Kansas Center for Autism Research and Training

EXCITING TIMES

K-CART : The First Three Years: 2008–2010

KU KANSAS CENTER FOR AUTISM RESEARCH & TRAINING

Life Span Institute

The Kansas Center for Autism Research and Training is committed to the discovery of new knowledge and dissemination to benefit people with autism, their families, our communities and beyond.

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Life Span Institute

In 2008 the University of Kansas and University of Kansas Medical Center provided $1 million in seed money for the state's first multidisciplinary center promoting research and training on the causes, nature and management of Autism Spectrum Disorders. Since then the Kansas Center for Autism Research and Training (K-CART) has made significant progress in attracting an esteemed group of researchers and clinicians who are making an impact on multiple fronts.

Scientists from KU, KU Medical Center and other KU research groups are conducting truly groundbreaking studies on the causes and neural mechanisms underlying ASD. Research interests include such areas as cognitive neuroscience, psychiatry, behavioral, clinical and developmental psychology, special education, occupational and speech therapy and other fields. Multiple projects directly or indirectly related to autism have already been funded through government grants and private sources to these K-CART investigators. We expect increased collaboration across disciplines and campuses to increase our autism research and training portfolio.

Clinical services affiliated with K-CART have chalked up equally impressive achievements. By training diagnostic teams based in rural communities and through telemedicine clinics, the Center for Child Health and Development has lowered the average age of autism diagnosis in Kansas, which means that intervention can begin earlier for children at risk for developmental delays. In an academic year, more than 100 graduate and undergraduate students from the KU Lawrence and Medical Center campuses receive interdisciplinary training in autism clinics. These students receive training in screening and diagnosing autism as in well as using empirically supported treatments for these children.

K-CART also secured funds through the Kansas State Social and Rehabilitation Services to conduct experiential training for service providers and families receiving funding from the Medicaid Autism Waiver. This project, the Autism Training Program, is in its third year and has trained more than 220 providers to provide quality services across the state.

These are exciting times. We have a vision for the future to make a difference in the lives of people with autism across the life span, from early detection to adulthood. Committed to the highest standards of scientific rigor, K-CART strives to generate new research discoveries to prevent and treat ASD and to ensure the dissemination of research-based practices throughout the state and region by training professionals and paraprofessionals who serve children and adults with autism and their families.

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

Sincerely,

Debra Kamps, Director

Matt Reese, Co-Director

K-CART Community Advisory Board

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.

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Kansas Center for Autism Research and Training

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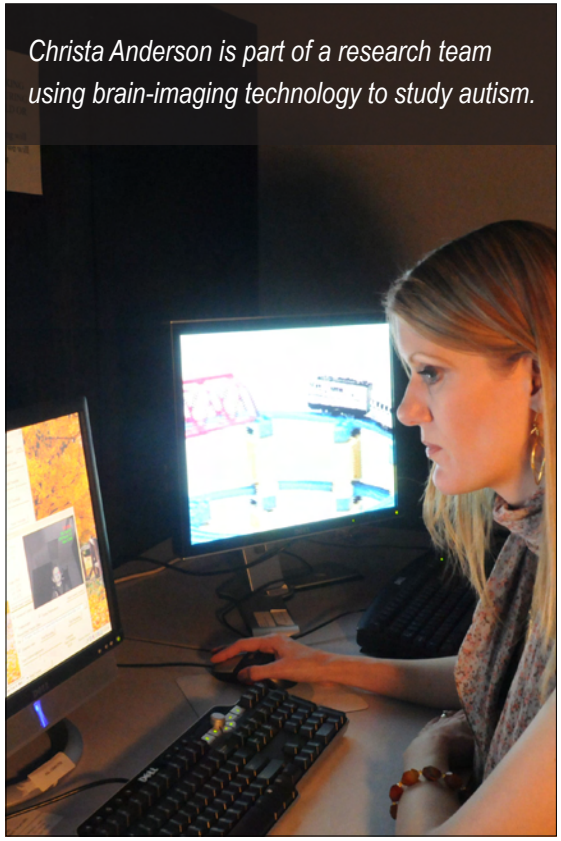
A driving force behind the creation of the Kansas Center for Autism Research and Training in 2008 was the need expressed by Kansas parents, professionals and service providers for the leadership of University of Kansas scientists and clinicians in both researching Autism Spectrum Disorders and in disseminating evidence-based training and practices.

Director Debra Kamps and Co-Director Matthew Reese forged a mission that unequivocally recognizes and addresses that need: to promote research and training on the causes, nature and management of Autism Spectrum Disorders that is committed to the highest standards of scientific rigor.

RESEARCH

exciting discoveries into causes



Christa Anderson is part of a research team using brain-imaging technology to study autism.

DISCOVERY GRANTS

One of the first things K-CART Director Debra Kamps and her colleagues decided to do was to attract more scientists from across KU, KUMC and other regional universities to research Autism Spectrum Disorders. Beginning in 2008, this became the Discovery Grant program that awarded small grants for critical pilot research each year. The program was made possible by a combined KU/KUMC five-year $1 million contribution. Funding for pilot research is scarce but data from such studies are often critical to win external support from government and private funders.

The award winners competed for the $25,000–$40,000 grants that recognize original empirical research that advances scientific knowledge and contributes to the overall competitiveness of K-CART for external funding.

"K-CART is committed to the discovery of new information and dissemination to impact people with autism. The awardees exemplify collaboration among disciplines and across campuses to address the complexities and challenges in Autism Spectrum Disorders," said Debra Kamps, K-CART director.

2008 AWARDEES

Bisphenol A affect genes suspected in Autism Spectrum Disorders

Kathryn Ellerbeck and Jill Jacobson have found that exposure to Bisphenol A (BPA) causes certain genes associated with autism to "upregulate" or turn on.

According to Jacobson, Bisphenol A or BPA, is an environmental toxin, although it is used as a plasticizer and is present in many household products including the linings of most canned foods. BPA was originally developed as a

synthetic estrogen but was largely replaced by diethylstilbesterol (DES).

"Scientists have suspected that environmental toxins may be contributing to the increasing number of children with ASD," she said.

The researchers had previously found that white blood cells from patients with autism display an "upregulation" or turning on of two genes involved in cellular signaling, called GNAS and GNAQ. These two genes encode for G proteins, which play important roles in sending signals from the outside of the cell to the inside. What's more, many of the hormones that control puberty signal through these G proteins.

"At the same time that we are seeing increasing numbers of children being diagnosed with ASD, we are also seeing increasing numbers of children who display early puberty," Jacobson pointed out.

Jacobson and Ellerbeck hypothesized that exposure to BPA would also upregulate the same G protein genes that they found to be upregulated in children with ASD. So the researchers exposed the brain cells of mice to BPA in tissue culture dishes. Both genes, GNAS and GNAQ, were turned on with exposure to BPA. What's more, they also exposed pregnant mice to BPA.

"When their pups were 28 days old, we found that GNAQ was turned on in organs involved in puberty: the pituitary gland and ovaries," said Jacobson.

"There is a mechanism involved in biology called epigenetics," Jacobson explained. "Put simply, epigenetics involves changes to the DNA structure that change expression of the gene but do not involve changes to the DNA sequence."

"BPA is now known to turn on expression of certain genes that are normally 'imprinted' or turned off."

The researchers are currently testing to see if BPA exerts actions on not just a handful of imprinted genes but more globally, on imprinted genes in general.

Ellerbeck is a developmental-behavioral pediatrician at KU Medical Center's Center for Child Health and Development. Jacobson is a professor of pediatrics/endocrinology at the University of Missouri-Kansas City School of Medicine.

Brain imaging technology allows new insights to ASD

Three neuroscientists, Cary Savage, Christa Anderson and John Colombo, are using brain-imaging technology to literally see into the brains of children with ASD while they look at pictures of human faces and toys. This noninvasive technology – fMRI – is available to investigators in only a limited number of research centers, one of them being the KU Hoglund Brain Imaging Center.

According to Anderson, the exact brain regions that are affected in autism are currently unknown. The researchers will be examining the functioning of several brain regions that control the size of the pupil that they found in previous studies to be atypical in children with autism. "The examination of these brain regions will help us to determine if these areas may be a key to identifying and diagnosing children with autism," she said.

Savage is the director of the Center for Health Behavior Neuroscience at KUMC and the John H. Wineinger Professor of Psychiatry and Behavioral Sciences. John Colombo is professor of psychology and KU Life Span Institute director. Christa Anderson is a research associate at the Life Span Institute.

K-CART researchers have found that exposure to Bisphenol A (BPA) causes certain genes associated with autism to "upregulate" or turn on. Bisphenol A is present in many household products including the linings of most canned foods.

Researchers are studying the ability of children with ASD to learn social and academic skills while working in small groups with typically developing peers.

K-CART researchers found compromised immune systems in children with autism, specifically, in cytokines, proteins that help regulate cell growth, proliferation and moderate the body's response to infection, injury and inflammation.

Technology looks promising for social communication

Kathy Thiemann-Bourque, assistant research professor, is studying how to increase communication between preschool children with Autism Spectrum Disorders and their typical peers through assistive communication devices. Four children with moderate to severe autism and five typical peers participated in the social communication intervention for six months.

A child with moderate to severe ASD was paired with a typically developing peer classmate during preschool centers (e.g., art projects, puzzles, doll play, snack). The peers had been taught to "Stay-Play-and-Talk" over five 30-minute sessions using a published peer-training program. During the "talk" phase, they were taught to use the Picture Exchange Communication System (PECS) to respond and initiate to the children with autism. All four children with autism showed improvements in average rates of initiations and responses to request items or turns from peers using PECS. Peers also increased their rates of initiations and responses to the focus children with autism. "It appears that with brief training, children with autism and typical peers can learn to communicate using PECS as an assisted communication system," Thiemann-Bourque concluded.

Now Theimann-Bourque is determining if the outcomes of the first study can be replicated when a Go Talk speech-generating device is used by the children.

Exploring use of MEG to profile behavior patterns

Winifred Dunn, professor and chair of the Department of Occupational Therapy Education at the KU Medical Center, is identifying and validating methods for behavioral assessment that reflect brain activity of individuals with Asperger's Syndrome, focusing on sensory processing, temperament and brain activity through the use of MEG. Magnetoencephalography (MEG) is a noninvasive technology that maps brain activity. Mihai Popescu, research associate at the Hoglund Brain Imaging Center, and Kathleen Gustafson, research assistant professor in the Department of Neurology at the KU Medical Center, will be collaborating on the project.

2009 AWARDEES

Compromised immune systems in children with autism

Merlin Butler, professor of psychiatry at the KU Medical Center, and a multidisciplinary team is studying the immune profiles of children with ASD and, specifically, their cytokine levels.

Cytokines are intercellular signaling proteins released from cells that help regulate cell growth and proliferation. They also moderate the body's response to infection, injury or inflammation. Cytokines are divided into four families: hematopoietin, interferon, chemokine and tumor necrosis factor.

Butler and colleagues analyzed 39 blood serum cytokine levels of 104 children diagnosed with classic autism (76 males and 28 females; mean age 7.8) and 48 unrelated children with no known health problems (33 males and 15 females; mean age 7.7). The results indicated that the children with autism have compromised immune systems. Eighteen cytokines of the children with autism were significantly lower—13 in both genders and five in males only. Eleven were classified as hematopoietin, five were chemokine, one for interferon and one for tumor necrosis factor. Butler says that the findings support the possibility that cytokines interfere with neuronal (nerve cell) development and function and could cause autism. He suggests that genes encoding cytokines are fertile ground for further study linking them to ASD. K-CART investigator Jessica Hellings, M.D., professor of psychiatry and pediatrics, was a co-investigator on this project.

Effects of drug possible clue to environmental basis of ASD

Qian Li, research assistant professor of pharmacy and toxicology, is exploring whether or not epigenetic alterations and autistic-like behaviors are caused by environmental factors early in life. Li is taking a close look at valproic acid (VPA), a compound found in medications used to treat epilepsy, migraine headaches, bipolar disorder and schizophrenia that has been linked to birth defects in children of mothers who took certain medications while pregnant.

Li is testing her hypothesis that prenatal treatment of valproic acid will cause epigenetic changes in both somatic cells (body) and germ lines (sperm and ova) of the offspring and that these changes can be further transmitted to the next generations. Epigenetic changes to genes in a cell, organ or an individual do not alter its DNA sequences but modify the DNA structures. This can alter “gene expression” or gene behavior. Recent studies have shown that some epigenetic changes can be inherited. Li used a mouse model for this hypothesis by treating pregnant mice with VPA. She then tested the offspring of these mice, as well as the next generation, for social and anxiety behaviors, locomotor activity and sensitivity to stress in comparison to a control group injected with saline. The results showed reduced social activity, increased anxiety behavior and stress responses in the first generation of mice treated with VPA. And for the first time, Li has shown that the second generation of VPA mice are also affected. Li said that this supports her hypothesis that VPA affects both the somatic cells and germ lines.

Currently, Li is testing the behaviors of the third generation of prenatal VPA treated mice. If there are alterations in their behaviors, it is possible that epigenetic alterations may be transmitted across generations. “This may explain the high heritability and rapid increase in the occurrence of autism,” she said. As a next step, Li will determine epigenetic alterations in the first, second and third generations of prenatal VPA treated mice through genetic analysis.

A Discovery Grant is evaluating an intervention to improve social communication in adolescent girls with autism.

2010 AWARDEES

Juan Brusés, associate professor of anatomy and cell biology, is studying the effect of cytokine levels, part of the immune system response, on the developing brain in a mouse model.

Winifred (Winnie) Dunn, professor and chairperson, occupational therapy education, and Lisa Mische-Lawson, research assistant professor, occupational therapy education, are testing the effectiveness of a sensory processing intervention with children with ASD.

Rene Jamison, assistant clinical professor, is evaluating an intervention aimed at improving social communication in adolescent girls with ASD.

Nancy Brady, assistant professor, speech-language-hearing, and Christa Anderson, research associate, are developing a nonverbal method to test language comprehension using eye-tracking technology and eye movements.

The Girls at Work project helped young women with disabilities pursue new kinds of employment.

EXTERNALLY FUNDED RESEARCH

Since it was established in 2008, K-CART has affiliated with 36 researchers focusing on autism and related research from four KU campuses and many scientific fields, to raise awareness and to pave the way for collaboration and consultation. These affiliates are currently pursuing several externally funded research projects supported by federal, state and private grant competitions. See kcart.ku.edu/research for more information.
The following grants typify how KU scientists are approaching autism's challenges from basic to intervention studies.

Communication Success and AAC: A Model of Symbol Acquisition

Many children with developmental delays, including autism, are at risk for not developing symbolic communication (words) so they are often taught to use augmentative or alternative communication (AAC) such as signs, picture selection, and/or voice output communication aids. Although the use of AAC by preschool children, with very different histories and characteristics, is increasing, there is not much research to guide researchers or practitioners. This longitudinal study is testing the relationships between variables and three different outcomes: symbolic vocabulary development, communication success and symbol substitutions. One hundred young children with developmental disabilities and 20 young children with autism spectrum disorders (ASD) who are learning AAC are participating in the study. This research is expected to produce the largest data set collected so far from a prospective study of young children learning AAC. Nancy Brady, associate professor, directs the study with Kathy Thiemann-Bourque, assistant research professor, as co-investigator. The project is funded by the National Institute on Deafness and Other Communication Disorders.

Girls at Work

Girls at Work, a project funded by the Women's Educational Equity Project, has successfully forged a way forward for transition teams at schools to help young women with disabilities to determine and pursue new kinds of employment as adults, including self- and customized employment. An online curriculum assists middle and high-school girls in a problem-solving process focusing on postsecondary education or employment. Twenty-three Kansas schools implemented the curriculum. Forty-four young Kansas women with developmental disabilities obtained employment and/or are attending postsecondary programs. Girls at Work products and activities are continuing beyond the scope of the project. The curriculum is being widely disseminated in Kansas and nationally and several participating school personnel are using the Girls at Work curriculum as part of their teaching practices even though the project has ended. Building on the success of this project, project director Research Associate Professor Wendy Parent was awarded a grant by the U.S. Department of Education to design a web-based curriculum for both boys and girls with severe developmental disabilities, maintaining the theoretical foundation of self-determination, gender awareness and customized employment.

Promoting Social Communication Competency in Toddlers with Autism

As infants transition into toddlerhood at 12 months, nonverbal social communication in the form of joint attention typically emerges. However, this is not the case for children who will later be diagnosed with autism. Joint attention, a critical social-communication milestone, is defined as visually coordinating attention with another person in relation to an object or event, sharing social

interest and perceiving the partner's mutual interest. Joint attention supports communication, cognitive and social-emotional development. Research has shown that deficits in joint attention have a cascading effect on language development. Kathleen Baggett, assistant research professor, along with colleagues at the University of Northern Colorado and University of North Carolina, are testing an intervention model that is based on knowledge of early development in autism that can be implemented by parents. The three-year project is funded by Autism Speaks.

Autism Peer Networks

Core features of Autism Spectrum Disorders in children include problems learning basic social and communication skills, a gap that widens over time. According to K-CART Director Debra Kamps, senior scientist, Peer Networks teach those necessary survival skills as children begin kindergarten and first grade: early social-communication skills to interact with peers and teachers; literacy skills that are the foundation for all academic content and classroom functioning, and the ability to participate in groups. The Peer Networks project, headed by Kamps at KU with Ilene Schwartz, chair and professor of special education at the University of Washington, will examine how well children with ASD learn both social and academic skills working in small groups with typically developing classmates.

Eight districts, 35 schools across two sites and 55 teachers are participating. Thirty-two children (kindergarten and first grade) with autism and 158 peers are enrolled in social networks; 39 peers are enrolled in reading networks with the same students. Over four years, 60 children will receive the intervention and 60 children will serve as a comparison group. Using culturally diverse classrooms in Kansas and Washington, the randomized four-year trial will evaluate if and how to teach and sustain generalized learning and social skills necessary for the successful participation of children with ASD in typical school settings. The project is funded by the Institute of Education Sciences. Linda Heitzman-Powell and Kathy Thiemann-Bourque are co-principal investigators for the KU site.

K-CART and University of Washington researchers are testing a literacy intervention program for kindergarten and first-grade students with autism.

KU and University of Washington researchers are conducting a randomized trial across two sites that will test a peer network intervention on social-communication, literacy and adaptive behaviors for young children with ASD in school settings. Peer networks are small groups of children with and without ASD.

When a parent suspects a child is developing slowly or atypically, alarm bells go off. A mom may voice concerns to a preschool teacher, or a dad will volunteer his suspicions during a routine, well-baby checkup. It's often the start of a long, puzzling process for the family, fraught with uncertainty and delay, sometimes resulting in a diagnosis of autism.

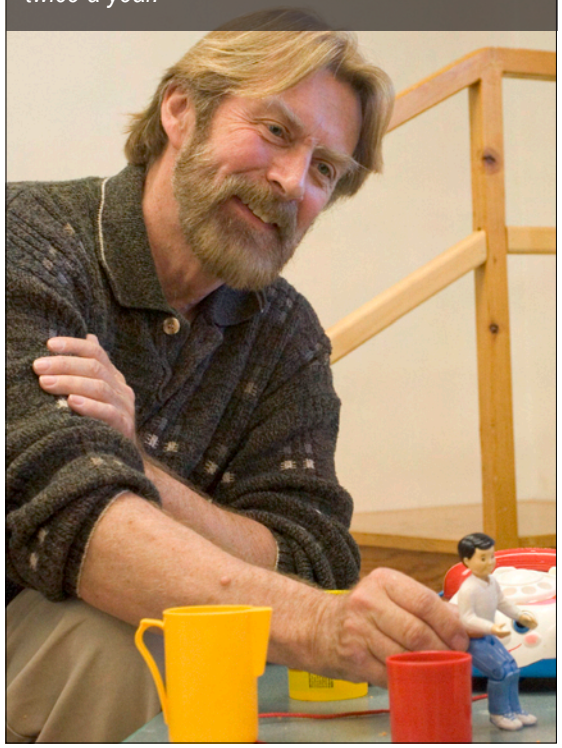
But a diagnosis is not an end when it comes to autism but a beginning, a jumping off point for critical intervention services. And research shows that the earlier intervention starts, the better the outcomes for child and family.

The American Academy of Pediatrics recommends screening and diagnosing children for ASD between 12-24 months of age. But, in practice, the national average is 4 ½ years.

CLINICAL SERVICES

exciting achievements in diagnosis

Psychologist Matt Reese takes a traveling team of clinical faculty and staff on the road at least twice a year.



The reasons are many, according to Matthew Reese, K-CART co-director, psychologist and director of the Center for Child Health and Development (CCHD) at the KU Medical Center, K-CART's clinical partner. Symptoms aren't always unique to autism. Many children lack access to good health care. Socioeconomic factors can mask developmental disabilities, especially among non-English-speaking or low-literacy families. Physicians with little training in ASD sometimes encourage parents to simply wait it out.

Lowering the average age of diagnosis in Kansas is no simple matter, Reese said. Ideally, families who are worried about their child would talk to a medical provider but many small towns in western Kansas don't have a pediatrician, a primary-care physician or even nurse practitioner.

TELEMEDICINE

As a result, Reese and colleagues have worked to identify and train teams of non-medical professionals across the state who can screen and assess children locally. Composed primarily of infant, toddler and early childhood teachers, the local team collects information from the family, performs evidence-based assessments, and links via telemedicine with Reese at the CCHD in Kansas City, Kan.

Reese reviews the family's medical history, performs test-and-retest reliability checks, rules out other medical conditions and provides a diagnosis, all long distance. Reese, the child, the parents and the assessment team are together, virtually speaking, which has made a critical difference. "You have all the players in the same room who can run with the ball and help with the next step," Reese said. "The parents walk away with a game plan."

The Kansas Instructional Support Network and CCHD have already trained 30 out of 75 targeted autism teams, focusing first in western Kansas. Plus those teams do more than assess—they are community-based advocates for early intervention.

ON THE ROAD

Reese also takes a traveling team of CCHD clinical faculty and staff on the road at least twice a year—physicians, nurses, psychologists, occupational therapists and speech-language pathologists trained in developmental disabilities. Each team can screen and diagnose as many as 10 children in a single community for a range of developmental delays, not just autism.

Efforts are paying off. In the last two years the average age of children diagnosed with autism in Kansas has dropped to 3.5 years, a full 12 months younger than the national average. In its 2010 report to Congress, the Combating Autism Act singled out Kansas for making significant progress toward lowering the average age of diagnosis and increasing the ability of local communities to diagnose and treat ASD.

RESEARCH TREASURE TROVE

In 2010 the partnership between K-CART and CCHD produced another milestone: the first database in Kansas containing critical information about children suspected of autism. The brainchild of Sean Swindler, K-CART's director of community program development and evaluation, the CCHD database is a searchable resource that compiles family medical history, lifestyle, information on health issues that surface with autism (sleep problems, gastrointestinal distress) and details such as if or when a physician was consulted.

Reese estimates that data on more than 1,000 families calling into the CCHD every year is now being collected and will constitute a raw data gold mine for clinical teams, researchers and epidemiologists. The data will also be used to improve the clinical experience for children and families coming through the CCHD.

FUTURE LEADERSHIP

Reese also directs a nationwide training program that is working to pack the pipeline with young physicians and healthcare personnel who can make a difference in small and large communities alike. The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, funded by the Bureau of Maternal and Child Health, awards grants to research institutions to provide future physicians, dentists, psychologists, occupational and physical therapists and speech pathologists with clinical experience in developmental disabilities.

KUMC's program targets medical and graduate students from low-income, underserved, non-English speaking or rural communities. Since it began in 2007, Reese and CCHD colleagues have provided training for 88 students through the LEND program, one-fourth of them from culturally diverse backgrounds or underserved, rural areas.

In 2007, Reese also received a supplemental $200,000 grant from the LEND initiative to train interdisciplinary graduate students how to screen and diagnose ASD, specifically. About 100 students a year rotate through the clinic in month-long training sessions. "It's impossible these days for a graduate student to rotate through our center and not have direct experience with autism," Reese said.

"K-CART and CCHD are major partners in building capacity throughout the state," he added. "It all seems to be working really well."

2010 CLINICS
Center for Child Health and Development

Children and Youth with Special Health Care Needs

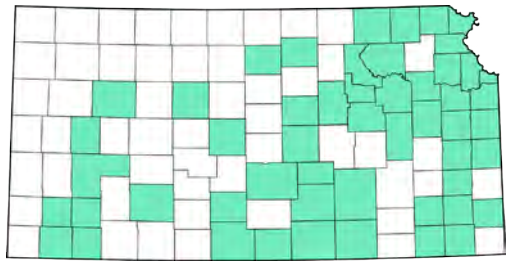
1500
Children seen annually in clinics

600
Children screened specifically for ASD

11
Weekly ASD clinics

60%
Frequency of ASD diagnosis

Waiver Participants in Kansas



TRAINING

exciting programs in treatment

In 2004 Linda Heitzman-Powell and colleague Jay Buzardt were researching ways to help parents improve the social and communication skills of their children with autism. “Parents were hungry for knowledge,” recalls Heitzman-Powell, a researcher at LSI’s Juniper Gardens Children’s Project. Heitzman-Powell and Buzardt took training materials for educators and translated them into strategies that a mom or dad could use at home.

Heitzman-Powell recalls one mother of a son with autism. Several months into the project, the woman gave birth to her second child, also a boy, also ultimately diagnosed with autism. But what might have been a devastating experience for the family was transformed by early intervention. “I want to say thank you for everything you do for me and my kids,” the mom later wrote Heitzman-Powell. “But how do you say thank you to somebody for giving you your kids back?”

K-CART’s training program, directed by Linda Heizman-Powell, is the only state-approved training for providers of ASD services.

The memory still evokes an emotional “what if” response in Heitzman-Powell, associate research professor and director of training for K-CART. “The thought of parents going without intervention for their kids is heartbreaking.”

But until 2007, Kansas, like most states, had no system in place to train therapists or parents to provide early intervention autism services, outside of traditional graduate and clinical programs. This was a full decade after the Surgeon General of the United States declared autism “the most pervasive developmental disorder” in the country with estimates that 1 in every 110 children would be diagnosed with ASD.

A HISTORIC CHANGE

When K-CART opened its doors, one of its main thrusts was to provide a comprehensive statewide training program specific to ASD. The timing was no coincidence: Kansas stood on the brink of launching a new program for children diagnosed with ASD.

Approved by the legislature in late 2007, the Home and Community Based Services Early Autism Waiver was designed to provide children with an ASD diagnosis, from birth through age five, with access to services not covered by their health care plan. For the first time Medicaid funds in Kansas could support clinical and consultative interpersonal communication and therapeutic services (including services from autism specialists); intensive individual support; respite care for families; parent support and training and family adjustment counseling. Heitzman-Powell said the official recognition by the state that autism places a tremendous financial burden on families opened the door for the implementation of the program. “You need access to early quality intervention implemented by trained, well-qualified staff regardless of how much money you make.”

In January 2008 the Kansas Department of Social and Rehabilitation Services (SRS) began accepting applications from eligible children and families. And when SRS looked for an entity to train the providers to serve

those children, it turned to K-CART. K-CART's training program became the first state-approved training for providers of ASD services. K-CART offered its first session in May 2008 and in just three years 221 providers have completed the training.

Using evidence-based practices, the program teaches providers and parents how to improve children's communication, social interactions and everyday skills needed to function at school or at home, such as following directions or transitioning from one activity to another. Ten training modules include the following content: (1) job responsibilities and characteristics of autism, (2) behavior analysis and data, (3) principles of behavior, (4) teaching strategies, (5) conducting teaching sessions, (6) variables that affect behavior, (7) behavior reduction strategies, (8) determining the function of behavior, (9) including peers and (10) team meetings and wrap-around services. Jill Koertner directs the Autism Training Program. Other ATP partners include Claudia Dozier and Pam Neidert, both assistant professors of KU Applied Behavioral Science; Community Living Opportunities; Kansas City Autism Training Center; Integrative Behavioral Technologies and Partners in Behavioral Milestones.

BEYOND THE WAIVER

Heitzman-Powell and her team are also developing and testing a training system for parents who live in rural or remote regions of the state. Funded by the National Institute on Disability and Rehabilitation Research, the system uses video conferencing and some face-to-face sessions to help parents improve their child's language and social skills. So far 24 parents have received education, training and on-going feedback on intervention techniques. Heitzman-Powell and colleagues plan to distribute the training curriculum as an evidence-based parent education and training manual for other researchers and trainees.

CHANGING THE LANDSCAPE

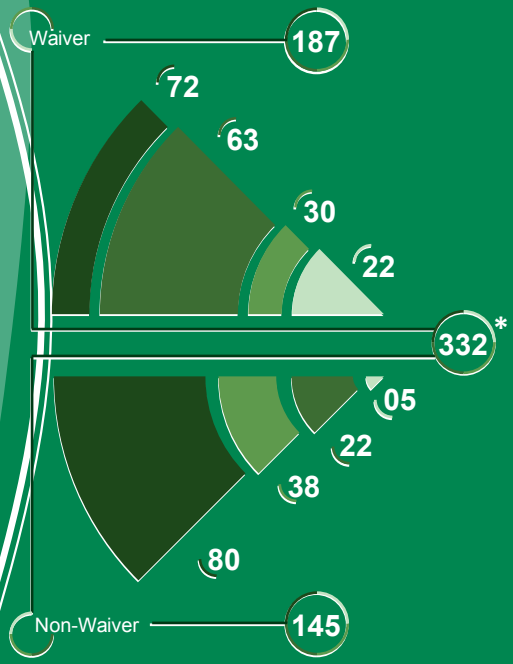
In 2011 the Kansas legislature approved insurance coverage for autism-related services for those covered by the state employee health plan, roughly 97,500 people. According to the law, the plan will cover "evidence-based medically necessary autism therapies such as applied behavior analysis."

Heitzman-Powell recites a long list of ways that K-CART's training program has changed the landscape for Kansas children with autism. "We're working on research to continue to identify strategies and techniques that have the most impact," she said. "We need to be able to provide services for more kids."

"More" is the operative word since the state's Medicaid waiver accommodates only 45 children at a time. Heitzman-Powell said more than 250 children are on the waiting list and many will age out before ever getting services.

Fueled by the memory of one mom, two sons and a thank-you note, Heitzman-Powell grows passionate. "We need to get those kids off the wait list," she insisted. "The impact that intervention has on families is more than just child outcomes and is well established. We now need to move beyond this to identifying how these interventions interact with the different subtypes of autism, how to more fully include these children in their natural communities and what strategies are beneficial for older children and young adults. There's still work to be done."

K-CART Provider Trainings by Tier 2008-2010



152 intensive support

085 respite care

068 autism specialist

027 parent support

*** Trainees may be trained to serve in multiples roles. 221 were trained : 112 waiver / 109 non-waiver**

SEMINAR ON HEALTH INSURANCE FOR ASD IN KANSAS

In 2011 Kansas joined Missouri and several other states in passing autism insurance legislation. In January, K-CART and the Kansas Coalition for Autism Legislation (KCAL) co-hosted a community seminar to provide information on the new insurance bill. Guest speakers included Mike Wasmer, founder of KCAL, Dan Unumb with Autism Speaks, Representative Thomas "Tim" Owens from Overland Park, Kan., and representatives from the Kansas Health Policy Authority and the Kansas Insurance Department. Approximately 200 parents and service providers attended the forum.

MILESTONES

exciting growth and outreach

Sean Swindler reviews materials with parent Danielle Underwood at the Autism Resource Center.

AUTISM ACROSS THE LIFE SPAN

K-CART sponsored the first two statewide research-based autism conferences in Kansas for educators, families, researchers and service providers that featured nationally known speakers as well as practitioners. Autism Across the Life Span conferences were held November 2009 in Wichita and October 2010 with Johnson County Community College in Overland Park, Kan. Each conference drew more than 300 participants from all corners of the state.

AUTISM RESOURCE CENTER OPENS

When K-CART opened the doors of its new Autism Resource Center at the KU Edwards Campus, it was cause for celebration: no other such public center for parents and practitioners exists in northeast Kansas. The official open house and dedication on March 24, 2009, featured a formal program with Peter Bell, vice president for programs and services at Autism Speaks.

The center is a referral and information service for family members, teachers and teenagers and adults with autism and the general public. DVDs, books and other printed materials are among the center resources.

For Danielle Underwood, a Kansas City parent of a child with autism, the resource center was the go-to place when she needed specifics on how to improve her son's social skills. She and her son's behavior analyst visited the Autism Resource Center together and came away impressed with the hands-on help that is available.

"Parents of children with Autism Spectrum Disorders have many extra demands on their time. They need help narrowing down all the information that's out there in order to find the gems," she said.

The Autism Resource Center was made possible by a collaboration of public and private entities. Edwards Campus Vice Chancellor Bob Clark contributed the suite of offices. Materials were purchased using gifts to K-CART from the Autism Society of the Heartland and special fund-raising events. Interior design students and faculty

at Johnson County Community College volunteered their time to design the space, furnishings and other visual elements.

NATIONAL TOWN HALL

In another demonstration of its growing stature, K-CART was tapped to be one of 16 regional sites of a national town hall meeting on autism broadcast on Nov. 13, 2009. Local co-sponsors were Children's Mercy Hospital and Clinics in Kansas City, Mo. and the Bi-State Autism Initiative. Sixty-five participants from Kansas and Missouri attended the regional event, held at the Kauffman Center in Kansas City, Mo. The National Town Hall Meeting was organized by Advancing Futures for Adults with Autism and designed to shape a nationwide policy agenda to increase independence, engagement and quality of life for adults living with autism. The Autism Alliance of Kansas City, Autism Speaks and the Autism Society of the Heartland continue to provide time and donations to support this effort. The KU Beach Center on Disability and the Department of Special Education also supported this effort.

PYLE ESTATE GIFT

In February 2008 the KU Endowment Association announced a bequest of more than $1 million from a rural Chase County couple for disabilities research at KU. Wanda and Thomas Pyle were long-time ranchers in Elmdale, Kan., who stipulated that their estate be used to improve children's lives. The gift will support high-impact work on the causes and treatment of Autism Spectrum Disorders, including scientific studies by K-CART researchers.

CAEDEN'S CAUSE

More than 240 people attended a fundraiser held in July 2008 in Kansas City, Mo., sponsored by the family of Caeden Kephart, an Overland Park, Kan. boy with autism. Proceeds of $7,900 benefited K-CART, which used the funds to purchase materials for the Autism Resource Center.

BLUE VALLEY NORTH CLASS GIFT

The 2008 senior class of Blue Valley North High School in Leawood, Kan. designated K-CART as its class gift project in honor of one of their classmates. The class raised $2,500 to honor the accomplishments of Elizabeth Boresow, who spoke at Blue Valley commencement and enrolled at KU in the fall.

The Peer Mentors Social Club at Johnson County Community College in Overland Park, Kan., which is sponsored by K-CART.

YOUNG MATRONS BALL

Every two years the Kansas City Young Matrons, a philanthropic and educational organization of around 300 women, designate a local charity or non-profit group as the beneficiary of a black-tie ball. In 2009 the recipient was K-CART, which received $119,00 from the Matrons' Magic Ball. Funds were used to purchase materials for the Autism Resource Center, to remodel a space for social skills groups at the Center for Child Health and Development at the KU Medical Center, and to produce educational DVDs.

BORDER CHALLENGE

Each year K-CART and the Thompson Center for Autism and Neurodevelopmental Disorders reap the rewards of the historic KU and University of Missouri rivalry. The Border Challenge, co-sponsored by Project Change, Inc. (a corporate challenge group), Sfs Architects and Boulevard Brewery, all in Kansas City, Mo., pits the participation of Jayhawks against Tigers in an annual spring fundraiser for autism causes. Befitting the oldest athletic rivalry west of the Mississippi, victory has graced both schools over the years, with more than $10,000 benefitting K-CART alone.

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