with you through every stage of life

MMI
MUNROE-MEYER INSTITUTE
ANNUAL REPORT
2011
The UNMC Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation originated in the late 1950s as a place for children with polio to receive treatment. Today, Nebraska’s federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service annually provides diagnosis and treatment to more than 10,000 children and adults with diverse developmental and physical disabilities and genetic disorders.

With approximately 230,000 people with disabilities in the state of Nebraska, the need for specialized programs and support services to improve their quality of life is vital.

By utilizing professionals who specialize in more than 15 disciplines and programs, MMI provides an interdisciplinary team approach that assures a comprehensive diagnostic and treatment program.

Parents, teachers, therapists and community service providers are involved in the provision of services, which includes the development of innovative ways to promote inclusion of individuals with disabilities and their families into the community.

Since becoming a part of the University of Nebraska Medical Center in 1968, MMI’s research, education, services and statewide technical assistance training have been a source of hope for patients with developmental disabilities and their families.

MMI’s mission includes a dedication to basic and applied research conducted by faculty and staff members in all disciplines and programs. MMI is committed to training future health care professionals who will provide care to children and adults with developmental disabilities and genetic disorders and their families.
When most people think of the University of Nebraska Medical Center’s Munroe-Meyer Institute, images of cute, young children come to their minds. Those of us who work here at MMI know that the children pictured in those images grow up all too fast to become adults who may require services well into adulthood.

Just like those children, MMI has grown and changed over the years as well. When the need for adult services in the community arose, the faculty and staff at the Institute rose to meet those needs, along with the needs of other children with disabilities as they aged. We are still here for young children just like we always have been, but now we focus on serving individuals with disabilities throughout their lifespan, from prenatal genetic counseling to recreation therapy programs for adults.

And we don’t just offer services for those individuals. Every day, our researchers work to find answers and best practices that will hopefully improve upon our clinical services. And every day, our faculty educate future leaders in the disabilities field to serve these children and adults or to do research that may lead to a finding that will someday transform lives.

The goal of this annual report is to illustrate just how much we do for every age group, whether it be while they’re still in the womb, or whether they have gray hair. So next time you think of the Munroe-Meyer Institute, hopefully pictures of people of all ages are what come to mind, people throughout the lifespan.

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Web Extra
Look for this icon throughout the report for exclusive web content.
Visit unmc.edu/mmi to view web extras.

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Kourtney Case knew she’d find out the sex of her baby at her 20-week ultrasound. She didn’t know she’d learn her baby boy would be born without a hand. On Sept. 12, 2006 at 1:16 p.m., Braedyn was born. The development of his right arm stopped just below the wrist, but he had little finger buds with fingernails. Knowing this would be the case ahead of time, the first-time mom was able to fully appreciate the birth of her son.

The positive experience kept Case coming back for prenatal genetic counseling for her next two pregnancies. Because Fisher has more time with families than a physician might, she can sit down and explain testing procedures and potential results in non-medical terms using illustrations and analogies.

It helps that the lab that does the testing is right around the corner. The Human Genetics Lab at MMI receives samples from all over the world.

“Being just down the hall from the lab that does the testing is crucial,” Fisher said. “I have that direct contact since I know the name of the person to ask a question.”

Though not part of her official job description, Fisher also connects families with support groups and other families in similar situations. One of the families Fisher referred Case to is now a member of the Nebraska Children with Upper Limb Deficiencies (NCLUD) support group. The Case family founded the organization. The group features educational guest speakers and group outings for children with hand anomalies.

Case would, and has, recommended prenatal genetic counseling to others. “It helps you cope with the situation,” she said. “That way you can get all your questions answered.”

Like “Will I have to roll up his sleeves?”

The answer is no. Braedyn dresses himself and is on the cusp of tying his own shoes.

Many of Fisher’s patients are referred from abnormal ultrasounds like Case’s or abnormal first or second trimester screens. Her job is to help moms and dads make informed decisions about genetic testing options. “We provide information and test, not to change anything, but to prepare parents for a baby with whatever the condition is,” she said. “That way, they can be happy about the birth of their baby, rather than worry about a diagnosis in the delivery room.”

Counseling helped Case decide to do an echo-cardiogram as upper limb deficiencies can be associated with heart problems. Such was not the case with Braedyn. She opted not to do an amniocentesis after the ultrasound revealed that ABS was most-likely an isolated incident.

“The great thing about testing and screening is the peace of mind,” Case said. “If you know something ahead of time, you can come to terms with it, rather than having to go through that grief process when your child is born.”

Case writes on her website: “I was excited and even impatient to bring our first child into the world. I started thinking about the color of his hair and eyes and thinking less about what his hand was going to look like.”

Above: Four-year-old Braedyn Case shows his parents, Kourtney and Mark, along with prenatal genetic counselor Sara Fisher, how he writes his name. Fisher counseled the Case family after Braedyn was diagnosed with Amniotic Band Syndrome in utero.

Right: Braedyn Case flies a kite at an event for Nebraska Children with Upper Limb Deficiencies (NCLUD), an organization started by his mother, Kourtney. Prenatal genetic counselor Sara Fisher helped connect Case with other parents of children with upper limb deficiencies who are now members of NCLUD.

With the news came a barrage of questions.

How did this happen to my baby? Why me? What did I do wrong? Does it hurt him? Will my son have trouble making friends? Playing sports? Will he go to prom? Get married? Are there other underlying problems with this pregnancy? Is he going to be born healthy? Will I have to roll up his sleeves?

Thankfully, Sara Fisher, a prenatal genetic counselor at UNMC’s Munroe-Meyer Institute, was there with the answers.

As for how it happened, the official cause was amniotic band syndrome (ABS) in which the lining of the amniotic sac comes off in a string and acts like a rope, wrapping around the extremity and cutting off blood flow to the limb. Why her? There was no genetic reason for it.

What did she do wrong: Absolutely nothing.

Does it hurt him? No.

Will he have trouble making friends, playing sports, go to prom, get married? Five years later, Braedyn Wade Case is answering some of those questions himself. He writes his name, golfs with his dad and does typical five-year-old boy things like play Thomas the Train with his buddies.

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Five-year-old Trinity practices writing skills with her early intervention therapist, Tammi Perry. Diagnosed with autism at age two, Trinity is now educated in a typical kindergarten classroom. Her mom credits her success to early intervention.

“Driving,” responded Trinity, or as her mom calls her, Tinky. A high-five ensued.

Labeling the actions and emotions of other people builds a basic foundation to understand other people, which improves social skills. While it might not seem like a major feat for your average kindergartner, for a little girl with autism who almost broke her grandma’s nose because she didn’t like getting dressed, it’s a big deal.

And it’s all because of early intervention at UNMC’s Munroe-Meyer Institute (MMI). “I think early intervention will be the difference between whether she would’ve attended college or not,” said her mom, Brooke. “Now I know, Tinky’s going to college. The sky is the limit for her.”

About half of the children who receive intensive early intervention services at MMI go on to be educated in typical classrooms with minimal support. The other half shows improvement, though not as dramatic as children like Trinity.

“The brain is the most malleable at a young age,” said Wayne Fisher, Ph.D., director of the Center for Autism Spectrum Disorders at MMI. “If we don’t intervene early, we lose valuable time.

“We can make progress in those that are older, but a long history of reinforcing negative behaviors takes its toll.”

Once Tinky’s combative behaviors were under control, she became an easy-to-educate sponge, said her mom. Goals in early intervention often start small.

“Everything is individualized. We do assessments to evaluate social, communication and pre-academic skills and find the gaps,” said Nicole Rodriguez, Ph.D., coordinator of early intervention at MMI. “Often we find barriers to learning. For example, a child may have difficulty sitting in a chair and attending to academic materials. In that case, we might start by working on sitting and attending before we begin teaching more complex skills.”

Thruaghf at first applied behavior analysis methods of measuring every little behavior made it seem like her child was a series of numbers, Brooke now sees the reason for it.

“She’s doing awesome academically, has tons of friends and is the most outgoing kid at the Children’s Museum, always engaging everyone, but the results-based data and graphs help to see how far she’s come,” she said.

Those same goal meetings that helped Trinity are now helping her younger brother Roy, 2, who was diagnosed with autism at age 1.

“He was cooing, babbling and using silverware, but just stopped progressing at 12 months,” Brooke said. “Luckily, we had him in early intervention by 14 months. So far, his vocabulary is jumping off. He recently said, ‘Mama, I need help please,’ which is huge for him.”

Without intensive treatment like early intervention, the long-term outcomes for children with autism remain bleak. In a follow-up study of adults with autism, only 26 percent had one or more friends, 13 percent had independent jobs — most of which were low-paying positions — and only 4 percent lived independently.

Dr. Fisher’s program turns those numbers on their heads.

“We typically start by reducing stereotypic, repetitive and problem behaviors and replace those behaviors with language and social skills.”

Once skills are developed to 90 percent or better accuracy at MMI, Dr. Fisher’s team goes into the child’s home and school to educate parents and teachers on how to implement the skills across settings.

While that might seem cost-prohibitive, several cost-benefit analyses found that for every $1 spent on effective treatment like early intervention, more than $10 are saved.

Still, it’s not all about money.

“There’s a lot of information out there saying individuals with autism will never live on their own or go to college, but with treatment that all changes,” Brooke said. “Absolutely anything is possible with early intervention.”

“The Earlier, The Wordier

Watching 5-year-old Trinity rattle off answers to flashcards, you’d never know she once used grunts and screams to communicate.
Nine-year-old Noah Legros sits on one foot and deals out UNO cards to a group of four boys around the table. But this isn’t your average after-school gathering. The participants in the group have all been diagnosed with high-functioning autism, Asperger’s disorder or ADHD. Noah is in social skills class at UNMC’s Munroe-Meyer Institute (MMI).

For Noah, communicating and socializing with other children doesn’t come naturally. While he’s outgoing and articulate, if a peer were to accidentally drop a book on the ground, offering to pick it up doesn’t occur to him. That’s why psychologist Terri Mathews, Ph.D., and her team teach skills like “Offering Help” along with “Sharing ideas,” “Complimenting others,” “Recommending changes nicely,” and “Exercising self-control.” Together, they are the S.C.O.R.E skills.

“Very nice job on UNO, Aiden,” Noah replied. When they practiced sharing ideas, Noah approached Isaac and said, “Hey, let’s play Cars II on the Wii!” Isaac asked if he wanted to jump on the trampoline. Noah kept eye contact and responded, “Sure, that sounds nice.”

“He’s very social,” said Noah’s mother, Tatiana, “but he needs help with what to say and what not to say. He can talk about trucks for one hour. After five minutes, most people want to change topics and talk about the weather.”

Special interests are a frequent issue for children with autism, Dr. Mathews said. “Most children without autism pick up on what is expected of them socially,” she said. “They understand etiquette through modeling or observing. Children who have autism don’t seem to have the same innate ability to recognize what is expected in social situations.”

Yet it is possible for them to acquire these skills. Repetition is key. The classes are just the tip of the iceberg, Dr. Mathews said. “We spend eight, 1½-hour sessions learning about social skills, so we’re only able to cover the basics,” she said. “We want parents to take their children out in the community and find opportunities to practice the skills.”

After initially only offering the classes for children, Dr. Mathews added an educational parent training component so that parents could learn what the children were learning. “I realized a lot of what he does comes with who he is,” she said. “Now I have a clear idea of what to expect going forward. Social skills are not easy or automatic for him. I might have to say something 20 times, but we’ll keep trying.”

Noah has shown the most progress with the E in S.C.O.R.E., Exercising self-control. “He always was pleasant, but he also was sort of a “rule cop,” Dr. Mathews said. “Since the program started, he’s learned to restrain himself, allow others to speak and not dominate the conversation.”

His mother and father want what all parents want for their children: friends. Interacting with peers may not be a high-priority now, but as children with autism spectrum disorders become teenagers they begin to recognize that they don’t always fit in and they don’t know why. This can lead to loneliness. That’s when deficits in social skills become more of a detriment, Dr. Mathews said.

Her hope is that the participants in the social skills program will succeed in group settings. “I want them to be invited to birthday parties, to invite friends over and to have someone to sit with them at the lunch table” she said.

Hopefully someday, Noah will host your average after-school gathering with four boys he can call his friends.
Sarah Boucher lifted her gold bowling ball from the return and took a few tentative steps toward lane No. 1. As she approached the foul line, she brought the ball up by her chin and promptly threw a chest pass at the pins. Unorthodox, maybe, but the ball followed the arrows like they were directions. The bumpers were up, but not necessary for this turn. Crash! Half the pins down. Next turn: Crash!

“Yeah, I got a spare,” screamed 19-year-old Sarah. She turned and high-fived everyone around her.

While most patrons sat and watched each other bowl, Sarah and her peers all stood. They cheered each other on for 10 frames straight. Shouts of “Nice one!” and “That’s a way to bowl!” could be heard across the alley. For teenagers with disabilities, opportunities to get together with friends are a luxury.

Thanks to Arnold Stern Teen Nights hosted by the recreation therapy department at UNMC’s Munroe-Meyer Institute (MMI), Sarah and her friends can get together. The co-ed group formed a year after a similar “Girls Group” for female teens with disabilities launched at MMI.

“The teenage years are so peer-focused,” said Michael Crawford, R.D., director of recreation therapy at MMI. “But for teens with disabilities, their relationships are mainly authority-driven and teaching-focused at a time when teens naturally want to be with people their own age.”

From Omaha Maverick hockey games to Blue Man Group performances to movie nights to Husker football tailgates, the teens have done it all. Prior to the groups at MMI, there were few programs that encouraged teens with disabilities to get out in the community.

“Compared to most teens, these kids don’t have 600 friends on Facebook, so there’s a tendency to be isolated and shut-in,” Dr. Crawford said. “Having something on the calendar to look forward to is important for everyone.”

“Look forward to” might be an understatement.

“When Sarah gets a reminder postcard in the mail about an event, she starts jumping around like she won the lottery,” said her mother, Angela. “Most people take those opportunities for granted.”

Dr. Crawford said there are three kinds of pleasure participants receive from recreation. One is the anticipatory. The second is the activity itself, which is often short-lived. And the third is the pleasure of reminiscing to friends and family about the experience, which is what Sarah enjoys most.

She has a duplication on chromosome five, but it doesn’t stop her from being outgoing and friendly.

“She a socializer, but in reality, mainstreaming doesn’t happen,” Boucher said. “No one’s calling her to go to the mall.” That’s why her family is so thankful for the monthly MMI group outings.

“They give her the opportunity to go out in the community in a safe environment without us hovering over her,” Boucher said. “They know what to expect because they’re familiar with people with disabilities and treat them with respect.”

Safety is a priority for Dr. Crawford’s staff.

“In both programs, we’re able to serve kids that volunteer efforts can’t quite reach,” he said. “With our training, we’re able to take a few children who are medically fragile and in wheelchairs.”

In typical Nebraska fashion, there was a snowstorm raging outside the day of the bowling outing. When asked why the group didn’t cancel, all organizer Kelley Coutts had to do was gesture toward the teens. “This is why we don’t,” she said.

Now that’s a way to bowl.

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Train the Brain

Kim Kozelichki took a deep breath and began to walk along a hot pink string on the floor as if it were a tightrope. The way her husband, Todd, cheered her on, you’d have thought the string was 10 feet off the floor.

“Come on, Kim! Go! Go! Go!” he said. When she finished flawlessly, her husband of 17 years stopped recording video on his phone and looked at her. “Wow, Kim. That was unbelievable.”

Unbelievable because just mere months ago, Kim wouldn’t even attempt to walk along that hot pink string. She was afraid she’d fall over. Diagnosed with relapsing/remitting Multiple Sclerosis (MS) in May 1997 at the age of 26, the former collegiate tennis athlete used a wheelchair for long distances. Tremors forced her to stop using a pen.

Looking at her now, you’d never know thanks to a promising pilot study at UNMC’s Munroe-Meyer Institute. Kozelichki is one of five participants in a pilot study to determine if a device called the PoNS, along with a strict regimen of physical therapy, can help those with neurodegenerative diseases regain healthy areas of the brain.

A battery-powered device, the PoNS — developed by a trio of researchers at the University of Wisconsin — is placed in the mouth where thousands of nerve endings on the tongue can send messages to the healthy areas of the brain.

The idea is that the stimulation, in combination with therapeutic exercise, helps the brain form new neural pathways for recovering functions like balance and movement. Those skills are vital for people with MS, cerebral palsy, traumatic brain injuries, strokes and Parkinson’s disease.

“The cool part about the PoNS is that we’re actually seeing improvements that restore mobility and balance, which is the complete opposite of what drug therapies are after — slowing the degradation,” said Max Kurz, Ph.D., the director of biomechanics at MMI and lead investigator of the study. “For most people with MS, their motor skills get worse. Rarely do they maintain or improve.”

Kozelichki takes pills morning, noon and night, but none of those medicines has done what the PoNS seems to do.

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“She’s gone from dragging a leg — to — to see what exactly causes the improvement.

If the PoNS proves successful, Dr. Kurz hopes to start an FDA clinical trial that would lead to the device becoming more widely available. His hope is to return people to their lives pre-neuromuscular disorder.

Regardless, Kim refers to the PoNS as “the miracle unit.” She’s back on the tennis court again, returning the ball to Todd with her signature hot pink string on the floor as if it were a tightrope. The best part — she isn’t the only one with positive results. The study, which tracks participants about every four weeks, is putting up some big numbers.

Over an 8-week period, participants are showing 50 percent improvement in postural balance, a 55 percent improvement in walking ability, a 48 percent reduction in MS impact scores and a 30 percent reduction in fatigue.

“You don’t need data to see the changes,” Kurz said. “But the initial results are larger than we expected. I’ve never seen that big of a jump.”

Still, Dr. Kurz and his team of neurological physical therapists — Reggie Harbourne, Brad Corr and Kathy Volkman — are cautious.

After the pilot study is complete, they plan to conduct a study in collaboration with the University of Wisconsin that will test the PoNS against a regimen of physical therapy — rather than in addition to — to see what exactly causes the improvement.

Do not hallucinate.
Facts & Figures

Serving the Community

MMI provides technical assistance to other university departments and programs, community organizations and governmental agencies to transfer new knowledge from the academic setting into the community.

This year, 25,197 participants attended workshops, conferences, teleconferences and other community education activities. This chart illustrates the broad spectrum of issues and services for which MMI provides evaluation, assistance in program development or implementation, continuing and community education and a variety of other community services.

Funds Leveraged

Over the past five years, MMI has been successful in maintaining grants and contracts with existing partners in the community, and also in identifying new partnerships and funding sources to develop innovative programs and address emerging issues.

Interdisciplinary Trainees

MMI’s education program provided an interdisciplinary training experience for 177 students, interns, residents and post-doctoral fellows in 2011 for a total of 130,128 hours. More than half of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.
Fueling Our Mission
MMI’s complex mission requires that we seek support from a wide variety of sources. Patient revenues continue to be the largest part of our budget with state funds and contracts from public schools and state agencies providing a great deal of support. Private donations continue to be a very important part of our program as we develop cutting-edge programs to benefit Nebraskans with disabilities.

Patient Revenues — 48.09%
State Funds — 16.57%
Federal Grants — 8.61%
State Contracts — 6.19%
School Contracts — 9.6%
Private/Other Funds — 10.94%

Products Developed and Disseminated
MMI faculty members publish extensively in professional journals, monographs, periodicals and books and also disseminate best practices through reports, manuals and other informational materials. In 2011, MMI faculty members developed 120 new products and disseminated 131 different products to professionals, students, parents, people with disabilities and the general public.

MMI’s Mission:
To improve the quality of life for persons with disabilities and their families.
UNMC Munroe-Meyer Institute for Genetics and Rehabilitation
A university center for excellence in developmental disabilities education, research and service.

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