The Kansas Center for Autism Research and Training
The Life Span Institute
The University of Kansas

Synergy
2011-2015

KU KANSAS CENTER FOR AUTISM RESEARCH & TRAINING
Life Span Institute
The Kansas Center for Autism Research and Training was created in 2008 as the state’s first multidisciplinary center promoting research and training on the causes, nature and management of Autism Spectrum Disorders (ASD). With $1 million in seed money from the University of Kansas and University of Kansas Medical Center; a $1 million gift from the Wanda and Tom Pyle estate, thousands of dollars in private donations and the dedication of researchers, K-CART has become a center of exciting innovation and discovery.

Findings from the investigators who received K-CART Discovery Grants and numerous external grants to our research partners at KU and KUMC have contributed to greater understanding of the causes, diagnosis and treatment of autism.

Our work has already led to evidence-based interventions to improve the lives of children and adults with autism.

K-CART clinical services and training activities provide earlier screening and diagnosis throughout the state through face-to-face clinics, telemedicine and statewide assessment teams. Our Comprehensive Research Information System database now allows us to track intake information, child and family history, and individual clinical and diagnostic results for families who access services, benefitting both families and researchers. Our clinical researchers will expand their collaboration with KUMC and Children’s Mercy Hospital pediatrics departments to improve diagnostics and increase research and treatment efforts.

Training efforts also have greatly expanded. With continued funding from the Kansas Department for Aging and Disability Services, the Autism Training Program has provided training to 623 professionals, paraprofessionals, family members and others since its start in 2008.

Clearly, this kind of synergy between visionary partners in training, research and clinical services is making a difference. The future is bright for many reasons. We have outstanding support and collaboration from our community, advisors, families and people with ASD who challenge us and reinforce our efforts. We have an impressive group of partners across campuses whose research and training accomplishments are nationally recognized.

Through the Strategic Initiative Grant program at KU, K-CART received funding for a new position, a joint appointment in the Clinical Child Psychology Program and the Life Span Institute, in collaboration with the pediatrics department at KUMC. These funds will take K-CART to the next level and fuel the synergistic work underway by a growing number of researchers.

We greatly appreciate the time and energy of our community and our partners who have enabled us to expand K-CART. We invite you to support and join us as we move forward to provide hope, resources and answers to improve the lives of children and adults with autism and their families across the Heartland and beyond.

Sincerely,

Debra Kamps, Ph.D., Director
Kathryn Ellerbeck, M.D., Co-Director
MISSION
The Kansas Center for Autism Research and Training (K-CART) at the University of Kansas, established in 2008 with private and public funds, is a multidisciplinary center that promotes research and training on the causes, nature and management of Autism Spectrum Disorders (ASD). Committed to the highest standards of scientific rigor, K-CART generates new scientific discoveries about ASD, disseminates research-based practices by training professionals, practitioners and families who serve children and adults with autism, and provides clinical services through the Center for Child Health and Development at the University of Kansas Medical Center.
Developmental pediatrician named K-CART co-director

Kathryn Ellerbeck, associate professor of pediatrics and a developmental pediatrician, has been named co-director of K-CART and interim director of the Center for Child Health and Development at the KU Medical Center. She assumed both posts following the retirement of Mathew Reese in December 2014.

Ellerbeck will continue the work of overseeing K-CART’s clinical research efforts and developing partnerships to encourage other KU and KUMC researchers to utilize its clinical population and clinical database. “I am very excited about how the missions of CCHD and K-CART align to provide opportunities for our families to benefit from the groundbreaking research being done at KU and KUMC,” Ellerbeck said.

K-CART Director Debra Kamps lauded Ellerbeck’s 15 years as a clinician at CCHD and her role as a mentor for graduate students, medical students and interns in allied health. “Dr. Ellerbeck is a distinguished addition because of her leadership as a developmental pediatrician and clinical work using an interdisciplinary model for the diagnosis and treatment of autism spectrum disorder,” she said. “Her expertise will contribute to expanding the research agenda for K-CART and our service to families and children.”

Ellerbeck is the immediate past president of the Kansas Chapter of the American Academy of Pediatrics and a member of the American Academy of Pediatrics’ Council of Children with Disabilities’ Autism Subcommittee.

She completed her bachelor’s and medical degrees at the University of Missouri-Kansas City School of Medicine, her M.P.H from Johns Hopkins University and a fellowship in developmental-behavioral pediatrics at the University of Maryland.
Discovery Grants

In 2008 K-CART launched an ambitious research initiative to stimulate new scientific inquiry into Autism Spectrum Disorders. The need was clear: parents, professionals and service providers were clamoring for more knowledge about autism and proven training methods to address its complexities.

Through the Discovery Grant program, researchers at the University of Kansas, the KU Medical Center and other universities competed for $25,000-$40,000 grants for pilot research on autism.

From 2008 to 2011, K-CART funded 12 Discovery Grants, awarding a total of $850,00 to 16 investigators and their research teams. These projects and how they contributed to a growing body of scientific work on ASD include the following.

2008

Neurological profiles in Asperger’s Syndrome
Winifred Dunn, professor and chair of occupational therapy education at KUMC, is collecting sensory processing, temperament and brain function data on adolescents with and without Asperger’s Syndrome (AS).

Using magnetoencephalography (MEG), Dunn is testing adolescents with AS and comparing the results with adolescents who have a similar sensory profile but who do not have AS. Dunn has worked with scientists at KUMC’s Hoglund Brain Imaging Center for the study.

Preliminary findings suggest that sensory processing seems to reflect brain activity that is independent of a condition like AS.

Toxins and autism: Is there a connection?
Researchers Kathryn Ellerbeck and Jill Jacobson studied a possible correlation between the environmental toxin Bisphenol A (BPA) and autism. Ellerbeck is K-CART co-director and a developmental-behavioral pediatrician at the Center for Child Health and Development at the KU Medical Center. Jacobson is a professor of pediatrics/endocrinology at the University of Missouri-Kansas City School of Medicine.

Jacobson and Ellerbeck hypothesized that exposure to BPA would dis regulate two genes involved in cellular signaling, Gαs and Gαq. These genes encode for G proteins, which play important roles in sending signals from the outside of a cell to the inside. G-proteins are also important to signaling for hormones. In another study, Ellerbeck and Jill Jamison, KUMC CCHD clinical associate professor, studied the neurotransmitter oxytocin and G proteins in children with ASD.

Oxytocin is important in “social affiliation,” behaviors like bonding, social awareness and recognition. In additional work, Jacobson, Ellerbeck and other investigators studied the role of oxytocin and how its pathways in the brain might differ in children with autism.

Results of that work, the first of its kind, indicated that children with autism may exhibit a dysregulation in oxytocin and/or its pathways in the brain. The research was published in 2014 in Psychoneuroendocrinology.

Alternative systems and social communication
Kathy Thiemann-Bourque, associate research professor at KU, studied the effectiveness of a communication intervention with preschool children with ASD and their typical peers by using augmentative and alternative communication. Her first project featured peer-mediated interventions in which children with autism and their peers without ASD learned to use the Picture Exchange Communication System. A second study measured the effectiveness of the GoTalk assistive communication device in improving social communication between preschoolers with ASD and their typically developing classmates.

In both projects, children with autism showed improvements in average rates of initiating communication and responses to requests. Peers also improved, increasing their rates of initiations and responses to the children with autism and becoming more effective communication partners. “These experiences lay the foundation for relationships and friendships to develop in inclusive classrooms,” Thiemann-Bourque said.

Results of the two projects were published in 2012 in Perspectives in Augmentative and Alternative Communication. In 2013 Thiemann-Bourque and Nancy Brady, associate
professor of speech-language-hearing at KU, were awarded a four-year $1.2 million grant from the National Institute on Deafness and Other Communication Disorders to develop new methods to improve the communication, social reciprocity and play skills of children with ASD.

2009

Cytokine levels in ASD
Merlin Butler, KUMC professor of psychiatry and pediatrics (and the only board-certified geneticist in Kansas), and a multidisciplinary team studied the immune profiles of children with ASD and, specifically, their cytokine levels. Cytokines are signaling proteins released from cells that help regulate cell growth and proliferation. They also moderate the body’s response to infection, injury or inflammation.

Butler and colleagues analyzed blood serum cytokine levels of 104 children diagnosed with classic autism and 48 unrelated children with no known health problems. The results indicated that the children with autism had compromised immune systems. Eighteen cytokines of the children with autism were significantly lower. Butler said that the findings support the possibility that cytokines interfere with neuronal (nerve cell) development and function and could cause autism.

Results were published in 2012 in the International Journal of Developmental Neuroscience and in 2013 in Psychology Progress. Butler also was invited to present the results at the Luminex Scientific Symposium in Monaco in 2012.

Butler’s Discovery project, conducted with Jessica Hellings, professor of psychiatry and pediatrics, provided important groundwork for a subsequent study on exome sequencing in females with autism. The second study received partial funding by KUMC and the Center of Translation Science through the National Institutes of Health National Center for Advancing Translation Sciences. Results were published in 2014 in the International Journal of Molecular Science.

2010

Eye-tracking to measure verbal comprehension
Receptive language (the ability to comprehend words) is considered one of the best predictors of long-term language outcomes in young children with ASD. However, many standardized measures of early language development, including speech comprehension, are unsuitable for young children with ASD. One of the most widely used assessments, the Peabody Picture Vocabulary Test 4, requires that a child point to a picture that corresponds to a word read by a test administrator. This task is difficult for children with limited behavioral responses or motor delays.

Nancy Brady and Christa Anderson, research associate, studied the effectiveness of a nonverbal method to test language comprehension using eye-tracking technology and eye movements. Earlier researchers developed the Intermodal Preferential Looking Paradigm (IPLP), which analyzes looking or gaze patterns rather than gestures to assess word comprehension.

Brady and Anderson hypothesized that eye-tracking technology could facilitate the measure of preferential looking and that the assessment could be analyzed more efficiently and precisely than IPLP assessments.

They measured speech comprehension in 14 boys with ASD and 15 developmentally matched boys with typical development. Children in both groups spent a significantly longer amount of time looking at the target picture when previous testing indicated that the word was known. Children with ASD spent similar amounts of time looking at the target and non-target pictures when previous testing indicated the word was unknown.

"Future research is essential to ensure that the methodology can be applied to individuals with various levels of cognitive and language ability," Brady said.

The study was published in 2014 in Augmentative and Alternative Communication.

Sensory processing intervention
Winnie Dunn and Lisa Mische-Lawson, assistant professor of occupational therapy education at KUMC, tested the effectiveness of a sensory processing intervention with children with ASD. The purpose was to improve children’s participation in everyday life and to develop parental competence in supporting that participation.

The intervention involved three components: authentic activity settings, family daily routines and the child’s sensory
processing patterns. Results indicated that parents felt more competent and children significantly increased participation in everyday life, suggesting that the approach is an effective occupational therapy intervention.

The research was published in 2012 by the American Journal of Occupational Therapy with a related study published the same year in Physical and Occupational Therapy in Pediatrics. The project contributed to a subsequent research proposal that received funding in 2015 from the American Occupational Therapy Foundation.

**Social-emotional health at greater risk for adolescent girls with ASD**

Rene Jamison, KUMC CCHD clinical associate professor, studied an intervention aimed at improving social communication in adolescent girls with ASD. Social norms and expectations become more complex during adolescence and sex differences in social behaviors are more evident. Most social skills research focus on school-age males with ASD, with no intervention studies on adolescent females with the disorder.

Jamison evaluated a social skills and self-care program focused on the unique needs of adolescent females with ASD, targeting social conversation skills. Participants showed an increase in specific conversation skills, with some difficulties maintaining those skills over time, and improvements in self-perception and global social skills for some participants. Jamison’s Discovery Grant contributed to later uses of the intervention program and provided pilot data for grant applications.

Jamison and Jessica Schuttler, KUMC CCHD post-doctoral fellow, analyzed data collected over a five-year period during clinical activities and research as part of the Girls Night Out (GNO) intervention program at KUMC, which brings together adolescent girls with and without ASD in social activities.

According to Jamison, adolescent females without ASD reported greater social-emotional health compared to adolescent girls with ASD. Adolescent girls with ASD rated their social competence and self-perception significantly lower as compared to their typically developing peers and reported more internalizing symptoms. Results from parental ratings in the study showed a relationship between the severity of autism symptoms and the impact on their daughter’s social competence.

Jamison said the findings indicate that adolescent females with ASD are more vulnerable than their typically developing peers. “This is likely due to the compounded impact of ASD symptoms on social-emotional health and the higher risk for internalizing disorders for adolescent girls,” she said.

Jamison used her Discovery Grant data along with data from additional research to secure funding from the KUMC Department of Pediatrics, the Heartland Institute for Clinical and Translational Research, and Autism Speaks. In 2014 she presented her GNO program and related research at the International Meeting for Autism Research in Atlanta and at the Yale Child Study Center in New Haven, Conn.

**Externally Funded Research**

**Social communication in toddlers at risk for ASD**

Social communication is an ongoing challenge for children with ASD. An early marker of ASD is the absence of joint attention, which is the ability to shift attention back and forth between an object and another person for the purpose of social sharing. In typically developing children, joint attention tends to emerge by 11 months of age. It is a building block of social responsiveness and a precursor of verbal language.

Kathleen Baggett, associate research professor at the Life Span Institute Juniper Gardens Children’s Project (JGCP), along with researchers at the University of Northern Colorado and University of North Carolina, tested an intervention model that could be implemented by parents at home. Baggett and her colleagues studied the effects of the Joint Attention Mediated Learning (JAML) intervention among a group of toddlers at risk for ASD. JAML addresses the social functions of pre-verbal communication, such as focusing on faces, taking turns and joint attention.

The researchers found that the JAML intervention resulted in significantly more focusing on faces and joint attention. Children also showed significant improvement on standardized expressive and receptive communication measures. Autism Speaks funded the three-year project. Results were published in 2013 in Early Childhood Research Quarterly and included as part of the Autism Toddler Treatment Network’s report on successful parent-mediated interventions published in 2014 by the Journal of Early Intervention.

The next step for Baggett and her colleagues was testing the JAML intervention with a larger population. They received a four-year grant from the U.S. Department of Education to conduct a multi-site study involving 120 toddlers and their parents in Kansas, Indiana and North Carolina. According to Baggett, if very early social communication skills can be effectively promoted before patterns of social avoidance have become entrenched, difficulties with social engagement, which are pervasive in ASD, may be reduced.
Mobile technology and outcomes for teens

Individuals with ASD are less likely than their peers without ASD to attend college, receive vocational training or to be gainfully employed. Unfortunately, little evidence is available that might identify specific interventions to support and strengthen better post-secondary outcomes for high school students with autism.

Debra Kamps, K-CART director and senior scientist, is working with several colleagues including Rose Mason, assistant research professor, JGCP; Howard Wills, associate research professor, JGCP; Ben Mason, JGCP; Linda Heitzman-Powell, KUMC, and Jay Buzhardt, JGCP. The research team is developing a technology using online instructional modules; tele-coaching using live-streaming devices, and a mobile self-monitoring application to teach social competence, problem solving and organization, and self-monitoring skills for adolescents and young adults with ASD.

The research is based on prior online tutorials developed by Heitzman-Powell and Buzhardt to teach parents and service providers to work with young children with autism. The work follows pilot studies Wills conducted that developed a web-based application called I-Connect that helps teens with emotional and behavioral problems monitor and manage their behavior and set and achieve academic goals through wireless devices. Development and usability studies are currently underway for the on-line instruction and tele-coaching components for 20 modules and skills.

In the current research, Kamps and colleagues will test the effectiveness of I-Connect Plus with 50 students and young adults with ASD and their service providers, parents and community members. The study is funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

According to Kamps, the majority of online instructional products have been developed for parents and service providers. “This is one of the first to be developed for persons affected with ASD. Our vision is to use on-line instruction, tele-coaching and a revised I-Connect self-monitoring application to promote widespread use and independence for adolescents and young adults with ASD.”

Peer networks and social communication

Social networks serve an important role for children with autism just as they do for the general population: they teach people young and old how to interact with each other. Still, classroom teachers have often been at a loss at helping their students with ASD communicate better with their peers.

Kamps and her colleagues, Kathy Thiemann-Bourque and Linda Heitzman-Powell, conducted a four-year project funded by the U.S. Department of Education in which they studied the effectiveness of an intervention to improve behavioral and adaptive skills in young children with ASD. Along with partners at the University of Washington, Seattle, the researchers formed networks that included children with ASD and their typically developing peers to focus on teaching social communication skills such as requesting, commenting and using socially expected responses, such as please and thank you, during playtime.

Children who participated in the social peer networks made significant progress in social communication during the intervention and showed more growth in initiations to their peers in general. “Teachers also reported that children in the intervention were more social and had better classroom behavior,” Kamps said.

The research was published in 2014 in the Journal of Autism and Developmental Disabilities. Next steps would include expanding peer networks for older children with autism and refining the intervention for generalized use across multiple school and home settings. Kamps said future studies might also address the use of technology and mobile devices to increase the children’s independence use of social communication to novel environments and with new peers.

Alternative augmentative communication

Research by Kathy Thiemann-Bourque, JGCP associate research professor, has focused on the role of peer training and teaching strategies to improve social communication between children with autism and their classmates.

But in 2013 her work took a major leap forward with a four-year $1.2 million grant from the National Institute on
Deafness and Other Communication Disorders. Her latest project is looking at whether an iPad picture communication-voice output app can improve communication, social reciprocity and play skills of preschool children on the autism spectrum. “Many young children with autism have complex communication needs but do not develop functional speech,” said Thiemann-Bourque. “Alternative and augmentative communication can allow them to communicate independently but most studies that report success involve communicating with adults, not with peers.”

The current project will employ a voice output app as a speech-generating device, programmed to meet the individual needs of each child with autism. The app will then display pictures and photographs taken at home and school, for example, so that children can express wants and needs, greet others and make comments to better communicate with their peers.

To measure changes in the children’s complexity of prelinguistic and early linguistic communication, the study will use the Communication Complexity Scale, which Thiemann-Bourque assisted in developing with Nancy Brady. The study also will produce a manual for clinicians and videos for parent and teacher training.

Thiemann-Bourque said, “This research is vital for children with significant social and communication deficits related to autism or other developmental disabilities.”

**Family adaptation to Fragile X**

Steven Warren, professor of speech-language-hearing, and Nancy Brady are continuing their research into how families adapt to a child with Fragile X Syndrome. Fragile X (FXS) is the most common inheritable form of intellectual disability and often co-exists with autism.

Funded by the National Institute of Child Health and Human Development, their study of mothers and their children with FXS has found that a “responsive” parenting style has a strong and positive impact on a child’s communication development according to several measures of 55 children. The team began studying the children when they were two and are following them to age 10.

Responsive parents initiate communication with their children frequently and respond positively to reinforce their children’s non-communication attempts. The study has confirmed that parent-child interactions can change the course of development even in children with a genetically based, complex disability. Warren said, “The cumulative parenting effects grow stronger as we proceed with the study.”

**Self-determination in autism**

Self-determination refers to characteristics that enable people to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directing.

Yu-Chi Chou, Michael Wehmeyer, Susan Palmer and Jaehoon Lee with the KU Center on Developmental Disabilities (KUCDD) compared the scores of middle grade and high school students with ASD, intellectual disability (ID) or learning disabilities (LD) on the domains of autonomy, self-regulation, psychological empowerment and self-realization.

They found that students with ASD had significantly lower levels of autonomy than students with ID or LD; students with intellectual disability had significantly lower levels of self-regulation than students with learning disabilities but not those with ASD; students with ASD and students with ID had significantly lower levels of psychological empowerment than students with LD; students with ID had significantly lower levels of self-realization than students with LD but not students with ASD.

Another study by the same researchers and Karrie Shogren, also with KUCDD, examined the reliability and validity of two assessments of self-determination in students with autism. Their results supported the use of those measurements of self-determination in students with ASD for researchers and educators.

Data came from projects funded by the U.S. Department of Education, Institute of Education Sciences, National Center for Special Education Research and the U.S. Office of Special Education Programs.

In 2013 Wehmeyer and Shogren received a $1.6 million grant from the Institute of Education Sciences at the Department of Education to develop a self-determination assessment for a range of disability groups and for youth and young adults without disabilities. Measures of self-determination have historically only been developed and tested for a specific disability group.

The researchers are focusing on four characteristics of self-determination among 3,600 students, ages 13-22, with and without disabilities. Another 1,600 teachers, parents and caregivers also will complete the assessment.

End products will include the first fully developed and validated computer adaptive test of self-determination for youth with and without disabilities.
Clinical Research Database

Driving discovery with bioinformatics

K-CART’s seven-year partnership with the Center for Child Health and Development (CCHD) at the KU Medical Center has spawned invaluable connections between scientific investigators, clinical faculty and staff in the effort to diagnose autism as early in a child’s life as possible.

The collaboration has also produced a robust clinical research database on children and families who have been seen since 2010 by CCHD clinicians. K-CART invites new research partners, especially those in biomedical fields, to avail themselves of the database for studies on the causes and impact of autism.

Sean Swindler, K-CART’s director of community program development and evaluation, and former CCHD Director Matthew Reese saw the possibilities of maximizing the intake information gathered from parents and care givers seeking clinical services for children. Swindler and Reese transformed what was once an arduous paper-and-pencil task for parents into a web-based, data-gathering process.

CCHD uses the Comprehensive Research Information System (CRIS) database to track intakes, record child and family history, and individual clinical and diagnostic results for families who access services. CRIS gives CCHD faculty and staff the capability of reviewing their own data and collaborating with other regional and national centers researching autism and other neurodevelopmental disabilities.

Parents provide detailed information on their family demographics, insurance, primary care providers, family history, living situation and the medical history of family members. The process elicits more than 250 pieces of data including educational, behavioral, prenatal, birth and medical history and previous diagnostic testing.

Clinicians use the patient portal information as a reference when a child is seen at the clinic and add their findings to the database. Also included are psychological test results, such as detailed scores from the Autism Diagnostic Observation Schedule and Vineland Adaptive Behavior Scales.

The secure database now contains more than 6,000 patient information forms and more than 1,200 patients records with detailed psychological testing and clinical data. “This is seed data for clinical and translation research for partners on and off KU campuses,” Swindler said. “Regional diagnostic and treatment teams are using the database to exchange and store information and the CCHD uses it for quality assurance.”

The database has already been central to several research projects by K-CART-affiliated scientists, including studies on the concerns of caregivers and socialization and communication deficits in ASD and ADHD. A future goal is to work with partners in Missouri at Children’s Mercy Hospital and the Thompson Center for Autism and Other Neurodevelopmental Disorders to provide a larger, regional database for improving research and access to services.
It’s a difficult first step, the first in what may indeed become a 1,000-mile journey. For parents, the idea of speaking to a healthcare provider about a child’s atypical development is wrought with fear but the sooner that conversation can take place, the better.

The American Academy of Pediatrics and the Centers for Disease Control recommend that babies be screened during well-child doctor visits for autism at 18 and 24 months or whenever there is concern. But the average age of an autism diagnosis is much older – age 4 nationally, age 3.5 in Kansas. That’s why K-CART’s clinical partner, the Center for Child Health and Development (CCHD) at the KU Medical Center, plays a vital role in statewide efforts to lower the average age of diagnosis and begin intervention services.

Under the direction of Kathryn Ellerbeck, a developmental-behavioral pediatrician and K-CART co-director, the CCHD provides evaluations, diagnostics and specialty clinics. More than half of the children seen in CCHD’s weekly clinics are ultimately diagnosed with autism.

The CCHD also screens patients via telemedicine and by outreach to smaller communities. Teams of CCHD physicians, nurses, psychologists, occupational therapists and speech-language pathologists trained in developmental disabilities travel to rural communities and military bases. Each team can screen and diagnose as many as 10 children in a single community during an outreach visit for a range of developmental delays including autism.

Training future leaders

The CCHD is one of 43 university-affiliated facilities across the country training young physicians and healthcare professionals through the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. Funded by the Bureau of Maternal and Child Health, the LEND program, which Ellerbeck also directs, targets top students in their fields who demonstrate potential to be leaders in clinical practice, teaching, research or policy.

Through LEND, graduate and post-graduate professionals from a variety of disciplines bring their expertise to clinics while receiving hands-on experience in developmental disabilities. In fact, CCHD hosts short-term, intermediate and long-term LEND trainees every year —physicians, psychologists, occupational and physical therapists, speech pathologists, audiologists and dentists. Family members of people with disabilities also are recruited as LEND trainees. It’s a win-win: Children and families in CCHD clinics receive comprehensive diagnostic services and the LEND trainees are directly involved in diagnosing ASD and other disabilities.
One of CCHD’s most important community partners is the Kansas Technical Assistance System Network (TASN), funded by the Kansas State Department of Education, which provides assessment services for Kansas school districts. If a school is having difficulty responding to the behavior of a child and especially when a disability is suspected, a TASN consultant will conduct on-site assessments and recommend interventions to the school team. Kansas now has a large network of school autism diagnostic teams trained by the CCHD and TASN – a total of 46 teams serving 95 out of 105 counties. After the school teams assesses the child, TASN then refers the child to CCHD where faculty conduct a follow-up diagnostic interview to confirm the diagnosis at an abbreviated face-to-face clinic visit or via telemedicine.

Building bridges
When a child is diagnosed with autism, one of the most common questions posed by anxious parents is, “What can we do next?” Unfortunately, it can take months to line up what should come next: long-term intervention providers.

To bridge the period from diagnosis to intervention, the CCHD Bridge Clinic provides temporary services. The Bridge Clinic provides skills assessment, individualized programming, treatment of problem behaviors and treatment plans for daily living activities, such as dressing, toileting, language development and social skills. Typically the Bridge Clinic serves children for a period of two to six months before they transition to their own provider.

CHDC also offers a long-distance intervention and training program, the Online and Applied System for Intervention Skills (OASIS), that helps parents and other caregivers increase their children’s independent skills and reduce problem behaviors.

Research into practice
In 2008 K-CART awarded a Discovery Grant to affiliated scientists Cary Savage, Christa Anderson and John Colombo to study pupil and neural responses in children with ASD. Follow-up research by Anderson and Colombo discovered that one potential marker for ASD could be a large resting pupil size.

Based on this research, in 2012 the CCHD purchased a PLR 2000 pupillometer, a hand-held digital device to measure pupil size in clinical settings. Incorporating the results of using this device into the data that the CCHD is current collecting will determine its ultimate utility in assessments for autism.

The CCHD also has stepped to the forefront of creating bioinformatics on autism, including a database on all children who receive intake services at CCHD. CCHD now has a database of approximately 6,000 patients, including more than 250 data items on medical and diagnostic history.

CCHD faculty also participate in the national, multi-site Fragile X Clinical and Research Consortium to register individuals in the Consortium database and to offer opportunities to people with Fragile X to participate in clinical trials through the Consortium.

New collaborations
Ellerbeck believes that one of the most exciting new opportunities facing the CCHD is increased collaboration on autism with partners at KUMC and Children’s Mercy Hospital in Kansas City, Mo. According to Ellerbeck, the collaboration with clinicians and researchers in pediatrics at KUMC and Children’s Mercy will enhance care for children and expand collaborative training and research activities.

Projects include the following:
- Obesity and mealtime behaviors in children with autism: Ann Davis and Susan Patton, KUMC pediatrics; Rebecca Swinburne, LSI; Lisa Pham, Meredith Dreyer Gillette and Cy Nadler, developmental and behavioral sciences, Children’s Mercy.
- Parent health, well being and training: Candice Allen-Jarra, Cy Nadler and Sarah Nyp, developmental and behavioral sciences, Children’s Mercy; Rebecca Swinburne, LSI; Christy Roberts, pediatric nursing, University of Missouri-Kansas City and a graduate of the KUMC LEND program.
- Genetics: Merlin Butler, psychiatry and pediatrics, KUMC; Zohreh Talebizadeh, autism and genetics, Children’s Mercy; Sarah Soden and Stephen Kingsmore, pediatric genomic medicine, Children’s Mercy.

“There is tremendous potential for vigorous research, for sharing the CCHD’s clinical research database and for much more collaborative work in general,” Ellerbeck said. “We plan to integrate our efforts in exciting new ways to make a difference for children with ASD.”
In 2007 the Kansas legislature approved the Home and Community Based Services Early Autism Waiver, which for the first time provided intensive early intervention services to young children diagnosed with Autism Spectrum Disorders. But in the eight years since the autism waiver was implemented, the diagnosis rate of autism the United States has climbed from 1 in 88 children to 1 in 68. As a result, the demand for trained therapists who can provide specialized intervention services has brought even greater urgency to K-CART’s training mission.

From the very beginning K-CART took the lead in training providers and parents throughout the state. K-CART was the first—and remains the only—training program approved by the Kansas Department for Aging and Disability Services for the early autism Medicaid waiver program. K-CART’s Autism Training Program is clearly tackling a big job.

According to Linda Heitzman-Powell, associate research professor and director of training for K-CART, the state recognized from the beginning the need for a uniform training program in the basics of autism and intervention in order to ensure uniformity across the state. Since 2008 the Autism Training Program at K-CART has trained 623 professionals, paraprofessionals, family members and others. Seventy training sessions have been held throughout the state.

“The training is required, in varying degrees, for five of the six services offered by the state,” Heitzman-Powell said. These services are respite, intensive individual support providers (IIS), parent support and training, autism specialist and interpersonal communication therapy (added in 2012).

**Scope and focus**

Using evidence-based practices, the 40-hour training program for IIS providers covers the following: basic screening and autism characteristics; reinforcement; antecedent and consequential strategies to reduce problem behavior; peer networks and social skills; behavioral domains; home-based team meetings; wrap-around services, and Medicaid documentation. Training for autism specialists and interpersonal communication therapists focuses on understanding the function of problem behavior, developing peer networks and using assessments required for Medicaid recipients.

ATP Director Jill Koertner has seen the impact of the training on providers across the state. “The most common feedback we get is that trainees can’t believe what a difference this is going to make for their clients and themselves,” she said.

ATP training partners include two applied behavioral science faculty at the University of Kansas: Claudia Dozier, associate professor, and Pam Neidert, assistant professor. Partners across the state include the Kansas City Autism Training Center, Prairie Village; Kid’s TLC, Olathe; Integrative Behavioral Technologies, Basehor; the Summit Center for Child Development, Kansas City, Mo.; Heartspring, Wichita; school districts in central and southwest Kansas, and families in Kansas City, Manhattan and southeast Kansas who volunteer their children for hands-on demonstrations.
**Going the distance**

When trainers and researchers put their heads together to discover new ways of reaching the marginalized or underserved, real change comes about. Case in point: K-CART training and research partners are applying the latest technology to train parents and caregivers in remote areas of Kansas.

The plight of parents who can’t spend hours in a car to access face-to-face instruction led to a collaboration between Heitzman-Powell and Jay Buzhardt, a research associate professor at the Life Span Institute Juniper Gardens Children Project. Buzhardt specializes in employing new technology to reach people in outlying regions of the state. A licensed psychologist, Heitzman-Powell is board certified in applied behavior analysis (ABA), the most effective treatment for children with ASD.

Heitzman-Powell and Buzhardt developed a long-distance intervention and training program based on ABA principles that parents and other caregivers could learn at home to help them increase their children’s independent skills and reduce problem behaviors.

The training, the Online and Applied System for Intervention Skills (OASIS), includes interactive coaching via live interactive television, video conferencing, face-to-face sessions and online educational modules. Prior to each interactive session, families complete an online tutorial and quiz. Content is then discussed at an interactive session where family members practice techniques with their own child. Parent training coaches provide immediate feedback to promote the best outcomes for each family. To date 45 parents have received OASIS education, training and on-going feedback on ABA-based intervention techniques.

**Impact**

The researchers reported that parents who received the OASIS training increased their knowledge of ABA strategies by an average of 32-39 percent. They also showed a marked increase in the use of behavioral skills, such as gaining their child’s attention, prompting appropriate behaviors, and follow through on requests combined with reinforcing compliance during coaching and using tele-medicine sessions. Use of the strategies improved overall by 30-41 percent.

From the original cohort of family trainees, five participated in follow-up assessments ranging from six months to four years after the study. These families have maintained skills at or above their post-test scores.

The National Institute on Disability and Rehabilitation Research funded the development and evaluation phases of OASIS over an eight-year period. Results were reported in *Advances in Medicine and Focus on Autism and Other Developmental Disabilities*.

Heitzman-Powell and colleagues are now expanding the project to include intervention specifically for Spanish-speaking parents and will continue to reach out to underserved populations in Kansas.

As proof of the interconnected impact of K-CART, the Center for Child Health and Development at KUMC now offers OASIS training as a clinical service.
Outreach

Translating our work for those who inspire it

Beyond the Diagnosis conference
An annual conference that K-CART sponsors in partnership with Johnson County Community College has become one of the most effective opportunities in the state for autism researchers to connect with families and practitioners.

Held each fall in Overland Park, Kan., “Beyond the Diagnosis: Autism Across the Life Span” attracts nationally known speakers and invited community experts for keynote addresses and dozens of breakout sessions. Since it began in 2009, more than 200 family members and professionals have attended the conference on an annual basis. JCCC has co-hosted since 2010.

“It’s a key opportunity for K-CART and KU researchers on autism to discuss their research directly with the community,” said Sean Swindler, K-CART’s director of community development. “It’s an important part of our intention to translate scientific discoveries into practical applications for families and professionals in the field.”

Conference keynoters have included Steve Warren, professor in speech-language-hearing at KU and a researcher in the use of LENA technology for detecting autistic speech patterns in young children; Michael John Carley, consultant and activist; Eustacia Cutler, mother of autism activist Temple Grandin; and Robert and Lynn Kern Koegel, researchers at the University of California, Santa Barbara, and developers of Koegel's Pivotal Response Treatment for children with autism.

Supporting college students with ASD
K-CART’s partnership with Johnson County Community College includes facilitating the JCCC Autism Support Club, a group of students with ASD and their peers.

K-CART staff assist the group with activities on campus and recreational outings in the surrounding community. K-CART also consults with JCCC faculty on how to work effectively with students who have ASD.

New video Series
A series of up-close and personal videos depicting real kids and teens with autism and their parents as well as video from KU research in area schools debuted in 2014 at autismconnections.ku.edu.

“Autism Connections” consists of three professionally produced videos: “Connecting Kids,” “Connecting Teens” and “Connecting Parents.” The series grew out of the shared desire of Kansas City families and professionals for educational videos based on KU’s research on social skills, behavior and learning for kids, teens and parents.

The Young Matrons of Kansas City provided funds for the project. The videos were produced by K-CART, the Juniper Gardens Children’s Project and Wide Awake Films.

School spirit fuels autism research
The Autism Border Challenge, co-sponsored by SFS Architecture’s Project Change Team Awaken KC and Boulevard Brewery, pits the participation of KU Jayhawks against University of Missouri Tigers in an annual spring fundraiser for autism research and family services. Proceeds benefit programs and research underway at the Thompson Center for Autism and Neurodevelopmental Disorders at MU and K-CART.

More than $70,000 has benefited K-CART and the Thompson Center to date.

Autism Resource Center
The Autism Resource Center at the KU Edwards Campus is a place where families and people with ASD can receive one-on-one assistance in identifying community resources and supports and check out evidence-based information through its lending library.

The Center for Child Health and Development refers families with a new diagnosis to the center to help locate behavioral and educational resources.

K-CART works with the Autism Society of the Heartland, JCCC, Families Together, Autism Speaks and the Johnson County Community Developmental Disabilities Organization and its providers to maintain a network of contacts for families of children and young adults with ASD.
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