Unlocking POTENTIAL

Munroe-Meyer Institute for Genetics and Rehabilitation

2007 ANNUAL REPORT

Unlocking POTENTIAL

A University Center for Excellence in Developmental Disabilities Education, Research and Service
Director’s message

Change is in the air at the Munroe-Meyer Institute. After almost 25 years under the outstanding leadership of Dr. Bruce Buehler, we are in the process of recruiting a new director who will lead the Institute in the coming years. MMI is approaching its 40th year as a part of the University of Nebraska Medical Center. We have seen tremendous growth in the services and supports we provide in our pre-professional and post-doctoral training programs, through our outreach and continuing education activities and in our basic and applied research activities. From a staff of less than 10, and a budget of less than $1 million, we have grown to more than 250 faculty and staff with an annual budget of more than $20 million. With the guidance and support of our boards, foundations, community supporters and the leadership of the chancellor, we are entering 2008 as an independent UNMC academic unit. More than 40 faculty members from 11 disciplines now form the nucleus of the MMI faculty. Our new academic status will allow us to enhance our collaborations with other academic programs on campus and within the University of Nebraska system.

Our clinical programs for children with special health care needs continue to grow, bringing the face of UNMC across the state of Nebraska. Our statewide pediatric behavioral health clinics continue to expand. The Center for Autism Spectrum Disorders was created in response to the increased prevalence of autism in our communities. Our collaborative services with the greater Omaha school districts, clinics and consultative services to Children’s Hospital and other area hospitals continue to grow. Cytogenetic and molecular genetics diagnostic testing provided by MMI’s Human Genetics Lab has become an essential part of medical care and is part of the revolution in transplantation and cancer treatment. Our collaboration with The Nebraska Medical Center’s transplantation program and geriatric center provide quality cutting-edge services across the age span, from children in the pediatric feeding disorders program to adults in need of speech and language services and augmentative communication supports.

Where do we go from here? Over the next few years, translational interdisciplinary research will continue to expand to bring more empirically derived interventions into practice. New programs will be developed to support our clients as they age. Research in behavioral genetics, where we will see the intersection of behavioral interventions and laboratory science, will both validate present methodologies and pave the way for future treatments for children, youth and adults with disabilities. These new activities will require expansion of our educational programs and enhance the supports available to all Nebraskans with disabilities. New technologies, programs and initiatives will be in our future, as they have been in our past. Along with our entire faculty and staff, I welcome and look forward to these future challenges.

J. Michael Leibowitz, Ph.D.
Interim Director

Munroe-Meyer Institute first opened its doors in 1959 as a private therapy center to serve the children and youth of Nebraska with polio. In 1968, the Institute became part of the University of Nebraska Medical Center. Over the past 40 years, MMI’s mission has broadened to serve Nebraskans with genetic and developmental disabilities across the lifespan. The Institute now has premier programs emphasizing education of future professionals, clinical services, research, continuing education and technical assistance to programs across the state -- all provided in an interdisciplinary and collaborative environment.

As the Nebraska University Center for Excellence in Developmental Disabilities, one of 67 such federally designated centers across the nation, MMI is charged with promoting change within service systems, building the capacity of individuals and community programs to support persons with disabilities; and advocating for the needs of all people with disabilities.

Unlocking one’s potential for greatness is at the heart of MMI. And, for many, it happens here. Every day.
Individuals need to lead a healthy and meaningful life. “Many people with disabilities are able to work and want to own their own homes,” he tells students. “They just need support, as we all do. It’s about healthy interdependence.”

Regardless of their disability, all children have potential that can be unlocked, Smith says. “We work hard not to artificially limit kids,” he said. “Every child has some limitations, but we try to never say never when talking about children with developmental disabilities.”

“The biggest need families have in dealing with their children with special needs is information: knowing where to go and who to talk to in order to access services for their disability,” Smith said. “When a parent contacts us, we look at each child’s individual needs and then determine how and where they can best get those needs met.”

Smith serves as an advocate for families and individuals with disabilities -- sitting on numerous boards and committees that work to improve policies and services for people with disabilities at the local, state and national levels.

“We know that if individuals have supports, they can survive, thrive and contribute to society while enjoying a greater quality of life in the process,” he said. “It’s important to be a resource to individuals and families, but it’s critically important to ensure that support systems are family friendly and person-centered, are adequate to meet the overall need, and don’t unintentionally impede what they’re intended to support.”

Although historically focused on services for children, MMI is a lifespan institute, Smith said, noting the emergence of more adult programs. The institute provides training, access to resources and opportunities to meet other families that can provide mutual support and shared experiences.

“One challenge parents can initially face is a sense of isolation; a sense that ‘Ours is the only family like this,’” Smith said. “We know that is not the case and it can be enormously helpful to link families with similar experiences.”

“Many parents go through a grieving process because they have expectations that are suddenly dashed when they learn of their child’s disability. We stress that a parent’s dreams and goals might change because of a child’s disability, but their child can still reach their full potential and have a meaningful life within the range of their abilities.”

The Bartletts found MMI in 2003 when the military moved them to Nebraska from Wichita Falls, Texas.

Consumer Family Coordinator Mark Smith, left, discusses developmental disability resources with Michelle and John Bartlett.

“A big need families have is information about the community that offers services,“ Smith said. “Information about what services are available and how to access those services.”

“Wolf-Hirschhorn syndrome is a rare genetic condition characterized by reduced fetal growth, intellectual disabilities and distinctive facial features.”

Jacob Bartlett of Bellevue, Neb., makes weekly visits to UNMC for occupational and physical therapy. On this day, the 7-year-old with Wolf-Hirschhorn syndrome is carefree, clapping with glee as he swings in the giant swing – keeping a constant eye on the VeggieTales movie playing on his tiny mobile TV screen.

Within arm’s reach, his parents talk with MMI’s consumer family coordinator as he helps them navigate the frequently confusing world of disability services and programs.

“Special education and medical services are absolutely overwhelming,” said Jacob’s mother, Michelle Bartlett. “But MMI has helped us connect with services in the community and shortened the timeframe and the work I had to do to best advocate for my child.”

The Bartletts speak regularly with MMI’s Consumer Family Coordinator, Mark Smith, who works tirelessly to help families and individuals with developmental disabilities identify the resources they need.

“MMI and its advocacy services are fantastic,” said Michelle Bartlett, who was a social worker in Texas for adults with intellectual and developmental disabilities. “I refer people to them all the time.”

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The consumer family coordinator infuses the concepts of family and person centered care into the pre-service training programs at MMI. Family panel presentations and community case coordination activities allow future health care providers to learn first-hand about what life is like with a disability and what supports families and individuals need to lead a healthy and meaningful life.

“Many people with disabilities are able to work and want to own their own homes,” he tells students. “They just need support, as we all do. It’s about healthy interdependence.”

Regardless of their disability, all children have potential that can be unlocked, Smith says. “We work hard not to artificially limit kids,” he said. “Every child has some limitations, but we try to never say never when talking about children with developmental disabilities.”
Kyle Ohrt can’t speak a word, nor is he toilet trained. The 9-year-old with severe autism occasionally still wears a karate helmet to protect him from self-inflicted blows.

Kyle’s plight seemed hopeless – until he met Wayne Fisher, Ph.D., a world-renowned expert in treating children with severe autism.

Dr. Fisher, director of the Autism Spectrum Disorders program at the Munroe-Meyer Institute, has given the Ohrt family hope.

Dr. Fisher was recruited to UNMC in 2006 to develop a world-class autism center similar to those he developed at the Kennedy-Krieger Institute at Baltimore’s Johns Hopkins University, where he spent 13 years, and most recently at the Marcus Institute in Atlanta, which he formed in 1999.

Autism is a developmental disability stemming from a neurological disorder that disrupts normal brain function. Behaviors range from an inability to make eye contact to unresponsiveness to instruction to over-or-under sensitivity to pain and noise. Curing these behaviors is not Dr. Fisher’s goal. Instead, he and his team want to understand the social and environmental factors that lead to the behavior and then develop ways around and through those behaviors.

Here’s an example of how it works:

An autistic child holds a ball in his hand and has no intention of letting go. But, he has work to do with Dr. Fisher’s team – a learning exercise – and he’s not interested. He aggressively rejects any attempt by team members to take the ball from him or get him to do the exercise.

The boy is given a simple choice: Either do the work with ball in hand or give it to a team member.

Ball in hand, the boy completes the learning exercise. “We find what motivates these kids and use it to tailor an environment to suit them,” Dr. Fisher said.

Children who work through Dr. Fisher’s program average a 15-point increase in IQ scores, he said, and most show drastic reductions in many of their autistic behaviors. For many, that translates into a fairly typical life.

Dr. Fisher’s arrival at UNMC was a godsend for the Ohrt family, who adopted Kyle from Romania almost 10 years ago. With no comprehensive program in the region, the Ohrts made due with whatever help they could find locally. That included a long list of in-home specialists and technicians, as well as autism programs in the area.

Dr. Fisher and his team practice at the Munroe-Meyer Institute, where space has been renovated to meet the needs of the center.

“The clinic is providing service for so many kids that you wonder ‘what would all of us have done without it?’ ” said Kyle’s mother, Patti Ohrt.

Kyle’s autism is such that he will not be able to function independently as some of Dr. Fisher’s other patients will, Ohrt said. Still, progress has been made. “We want to keep Kyle in our home and Dr. Fisher has given us the tools to do that,” she said. “He’s made our life a bit easier.”

Kyle, who attends special education classes at an Omaha-area grade school, has had entire days at school during which he hasn’t hit himself. That was almost unheard of before Dr. Fisher’s arrival, Ohrt said, praising the MMI team for also providing assistance to the school.

She knows the day is coming when she and her husband, Tom, an offensive lineman for the Nebraska Cornhuskers in the 1970s, will not be able to physically deal with Kyle. He’ll simply be too strong. Dr. Fisher’s program brings hope that he’ll eventually be able to live in a group home.

Ohrt has one additional goal. “My greatest dream,” she said, wiping away tears, “is that one day he’ll be able to look at me and call me ‘Mom.’ ”
Moira Carrano loves her Camp Munroe T-shirts, all seven of them. Her enthusiasm for MMI is so great that her family doesn’t even talk about the program during the week. “If we did, she’d want to go there tomorrow,” said her mom, Wendy.

In addition to Camp Munroe, the 7-year-old with autism participates in MMI’s Saturday morning recreation program, where she loves swimming and cooking.

“From our first day, MMI has been amazing,” Wendy Carrano said. “Moira was talking a mile a minute and was so excited after that first day at Camp Munroe. She’s loved camp ever since.”

The camp, which celebrated its 25th anniversary this past year, is the flagship program in MMI’s Recreational Therapy Department, which today includes 16 unique programs for children, youth and adults with developmental disabilities. The programs range from aquatics and dining clubs to adult vacations and tandem cycling.

“Recreational therapy activities are a very important element to being self-determined and independent,” said Michael Crawford, Re.D., director of the recreational therapy program at MMI.

MMI’s recreational therapy programs are dedicated to maximizing each participant’s developmental potential. Last year, the department served more than 400 children and adolescents and more than 135 adults.

“Recreational services remain a very underdeveloped part of disability therapy, particularly when individuals turn 21,” Dr. Crawford said. “We’re working to change that.”

MMI has emerged as one of the top recreational therapy programs in the country, according to the National Institute on Recreation Inclusion, thanks to the generous support of the Hattie B. Munroe Foundation, the C. Louis Meyer Rehabilitation Foundation, the MMI Guild, the MMI Operating Board, the Enrichment Foundation of Omaha, and the GWR Sunshine Foundation.

Nathan Sangimino, 15, has developed social and phone skills, as well as friendships, through MMI’s school-based social club for middle and high school students with autism. This is one of many MMI programs Nathan has participated in since age 4.

“It was essential for me to have a place Nathan could go and be accepted,” said his mom, Kathy Sangimino. “He’s really benefited from the programs and has gained a great deal of maturity and awareness of his surroundings. The volunteers and staff are wonderful and have provided a great experience for my son to grow and have fun. We’d be lost without MMI.”

The social club, a service for students with Aspergers syndrome or autism spectrum disorders in the Westside Community Schools, Ralston and Papillion-LaVista Public Schools, is unique. “Our school-based clubs use the community as our clubhouse and help kids develop social skills and friendship circles,” Dr. Crawford said.

Kathy Sangimino says her son has enjoyed his Saturday night outings with friends in the program and repeatedly looks at the notebook where he records club activities through words and photos and keeps lists of friends to call prior to outings.

Through the adult vacation club, Sarah Gardels has seen tulips in Pella, Iowa, cheered the Huskers in Lincoln, Neb., watched her first NBA game in Minneapolis, and enjoyed musical performances in Branson, Mo.

“We’re trying to give participants a once-in-a-lifetime, first-in-a-lifetime quality experience,” Dr. Crawford said, whether it’s through trips, dining out or outdoor trail riding events.

For Sarah, it’s a treat “just hangin’,” with MMI friends, she says. Her mother, Linda, said the MMI experiences instill greater independence in her 24-year-old daughter with intellectual disabilities. “She really looks forward to the adult rec therapy programs, which provide her with as many normal activities as possible,” she said. “That’s really cool.”

“And fun,” adds Sarah.

A barrier-free water park is the newest addition to MMI’s Recreational Therapy Department and a favorite among participants in MMI’s Camp Munroe, a day camp that celebrated its 25th anniversary this past year.
It is not unusual for Cate Jones-Hazledine, Ph.D., to travel more than 200 miles of Highway 20 in northwestern Nebraska each week to help children and adolescents with behavioral issues.

A psychology faculty member with UNMC’s Munroe-Meyer Institute, she staffs primary care clinics in Chadron, Crawford, Rushville and Gordon.

**Behavioral health clinics reach rural areas**

Loretta Gilman of Chadron is grateful. Her 4-year-old son, Zachary, has benefited from her visits with Dr. Jones-Hazledine to sort through sleeping, eating, speech and toileting issues. “Her suggestions really seemed to work with him,” Gilman said.

At 18 months, Zachary Gilman knew only three words: mom, dad and ball.

Dr. Jones-Hazledine taught him to mimic adults who, with the help of his school-based team, taught him sign language to bridge the communication gap. Today, the blue-eyed toddler with autism uses four- to five-word sentences and engages in pretend play, such as talking on the phone like mom and dad. “Cate has really helped bring that along,” Gilman said.

Through 14 rural outreach clinics, MMI’s Behavioral Health program last year provided more than 7,500 clinic visits in 220 Nebraska communities. “Before

MMI established the clinics, child-oriented behavioral health services weren’t available in western Nebraska,” said Dr. Jones-Hazledine, who is an assistant professor at MMI. “Folks mostly did without or traveled to Omaha or Denver.”

The clinics are a cooperative effort between community primary care pediatricians/family practice physicians and the Psychology Department at MMI. The program started in 1997 with one clinic in Columbus, Neb.

“In addition to serving Nebraska families, our goal is to attract, recruit, train, place and retain behavioral professionals in rural areas,” said Joseph Evans, Ph.D., director of MMI’s Department of Psychology. Of the state’s psychiatrists, psychologists, social workers, counselors and family therapists, 74 percent are practicing in urban areas, while 26 percent are covering the other 70,000 square miles of Nebraska. “There’s an imbalance and it’s getting worse,” he said.

MMI faculty and staff are specially trained in behavioral pediatric psychology and provide integrated clinical services. Dr. Evans’ goal is to have a behavioral health provider in every pediatric clinic in Nebraska.

Reaching all corners of the state is important, said Dr. Jones-Hazledine, who also uses telehealth capabilities to see patients in such communities as Alliance, Bridgeport and Valentine. “We get a lot of physician and school referrals that cover the gamut from ADHD assessments, sleep problems, toileting issues and oppositional behaviors to depression, anxiety, panic attacks, school problems and self-injurious behavior,” Dr. Jones-Hazledine said.

She also works closely with schools that have identified children and adolescents with behavioral issues, assisting them with the child’s individualized education plans and helping students with skill building. “We know medications can be helpful in controlling symptoms, but that doesn’t really change anything when medication is stopped, so we implement behavioral interventions to build long-term skills,” she said.

MMI is working to increase the number of behavioral health providers in rural underserved areas through its pre-doctoral internship training. MMI is a member of the Nebraska Internship Consortium in Professional Psychology, one of only two American Psychological Association approved intern-training programs in the state. MMI is the only member of the consortium focused on community and rural-based training.

MMI expanded its capacity to provide behavioral health services in rural areas in 2007 with the passage of the Nebraska Rural Behavioral Health Training and Retention Act. This legislation provides $200,000 annually and, to date, has trained 74 students, interns and post-doctoral fellows with a 54 percent placement and retention rate. Annually, this program provides more than 5,000 clinic visits, which would not be available without support by MMI and the state of Nebraska.
In Service to Our Community

MMI’s education program provided an interdisciplinary training experience for more than 250 students, interns, residents, and post doctoral fellows in 2007. Approximately one-quarter of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.

Funding Sources

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 to address emerging issues.

MMI Interdisciplinary Trainees

Funds Leveraged

Over the past five years, MMI has a budget of more than $20 million which supports more than 250 faculty and staff. Funding sources are diverse and include federal, state and local grants and contracts, revenue from services, and generous support from numerous boards, foundations and individuals across Nebraska.

Technical Assistance and Community Services

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 2007, we developed 144 new products and disseminated more than 150 different products to professionals, students, parents, people with disabilities and the general public.

In the Community

Nebraskans with disabilities benefit from the therapy and diagnostic services provided in rural and urban counties across the state, at Indian reservations in Nebraska and South Dakota, and through our video telehealth network. Last year, more than 10,000 individuals received clinical services and more than 45,000 clinic visits were provided. The following clinics address a variety of disabilities and disability-related needs for both children and adults, and in many cases are conducted in a collaborative manner with other hospitals and programs.

ADHD Clinic
Augmentative Communication Clinic
Autism Clinic
Behavioral Health Clinics
Cardiovascular Follow-Up Clinic
Cerebral Palsy Clinic
Children’s Hospital Developmental Clinic
Craniofacial Clinic
Developmental Pediatric Clinic
Developmental TIPS Clinic
Endocrine Clinic
Feeding & Swallowing Clinic
Fetal Alcohol Syndrome Clinic
Genetics Clinic
Helmet Clinic
Metabolic Bone Disease Clinic
Metabolic Disorders Clinic
Midline Neurologic Clinic
Motion Analysis Lab
Neurobehavioral Pediatric Clinic
Neuromuscular Adult Clinic
Neuromuscular Pediatric Clinic
Neurosensory Genetics Clinic
PDD Management Clinic
Seating & Power Mobility Clinic
Transition Clinic

In 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, 26,812 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.

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Transition Clinic
This annual report is the beginning of a new era at Munroe-Meyer Institute. I look forward to witnessing the Institute’s future accomplishments under new leadership.

MMI is a special place for families. Every faculty and staff member is dedicated to helping children and adults with special needs attain their life’s goals and realize their potential. There is nothing unique about my 25-year tenure as the director of MMI, except the fantastic luck I’ve had in bringing in the very best people from around the country, giving them the resources they need, and then getting out of their way.

These individuals have built our programs and services through hard work and dedication and I have watched them grow and take leadership in their professions. Their unwavering focus on the needs of people with disabilities and their families makes remarkable things happen.

I have had the pleasure of working with the finest people ever assembled at MMI, from our board members to our community volunteers. I am proud of them for making MMI a true jewel for the state of Nebraska, the region and the nation.

I know that if the bricks and mortar of MMI were removed, there would still be a foundation of commitment that would support education, research and services for people with special needs and their families. This will continue long after I am a memory. Thanks for so many years together.

The leadership of Bruce Buehler, M.D., has helped elevate the Munroe-Meyer Institute into one of the top programs in the country for genetics and treatment of developmental disabilities. This fall, Dr. Buehler stepped down from his dual role as MMI Director and Chairman of the UNMC Department of Pediatrics.

During his tenure, Dr. Buehler helped orchestrate a remarkable period of expansion for MMI. He oversaw more than $11 million in construction of building additions on the UNMC campus, thanks in large part to the financial support of the Hattie B. Munroe Foundation.

“It’s been a team effort involving schools, government, the foundations and UNMC administration,” Dr. Buehler said. “The thing I am most proud of is that we’ve brought services to Nebraska, so that now there is no reason for any family or person with a disability to leave the state to get the help they need.”

The commitment of these boards and organizations, along with the support of numerous individuals, has enabled MMI and its programs to flourish. Charitable support provides essential resources for the ongoing growth of clinical programs that enhance peoples’ lives and research that offers tremendous hope.

You can help us unlock the potential of every individual we serve by making a gift to benefit MMI today. For more information about supporting MMI, please contact Tom Thompson of the University of Nebraska Foundation at 402-502-4116 or tthompson@nufoundation.org.

Special thanks
Faculty and staff of MMI extend their gratitude to the following boards and organizations for their generous and ongoing support of MMI and its programs.

- Hattie B. Munroe Foundation
- MMI Board
- C. Louis Meyer Rehabilitation Foundation
- MMI Guild
- G.W.R. Sunshine Foundation
- Enrichment Foundation
- Scottish Rite Masons of Nebraska

MMI blazes trail under Dr. Buehler

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