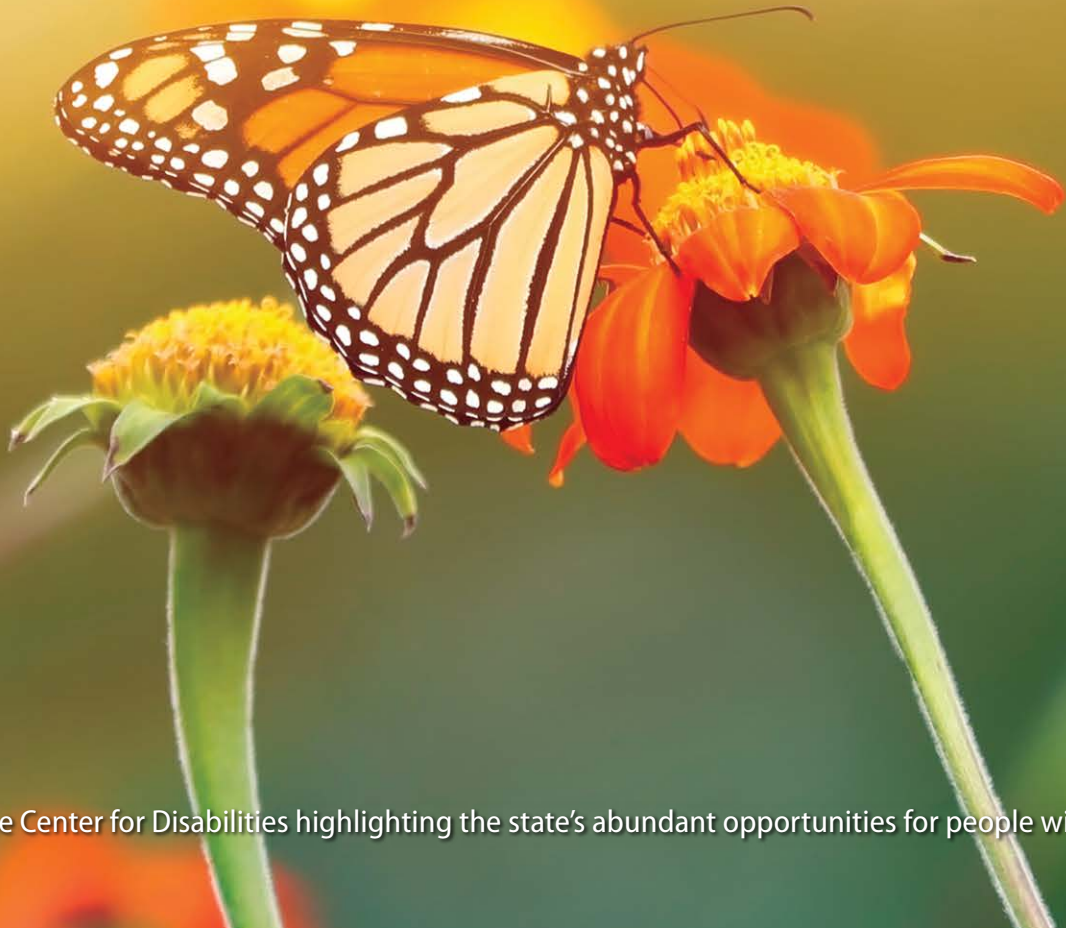


South Dakota

Possibilities 2020



A publication by the Center for Disabilities highlighting the state's abundant opportunities for people with disabilities.

Executive Director, Center for Disabilities:

Eric Kurtz, Ph.D.

Executive Director, South Dakota Council on Developmental Disabilities:

Arlene Poncelet

Principal Writer:

Jill Callison

Managing Editor:

Kendra Gottsleben

Contributing Photographers:

Tana Buresch, Teri Bukowski, Jessica Nordhus, Dan Rounds, Russell Jensen of Sage Studios

Design:

Eric Dalseide

Center for Disabilities

Health Science Center, 1400 W. 22nd St., Sioux Falls, SD 57105

Phone: 605-357-1439 • Fax: 605-357-1438 • cd@usd.edu • usd.edu/cd

Twitter: [@CD_SouthDakota](https://twitter.com/CD_SouthDakota) • Facebook: [The-Center-For-Disabilities-South-Dakota](https://www.facebook.com/The-Center-For-Disabilities-South-Dakota) • YouTube: [/Center4Disabilities](https://www.youtube.com/Center4Disabilities)

© 2020 Center for Disabilities, University of South Dakota Sanford School of Medicine

This publication is available in alternative format upon request.

This publication was supported in part by grant number 1901SDSCDD-03, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. Visit their website at <http://dhs.sd.gov/cdd.aspx>.

From the Executive Director

This year has presented many challenges and we continue to experience elevated levels of stress and uncertainty related to this ongoing pandemic. All of us have undoubtedly been impacted in some way by this crisis. However, our neighbors who are aging, who have disabilities or chronic health conditions, and our Native American community have been disproportionately impacted.

We have been working diligently with our partners to ensure we understand the changing needs of individuals with disabilities and their families and are prepared to respond, while also supporting the workforce of providers and professionals. Additionally, issues related to social injustice and racism in America are challenging us daily to work toward fundamental change. The Center for Disabilities is committed to continuing to increase awareness of racism, privilege, and inequity in our communities and promote diversity, inclusion and equity. We have many challenges ahead, but together we can make significant progress toward an even brighter future.

Despite this year's challenges, we are happy to be able to provide some powerful examples of resiliency and resolve in the era of COVID-19. Inside this publication you will find stories of independence, perseverance, optimism, and dedication to pursuing one's life goals. We hope you enjoy the empowering stories of the South Dakotans featured in this issue.

South Dakota has an abundance of amazing individuals and organizations who work tirelessly to help us achieve our mission to improve the lives of people with disabilities and their families. The possibilities are endless, and the potential is great!

Take care of yourself, and one another.



Sincerely,
Eric G. Kurtz, Ph.D.
Executive Director, Center for Disabilities

Contents

2 Flutter Productions
Sharing the Magic with All Abilities

6 Michael Bethke
The “King” of Ken’s Dairy Department

9 Teresa Nold
Advocacy that Leads to a Career

12 Kiva Sam
Returning Home to Make a Difference

16 Alex Sass
Can-do Attitude Leads to Community Recycling

19 Project SCOPE
Initiative Focuses on Opioid’s Harm on Newborns, Children and Families

22 Tria Dennis
Determined to Start a Day Care of Her Own



Sharing the Magic with All Abilities

COVID-19 and its attendant precautions kept the curtain closed on Flutter Productions' planned performances in 2020. It caused a long-anticipated art show to lose most of its intended audience, and momentum has slowed.

However, Flutter Productions' founder and artistic director maintains her optimism as she looks to the future of the all-ability dance and theater company as it begins its 13th year.

"What is exciting about Flutter Productions is we were the first organization in the state to offer all-abilities productions and to amplify the voices of those who have been historically disenfranchised and not always had a seat at the table to tell their story," says Heather Pickering. "This has been such a powerful experience."

Flutter Productions' roots go back to 2008 after the Black Hills Community Theater (BHCT) hired Heather as its education and outreach director. BHCT had received a grant from the National

Endowment of the Arts to produce an all-abilities show, working with a puppeteer. She began with ideas and a grant but no script, Heather recalls.

Over about six months, that changed. A script was written and the production offered to the public. Today, Flutter Productions is part of Black Hills Works, an agency that supports more than 600 adults with intellectual or developmental disabilities, visual and hearing loss, brain injuries and chronic illnesses, physical disabilities and more.

That six-week rehearsal period allowed the production crew to witness something amazing, Heather says.

"What we saw behind the scenes during the rehearsal process was the creation of friendships and creative connections forming between people who have been historically disenfranchised with people of all ages in our community," she says. "Those connections and friendships might not have otherwise had the opportunity



Heather Pickering

to occur. Watching people feel what it is like to accomplish something, to receive the applause of an audience, to see young individuals in our community working with adults that were diversely abled was such a powerful experience. The behind-the-scenes experiences outweighed the production itself in many ways. It felt as if all-ability performance opportunities needed to continue to present themselves.”

Heather returned to her job as a high school educator, but continued to collaborate with the Suzie Cappa Art Center, another member of the Black Hills Works family that supports artists of

all abilities, to create and produce more all-ability dance theatre productions on a biennial basis. A few years later, while in graduate school at the University of Wisconsin, she also began to collaborate with the LifeScape Center for the Arts in Sioux Falls, South Dakota, and Flutter Productions started holding shows in both Rapid City, South Dakota, and Sioux Falls. In 2015, eight years after Flutter’s inception, it incorporated and became part of Black Hills Works; that same year, it began offering several all-ability dance theatre productions and weekly classes.

“ABLE: The Disability Chronicles,” was one such production. It was the first production consisting of a series of contemporary dance and spoken-word vignettes written by individuals with disabilities and their advocates in South Dakota. The production tackles subjects such as labeling those with disabilities, Down syndrome, one person’s experience with Autism and overcoming challenges. One member of the play-writing class, “JJ,” or James Janis, contributed several pieces to the production.

Some of the productions came out of classes offered by Flutter Productions. Those included acting and play-writing. An Introduction to Theatrical Design class led to the creation of FashionABLE, a biannual fashion show where an individual with a



Flutter Productions

disability partners with a volunteer to make their design a reality.

The play-writing class led to both poetry and short skits. Through that class, James Janis wrote a series of poems that have been turned into his first book, *The Chair is Not Me*. JJ, as his friends call him, and Heather worked with Suzie Cappa artists to illustrate the poems, and the book was published in 2018.

“The poems are entirely from the heart,” says JJ, who was born with cerebral palsy and uses an electric wheelchair for transportation. “Whatever I see, whatever I hear. Sometimes, how I interpret different people’s expressions. Or by listening to the news, by listening to the radio.”

His mission in writing the poetry for *The Chair is Not Me* is to open people’s eyes and to allow others who use wheelchairs to be allowed to stop explaining themselves to others, JJ says. In the poem “Listen,” he writes, “Sometimes I need you to be the calm before a storm and let me be the babbling brook.”

In “Walking Pharmacy,” he gives a glimpse of his daily routine, saying “A pill to walk, another to talk. A pill to wake. A pill so I don’t quake and shake. A pill to sleep. A pill not to weep.” In “Flag-Bearer,”

he shares sorrowful memories of prejudice he has faced as a member of the Oglala Sioux tribe. “You mimicked what you saw on the television, dancing out of step, yelping in high pitched tones, exclaiming, ‘We’re crying for war!’ ‘Do your people still scalp people?’ It felt like you pelted me with rocks.”

JJ’s book and artwork took Flutter Productions into another direction. Chance Whelchel, owner of The Perfect Hanging Gallery, approached Flutter Productions and offered to volunteer his time and resources to turn *The Chair Is Not Me* into a traveling art show. The gallery framed the original pieces and helped prepare the art show to tour. According to Heather it gives Flutter Productions an opportunity to reach people and to change any pre-existing perceptions of the capabilities of people with disabilities.

James Janis



The show went on display at both Dakota State University and the University of South Dakota shortly before the COVID-19 pandemic closed the campuses. Plans for the future include a show at the Homestake Opera House in Lead, South Dakota, in April/May 2021 and a show at the Matthews Opera House in Spearfish, South Dakota, in March 2022. Flutter Productions' summer art camp and fall 2020 productions were canceled.

The work continues, however. Flutter Productions recently finished a three-year grant from the National Endowment for the Humanities. Flutter Productions partnered with the University of South Dakota School of Medicine's Center for Disabilities to evaluate the effects of all-abilities arts programming – not only on participants but staff members and audience as well.

That major grant also allowed for the book's publication and traveling art show.

Heather shares, its work will continue to impact all ages and in ways that are not always readily apparent.

"A magical thing occurs at Flutter Productions with a cast that is typically a 50/50 mixture of individuals of all ages, with and without diverse abilities," she says. "We have had people as young as 4 and as old as 86 consisting of professionals, non-professionals, professionals in training, first-timers seeking an artistic experience and theater fans who have joined us on the Flutter stage. While the productions and the production process are often full of magic, the magical moments and connections often continue long after the productions are over." •

Gift for Words Leads to Book

For a child born with cerebral palsy, a red wagon represented freedom.

Never mind that the paint was cracking. Never mind that the axle would squeak harshly when his cousins/chauffeurs would try to sneak up on people, giving away any hopes of a surprise entrance.

That wagon allowed James "JJ" Janis the freedom every youngster craves.

Until one day, it was gone. Stolen. His ticket to adventure, gone forever.

Decades later, JJ wrote a poem about what the loss of four-wheeled transportation meant to him. "Tears flowed like rainwater," he recalls. Unable to play with his companions, his parents would carry him to the couch, and TV shows filled the hours: "Tennessee Ernie Ford, The Mickey Mouse Club and soap operas became my only friends."

Resurrecting the memory was difficult, even though it eventually came with a happy ending. But for 66-year-old JJ, sharing such recollections, observations on everyday life, advice and imagery helped him achieve a longtime dream.

"I've been wanting to write a book since I was 15 years old," the Rapid City, South Dakota, native says.

"I started to write back in the 1970s, and that's when it really took off. Then my writing lay dormant until 2015, and one day I went to see Heather."

JJ is referring to Heather Pickering, founder and artistic director of Flutter Productions, an all-ability dance and theater company. JJ and Heather became friends through a playwriting class offered through Flutter Productions. JJ's uncanny knack with rhyming puts Heather in mind of poets Shel Silverstein and Dr. Seuss.

"He just has a gift for words," Heather says.

The ‘King’ of Ken’s Dairy Department

Michael Bethke, once homecoming king at Clark High School, nowadays can be described as “king of the dairy” at Ken’s SuperFair Foods in Clark, South Dakota.

Of course, it’s not his official title. That would be dairy manager. It’s not even his unofficial title. That’s “dairyman.” But when you look at what Michael has achieved since he began working at the grocery store as a high school student to his rise to his current position, it’s easy to give him a royal designation.

Ken’s manager Scott Drexler would be happy to clone 24-year-old Michael five times over because of his enthusiasm, personality and reliability.

“He’s very willing to learn,” Scott says. “He just wants to grow with the company, and he has. He’s moved from part-time school kid to dairy manager. Plus, his personality has just bloomed since he started working. He enjoys talking with customers.”

Jerry Hartley knows how important Michael’s job is to him. Jerry, the retired principal at Clark High School, met Michael when he moved from Texas after his father’s death. At one point during high school, Michael lived with the Hartley family.

“When he was named dairy manager, my phone blew up, my wife’s phone blew

up, he was so happy he had ‘manager’ behind his name,” Jerry says. “He’s just a super young man.”

Michael, who has a cognitive disability that means he learns differently than most people, started at Ken’s through Project Skills, a paid work experience program in South Dakota for high school students with disabilities. The program is a cooperative arrangement between the state vocational rehabilitation agencies and the local school districts. After Michael completed his 250 hours of work experience, with job coaching from Clark High School paraprofessional Sherry Swanson, Ken’s SuperFair Foods hired him.

“This is the way we hope that it will work,” says Susan Schmit, Michael’s special education teacher when he was a student. “We have another student in Clark, she did a Project Skills position at a hair salon and now has opened her own. We try to find jobs in areas kids are interested in.”

Moving to a full-time position also meant another important milestone to Michael – he no longer is eligible for Social Security supplemental funds.

When Michael started at Ken’s, he bagged customers’ groceries and carried the sacks to the car, stocked shelves and



Michael Methke



unloaded delivery trucks. He started every shift remembering three rules that Sherry had taught him: Ladies first, customers first, safety first.

Those rules still guide his days, which can start as early as 4:30 a.m. when delivery trucks arrive. Michael knows what will be on those trucks since it is his responsibility to order milk three days a week and other dairy products twice a week. That includes everything but the ice cream. When Scott went on vacation this summer, he said he had no worries about leaving the dairy department in Michael's hands.

"He does it himself," Scott says. "I tutored him, but when I was gone, he was on his own, and he did just fine."

"I love it, I love it a lot," Michael says of his position as dairy manager. He also helps elsewhere in the store and speaks knowledgeably of what it takes to be successful in attracting customers. Michael acclimated himself to the Project Skills job within two weeks, Jerry says. His job coach reported almost immediately that he was successful, and customers and employees enjoyed the interaction.

"He has a heart of gold, he's upbeat, he's smiling, that's why they love him at Ken's," Jerry says. "Our special education program in Clark is one of the best in the state

helping kids transition from school to work."

Michael attended the Youth Leadership Forum in 2014 and returned as an assistant leader in 2016. The forums bring young people with disabilities together to learn from each other. For Michael, it was a challenge, and as he says, "I like challenges."

That's good, because at times his life has been challenging. Tim and Kyong Bethke adopted Michael as an infant. When Tim died suddenly nine years ago while the family was living in Houston, Texas, Kyong temporarily returned to South Korea while Michael opted to move to Clark where his late father had family. At Michael's urging, Kyong also now lives in Clark with their apartments across the hall in the same building. Kyong is deaf, and Michael communicates with her through sign language.

In high school, Michael took part in Special Olympics with basketball and bowling, his favorite sports. He also served as assistant manager for several sport teams. Now, on Tuesdays and Fridays, he calls bingo games for residents at the Fay Wookey Assisted Living Center. Playing video games also helps him pass the time when he can't be where he really wants to be: Ken's SuperFair Foods, helping customers find the items they need, preparing the weekly orders and sharing conversations with his coworkers.

While grocery stores can offer a stressful environment—picture one day before Thanksgiving or when a blizzard is predicted—it never seems that way to Michael. It's all in the attitude, he says, and he makes sure his attitude is A+.

"I see the best in everything. I'm a positive man." •

Advocacy that Leads to a Career

Teresa Nold first learned of South Dakota Parent Connection as a mom seeking services for her son, who was born with multiple disabilities.

Then she joined its board of directors, helping to guide the agency for six years. Next, she accepted a position as an outreach specialist, continuing to advocate for other parents and children for about seven years.

Now, although Teresa left South Dakota Parent Connection earlier in 2020 to continue her mission in California, she continues to praise the agency that helped give her family – and others – the best possible life.

Anne Land's family was one of those

beneficiaries. Her son, now 20 years old, has Tourette syndrome, and she met Teresa through South Dakota Parent Connection while trying to establish a support group.

"I have never learned so much as I did working with Teresa," Anne says. "She was there at the beginning. She's helped with endless amounts of work that's been done legislatively. She wears many hats."

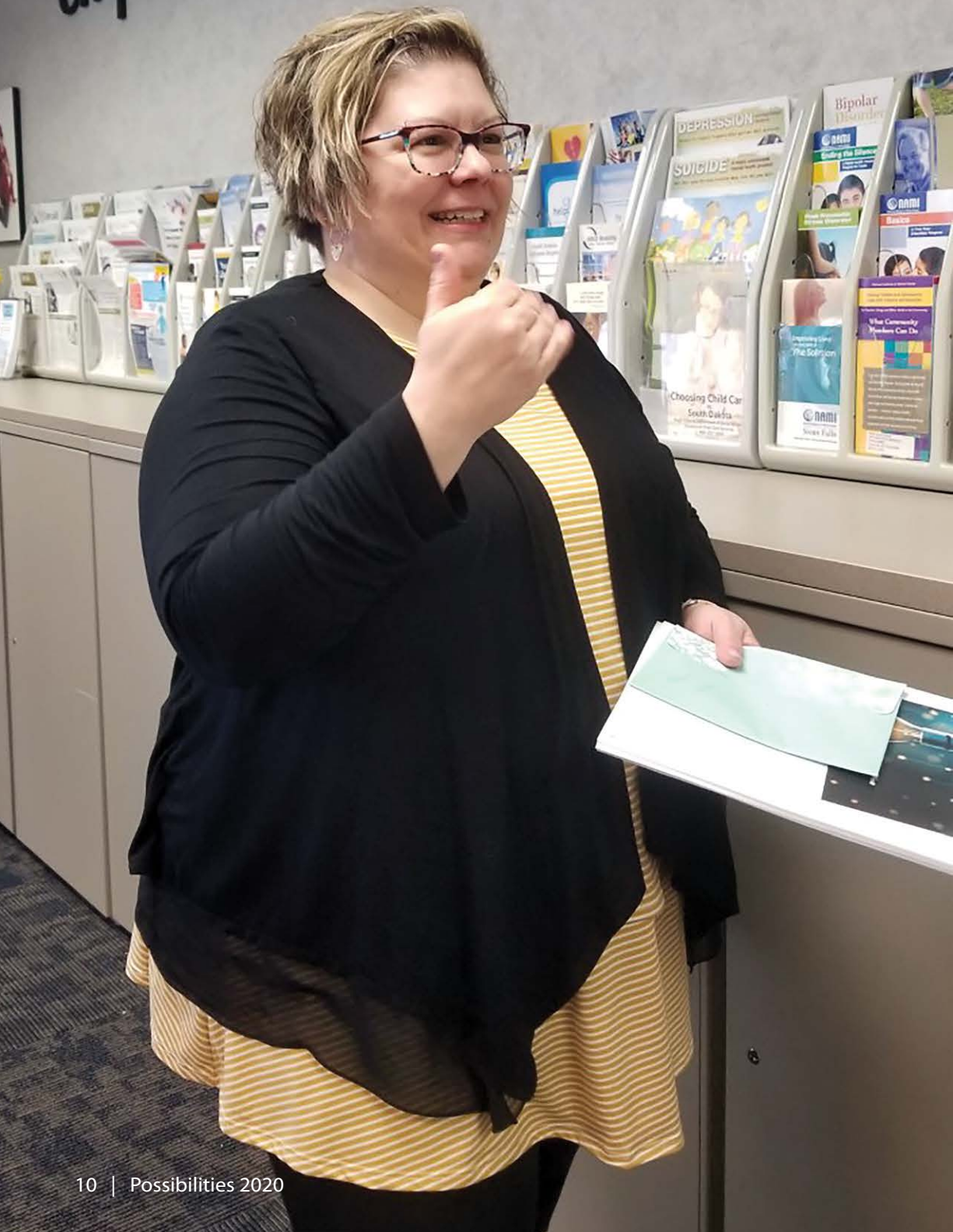
Funded by the federal Office of Special Education, South Dakota Parent Connection serves as the training and information center for those raising children with disabilities and challenges.

"If parents receive services through a school, South Dakota Parent Connection



empowering families . . .

lies . . . emp



Teresa with husband, Tim



helps parents navigate the system,” Teresa says. “The agency figures out what services are needed for their kids.”

Teresa and her husband found themselves turning to South Dakota Parent Connection after the birth of their son, Isaac. The Nolds were born Deaf, as they prefer it to be spelled, and Isaac is what they refer to as Deaf-plus.

“His deafness is an identity for him,” Teresa says. “The other disabilities are just pieces of him.”

Teresa was raised in a Deaf family with her sister and her brother. All three have a level of hearing, but it can be unreliable, and they don’t depend on it for communication with others. Her husband was born with a hearing loss after his mother contracted rubella while pregnant with him.

Isaac’s disabilities meant Teresa needed to expand her knowledge of what the system has to offer.

“Being Deaf and the additional difficulties have presented challenges while advocating for him, myself and my husband as his parents navigating the system,” she

says. “We have to advocate for services that are appropriate.”

Part of that advocacy requires explaining the nuances of American Sign Language (ASL) as a formal language that has evolved over time with its own grammar, set-up and Deaf culture norms. “We get information from each other, so sometimes we ask questions that might seem too personal,” Teresa says. “If you get a new car, we want to know what it costs. Hearing people have conversations that allow for incidental learning. We miss information that way, and we’re curious. We want to know.”

South Dakota Parent Connection also provided services for the Nolds’ second child, Caleb, who was diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD). While Isaac’s easy-going personality had become routine, Caleb’s energy provided new challenges that the agency helped the Nolds navigate.

Parents receive referrals to the agency through various sources, Teresa says. Parents learn about it from other parents, through referrals through a school district’s counselors and from private counselors or psychologists. Doctors, nurses, grandparents, social workers – they all direct people with questions and concerns to South Dakota Parent Connection.

The agency helps in one essential way, Teresa says – it offers a place of belonging for those on a trip without guideposts.

“Every parent’s journey is their own journey,” she says. “Every child is a different person. Challenges can come at any time when your life is a little bit different. When challenges come and that is not what your prepared for, South Dakota Parent Connection understands.” •

For information on South Dakota Parent Connection, visit www.sdparent.org.

Returning *Home* to Make a Difference

When you hold a seashell to your ear, you hear the mighty rolling of waves crashing onto the beach before returning to their ocean home. Kiva Sam, whose Lakota name, Wamnuga Win, means “Little Seashell Woman,” has heard that call of restless waves. Now, through a University of South Dakota Center for Disabilities’ program, she has returned to her home, dedicated to helping others.

The South Dakota Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program provides a graduate-level leadership traineeship and one year of interdisciplinary training, giving trainees the tools to guide public policy and healthcare practice in their respective fields. The South Dakota LEND Program has trainees in audiology, clinical psychology, genetic counseling, nutrition, occupational therapy, physician assistant, physical therapy, school psychology, social work and speech-language pathology as well as parent and self-advocate trainees.

South Dakota LEND faculty come from the University of South Dakota, Augustana

University and South Dakota State University. They work with colleagues from other institutes of higher learning, hospitals, clinics, nonprofit agencies, South Dakota Departments of Education, Health, Human Services, Social Services, and the South Dakota Title V Program, among others. More than 80% of South Dakota LEND’s graduates have assumed leadership roles in their field, practiced on interdisciplinary teams and provided specialized care in maternal and child-health settings.

“The South Dakota LEND program has been here for 30 years,” says Marni Johnson Martin, Au.D., interdisciplinary training and clinic director at the USD

Kiva Sam



Center for Disabilities. “It’s highly successful because of our strong partnerships within the state, region and nation. We’ve been able to expand our program by adding different disciplines and faculty members over the years.”

Marni never expected to find herself in higher education, but her work through LEND allows her to impact many people as she learns along with her students.

“It’s rewarding to be a little part of their journey,” she says. “I learn as much, if not more, than they take from me and our program. They’ll go on to do great things.”

For Kiva, now completing a second-year Leadership Traineeship in the South Dakota LEND Program, that means one day returning to the reservation where she was raised to pursue her passion for advocacy and changemaking.

“I want to advocate and acknowledge and re-educate and reiterate the importance of Indigenous people,” Kiva says. “There’s a lack of understanding and misunderstanding and prejudices that can cause damage and harm not only for children but people who have grown up on the reservation.”

Kiva lives in Sioux Falls, South Dakota, but ride-shares with a classmate to the USD campus in Vermillion for classes. She also is interning with the USD Center for Disabilities in Sioux Falls while conducting research for her dissertation.

As her second year began, Kiva dove deep into a consideration of what she intended to accomplish.

“For me, why I started this internship was to explore fetal alcohol spectrum disorders a little better,” she says, referring to the conditions that can occur in children exposed to alcohol prenatally. “And leadership team development collaboration is personally something I would like to work on. I want to know who I am as a leader.”

At the Center for Disabilities, on the USD Sanford School of Medicine campus in Sioux Falls, Kiva leads a collaborative initiative to create a database for the Fetal Alcohol Spectrum Disorders Clinics. Faculty and students will be able to conduct research using existing clinical data collected over the years; this process will be streamlined with the new database, allowing them to contribute to the current research base on this topic. Kiva hopes the database



can be expanded to other clinics including the Center's Autism Spectrum Disorders and LEND Developmental Clinics. Knowledge is power, and the information gathered through research may open doors for future funding opportunities and an allocation of resources to those who need it most.

This second year also will allow Kiva to develop more in-depth relationships, both with the people she sees and the people she works with. The network she forms now will allow her to connect with others when she moves into a leadership position, she says.

Marni describes Kiva as "a true leader." She is committed to returning home to help her fellow tribal members. "She can relate to a lot of people," Marni says. "She's very insightful, very curious and supportive of her fellow students, the families that she serves and she really wants to learn from her colleagues and faculty members as well."

Kiva, an enrolled tribal citizen, grew up on the Pine Ridge Reservation in Kyle, South Dakota, in the Pejuta-Haka

District, raised by her grandparents. An early goal was to attend Harvard University, and after her freshman year in high school she enrolled at Proctor Academy, a private boarding and day school in New Hampshire. Kiva left after one year.

"It was the first time I experienced culture shock," she says. "It was a lot of differences on and off the reservation, in the school system, being in a residential school. And my grandparents were not there for support."

Kiva returned and enrolled at Bennett County High School in Martin, South Dakota. When she was a junior, she gave birth to her oldest son, now 13. For some, that would have meant the end of any ambitions. Not Kiva. She studied government at Dartmouth College in Hanover, New Hampshire, then interned in the Rapid City, South Dakota, office of then U.S. Sen. Tim Johnson. After training with the Teach for America program, she taught high school social studies for two years.



“My goal was to go to graduate school,” Kiva says. “Initially I wanted to go to law school to serve the tribe in that capacity. But a lot of what would be involved with becoming an attorney and various goals, that’s not the area I was passionate about. I’m passionate about working with youth, increasing opportunities, helping them have systems in place so whenever they choose to do higher education, it won’t be such a shock.”

For three years she served as a behavioral interventionist, working with about 150 students in special education, some of whom were at higher risk. Of a caseload of about 35 young people, 14 to 16 had high needs, and Kiva checked in daily or weekly to ensure their academic success by making sure their social-emotional needs were met.

That role opened her eyes to the failure of some outside services to understand the cultural and environmental challenges

facing Native youths. It led Kiva to decide becoming a school psychologist would be the best avenue to help school systems systematically address the issues and help her put the proper programs and resources in place.

In the fall of 2018, she enrolled at USD. While she is scheduled to complete the necessary coursework in August 2023, Kiva would like to take an extra year to finish up.

“Rural Psychology I feel would be a very beneficial class to give me the skills to be a better provider or resource for my community. There’s a lot of historical traumas our people face, and it would be interesting to understand mental health from a public health perspective,” she says. Rural Psychology focuses on the competencies, techniques and strategies needed to work in rural settings. Another course, Epidemiology of Mental Health, examines understanding mental health from a public health perspective.

That is why her research through LEND is focusing on trauma. Her end goal is to help develop a multipurpose trauma center that brings a culturally responsible approach to helping students navigate through life.

South Dakota LEND will help Kiva get to that goal. The program has served as a springboard for internal personal and professional reflection, Kiva says.

“The cases I have come across have been really helpful and helped me think really quickly on my feet,” she says. “As a school psychologist, I will have to do that. The strategies I’ve learned help me to see we’re all working together for the same goal. We’ll be better clinicians because of this and take a more holistic approach.” •

For information on LEND, visit www.usd.edu/medicine/center-for-disabilities/lend.

Can-do Attitude Leads to Community Recycling

Every day he goes to work, Alex Sass demonstrates a can-do spirit through the business he and his parents created, Elk-Can Initiative.

The 24-year-old Elkton, South Dakota, resident developed the recycling business, which allows him to provide a service for his adopted community as well as be self-employed, with the assistance of his parents and his Family Support 360 provider, Ted Eining.

Alex has been so successful in his endeavor that Jay Hill, his family support coordinator with Benchmark Family Support, says the venture offers hope to other adults with disabilities.

“It’s kind of what we hope for, for all of our adult clients,” Jay says. “It offers meaningful work outside typical employment. It’s not the norm you see most of the time.”

Alex, who was born with developmental disabilities, had turned to vocational-rehabilitation programs for his past employment, says his mother, Teri Bukowski. It is a familiar path and one that was successful for her older son, Mike Sass,

but the process proved wearying for Alex.

Self-employment, with help from his parents and Ted, has proven to be the path that gives Alex independence, confidence and goals.

“You can always see he feels fulfilled at the end of his working day,” Ted says. “He asks me if he’s done a good job, and he feels excited about what he’s done.”

Since its inception in the spring of 2019, Elkton residents have shown enormous support for Elk-Can Initiative, which collects and recycles aluminum soft drink and beer cans. Alex’s parents approached a member of the Elkton City Council, Niema Thasing, about recycling options in Elkton and the community has embraced the idea. The Elkton Volunteer Fire Department, which had operated an aluminum can drop-off site, even asked if Elk-Can would handle its donations. In return, Elk-Can will make regular community donations through the sale of the aluminum cans.

When Alex’s parents were identifying how to create a meaningful day experience for him, Teri used her knowledge of the



Ted, Alex and Kristi

resources and of Charting the LifeCourse. As a member of the South Dakota Community of Practice for Supporting Families they used Charting the LifeCourse tools such as the Integrated Support Star and Good Life Trajectory.

“They really helped us plan how to create Elk-Can Initiative,” Teri says. “We literally had graphs and charts posted in our home, which helped us identify what a ‘good life’ plan looked like to Alex from our perspective, and then from his view and how we could create Elk-Can Initiative.”

His main job, Alex says, is giving his brother Mike and friend Ted a hard time. On Wednesdays, however, he expands his duties to head out in a golf cart or car to collect the bags filled with aluminum cans that residents have left at the curb for him. In return, Alex leaves a replacement bag behind for the next pick-up day.

On Fridays, Ted once again accompanies Alex to part two of the process, which is crushing the aluminum cans. The can crusher’s location is a perfect example of

the support Elkton has extended: Business owner Kristi Thielen offered Alex the use of her store’s back room. She operates Quilt Store & More, and Alex has taken over responsibility for her lawn mowing and snow removal as a way of paying rent.

“She came to us and told us we could put our business in the back of her place,” Teri says, sounding still a bit amazed at the generosity. Nicema had told Kristi what Elk-Can Initiative wanted to achieve. “Kristi loved the idea of ‘meaningful day’ and how that is really what all of us strive for,” Teri says.

Elk-Can Initiative, which officially started picking up cans in August 2019, gives back to the community through donations of the money Alex makes selling the aluminum cans. In fact, even the prize money Elk-Can Initiative won in the community’s annual Christmas tree contest sponsored by the Elkton Community Club was donated. Alex distributed it to the Community Childcare and Education Center fund.

Elk-Can Initiative, hampered in part by



Alex Sass

a work stoppage during the COVID-19 quarantine, had not made a profit as it neared its first anniversary, but that's not the point, Teri says.

"Alex, like all of us, wants to have a purpose. He wants to be missed when he can't be somewhere, and he wants to be valued. And now the people of Elkton have become his neighbors."

Alex and his older brother moved to Elkton more than three years ago to be closer to their mother and stepfather. Mike began living independently first,

followed by Alex, who took time to make the transition. They are joined by their dog, Tommy, and with Ted's help have developed a weekday routine.

Ted has been the brothers' family support provider for about 18 months. His responsibilities include getting their day started, helping prepare meals, supervising upkeep of their house and acting as both friend and companion. Teri describes him as "a gold mine" and an example of a provider who feels a sense of purpose. "He knows what's good for them. It's not necessarily what mom wants. It's separate things."

For Ted, it's simple: "Alex is family," he says. A native of Dell Rapids, South Dakota, who enrolled at South Dakota State University in Brookings, South Dakota, he is an enthusiastic cheerleader for Elk-Can Initiative. Elkton's embrace of the project does not surprise him, he says.

"I'm thankful for the success we're having, but with all the support the community's giving us, I'd be surprised if it wasn't going well," Ted says. "It really helps

Alex out a lot with that sense of purpose and fulfillment you get from having work."

Jay uses Elk-Can Initiative, which derived its name from the town of Elkton and its can collecting, as an example of outside-the-box thinking.

"We need to be more creative in finding meaningful work and listening to what participants want to do, what has great meaning for them," Jay says. "If they want to work on cars, don't bring up the possibility they would never be able to do that. Instead, we need to ask if we can find other avenues. We need to be creative, to build relationships, and to ask the right questions. If someone doesn't want to work in the traditional jobs like restaurants or grocery stores, we need to learn what they want to do."

While Mike sometimes assists his brother with Elk-Can Initiative, it very much is Alex's project, Teri said. Her sons support each other in their diverse interests. Mike provides companionship for Alex when he is on the Wednesday route but lets Alex be in charge, Ted says.

Alex's other interests include playing games, taking care of Tommy and watching television shows depicting law enforcement officers at work. His goal is to buy a new riding lawnmower, one that might allow him to expand his secondary business.

And there's always Mike and Ted to tease. But whether he knows it or not, Alex has taken on another job, this one is a volunteer one. He serves as a role model for others.

"It's been very inspiring," Jay says. "I use Alex and Elk-Can a lot with other adults I'm working with. Here is an example of someone who found other options." •

Initiative Focuses on Opioid's Harm to Newborns, Children and Families

An opioid crisis exists in the United States, and South Dakota is not immune to its effects, especially on the youngest residents.

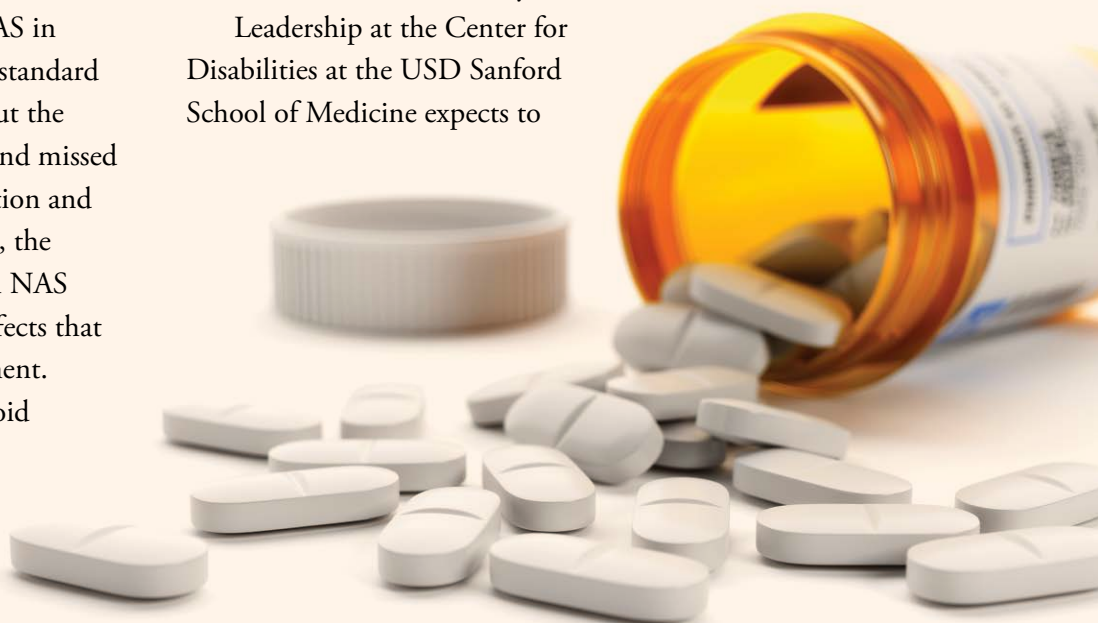
Opioid-use disorder is impacting more South Dakotans every year, resulting in an increase in Neonatal Abstinence Syndrome (NAS)/Neonatal Opioid Withdrawal Syndrome (NOWS) in newborns. NAS or NOWS may occur when a woman uses opioids during pregnancy. The rate of NAS/NOWS in South Dakota has nearly doubled in cases per 1,000 hospital births in the last 10 years.

One challenge to identify NAS in South Dakota is the fact that no standard in coding practices exists. Without the necessary training for providers and missed opportunities for early identification and intervention services for children, the impact will be great. Infants with NAS face immediate and long-term effects that negatively impact their development. Affected babies experiencing opioid withdrawal may have tremors (trembling), irritability (excessive crying), sleeping and feeding difficulties, tight muscle

tone (stiffness), hyperactive reflexes and possibly seizures.

Longer-term impacts include an increased number of children with delays in motor development, brain development, sensory processing, cognitive development, behavioral challenges and speech and language delays. Affected children are more likely to be diagnosed with ADHD, impairments in memory and organization and visual difficulties. There is also an increased risk for early initiation of substance use and other risky behaviors.

Leadership at the Center for Disabilities at the USD Sanford School of Medicine expects to





make a positive impact on children exposed to opioids through implementation of the national training initiative, Supporting Children of the OPioid Epidemic (Project SCOPE). Developed in 2018 by the Wyoming Institute for Disabilities, in partnership with the Nisonger Center at The Ohio State University and the University of Cincinnati Center for Excellence in Development Disabilities, the pilot program has now expanded to nine more states, including South Dakota.

The goal of Project SCOPE is to build nationwide provider capacity and confidence in applying evidence-based practices in screening, monitoring and interdisciplinary support for children and

families diagnosed with NAS/NOWS or who are suspected of being impacted by opioid use, trauma or related exposure.

This initiative will utilize the effective Project ECHO™ virtual professional development model. The heart of the ECHO™ (Extension for Community Healthcare Outcomes) model is its hub-and-spoke, knowledge-sharing network, led by expert teams who conduct case-based learning sessions. Over the course of two to three months, eight to 10 sessions of 75 to 90 minutes each will be conducted every other week at no cost to participants. The first half of each session will present leading edge, evidence-based information to participants, while the second half will focus

on individual real-life cases brought to the expert panel by select participants, allowing for comprehensive, interdisciplinary feedback and problem-solving.

The Center for Disabilities is preparing to launch this initiative in early 2021. Participants will include a mix of interdisciplinary professionals from health care, early intervention, education, mental health and addiction fields from across the state.

“Our first step was to identify our state hub team and work with our national partners on curriculum development,” says Eric Kurtz, Ph.D., executive director of the Center for Disabilities. That core team, which includes practitioners in areas of neonatology, pediatrics, psychology, early childhood education, speech, physical and occupational therapies and others, will help place Project SCOPE in the hands of providers from across the state and region. “This initiative will be especially impactful in rural areas of our state where specialized services are not always available. By removing the barriers of cost and access to specialized knowledge, outcomes for children and families are more likely to be improved,” Kurtz says.

Multiple issues have affected efforts to obtain reliable data on the number of babies affected by opioids. “We are hoping to raise awareness of the impact of NAS on babies and their families in South Dakota,” Kurtz says. Many pregnant women in South Dakota are not screened, and in many cases their newborns are discharged by the third day. NAS associated with long-acting opioids may not be apparent immediately, so affected infants may not be identified before leaving the hospital.

“This will also help the providers who see the babies and families after they come

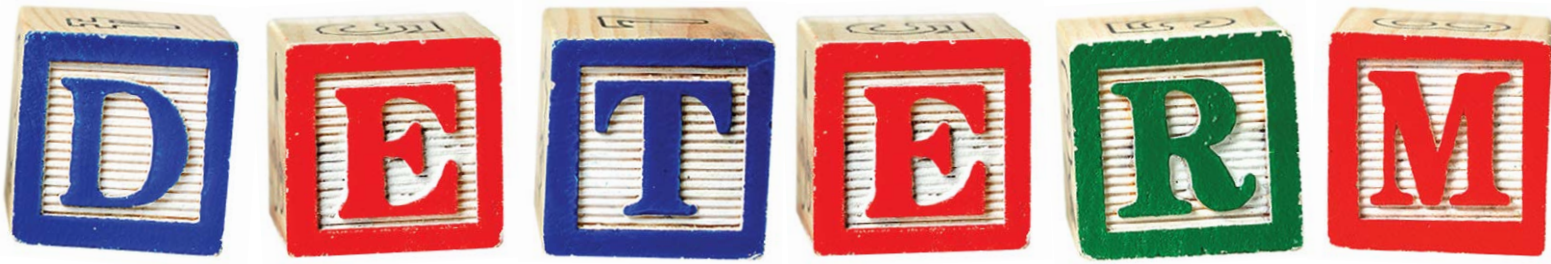
home,” Kurtz says. “We know those children are at higher risk for being placed in foster care and tend to require interdisciplinary teams of professionals to support them throughout their early development.”

The Center for Disabilities’ extensive statewide network of partners supporting Project SCOPE includes the South Dakota Departments of Education, Health, Human Services, and Social Services; Sanford Health; Avera Health; Monument Health; Volunteers of America-Dakotas and other local health, mental health, education and law enforcement professionals as well as families.

Offering Project SCOPE in South Dakota will provide another benefit: reaching others in neighboring states. “The Sioux Falls area has the largest health care systems in the region. Many people come here for prenatal care and many across the area give birth in these hospitals, so this will have a regional impact,” Kurtz says.

The Center for Disabilities intends to sustain this program and expand the ECHO™ training model to additional topical areas and providers across settings.

“It fits in well with the multifaceted organization’s goals and mission to evolve with the challenges facing South Dakota,” Kurtz says. “In South Dakota, we’ve got these little ones and their families going untreated in many cases. About 84% of people in South Dakota suffering from addiction go untreated, and that can impact a lot of newborns. We’ve got a responsibility to help those children facing long-term challenges and negative outlooks. We’re positioned as well as anyone to make help accessible to professionals and families across the state. We’re a perfect fit.” •



to Start a Day Care of Her Own

How do you recognize when someone is a natural-born teacher? When she turns a summer fishing trip into a lesson for kids that they talk about for days and days.

Twenty-three year-old Tria Dennis' job title is childcare provider, but the Pierre, South Dakota, native takes it far beyond that.

"I help kids improve their lives," Tria says. "I help them learn things they need to learn in real life. I teach them things they wouldn't learn in school."

That is why, when Tria and three others traveled to Mobridge, South Dakota, last summer in search of fish, her cousin's capture of an alligator gar meant more than a meal of fish fillets to her. Instead, she kept the creature's skin and head and took it to Faith Lutheran Daycare Center so her summer charges, who ranged in age from 5 to 12, could have a science lesson outside their classrooms.

"The kids really enjoyed it. They thought it was really cool," Tria says. "They kept asking questions and they were into it. I left it on the table so the parents could see, and the kids kept bringing their parents over

and telling them about it. They did a good job of remembering."

Tria, the only child of Robert and Anna Dennis, always knew she had a calling to work with children. After Tria was able to quiet down a crying infant when the child's parents had failed, a cousin dubbed her "the mother hen of the family." Following her freshman year at T.F. Riggs High School in Pierre, a job coach helped Tria find a part-time position at Faith Lutheran Daycare. Tria worked Mondays through Fridays all summer with the elementary school children. In the fall, as the COVID-19 pandemic permitted kids to return to the classroom, Tria worked with preschoolers from 7:30 a.m. to 2:30 p.m., then with the elementary school kids from 3:30 p.m. to 5:30 p.m.

Her post-high school training has included classes for the visually impaired in Sioux Falls, South Dakota. When Tria was 4, she was diagnosed with a rare form of glaucoma, a degenerative eye disease that generally affects the elderly.

"It's a one-in-a-million thing," Tria says in a matter-of-fact tone. "I am legally blind



in my left eye, and I can see perfectly fine with my right. Growing up my doctors always told me I could wake up one day and be totally blind. That took some years to get used to.”

Tria also was diagnosed with severe migraines and underwent her first spinal tap at the same age. She struggled with the debilitating pain throughout school.

“I would get migraines so often that my teachers would realize when I was having the starting of one,” Tria says. “They would instantly call my mom, and my mom would come and get me.”

Several years ago, she was placed on a medication that has eliminated the most severe migraines.

In addition, Tria was diagnosed with dyslexia. Despite these multiple challenges, Tria approaches life with a positive attitude, says Sue Morth, who served as Tria’s special-education tutor at Riggs.

“From the first time I met her I saw she was just such a warm, kind, loving person,” Sue says. “I just enjoyed getting to know her better over the years she was in high school. We kind of adopted each other. I was her school mom.”

Sue, who now lives in Oregon, ran an in-home day care for more than 26 years. Tria’s work with children makes Sue feel almost as if a daughter is following in her footsteps.

The similarity might move a step closer.



Tria Dennis

Tria’s eventual goal is to start her own day care. She would like to have accomplished that within the next 10 years.

“I want to be able to help more kids that are like me,” Tria says. “I want to be able to get them the help they need to become

a better person and become who they're meant to be.”

Some of Tria's self-confidence in pursuing that goal comes from her participation in the Youth Leadership Forum (YLF) the summer before her senior year in high school. YLF is a weeklong leadership training and career

awareness program for high school students with disabilities.

She applied at the urging of her special education teachers, and today, Tria is grateful they made that suggestion.

“I'm more outgoing than I was before YLF. Before I was a shy, keep-to-myself kind of person. YLF helped me speak out more, and it helped me find my words to tell people what I felt about things.”

Sue witnessed the changes.

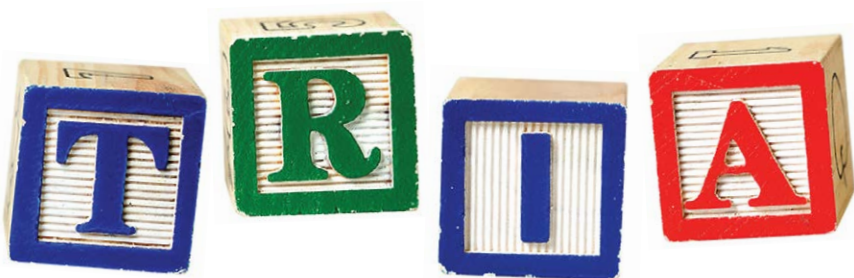
“It was really neat to see her go back the next year as a speaker and a mentor to some of the students. That was a wonderful opportunity, and she really grew a lot.”

Tria continues to use what she gained through YLF in her daily life. She describes herself as an outdoors person who loves hunting, fishing, camping and hiking. Her favorite camping spot: the Big Horn Mountains of Wyoming. Tria also is quick to pick up a book and lists Nicholas Sparks as her favorite author.

Tria lives at home, paying her share of the bills, so she can remain on her parents' insurance. The issues with her vision mean, among other things, frequent updating of her eyeglasses.

Her daughter has a heart of gold, Anna Dennis says. Tria's heart shines even brighter since YLF gave her confidence in what she has to offer.

“She sees an elderly couple trying to put stuff in their car, she's right there and helps them out. She literally goes way beyond what she has to do. She's not scared to help people, but before YLF she wouldn't have done that.” •



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.



UNIVERSITY OF
SOUTH DAKOTA
SANFORD SCHOOL OF MEDICINE

Center for Disabilities

1400 West 22nd Street • Sioux Falls, SD