The UNMC Munroe-Meyer Institute 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.
Dear friends of the Munroe-Meyer Institute,

Clinical and translational research: That’s what this year’s Munroe-Meyer Institute (MMI) annual report is all about. The progress MMI has made in this arena compliments what our faculty and staff have been doing for years in the fields of education and service. Through research, MMI faculty and staff develop new clinical strategies and therapies. Research also enhances our educational programs and leads to a better understanding of disabilities.

Improving the quality of life for persons with disabilities continues to be at the center of everything we do and we couldn’t do it without our supporters. I would like to thank UNMC Chancellor Harold M. Maurer, M.D., for his guidance as we transitioned to become an academic unit at UNMC and the support of our community boards and benefactors.

We are fortunate to have numerous supporters including the Hattie B. Munroe Foundation, the MMI Board, the C. Louis Meyer Rehabilitation Foundation, the MMI Guild, the Autism Action Partnership, the Enrichment Foundation, the Scottish Rite Foundation and the C. Louis Meyer Family Foundation who make many of our activities possible through their guidance and financial support.

Additionally, thanks to the University of Nebraska Foundation Campaign, “Unlimited Possibilities,” MMI now has a talented committee of individuals whose mission is to help raise $20 million for future initiatives that will further improve our ability to provide 21st century solutions in many critically needed areas. You can read more about these initiatives on page 17.

As you peruse the following pages, keep in mind that the stories you read are only parts of a greater whole that make up MMI, the state’s federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service.

I invite you to submit feedback on our redesigned Web site, www.unmc.edu/mmi, and to request additional information about our programs.

I hope you enjoy the 2009 annual report.

Sincerely,

J. Michael Leibowitz, Ph.D.
MMI Director and Hattie B. Munroe Professor

This report can be viewed online along with web extras that are identified throughout the report by the web extra icon.

You can also provide feedback about this report online by visiting our Web site.

www.unmc.edu/mmi
5 Big lessons from little ones
Statewide program tracks development of premature babies

7 Sit. Play. Learn.
Study explores how kids with cerebral palsy best learn to sit

9 Finding how genes fit
Researcher’s discovery may change treatment of reading and language disabilities

11 Help close to home
Families receive behavioral health care without leaving their community

13 department highlights

15 facts and figures

This annual report highlights only a few of the programs, activities and services offered by the UNMC Munroe-Meyer Institute. For more information, we invite you to visit our facilities on the UNMC campus, our clinics and other programs across the state, or our Web site.
Two premature babies. Two different paths. Sharan Bryson’s son, Chris, was born at 34 weeks old and weighed only four pounds, three ounces. Fifteen years later her daughter, Meah, was born at just 26 weeks. She weighed a mere two pounds, one ounce.

Risks for premature babies can include heart and lung complications, cerebral palsy, blindness and deafness. In addition, premies also are five to eight times more likely than babies born at term to need special education services for developmental or learning problems.

Though she was at higher medical risk than her brother, Meah has had better developmental outcomes. Because of a unique Nebraska program called Tracking Infants Progress Statewide (TIPS) her needs for development services were identified earlier. At just 16 months of age, she was referred to Omaha Public Schools for speech therapy.

Prior to TIPS, there was no organized follow-up program for NICU graduates. MMI spearheaded a plan that resulted in the TIPS model. TIPS has grown to a collaboration among 10 hospitals in the state, the Nebraska Department of Health and Human Services, Nebraska Department of Education and MMI. It’s the only known statewide follow-up program and is a primary referral source for the Early Developmental Network.

Before speech therapy, Meah wouldn’t mimic or even mumble speech sounds. The lack of communication left both her and her mother frustrated. Now 3, Meah’s able to share her wants and needs.

“Instead of whining or crying, she’s able to express herself more and tell me things like ‘Mommy, I’m hungry,’ or ‘Mommy, I want my blanket,’” Bryson said.

Meah graduated from special education services and now attends a Head Start program in Omaha where she continues to work on her communication skills.

Big Lessons from little ones

Founded at the University of Nebraska Medical Center Munroe-Meyer Institute (MMI) in 1999, TIPS provides specialized, systematic developmental follow-up at 6, 16, 24 and 36 months for most babies who have been in a Neonatal Intensive Care Unit (NICU). It offers a more formal, in-depth screening than most physicians can provide and assesses overall developmental milestones.

“The goal is to gather information about how babies who have been in the NICU grow and develop in order to learn how to better meet their unique needs now and in the future,” said Barb Jackson, Ph.D., co-director of TIPS and director of education and child development at MMI. “If we can catch a problem at 6 or 16 months, we can implement early intervention as soon as possible. Doing so maximizes positive impact and potentially prevents the need for specialized services in kindergarten.”

WebExtra

View more photos.

www.unmc.edu/mmi
“It’s amazing how far she’s come,” Bryson said. “I can really see the difference between her and her brother. There was a lot more support with her than with him.”

After tracking the progress of more than 10,000 children, TIPS not only has touched the lives of families across Nebraska, but also has contributed to national knowledge that guides practice and policy through its research.

For example, TIPS data has shown that late pre-term babies like Chris who are born as late as 34 or 35 weeks still have a high risk for referrals for special education services.

“The results from that study indicate that these babies have more risk for developmental problems than previously thought,” said Howard Needelman, M.D., medical director of TIPS. “The implications are that health care providers become aware of the risks associated even with these bigger premies. We’re working to change the dialogue with obstetricians and family practitioners so they’re less willing to deliver at 34 weeks and put babies at risk.”

Drs. Jackson and Needelman are hopeful that data collected from TIPS can lead to other improvements in clinical practices. A current study monitors premies who are now in first grade, not only for educational outcomes, but to study their social and emotional development as well.

“We have such a rich source of data that our challenge is to find new research questions to inform future policy and practice,” Dr. Jackson said. “Such information contributes to the critical discussion related to the costs and benefits of health care investments.”
But, thanks to a sitting study at the University of Nebraska Medical Center Munroe-Meyer Institute (MMI), Ethan now sits up straighter and holds his head higher, making it easier for his mom to snap photos at his horse therapy sessions.

Reggie Harbourne, Ph.D., assistant professor of physical therapy at MMI, has studied sitting in children with moderate to severe cerebral palsy for much of her career.

"It's an issue because most things people do require an upright posture," she said. "If you can't sit up, you can't interact with the world."

Her latest study is funded by a $600,000 three-year grant from the National Institute on Disability and Rehabilitation Research. In collaboration with Nick Stergiou, Ph.D., a biomechanist at the University of Nebraska at Omaha, the study compares two treatments designed to improve sitting ability.

The control group receives physical therapy treatments twice a week while the experimental group receives the same therapy, but on top of a mat that vibrates randomly at different frequencies.
The idea is that the feedback from the mat amps up the ability to sense where one’s body is in space,” Dr. Harbourne said, and therefore improves sitting skills.

Harbourne got the idea for her research from James Collins’ studies at Boston University. He placed vibratory insoles in the shoes of stroke and Parkinson’s patients to help them balance when they walk.

“These techniques have been used in studies of the elderly and standing, but there is not much out there about sitting, and sitting comes before standing,” Dr. Harbourne said.

Early results indicate that those using the vibratory mat have improved their sitting ability slightly more than the control group, though both groups have become more stable at sitting.

“If there is a meaningful difference, we would like to convert the mat into something children with cerebral palsy can actually use,” Dr. Harbourne said.

Ethan was in the control group. Not only did his sitting improve, but he also increased his play skills, another factor in Dr. Harbourne’s study.

“It’s not important that you just know how to sit, it’s what you do while sitting that’s important,” she said. “Play is a child’s work, where they learn gravity, force, spatial skills and how things work in general.”

Ethan learned to anticipate and adjust to a ball when playing catch with his twin brother, Andrew. Because he could sit up, Ethan was better able to use his hands and even increased his attempts to communicate because he had things to look at. “Therapy made him stronger and improved his balance,” Falk said. “It even translated to brushing his teeth and washing his face.”

Eating also has gotten easier and more enjoyable for Ethan. “Before, he was working too hard to get food down, burning more calories than he was consuming,” Falk said. “Since he sits up straighter now, swallowing is easier and he doesn’t work as hard. He even gained two pounds in four months and he hadn’t gained that much in the last two years.”

At horse therapy sessions, Ethan is better at spotting things around the arena. He looks up, not because of prompts or cues, but because he wants to see the world around him.
Everyone knows Thomas Edison was a brilliant scientist. Most people don’t know he was dyslexic. Kicked out of school because he was “dumb,” the inventor of the phonograph, motion picture camera and lightbulb also struggled with words and speech.

A researcher at the University of Nebraska Medical Center Munroe-Meyer Institute may have the answer as to why. Shelley Smith, Ph.D., studies the relationship between genetics and learning disabilities. She recently helped discover a link between a particular gene and language impairment, along with Mabel Rice, Ph.D., of the University of Kansas and Javier Gayán, Ph.D., of Neocodex in Seville, Spain.

Funding for the study was provided by a grant to Dr. Rice from the National Institute on Deafness and Other Communication Disorders, one of the National Institutes of Health.

The “KIAA0319” gene on chromosome 6 had previously been associated with reading disability. The new finding shows it can affect both reading and language.
It has been thought that reading disability, language impairment and speech disorder were entirely separate conditions, and they are usually diagnosed separately and treated separately,” Dr. Smith said. “This finding confirms that there are common factors. It also helps explain why some kids have problems in more than one area.”

Dyslexia is the most common learning disability with a prevalence of about 9 percent in American school children. Language impairment is the second most common at about 7 percent. Speech disorders rank high as well.

While language involves vocabulary and grammar, and speech involves accuracy of sound production, both contribute to a child’s ability to read. The finding that a certain gene could influence all three abilities suggests a common pathway contributes to overlapping strengths or weaknesses across speech, language and reading.

Redefining the conditions to recognize the overlaps could lead to more effective treatment, whether it is through clinical therapy or medication, Dr. Smith said.

Previous studies had not found such overlap. Reading disability genes appeared on certain chromosomes, and language impairment genes had been localized to other chromosomes.

“It made us think that maybe there were fundamental differences between the two disorders, but that seemed unlikely since they were often seen in the same kids,” Dr. Smith said. “Our finding helps to clarify things. We’ve shown that in some cases there really are genetic overlaps between the two disorders.”

“We also found some association with speech problems, but to test that completely, we need to test a population of kids who are primarily diagnosed with speech disorder.”

As the genes that influence learning disabilities are defined and the cognitive overlaps between disorders worked out, genetic studies will be able to confirm which diagnoses have common genetic effects and which are distinct.

“It’s likely that the current diagnostic criteria may be modified,” Dr. Smith said. “A better definition of the three disorders should lead to optimal treatment procedures based on deficits that are closer to genetic makeup than clinical symptoms alone.”

Dr. Smith believes other genes also will be found that account for all three disorders, and hopes to do further studies to determine how the genes interact in order to better understand how the brain handles reading and language information.

“Further gene studies could help define types of problems that are based more on their underlying causes,” she said.

“We hope to do some basic science studies to see exactly what these genes do and how they really interact, which will tell us about normal brain development and what goes wrong in these disorders.”
Maya Holmes and her son Isaac bond over pancakes more often now that Isaac’s behavior issues are being treated. The two were able to see a behavioral psychologist in their hometown of Chadron, rather than commute to the closest city more than 100 miles away.
Maya Holmes thought her son Isaac’s naughty behavior might be a phase. But when the 3-year-old’s aggressiveness escalated to hits, kicks and bites, she knew he needed help.

Though the closest city was 100 miles away in Rapid City, S.D., Holmes didn’t need to travel far for treatment. A UNMC licensed behavioral psychologist was within walking distance from her house in Chadron, Neb. In fact, Cate Jones-Hazledine, Ph.D., was staffed at the same clinic Isaac went to for his checkups.

“If a behavioral psychologist wasn’t here in town, there’s no way we could have gone. I couldn’t have afforded to take the time off of work to travel,” said Holmes, a single mother who works 44 hours a week and attends grad school.

Joe Evans, Ph.D., director of psychology at the University of Nebraska Medical Center Munroe-Meyer Institute, has placed 15 behavioral psychologists within rural pediatric and family medicine clinics since 1997.

“Our research demonstrates that availability, quality and cost-efficiency in the treatment of behavioral health disorders can be significantly improved by integrating mental health care professionals into primary care practices,” Dr. Evans said.

His research also shows patients only follow through with physician referrals to mental health providers about 25 percent of the time. However, when a behavioral psychologist is integrated into the practice, the follow through rate jumps to 81 percent.

Holmes can attest to why.

“The biggest thing for people from smaller towns is the comfort level,” she said. “I was really comfortable with the clinic because I’ve gone there my entire life. I already knew the staff, the check in procedures and had heard Dr. Cate (Jones-Hazledine) was amazing.”

Not only is Dr. Evans’ model more convenient for patients, but physicians reap the benefits as well. Pediatrician Steven Haskett, M.D., took the job at the Kearney clinic, in part, because it had an in-house behavioral psychologist from UNMC.

“As a pediatrician, behavioral health is something you deal with on a daily basis, and it’s something I’ve never been really comfortable with,” he said. “Rather than refer patients elsewhere, I love being able to walk down the hall and have a face-to-face conversation with our behavioral psychologist.”

If referred elsewhere, the wait time to see a professional psychologist can be months unless parents opt for their children to be seen by someone not trained to work with children, said Tina Scott, M.D., a pediatrician at the Plattsmouth clinic.

If pediatricians try to treat children with behavioral problems, it can be time-consuming.

“Our average day is 20 to 25 patients, with time slots of 10 minutes a piece,” Dr. Scott said. “Some behavioral evaluations take 40 minutes, so if Dr. Judy Mathews (the psychologist assigned to Dr. Scott’s clinic) can address those things, it’s incredibly time-saving for me. I can get more quality time with patients and take walk-ins who need to get in.”

Drs. Scott and Haskett wish there were more behavioral psychologists staffed in rural clinics to meet the needs of children in smaller communities.

“Access to behavioral health services is a significant issue for many families in rural areas of the country,” Dr. Evans said. “Parents frequently complain that they cannot get mental health services for their children, which can lead to further problems in adolescence and adulthood.”

Holmes is grateful for her weekly appointments with Dr. Jones-Hazledine. Through family interventions, Isaac has learned if he listens, doesn’t interrupt and follows the rules, he gets plenty of positive attention. His mom rarely has to give him timeouts as he realizes there are consequences for his actions. His aggressive behavior is all but non-existent.

“He’s made such good progress in a short time,” Holmes said. “If you can instill those values now, it helps so much in school and later on in life. We have a lot more fun together as a family now.”

View a map of the behavioral health clinics.

www.unmc.edu/mmi
Department Highlights

**Autism**
UNMC was listed as one of the top 20 medical centers for autism by ABC News due to the comprehensive autism services available at MMI.
http://abcnews.go.com/Health/Autism

**Clinical Genetics**
The facility has been approved by the American Board of Medical Genetics for a clinical genetics fellowship. Two clinical fellows are slated to start the program in July.

**Developmental Medicine**
The developmental medicine department established a clinical nurse manager position to improve clinical care and case management for patients and families.

**Education**
Developmental TIPS (Tracking Infants Progress Statewide), the only known statewide NICU (Neonatal Intensive Care Unit) follow-up program, marked its 10th year of service. (see story on page 5)
The Interdisciplinary Center for Program Evaluation was one of the state’s primary providers of program evaluation for private and public early childhood initiatives.

**Human Genetics**
The Human Genetics Laboratory experienced a 16 percent increase in its caseload in 2009. With increased use of automation, the lab managed the additional 16 percent caseload with only a 4 percent increase in staff.
The Human Genetics Lab was the first laboratory in the nation to incorporate automated scanning. The lab purchased two “Genetix” Metaphase scanners and several software programs that have improved productivity and turn-around times.

**Molecular Genetics**
Molecular genetics recruited for faculty to expand basic research efforts in autism and neurodevelopmental disorders. Two new faculty accepted offers to begin in July.

**Occupational Therapy**
A department staff member became only the third occupational therapist in the state to obtain her board certification in pediatrics. All three board certified therapists work for MMI.
The occupational therapy department teamed with local schools to gather data for a “Response to Intervention” project, which tests the effectiveness of handwriting instruction/intervention and the links to emergent literacy in kindergarteners.

**Pediatric Feeding Disorders**
The Nebraska Legislature passed LB 342 to help reduce the cost of care for children with significant feeding problems. The legislation was passed, in part, based on the 90 percent success rate of MMI’s Pediatric Feeding Disorders program. The bill also allows for reimbursement for children with Medicaid to participate in the program.
The Center for Autism Spectrum Disorders and the Pediatric Feeding Disorders program were licensed as a health care facility.

**Physical Therapy**
The Bob Kerrey Prosthetic Fund was established at the NU Foundation to allow the physical therapy department to provide assistance to pediatric patients who require a prosthetic device due to anatomical loss from trauma, disease or congenital conditions.

**Psychology**
In September 2009, MMI launched a Ph.D. program in applied behavior analysis, one of only a handful of such programs in the country. The department of psychology and the Center for Autism Spectrum Disorders provide faculty for the program.
The MMI AmeriCorps program was named the “program of the year” and received the “Impact Award” from Nebraska’s First Lady—Sally Ganem—and the Nebraska Volunteer Service Commission.

**Recreation Therapy**
The recreation therapy staff provided services to a record 600 participants.

**Speech/Language Pathology**
The RiteCare program for children with speech and language problems added a speech pathologist to its clinic in Hastings, Neb. The program, funded by the Scottish Rite Masons, serves approximately 330 children with speech and language disorders.
Speech pathologists at MMI are conducting a research project that examines the use of sophisticated computerized devices and simple communication boards to enhance the communication of children with apraxia.
The first Big Splash event brought together swimmers of all ages and abilities on Aug. 28 and 29 to promote inclusion and awareness of those with disabilities.

In total, the event, organized by the University of Nebraska Foundation, raised nearly $32,000 to expand services and programs for individuals with disabilities at the UNMC Munroe-Meyer Institute (MMI).

MMI Director Mike Leibowitz, Ph.D., said the Big Splash epitomized MMI’s mission.

"MMI is all about children with disabilities being part of the community and helping them to achieve everything they can achieve," he said. "The Big Splash made those ideals a reality."
Interdisciplinary Trainees

MMI’s education program provided an interdisciplinary training experience for almost 200 students, interns, residents and postdoctoral fellows in 2009 for a total of 86,831 hours. Approximately one-quarter of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.

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, 28,348 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 to address emerging issues.
Fueling our mission

MMI has a budget of more than $24 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.

Facts and figures

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 2009, MMI faculty members developed 105 new products and disseminated more than 121 different products to professionals, students, parents, people with disabilities and the general public.
A comprehensive fundraising campaign is underway at the University of Nebraska and University of Nebraska Foundation. The Campaign for Nebraska: Unlimited Possibilities seeks to raise $1.2 billion to meet high-priority needs for the university’s four campuses. For the first time, MMI has organized a committee to focus specifically on MMI priorities that, when achieved, will shape health care and benefit Nebraskans with disabilities in unprecedented ways.

When you give to MMI, you unlock the potential for each child and adult with a disability to succeed at home, school, work and in the community.

MMI priority areas include:

**Autism and related neurodevelopmental disabilities**
World-class status requires cutting-edge basic and translational research, which results from increased funding for scientists, fellowships and seed grants, as well as support for faculty to lead and train future practitioners.

**Center for Biomechanical Rehabilitation**
Support for faculty, equipment and software is necessary for engineers and clinicians to collaboratively design, develop, adapt, apply and distribute solutions that help children and adults with disabilities.

**Statewide Pediatric Behavioral Health Clinics**
Additional faculty positions and fellowship support is needed to replicate MMI clinics and university training programs across the state, expand telehealth services at local hospitals and serve as a national model.

**Genetics and Developmental Medicine Fellowships**
Additional faculty and staff are critical to the establishment of fellowship programs. These faculty members will train future practitioners, expand greater Nebraska services and establish MMI as one of few academic programs in the Midwest capable of training pediatricians for board certification in the disabilities field.

Through your generosity, the promise of unlimited possibilities in the lives of these children, adults and their families can become a reality. Most importantly, your gift will transform lives and change the future.

For more information about the campaign or to make a donation contact mwelsh@nufoundation.org or (402) 502-4117.

Sincerely,

Melanie S. Welsh
Director of Development for MMI
University of Nebraska Foundation
Wayne Stuberg, Ph.D., professor and director, Physical Therapy, UNMC, MMI, assists a patient in the Motion Analysis Lab at the UNMC Munroe-Meyer Institute. One of MMI's Campaign for Nebraska priorities includes the creation of a center for biomechanical rehabilitation to enhance the Motion Analysis Lab and create new programs for children and adults with disabilities.
UNMC Munroe-Meyer Institute
for Genetics and Rehabilitation
A university center for excellence in developmental
disabilities education, research and service.

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