SOUTH DAKOTA Possibilities 2022

A publication by the Center for Disabilities highlighting the state's abundant opportunities for people with disabilities
Welcome to Our Seventh Edition of South Dakota Possibilities!

This publication was created as a way to share the successes of individuals with disabilities and their families. It is our goal to continue to raise awareness and highlight the skills and unique talents of people with disabilities.

In this edition, you will find stories of independence, diligence, optimism and commitment to pursuing one’s life ambitions. No matter how big or small, everyone has something to contribute. We are eager to share with you the truly great faces of South Dakota. The possibilities are endless, and the potential is great!

We are always looking for more people to feature from around the state. If you know of someone who might be interested in being in our next issue, please send an email to cd@usd.edu with the name and contact information.

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Birth to Three Program Offers Early Intervention for the Youngest

Carla, Lena and Ashley Rigge
Only six months after giving birth to her daughter, Ashley Rigge never would have suspected something could go wrong.

Tiny Lena Rigge’s fists would clench, her legs would buckle and she would fall into a deep sleep. A puzzled and worried mother and her husband, Matthew, turned to a neurologist for answers. From that appointment, they were connected to a support system, the Birth to Three Program offered through the University of South Dakota Sanford School of Medicine Center for Disabilities.

Jamie Butler and Nicole Saue are service coordinators with the Birth to Three Program and have been in this position for seven and 10 years, respectively. Butler has a degree in human development and family studies while Saue majored in social work. They both worked at the Helpline Center for several years before joining this program.

Service coordinators (the role Butler, Saue and others play) can be described as the “tour guides” of the Birth to Three Program. The process begins with the initial referral process which can be from a physician’s office, a family member, parents or another individual. The service coordinators meet with the parents and discuss their concerns with the infant or toddler. A developmental screening looks at every area of a child’s growth. Sometimes the child has a medical condition that automatically leads to an evaluation.

The Birth to Three Program goes by different names in other states, but its goal is
the same: to offer early intervention to children with disabilities. This federal program has been operational since the early 1990s.

South Dakota has divided the early intervention program into six regions with 23 different service coordinators. The Center for Disabilities’ Birth to Three Program covers Minnehaha County and expands to the counties of Brookings, Kingsbury, Sanborn, Miner, Lake, Moody, Davison and McCook.

“The Center for Disabilities covers those counties, but South Dakota as a whole is served completely by the Birth to Three Program,” Butler summarized.

In 2021, the Birth to Three Program served 853 individuals with unduplicated services. While services dropped temporarily during the COVID-19 pandemic in the first half of 2022, they have risen to previous levels.

“In fact, I feel that since COVID we’ve had an increase in concern for their kiddos from families,” Saue explained. “I think a lot of that is due to being at home and not having social interaction with their peers at daycare.”

Limited interaction during the pandemic also led to a delay in well-child visits with doctors. That, in turn, delayed referrals.

“None of that is research based, but we feel that echoed with other coordinators,” Butler reported.

Most school districts start off with a screening. Those scores let the service coordinator know if a child qualifies for the Birth to Three Program.

“Once all testing is done, we coordinate the meeting,” Saue stated. “We go to the family home, discuss the testing results, explain their eligibility, and determine if they want to start therapy services. If therapy is desired, an individual family service plan is prepared, therapy begins and monthly checks start.”

The Birth to Three Program is offered to families at no cost using federal funding along with an allotment from the state Department of Education. Therapists can bill Medicaid if a family is eligible under that program. Children served by the Birth to Three Program come in with a wide range of concerns.

“The main therapies are physical therapy, occupational therapy, speech therapy and special education,” Saue said.

A baby may come in with a tight muscle on one side of the neck. A physical therapist can show the parents stretches, stretching exercises and positioning exercises to prevent a flat spot. A physical therapist also will guide the child
through gross motor
development exercises,
making sure they meet
those milestones.

A child with a
speech delay will meet
with a speech therapist,
working with the family
to help advance language
and community
development.

Rigge’s issues meant
she needed the services
of speech, physical
and occupational
therapists. She saw an occupational therapist
the most frequently to make sure she hit her
age-appropriate milestones as close to the usual
schedule as possible.

The Rigges and their doctors still do not
know why she began having seizures in March.
She would squeeze her fists, and when her
legs folded, she fell forward. After the seizures
ended, Rigge would show anger at having her
playtime disrupted, and she needed a lengthy
nap afterwards.

The seizures became repetitive, happening
three and four times a day. That is when the
Rigges turned to a neurologist for answers. No
definite diagnosis has been determined, but
the existing diagnosis is infantile spasms. Her
neurologist examined case studies from the
United Kingdom and Australia. She does not
believe there will be long-term effects.

“The whole basis of Birth to Three is family
education,” Saue disclosed. “Therapists are
showing those families what they need to do
and what they need to follow up on to help
their child.”

“We worked together as a team,” Rigge
said of the therapists who came to the family
home to offer her daughter services she needed.
“We’re partners. They don’t say, ‘we’re in
charge.’ They say, ‘your child is in charge now.’
I’ve always felt supported and helped. They
want the best for her and our family.”

Rigge describes her daughter, who
celebrated her first birthday on Sept. 28, 2022,
as a happy kid who loves to laugh. She’s truly a
honey bun, and she loves her big sister.

Rigge will always be grateful for the Birth
to Three Program and its therapists. She
hopes other parents in similar situations will
be directed toward Birth to Three for the
necessary support.

“If you feel your child needs extra help,
don’t be afraid to put forth the effort to have
them be screened,” she summarized. “The
people involved in the program know what
they’re doing.”

Rigge expressed. “I felt
the weight go off my shoulders.”

At her home Rigge has seen her speech,
physical and occupational therapist. “That is
a relief, too,” Rigge commented, “because the
sessions take place in surroundings familiar to
Lena, and she does not have to be bundled up
and taken somewhere else.”

Clara, Rigge’s big sister, also has become
part of the process. She watches closely as the
therapist positions her sister’s hips to enable her
to crawl.

“The therapists are good with the siblings,”
Rigge disclosed. “I can tell they want them to be
as involved as possible.”

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LEND Program Prepares Trainees for their Futures

As a trainee with the Leadership Education in Neurodevelopmental Disabilities (LEND) Program through the University of South Dakota (USD) Sanford School of Medicine Center for Disabilities, Blake Warner’s time there led to life-affirming experiences and a promising career trajectory.

“The LEND Program has been federally funded for more than 30 years,” summarized Marni Johnson, Au.D., the Center for Disabilities’ interdisciplinary clinic and training director. “LEND programs provide long-term, graduate-level interdisciplinary training as well as interdisciplinary services and care. The purpose of the LEND training program is to improve the health of infants, children and adolescents with disabilities. Programs accomplish this by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields. It also ensures high levels of interdisciplinary clinical competence,” Johnson said.

The son and brother of special-education teachers, Warner never would have predicted that would be his future. In high school he acted as his mother’s teaching assistant and learned about the field firsthand. Despite that, true passion didn’t spark until the opportunity to train with LEND arose.

“I fell in love with the population and the work, and the Center for Disabilities was there as well,” Warner claimed. “I realized this is something I can do with my life where I can help others, and I’m really passionate about.”

Currently, Warner is a doctoral student in clinical psychology at USD. He earned both his undergraduate and Master of Arts degrees from USD. His M.A. in clinical psychology was awarded in May 2022.

The Windom, Minnesota, native concluded 2022 by proposing his doctoral dissertation in October and applying to year-long residencies. He will learn in February which school he has been matched with; his internship will start next summer. The months in between will be focused on writing his dissertation.

His career goal is to work in the disability field which he describes as his passion.

“I hope to be working as a clinician with individuals with intellectual and developmental disabilities,” Warner expressed. “If we look further into the future, maybe I would be in a place like the Center for Disabilities in a more administrative position. I hope to be in
a position where I can do a lot of different roles and have my hand in a lot of pots.”

“LEND is such a valuable experience for trainees and is something that sets them apart from others in their respective fields,” Johnson explained. “Employers seek out former LEND trainees when hiring clinicians because they know of their specialized training in supporting individuals with disabilities and their families and their focus on leadership development, policy and advocacy. LEND trainees really are the best of the best.”

Warner had learned about LEND through others who had passed through the program. “USD’s clinical psychology program is tightknit,” he stated, “with only six students per year. At least one typically is a LEND trainee. Other trainees had nothing but good to say about the program, and, lo and behold, they were right. It was an amazing opportunity, and I’m all the better for it.”

LEND trainees come from various disciplines, including but not limited to audiology, clinical psychology, genetic counseling, medicine, nutrition, occupational therapy, physical therapy, school psychology, speech language pathology and social work. In addition, there are self-advocate and parent trainees who come with such valuable lived experiences to share, and they are fully integrated participants in the program.

Warner views the program as being comprised of three parts: education, research and clinical, as well as being self-reflective on your own beliefs regarding various topics. Trainees go through the process of learning to provide services to individuals and families.

The education component allows the trainees to learn from experts in the field. Warner learned from panels comprised of self-advocates and caregivers who came in to talk about what works and what doesn’t work in the field of disabilities. They enhanced the importance of advocating for individuals and families.

“In the research component, we have hours of experience with a research project, and we learn to go through the steps of research. We take our knowledge of disabilities and work to contribute to the literature,” explained Warner.

“Current trainees must complete a minimum of 360 hours total – 120 in clinical training, 120 in leadership training, and 120 in research,” Johnson described.

The third part is clinical experience. The LEND trainees observe a variety of interdisciplinary clinics related to neurodevelopmental disabilities. In some cases, they actively participate in LEND developmental, autism and fetal alcohol spectrum disorders clinics among others.

“We see real patients coming in for diagnostics or go to partner clinics and watch a professional as they go through the business of the day,” Warner summarized. “LEND really shines in its interdisciplinary work and its in-depth training in neurodevelopmental and related disabilities.”

Warner is especially knowledgeable about LEND since he had the opportunity to go through it twice. His first LEND year was 2019-2020 with the second in 2020-2021.

“LEND has been the best opportunity of my graduate training,” Warner exclaimed. “I felt like I had so much more to learn, and so much more that I could get from being a LEND trainee, I did it twice. In my first year of LEND, I did a lot of
observation. I really wanted to be able to extend that focus more on leadership and advocacy the second year.”

Warner left his two years of LEND with a great sense of confidence.

“The psychologist I worked with during my second year did a great job of taking a back seat but still consulting with me, telling me what I did well, and what I needed improvement on,” credited Warner. “We would have great discussion on what it takes to be a psychologist in an interdisciplinary setting.

“People should not be placed in metaphorical boxes but allowed to grow in all possible directions. My two years in LEND reenforced that,” Warner concluded.

“There’s lots of different things you can do if you’re a provider,” he added. “There’s so little utility to putting someone in a box labeled ‘disabled.’ People have lots of different facets to them. To just place them in little boxes removes their humanity. It takes so much away from their story and does not allow them to show who they could be.”

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Life
When Sydney Arrington first met Will Roths in 2020, she knew their conversations would be brief. “He'd say, 'Hi, nice to meet you,' and didn't have anything else to say,” explained Arrington, who had started her job as a success coach at Brandon, South Dakota’s Teachwell Solutions. Teachwell Solutions has regularly placed students through the state Department of Vocational Rehabilitation’s Project Skills program where a student is able to work for a business and receive a salary.

A native of Salina, Kansas, 22 year-old Roths moved to Sioux Falls, South Dakota, when he was in first grade. His family includes his parents, Nichole and John Roths; younger sisters, Ella and Addie; and his goldendoodle, Louis.

Born with cerebral palsy and later diagnosed with what Roths calls “a little bit of autism,” he uses a wheelchair for mobility. When the weather is good, it takes him outdoors where occasionally he goes fishing and spends Saturdays at the lake.

Two years later Roths bubbles over with excitement about his recent internship at the Sioux Falls Union Gospel Mission (UGM) and his classes at the Sioux Falls Southeast Technical College (SET). Arrington sits back and listens with a smile on her face.

A 2019 graduate of Brandon Valley High School, Roths is nearing the end of his three-year transitional services time preparing him for future employment. Thinking about the relationship’s end makes her emotional. “I could just talk on and on and on about Will,” she expressed. “He has a big heart, he’s smart, he’s driven—he’ll go home and finish his homework assignment the first day even though it’s not due for two weeks.”

Roths is UGM’s first intern. He started in December
2021 and quickly immersed himself in the marketing team’s needs by coming in to the UGM’s office three days a week.

Elly Heckel, communications and marketing development director at UGM, feels the same as Arrington. Heckel spent more than half of 2022 working with Roths through his internship with the UGM. It describes its mission as a Christ-based shelter that helps “the hungry, homeless, and lost.”

From the first day, Heckel was determined to make the internship an activity that would advance Roths’ goals.

“I was really adamant that this would go beyond tasks for Will,” she explained. “What he was able to accomplish at the Mission would involve personal and business development growth for him as an individual.”

That’s why, if you saw a billboard for UGM last year, chances are good that Roths designed it. If you read a social media post about the Mission on Facebook or other sites, Roths wrote it or created the video. Other digital media projects included the UGM newsletter, marketing materials, website content, creating press releases and helping plan for the UGM’s 122nd Anniversary Celebration.

Roths particularly made his mark in video creation. UGM sends its donors and partners one-minute weekly updates on the community’s urgent needs and other issues. The UGM also prepares personalized thank-you videos to donors and partners. Through those, Roths claimed that he learned about relationship building with volunteers, community business leaders and government officials.

He also learned how nonprofits play a role in making Sioux Falls a good place to call home.

“I feel like I’ve gotten to know a lot of really generous people,” Roths mentioned. “I didn’t even know about this place before I started here.”

He developed such a close tie that after his internship ended, Roths spent the summer volunteering with UGM’s marketing
department. He continued to go to the Mission’s East Eighth Street administrative office three days a week and worked from home Tuesdays and Thursdays depending on the workload.

Through those months at the Mission, he received a social media certification. Roths will be able to use the accreditation as he moves forward into graphic design and media communications.

UGM also arranged an interview between Roths and Miss South Dakota 2021, Kaitlyn O’Neill. Its purpose was to prepare him for wherever his education and interests might lead him by practicing a real-world interview with an advertising agency or a technology firm.

“It is hard to calculate the benefits Roths received from his internship at UGM,” Arrington exclaimed. “His confidence from working with Heckel and his general satisfaction have increased tremendously.”

Roths will next pursue his associate degree in media design at SET. During his three-year transition period with Teachwell Solutions, Roths took all the basic SET classes he needed.

He always has been interested in design. His senior year at Brandon Valley High School, Roths took a multimedia class where he learned how to edit videos, work with a camera and master Photoshop.

“I think creativity means getting to make my own story,” Roths exclaimed. “If there’s a story you don’t like, you can always change the way it goes. Come up with your own ending. Create your own characters.”

Roths now knows what it’s like to change his own story. He had considered pursuing a career in computer programming, but now knows, design is what he wants to spend his life doing.

It was his months at UGM, however, that really solidified his life’s goals.

“I feel when you’re a designer, you are able to meet different people, get to learn about different companies, what they’re looking for, and what they do,” he stated. “You get experience building up a network by collaborating and communicating with them.”

Roths’ accomplishments have received statewide attention. In June 2022, Roths learned the South Dakota Council for Exceptional Children had honored him with the 2022 “Yes I Can” award. It recognized his “achievements in the area of transition.”

In addition, the committee had forwarded Roths’ nomination to the national Council for Exceptional Children for consideration for the 2023 “Yes I Can” award in transition.

Teachwell Solutions’ Arrington reported that Roths’ success with his internship meant other young adults with disabilities who are in transition would have increased opportunities for career-driven internships.

While Arrington no longer works directly with Roths, they still maintain contact through a newly established club. Roths has been chosen as its president.

Heckel with the UGM wants other organizations to realize that the benefit of this internship allowed Roths to learn from Heckel, and she learned from him as well.

“Will has just been part of our team,” Heckel expressed. “His title was intern, but he was part of our team at UGM just like the rest of our staff who are here full time. I’ve just personally been so amazed at what this has turned into. I want to see more of this in our community. We’ve been given individuals who have been identified with a disability who are passionate about marketing, and they just need a place to learn and grow.”

Roths echoed this and added that even though he has a disability and has some limitations, he can still work as hard as anybody else. ●
When Jim Warne agreed to speak at a University of South Dakota Sanford School of Medicine Center for Disabilities' symposium in 2016, he did not realize what he was actually doing was curating a path that would postpone his retirement indefinitely.

Warne, retired from San Diego State University where he had created the Circle for American Indian Rehabilitation and Education (CAIRE), agreed to speak on Native American issues at the annual symposium and show his film, “7th Generation.” His presentation left listeners convinced: bold steps need to be taken to support South Dakota’s Native population, and that he is one of two men capable of creating an outreach program to help. It would be built upon the foundations of the Lakota word for people and the continuous circular patterns of life – Oyate Circle.

The other man? Wayne Weston, like Warne, an enrolled member of the Oglala Sioux and Isanti Dakota tribes. In fact, the two men are tâhansi (cousins).

In the years since then, Weston, the Oyáte Circle director, and Warne, the Center for Disabilities community engagement director, have pooled their strengths to resolve issues in the Native community and work with Native and non-Native allies that want to better serve tribal members with disabilities.

“We come from very different backgrounds, he is from urban areas and I lived on and off reservations most of my life,” Weston said. “Jim played in the NFL and the Rose Bowl. He’s
been in movies, now he's created movies. I have a background in law enforcement, and I was executive director of emergency management and acting director for the domestic violence program. I was director of student affairs at Oglala Lakota College before the University of South Dakota. Today I work with the Center for Disabilities here in Sioux Falls.”

The Center for Disabilities has served as South Dakota’s University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) for the state of South Dakota since 1971. As one of 68 UCEDDs nationally, we have partnered with people with disabilities, their families, as well as numerous academic institutions, health care organizations, schools, government agencies, business and industry, and a diverse range of community-based organizations to improve the lives of individuals with disabilities and their families. “Reaching Tribal communities across South Dakota has been central to our work since the beginning,” said Eric Kurtz, Ph.D., the Center for Disabilities’ executive director.

Warne left South Dakota as a child and was raised in Arizona. Doctors diagnosed his father with multiple sclerosis when Warne was a boy and that impacted his desire to help others with disabilities. He shared he became an advocate before he even knew what the word meant.

Warne and Weston both are known in Indian Country and to the state agencies that work with the indigenous population. Warne describes Weston as a respected elder who makes his own job easier. Weston’s credibility throughout tribal communities allows for access to leadership, elder committees and others with the ability to impact positive change.

To accomplish their work, Warne and Weston put on more than 15,500 vehicular miles in the first five months of 2022. Weston lives in Rapid City, South Dakota; Warne flies in from his home in California.

Warne shared that Natives make up nearly 10% of South Dakota’s population and the Native population has the highest rate of disability. The definition of disability goes beyond physical issues and includes areas such as intellectual and developmental disabilities, autism and mental health issues, Warne added.

Disability awareness, leadership training and advocacy are necessary to help the communities on the state’s nine reservations,
Jim Warne and Wayne Weston

Warne explained, and education now can prevent potential disabilities later.

“It’s key that they are aware of some of the behaviors and public health challenges that may lead them to disability later,” he stated. “Our goal is prevention. Poor health impacts the population and leads to more disabilities.”

Food deserts also are a reality for diabetes and other disabling conditions. It is not uncommon for some to rely on gas stations as the primary food source which impacts the health of the entire community.

What makes Oyáte Circle unique is the ally-building it does with tribal and state agencies, Weston imparted. The relationship between the tribes and state officials has been challenging in the past, he said, but that is changing.

“I’m not kidding, there’s an abundance of people really wanting to help,” Weston stated. “We have caught the movement in wanting to make some really positive changes and not just programmatic changes. We’ve been allowed to look for the driving force to heal a population that historically has been pretty much underserved and almost completely misunderstood.”

Warne and Weston both describe the work Oyáte Circle is doing as “indigenizing the process.”

“Basically, we’re putting our cultural flavor into a lot of programs out there,” Weston noted. “There’s no word for disability in our culture. So, basically, it is readjusting and finding your place again.”

Added Warne, “Disability is a natural life process. We all will face disabling conditions if we are fortunate to live a long life.”

Oyáte Circle began by focusing on two areas: cultural competency and disability awareness. Cultural competency has been defined as being aware of one’s own cultural beliefs and values and how they may be different from other cultures – including being able to learn about the diverse cultures of someone you may work or interact with.

“We’ve held trainings across the state for a variety of audiences,” Weston clarified. “For disability awareness, the audience was twofold. One was our Native audience because many people had never utilized services that are available to them. No one had ever really explained how it could be user-friendly to them.”
The second audience was the cooperating agencies through the state of South Dakota. Workshops addressed any questions or hesitations that professionals and providers might have.

“I thought it was really important to put providers on the reservations,” Weston stated. “About 85% of the professionals we trained had never been on a reservation or didn’t realize they had been.”

The approach Oyáte Circle took has historical roots, Weston added. The earliest Lakota/Dakota/Nakota interpreters were called iyeska. Not only did they interpret, but they advocated for their people, Weston explained.

“So, Jim and I, we’ve taken that approach. We’re going to listen to our people, teach others what the people on the reservations are wanting,” Weston said. “In the same way, we listen to the goals and objectives of the different agencies and determine how we can integrate those into the tribes. We tie those together and open a line of communication to increase services for tribal members on our reservations.”

Like the Center for Disabilities, the Oyáte Circle’s goal is not to support just people with disabilities, but their families and communities, as well.

Weston describes the relationship between the Center for Disabilities and the Oyáte Circle as “the perfect storm. The energy and the spirit are just right.”

One of the Oyáte Circle’s success stories is the fact it is becoming a training and technical assistance hub for agencies across the United States, Weston noted. For example, it is working with maternal child health agencies throughout South Dakota, North Dakota, Colorado, Montana, Wyoming and Utah. The Oyáte Circle also is working nationally with Head Start and providing information to other agencies.

The Oyáte Circle collaborates with older tribal members with disabilities. Currently, it is working with the Oglala Sioux Tribe’s housing authority, which has received funding to build houses for people with disabilities. The goal is to build an entire community of homes, Weston said, with an Oyáte Circle office at its heart.

“If we can get this project off the ground, we can actually have on Oyáte Circle office that provides all of these services,” Weston mentioned. “It’s early right now, but I think it’s going to be something that comes to fruition.”

The Oyáte Circle can be described as a resource, education, outreach and training effort for Native Americans with disabilities in South Dakota, but it also works in other areas. Adventure for Leadership and Fulfillment with Access (ALFA) camps, Disabilities Awareness Training (DAT), and leadership and advocacy are examples of that work. While DAT will benefit people with disabilities, the focus was on educating those who will assist them.

**ALFA Camps**

ALFA camps encourage young Native adults to look toward their futures. The goal is to allow them to dream of doing more than just hold a job but also to find a career that will provide the chance for leadership and advocacy.

The most recent camps took place in June, July and August 2022 with participants aged 16 to 21. Camps were located on the Pine Ridge Reservation, Little Wound High School in Kyle, Lakota Tech School near Pine Ridge and on the Sisseton Wahpeton Reservation at the Sisseton Wahpeton College.

During ALFA Camps participants learn to be workplace ready, explore potential jobs and careers and become confident that employment can be fulfilling. Topics include self-advocacy, workplace readiness, business plans, job exploration and entrepreneurship. Resources were available there too.

“It’s pre-employment in a way but a lot more,” Weston explained. “It’s working with
these young people and talking to them and looking at what they want to do. And it looks at the culture that they’re going to be entering.”

During the ALFA Camps, participants discuss the changes they might encounter between the Native culture and mainstream expectations. For example, the indigenous culture views relationships as more extensive. A Native youth can view multiple women as his mother or grandmother. A white employer, however, may look askance at the second or third request for funeral time for someone they view as not having a blood relationship.

During the camps, Weston often saw participants have what he called a “light bulb moment.”

“We were asking them questions, and we saw these light bulbs go off. ‘Oh my gosh, this is what they’re saying, I do need to go to school. I want to start a business, but I need business funding.’ It wasn’t us telling them, we showed them,” Weston said.

Warne, Weston and Heath Ducheneaux with the Oglala Sioux Vocational Rehabilitation wove Native culture and traditions such as smudging, talking circles, storytelling and tribal protocols into the camps.

DAT for First Responders

A small but dedicated group participated in First Responders Disability Awareness Training (DAT) for tribal nations in June 2022. David Whalen of Niagara University in Buffalo, New York, led the training, the first of its kind in the United States.

Whalen founded DAT in 2004 to both sensitize and educate participants on all aspects of disabilities. That includes etiquette and interaction skills, stigma and misperceptions, initiative-taking approaches to community inclusion and integration, the Americans with Disabilities Act (ADA) and how to overcome barriers through advocacy.

While Warne was in Seneca Nation conducting a youth football and life-skills camp near Niagara, New York, he met with Whalen. They discussed a partnership working together to initiate an indigenous First Responder DAT for South Dakota.

“We hope to develop this model into a national project,” Warne added.

Warne and Weston made the DAT unique by providing the Native point of view. Also sharing their perspectives were representatives from the Rapid City Fire and Police Departments, South Dakota Vocational Rehabilitation, FEMA and DakotaLink (a program of the South Dakota Department of Human Services, Division of Rehabilitation Services) which aids the blind and visually impaired. The South Dakota Council on Developmental Disabilities sponsored the event.

COVID and tribally imposed public-health restrictions on travel limited the number of Native participants in the last two years, Warne explained. The next training will take place at tribal offices on the reservations.

In November 2022, Warne screened his film, “Remember the Children,” at the American Public Health Association. It addresses the long-term effects of Indian boarding schools. Also that month, he shared the story of the Oyáte Circle at the Association of University Centers for Disability Conference in Washington, D.C., as part of the Leading Change Session: Ensuring Access to High-Quality Health Care.
Participating in the RISE-UP program in the summer of 2022 affected Emma Saucerman’s life in ways she didn’t expect.

By the time she concluded the 10-week program that focuses on public health, the 20-year-old Rapid City, South Dakota, native knew two facts. One, her determination to live and work with her family in Pine Ridge, South Dakota, had not changed, and two, the role she would play had altered.

Saucerman originally enrolled at the University of South Dakota with a major in medical biology and expected to become a physician. By summer’s end, she had switched her major to social work and plans to pursue a Master of Social Work. Her career goal is either to be a mental health counselor or work for Child Protection Services.

“I would say a mental health counselor would be my top choice,” Saucerman explained. “I’m still planning to work on the Pine Ridge Reservation, just in a different career.”
What helped change and solidify Saucerman’s plans is the Maternal and Child Health Careers/Research Initiatives for Student Enhancement (MCHC/RISE-UP) program. “It gives undergraduate students who have an interest in public health the opportunity to explore future careers in the field,” expressed Ann Wilson Ph.D, senior research associate and professor of pediatrics with the USD Sanford School of Medicine Center for Disabilities.

The RISE-UP program’s purpose is to develop a national consortium of institutions and universities built on the Leadership Education and Neurodevelopmental Disabilities (LEND) training framework and an earlier CDC-funded RISE-UP grant. The Centers for Disease Control and Prevention (CDC) awarded the Kennedy Krieger Institute (KKI) the MCHC/RISE-UP grant funding 10 years ago.

The University of South Dakota Sanford School of Medicine Center for Disabilities in Sioux Falls, South Dakota, is one of four MCHC/RISE-UP training sites. The other three are located at KKI/Johns Hopkins University in Baltimore, Maryland; the University of California at Davis in Davis, California; and Aaniih Nakoda College in Harlem, Montana.

“The program’s goal is to introduce undergraduate students, especially those in underrepresented groups, to the field of public health. RISE-UP provides opportunities to understand how public health relates to South Dakota’s American Indian population,” Wilson said. “Students learn the variety of ways they can pursue a career in public health. It helps them understand the social determinants of health, and the importance of achieving health equity.”

Saucerman, a member of USD’s honors program, learned about MCHC/RISE-UP when Wilson talked about it with students at the Native American Cultural Center. “I had great discussions with Wilson, and that’s what helped me make the decision to apply for the program,” Saucerman shared.

Saucerman was one of 16 students taking part in the summer program. The attendees consisted of another student from USD, one from Augustana University in Sioux Falls and the rest were from other states across the nation. “RISE-UP gives members a network of lifelong colleagues,” Wilson added.

For Saucerman, it was the first step in establishing the connections that will be invaluable in the future. It is especially important for someone who will be the first member of her family to earn a four-year college degree. She graduated from high school in 2020 and will finish her undergraduate degree in 2024 with the goal of following that with the one-year Master of Social Work program.

Saucerman's summer started with a trip to Baltimore, Maryland, to hear speakers at Johns Hopkins and tour the facility. Upon her return, she was assigned to South Dakota Parent Connection which connects parents of children with disabilities with the necessary resources. “I got to shadow at the hospital. I got to talk to a lot of nonprofit organizations in Sioux Falls, and I got to attend a lot of the workshops that South Dakota Parent Connection sponsored. I got to see how a nonprofit works day-to-day and visit with clients,” Saucerman said.

A Spanish minor at USD, Saucerman put her fluency in that language to work at South Dakota Parent Connection. “We were delighted to host Emma over the summer as a member of our team,” said Lisa Sanderson, family-to-family project coordinator for South Dakota Parent Connection. “Having an additional staff member who provides multiple benefits from extra help at conferences and on projects to addressing unique unmet
needs such as Saucerman translating some of our materials into Spanish.”

Sanderson described Saucerman’s weeks with South Dakota Parent Connection as “an investment in increasing our organizational awareness and outreach for today and in the future.”

Again, it’s all about connections. As Saucerman shares information about South Dakota Parent Connection within her personal and professional networks she will link two groups with the nonprofit. Those are families of children with any type or degree of special health need or disability, and the professionals serving them. South Dakota Parent Connection will offer the information, resources and support they need.

Saucerman now is fully aware of that.

“South Dakota Parent Connection can help parents navigate the school system, connect families to medical professionals if they need screening done, and find resources that can help their children succeed,” Saucerman shared. “It opened my eyes to different family, school system, health-care dynamics and how all of that is interconnected.”

“RISE-UP helped acquaint me with the role public health plays in society,” Saucerman added. She now defines public health as helping create health care that is more equitable for the general population, and improves the quality of life for a population, regardless of socio-economic background or race.

As the summer session neared an end, participants prepared posters to present at a virtual conference for the CDC, along with five- to seven-minute presentations. Saucerman focused on what she had learned about how poverty affects families who have children with autism. “I talk about how I had learned how the South Dakota Parent Connection helps, specifically families in poverty, to overcome these obstacles.”

Wilson remains in contact with previous RISE-UP participants. Almost every individual has chosen a career path that impacts public health.

“Medicine, nursing, public policy, law – they’ve all found a career that relates to enhancing public health,” Wilson shared.

An enrolled member of the Oglala Sioux tribe, Saucerman intends to make a difference for her relatives who live in Pine Ridge.

“The RISE-UP program has put me on solid footing,” claimed Saucerman. “Having connections is the biggest benefit for me especially in South Dakota. While I was building connections in South Dakota, I was also building connections across the nation. Knowing the resources we have in the state is going to be very, very beneficial as I am helping South Dakotans in the future.”
Dr. Aimee Deliramich, a clinical psychologist at the Center for Disabilities, has been selected to become a Children’s Mental Health Champion through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) and the Association of University Centers on Disabilities (AUCD). Many top-tier professionals from across the nation applied, and only 12 were selected for this funded work.

As the Children’s Mental Health Champion for South Dakota, Deliramich will work to address the mental health needs of children and families by supporting the three pillars of the program which include: Connecting and creating family, school, health care and community partnerships; Identifying and intervening to ensure early identification and evidence-based treatment of children’s mental health needs; Preventing mental disorders and promoting mental health by sharing information and making sure there are prevention programs in multiple settings (such as schools, childcare and home) to support parents and caregivers. She will also serve as the state liaison to the CDC’s Children’s Mental Health program and resources; act as a community champion and change agent to increase awareness activities and improvement of children’s mental health practices; build partnerships to promote identification, screening, referral and intervention; and implement effective strategies for mental health promotion, prevention supports, creation of networks and connections between systems.

Eric Kurtz, Ph.D., executive director of the Center for Disabilities, says, “The Center for Disabilities and Dr. Deliramich have long been champions for change working to bridge mental health resources for children and their families in South Dakota and beyond. This national partnership will continue to strengthen these efforts, address increasing needs and strengthen South Dakota families.”
Kendra Gottsleben, the marketing communications specialist for the Center for Disabilities, has received international recognition by Diversability as one of its “D-30 Impact” 2022 honorees.

Diversability is an award-winning community business whose mission is to amplify the voices of individuals with disabilities and democratize disability visibility, representation and access. For the past three years, Diversability has developed its D-30 Disability Impact List, which honors the unique accomplishments of 30 people with disabilities that are the most impactful community members globally. This year, Diversability received almost 250 nominations from leaders with disabilities globally. Gottsleben is a lifelong advocate and educator for rare diseases and disabilities, and she is involved on numerous local, state and national boards and committees. She is an author and speaker and has received prestigious accolades, including the Governor’s Award for Outstanding Individual with a Disability in 2020. Gottsleben’s leadership, drive and passion are making a much-needed, significant and progressive mark on the Midwest.

“I feel incredibly blessed to have made the 2022 D-30 Disability Impact List,” says Gottsleben. “The changemakers and advocates on this global list are remarkable, and to be counted among them is an exceptional honor. I’m thankful to all who have supported my work in the disability and rare disease community.”

Gottsleben started her own non-profit, Rare by Design, which is dedicated to raising awareness of inclusion and proper representation as well as being a resource for individuals with rare diseases and disabilities. In 2022, she launched an inaugural fundraiser of a fully-inclusive fashion show, representative of true diversity from a tangible, local perspective, the first event of its kind in Sioux Falls.
Maddison Hajek, former SD LEND Trainee, was selected to be a 2023 Trainee Ambassador by the United States Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal Child Health Bureau (MCHB). In this highly selective position, Hajek will join a national Trainee Ambassador Group (TAG) which will work to foster connections between trainees across Maternal Child Health (MCH) Training Programs across the country, provide trainees with leadership development opportunities, and strengthen the link between trainees and HRSA/MCHB. Hajek’s 2023 TAG cohort will focus on an evaluation project intended to assess the needs of trainees across the MCH Training Program.

Through collaboration, the TAG will conduct an evaluation to:

- Learn about the needs and interests of MCH trainees
- Gather information on what engagement activities MCHB should provide trainees in future years
- Provide feedback to MCHB on how to best support the trainee network
- Strengthen the link between trainees and MCHB
- Increase current trainee awareness/knowledge about the full range of MCH training programs
- Improve communication and collaboration among trainees within and across training programs
- Facilitate connections between current and former trainees
- Provide trainees with additional leadership development opportunities
The Center for Disabilities would like to thank all the businesses, organizations and individuals who connected us with the extraordinary people featured in this publication.