthcare as a primary factor.

He now meets with healthcare professionals across the nation to discuss how medical facilities can better serve people with disabilities.

Gieschen is also a member of the Nebraska Council on Developmental Disabilities and works for Educational Service Unit 16, a job he’s had for 20 years. He sings the National Anthem at sporting and community events too.

“I tell them my story — what Special Olympics is about, what it provides for people with intellectual disabilities, and how much fun their athletes can have.”

Jason Gieschen

Council Member for the Nebraska Council on Developmental Disabilities

From being sent to the principal’s office to advocating on a global scale, Gieschen proves the right supports not only make a world of difference, it can make a difference in the world.

Guides for Along the Way

As they transition through life, people with developmental disabilities and family members who assist them can find the process of accessing services and supports overwhelming.

With funding from the NCDD, Lloya Fritz and Mary O’Hare, the partners of Fritz & O’Hare Associates, worked with self-advocates, parents and professionals to create the “Along the Way” series of guides.

The four guides provide information and resources related to advocacy, housing, education, healthcare, employment, benefits and financial planning at all stages of life.

“What we tried to do,” O’Hare said, “was not just put down lists. We also tried to put together brief info of what families and individuals need to know to access services and what those services can do for them.”

The user-friendly guides introduce readers to terminology, state and federal laws, and tips on navigating the process to help people with developmental disabilities live and participate in their communities as independently as possible.

“It is complicated,” Fritz said. “We’re not naïve enough to think this solves it, but we do hope it helps.”

For free digital guides, visit the Resources section of the NCDD website, dhhs.ne.gov/ddcouncil.

Taking Flight

BY JENNIFER XUE

Advocacy and self-determination mean Kiera Orduña's dreams are soaring.

Sharon Orduña is a staunch advocate for her 24-year-old daughter, Kiera, who was diagnosed as being on the autism spectrum as a toddler.

Her advocacy is also solely focused on Kiera following a path she has determined for herself.

"Self-determination is worth pursuing because individuals with developmental disabilities deserve to have their interests represented," Sharon said. "Like me, Kiera has specific likes and dislikes. She is passionate about having input regarding her future goals."

Kiera's primary interest since childhood has involved aircraft, airports and flight operations. In May 2019, she graduated cum laude from the University of Nebraska Omaha and now holds a bachelor's degree in multidisciplinary studies with an emphasis in aviation (as well as math and Spanish). This summer, she will go to Seattle to attend Alaska Airlines' INFLIGHT program.

Sharon's primary advocacy role is to parallel her daughter's journey every step of the way. "I completed a year-long travel academy in Omaha and was employed by two major air carriers to coincide with Kiera's formal training at UNO," she said. "Pre-teaching skills have been a valuable tool in educating Kiera."

In fact, the Orduñas have always gone the extra mile when it comes to Kiera's education. "We were located in [another state] at the time of the diagnosis and they were still of the mindset that students with disabilities needed to be segregated," Sharon recalled. "After an impasse with the central office, we left the school district."

They also left the state. They moved to Omaha later that year, where school staff were happy to work with Sharon and include Kiera in regular classrooms. "This was the best model for her to learn from her peers," Sharon said. "The time was limited at first and then increased as she met goals. In those early years, peers became natural advocates for

Kiera, and by the fifth grade, she was spending the entire day in regular education classes."

This inclusion had a big impact on Kiera's academic and career success, something Sharon intuitively felt at the time, and was confirmed as she learned more from professional resources and parent networks. "Parents must know without a doubt that they are the expert on their child — no one knows them better than the parent," Sharon said. "And they must advocate from that position of strength and knowledge."

Now an active Nebraska Council on Developmental Disabilities member, Sharon continues advocating for children with disabilities. "They must learn to use their voices to express their desires and needs to others," she said.

"Parents must know without a doubt that they are the experts on their child ... and they must advocate from that position of strength and knowledge."

Sharon Orduña
Mother and advocate



Kiera Orduña and her parents, Sharon and Paul.
PHOTO BY KAYLA WOLF

Advocacy Resources

- ▶ **Disability Rights Nebraska**
Operates seven federally funded Protection & Advocacy programs, including legal representation and other advocacy services designed to help secure individuals' rights, dignity and full participation as citizens.
disabilityrightsnebraska.org
402-474-3183 or 800-422-6691
- ▶ **Munroe-Meyer Institute**
Part of the University of Nebraska Medical Center, a designated University Center for Excellence in Developmental Disabilities (UCEDD), it offers leadership training opportunities for family member advocates and self-advocates.
unmc.edu/mmi
402-559-6418 or
800-656-3937 x96418
- ▶ **People First of Nebraska, Inc.**
The only statewide organization run for and by people with disabilities, with resources and training for community inclusion and self-determination.
peoplefirstnebraska.com
402-559-4892
- ▶ **The Arc of Nebraska**
Provides a wide range of training programs, including self-advocacy, person-centered planning, legislative advocacy, voting and social relationships.
arc-nebraska.org
402-475-4407

Haley Waggoner at work.
PHOTO BY KAYLA WOLF

Sweet Self-Advocacy

Haley Waggoner splits her time between cupcakes and influencing the state legislature

BY MATT CRAGGS

Nearing the end of high school, Haley Waggoner was thinking about cupcakes. Though an avid baker at home — chocolate mint and lemon blueberry cupcakes are two of her specialties — Waggoner was often told that because of her medical issues, learning difficulties and social anxiety, she would never find work in the baking world.

Through her public high school in Lincoln, Waggoner enrolled in Vocational Opportunity in Community Experience, a work-experience program that bolsters skills and connections to help individuals with intellectual and developmental disabilities transition into adult life.

To match her culinary interests, VOICE placed Waggoner at Hy-Vee in the regional supermarket's bakery. After her first year in the work-experience program, the store's

bakery manager, Ron Scholz, offered Waggoner a job.

"We could tell the potential for what a great worker she would be," Scholz said. "So we were willing to do whatever would make her feel comfortable in that position."

These accommodations included a temporary job coach and note cards she could read from if she needed to engage customers — little things that allowed Waggoner to perform her duties and hold a job.

"It's important to me because I can get out of the house and earn my own money, just like everyone else does," Waggoner said. "I may do it in a different way, but I'm still going out there and doing it."

"It's been wonderful," Scholz said. "She is great — hardworking, always does everything she's asked. She went from just wrapping products and putting them on the shelves to, now, she also decorates cupcakes and cookies."

Waggoner no longer relies on the note cards. In fact, working at Hy-Vee has helped her social anxiety because she's formed good friendships with co-workers who, she said, treat her as they would anyone else.

In addition to being a strong self-advocate, Waggoner advocates for others as an athlete and ambassador for Special Olympics and as a member of the Nebraska Council on Developmental Disabilities. Waggoner also organized a rally in 2012 with the Nebraska Youth Leadership Council, urging lawmakers to remove the phrase "mental retardation" from state

statutes. She worked with Sen. Colby Coash on Legislative Bill 343 to replace the offensive phrase with "intellectual disability" and, in 2013, the governor signed the bill into law.

While advocacy remains important to Waggoner, cupcakes are her dream. With more than 10 years — and counting — of professional baking experience, Waggoner hopes to one day take the skills she's learned and open her own bakery.

"If people say you can't do it, but you want to try it," Waggoner said, "try it."

"If people say you can't do it, but you want to try it — try it."

Haley Waggoner
Advocate and Hy-Vee employee



Competitive Employment Resources

Nebraska VR (Vocational Rehabilitation) helps people with disabilities succeed in jobs by providing support and training.

High school students receive pre-employment transition services — job exploration, work experience, college counseling, and building social and independent living skills. Nebraska VR also offers a variety of statewide programs.

- Project SEARCH offers students an introduction to the workplace with classroom training and hands-on experience at a variety of job sites.
- Transition Summer Programs feature partners hosting hands-on activities to develop skills for the workforce.
- Benefits workshops provide information on how to keep benefits while earning an income.
- Family Employment Awareness Training (FEAT), provided by PTI Nebraska, details state and federal employment resources, seeking to increase expectations for competitive employment.
- Supported Employment can be accessed after coming off the wait list.

For more information, visit vr.nebraska.gov.

Erin and Mary Phillips.
PHOTO BY KAYLA WOLF



Finding a Voice

Erin Phillips' self-advocacy started young and built a lifetime of pride

BY MATT CRAGGS

Erin Phillips isn't simply integrated into her community, she's shaping it. Erin, who has cerebral palsy, recently became a member of the Nebraska Council on Developmental Disabilities. She also actively advocates for others as a Disability Policy Specialist at People First of Nebraska, Inc., where she reviews proposed state legislation — drawing on both her professional and personal experiences to testify to the state legislature on the pros and cons of the bills' impact on the community.

"I can choose what I want to do and how I do it," Erin said. "I can speak up for myself. I can help give voice to those who don't have a voice. I can model how to live life for people who don't know how or can't."

According to Mary Phillips, Erin's mother and the director of Special Education for Educational Service Unit 6, Erin has an expectation for inclusivity, which became her daughter's norm. That, along with her self-determination, forged her into a strong self-advocate with a life integrated into her community.

"You can't grow self-advocacy overnight," Mary said. "When Erin was very young, we had her involved in 4-H, Girl Scouts and religious classes and she was educated in an inclusive environment at school."

Erin said she takes great pride in making a difference in people's lives through her work with the government, a patriotic path of service inspired by the military career of her father, Don Phillips.

Additionally, Erin has worked for nine years at a local grocer while volunteering at local organizations, including the Statewide Independent Living Council and The Arc of Nebraska where, in 2018, she helped organize a Disability Pride rally at the state capitol.

"We had a march on the capitol steps to show that we exist," Erin said. "There are people with disabilities in the world. We have a voice and we know how to use it."

Erin also utilizes her voice as part of the I²Choir, Lincoln's intergenerational, inter-ability choir. She crochets sweaters, hats and blankets, which she gives to friends and donates to her day program's silent auction fundraiser.

These activities all exemplify Erin's advice on life. "Get out into the community," Erin said. "Get off the couch and have fun. Meet new people, learn new things."

Mary also has advice. "Parents and caregivers need to start early and make this a natural part of living," Mary said. "Expose their children to the community and

"I can choose what I want to do and how I do it. I can speak up for myself. I can help give voice to those who don't have a voice."

Erin Phillips
Self-advocate

different activities and organizations that interest them so that it becomes part of their normal."

Of her future plans, Erin said: "Get married and adopt a child."

Society's Self-Worth

By creating more opportunities for people with disabilities to integrate into our communities, Wayne Stuber, PT, Ph.D., believes we can ultimately form a happier society.

The Associate Director of the Munroe-Meyer Institute at the University of Nebraska Medical Center, he sees the value of inclusion. How someone experiences societal expectations in areas such as education, employment and relationships informs how they feel about themselves, which has a ripple effect.

When these expectations are absent, or an individual feels they're not able to meet them,

it can drastically affect one's self-esteem.

"Part of general human nature has to do with your perception of your self-worth," Stuber said. "There's always that either implicit or explicit pressure to meet those norms. The better we can meet them, the better our sense of self-worth."

Through inclusive recreational, educational and vocational opportunities, he feels the entire community is transformed.

"How a society affirms its humanity," he said, "is when it best serves those who require assistance."

How to Make Our Communities More Inclusive



Employers:

People with disabilities want to be productive members of their communities. They have many skills, talents and abilities that make them valuable to employers who are willing to give them a chance and provide them with reasonable accommodations.



Inclusive Education:

All students are educated in age-appropriate general education classrooms; develop relationships with their peers; experience higher expectations and improved test scores; and attend their neighborhood schools. Students with disabilities are participating members of their school community and are prepared for a natural transition into meaningful adult lives.

Source: Disability Rights Nebraska



Serve on the Council:

Community members interested in serving on the Council can submit an application online at the Boards & Commissions webpage: governor.nebraska.gov/board-comm-req or by mailing a completed Executive Appointment Application to the Appointments Office at the Office of the Governor. People with disabilities and family members are encouraged to apply.

Learn more and find out how you can take action



Subscribe to the Council Website:

The Council awards federal funds to recipients who promote the goals and objectives outlined in the Council's five-year state plan. To learn more about Council projects and activities, scheduled public meetings and grant funding opportunities, visit and subscribe to the Council's website at dhhs.ne.gov/ddcouncil.

Projects noted in the publication that are funded by the Council include:

- Disability Rights Nebraska's Inclusive Education Lay Advocacy Program
- Munroe-Meyer Institute's Leadership Seminar Series
- People First of Nebraska
- Special Olympics Athlete Leadership Program
- Munroe-Meyer Institute's Respite Task Force Study
- Munroe-Meyer Institute's Dementia Capable Care Training



Subscribe to the Division of Developmental Disabilities Email:

DHHS-DD Division provides funding and oversight for the Medicaid home and community-based developmental disabilities waiver services. You can receive emails about local and federal information that affects people with developmental disabilities, as well as notices of upcoming changes and public events hosted by DHHS-DD Division.

To sign up, send an email to: DHHS.DDCCommunityBasedServices@nebraska.gov.

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