Discovery in the service of human health and development

THE LIFE SPAN INSTITUTE AT A GLANCE

Who  Investigators, research and administrative staff, graduate and postdoctoral students
The LSI brings together 177 scientists who are affiliated with 20 academic departments to study human development from its genetic origins to the final stages of life through 93 research projects. These investigators are supported by 182 research and administrative staff members, including 47 graduate research assistants.

The Institute has two affiliated multidisciplinary graduate/doctoral programs, the Child Language Doctoral Program and the Gerontology Masters and Doctoral programs, as well as dual-title doctoral degrees that combine training in gerontology with certain social and behavioral sciences and several postdoctoral training programs.

What  Research, training, technical assistance, direct services and leadership
Most of the easy problems in the behavioral and the biological sciences have been solved. Today the important problems are increasingly found and solved at the intersection of many disciplines. The Life Span Institute stands at such a convergence. At the Life Span Institute we know that our mission—to discover knowledge about human health and development—can only be achieved by problem-driven collaborations across many disciplines.

The Life Span Institute’s 12 centers and Peruvian affiliate currently have 135 active programs and projects that constitute basic and translational research, training, direct services, consultation and technical assistance. Last year, more than 58,600 Kansans benefited from the Institute’s direct services, training and technical assistance.

When  History
The Schiefelbusch Institute for Life Span Studies was established in 1990, when the distinguished 67-year-old Kansas Bureau of Child Research joined with the Gerontology Center and other new research groups to form one of the premier research institutes in the world on human and community development, disabilities and aging. The Bureau was directed for 35 years by Richard L. Schiefelbusch for whom the Institute is named. His appointment to lead the Bureau in 1956 was the beginning of its modern era.

The Institute has had three directors: Stephen R. Schroeder, from 1990 until his retirement in 2001, Steven F. Warren, from 2000 to March 2008, when he was appointed vice provost for research and graduate studies at KU, and John Colombo, who became the Institute’s third director in September 2008.

Where  Administrative and Research Locations
The Institute’s central office is in the Robert Dole Human Development Center at the University of Kansas in Lawrence with components at the John T. Stewart Children’s Center and Malott Hall. The Institute also operates in Kansas City at the Children’s Campus of Kansas City (Juniper Gardens Children’s Project) at the University of Kansas Medical Center’s Robert E. Hemenway Life Sciences Innovation Center and Center for Child Health and Development and at the University of Kansas Edwards Campus (Kansas Center for Autism Research and Training). A major center is also located at the Life Span Institute in Parsons, Kansas.

Much of the work of the Institute is accomplished in and directly benefits underserved Kansas City neighborhoods and rural Kansas counties. Several projects are collaborations with researchers in other parts of the state, region, country and world and are regional, national or international in scope.

How  Funding
The Life Span Institute attracts more combined federal, state and private dollars than any other designated research center at the University of Kansas, drawing $29.5 million in sponsored project support in FY 2012-13. Each state dollar brought in $7.28 external dollars this fiscal year.
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The year 2013 was punctuated by highs and lows, by triumphs and frustrations, but in the end, the Life Span Institute experienced a record year in external funding, bouncing back to eclipse its previous high year of 2011. The theme of this year’s Annual Report is “Big Ideas,” and in the past year, we’ve seen a lot of big ideas succeed. LSI invested in Wayne Sailor’s and Amy McCart’s big idea that resulted in KU’s largest ever grant, the SWIFT award (featured on the facing page). LSI saw a number of young investigators succeed in getting their first big ideas awarded, and many LSI scientists garnered international recognition and awards for big ideas that they’ve seen come to fruition over the course of their careers. At the same time, in late 2012, LSI (and KU) learned of the potentially devastating consequences of federal sequestration: award competitions from the U.S. Department of Education were suspended for a year and drastic cuts made to awards by the National Institutes of Health may persist long into the future. In the midst of such news, we also learned of the sudden passing of Betty Hart (memorialized on page 12 of this year’s report), whose big ideas exemplified the translational focus on which the LSI has been built.

In the wake of Betty’s passing, we were faced with the task of clearing out her office. In doing so, we came across a letter lamenting a crises facing the behavioral sciences at the University of Kansas, the uncertain state of federal awards, the loss of key grants, and the bleak nature of state funding. In a thoroughly unexpected and odd way, the letter gave me reason for hope—because it was written in 1984. It was a salient reminder that LSI has been through tough times in the past, and has always persevered. Our centers have been consistently successful at taking the small amounts of funding afforded to us by the state of Kansas and leveraging those investments to grow something bigger and better. For example, the external funds secured with those initial investments bring in other fresh, new energetic scientists (postdocs or new staff) who, in turn, learn how to compete nationally to bring new awards and new research programs to fruition here at Kansas that make life better for people all over the world.

So, let us celebrate this year—an excellent year for LSI and for research overall at KU—and take true comfort in knowing that we’ve been there and done that. LSI has always relied on big ideas to pull us through in the past, and there is no reason to think that we can’t count on them in the future. Enjoy this year’s Annual Report.

John Colombo, Director
The Schiefelbusch Institute for Life Span Studies
REDEFINE INCLUSION IN EDUCATION— AND TAKE IT NATIONAL

The aptly named SWIFT Center (Schoolwide Integrated Framework for Transformation), funded by the largest grant in KU history of $24 million, is rapidly hitting its goals in the first nine months of its existence since October 2012. Directed by Wayne Sailor, and Amy McCart, SWIFT director of technical assistance, the center will assist schools across the country to implement KU’s successful model for educating general and special education students together while improving academic outcomes for all students.

SWIFT named five states—Maryland, Mississippi, New Hampshire, Oregon and Vermont—where the K-8 initiative will be implemented in 64 schools beginning in the fall of 2013. The Center will provide each district with a highly skilled technical assistance team with targeted expertise based on the schools’ initial assessments.

“Many educational researchers around the country have taken on the problem of inclusion, bringing special education and general education more closely together in a cohesive framework, but KU’s success has garnered the most national attention,” said Sailor.

Earlier, SWIFT selected six schools to act as Knowledge Development Sites. These schools will be the basis of a comprehensive field study to add to the knowledge accumulated over ten years by Sailor, McCart and colleagues in several low-income urban schools in California, Kansas City, New Orleans and Washington, D.C.

SWIFT also convened two National Leadership Consortium meetings in Kansas City that brought together its national partners including the University of Oregon, the University of New Hampshire, the University of North Carolina, the University of South Florida, Arizona State University, the Council of Chief State School Officers, the National Association of State Directors of Special Education, TASH, the Institute for Educational Leadership and the Maryland Coalition for Inclusive Education.

The first Professional Learning Institute in Washington, D.C., July 23-26, brought together the representatives of the selected state and local education agencies, schools and family support groups.

The Beach Center on Disability, Department of Special Education, the Center for Research on Learning and the Life Span Institute are the SWIFT KU partners.

You can follow SWIFT’s progress at swiftschools.org.

Funding: U.S. Department of Education Office of Special Education Programs
CAN NUTRIENTS ADDED TO INFANT FORMULA MAKE KIDS SMARTER?

While DHA, an omega 3 fatty acid essential to brain and eye development, has been added to infant formula since 2001, in part based on research by John Colombo and Susan Carlson, the results of more recent studies on the cognitive benefits of the nutrient have been mixed.

But the two scientists, who have collaborated on examining the effects of DHA on cognitive development for 20 years, were convinced of the nutrient’s promise to boost brain development. This year, they reported a promise fulfilled from the results of a seven-year clinical trial.

They found that infants who were fed enriched formula from birth to 12 months scored significantly better than a control group on several measures of cognition, language, and intelligence collected between the ages of three to six years.

The children showed accelerated development on detailed tasks requiring planning, reasoning, remembering and self-control between the ages of three to five—all of which is part of something called executive function that emerges as children mature during the preschool period.

They also scored better on two widely used standardized tests of intelligence: the Peabody Picture Vocabulary Test at age five and the Weschler Primary Preschool Scales of Intelligence at age six. The improved scores at these later ages were largely driven by verbal ability.

Many of the earlier analyses that claim no benefit for DHA are based on standardized tests administered at 18 months and even Colombo and Carlson didn’t find that children fed the omega-3 formula performed any better on the Bayley Scales of Infant Development at that age.

“Clearly, studies of nutrition and cognition should include more comprehensive and sensitive assessments throughout early childhood,” said Colombo, an expert in developmental cognitive neuroscience.

DHA or docosahexaenoic acid is an essential long-chain fatty acid that accumulates predominantly in the brain and the retina of the eye. Babies obtain it largely from their mothers before birth and from their diets after birth, but the American diet is often deficient in DHA sources such as fish, said Carlson, a nutrition scientist.

Funding: Independent Investigator Trial grant, Mead Johnson Nutrition; National Institutes of Health
DO ANTI-HIV MEDS TAKEN IN PREGNANCY DAMAGE BABIES’ BRAIN DEVELOPMENT AND CAUSE SPEECH DELAYS?

Physicians concerned that anti-HIV medications prescribed for HIV-positive pregnant women damaged their developing infants’ brains and caused language delays, can take comfort in the results of a study by Mabel Rice along with scientists at the National Institutes of Health (NIH) and several other universities.

The findings of the study, which evaluated the language skills of nearly 800 children, showed that children born to mothers treated with anti-HIV medications while pregnant were no more likely to show language delays by age two than children of HIV-positive mothers who were not treated during pregnancy.

The children of mothers who took anti-HIV meds during pregnancy have shown higher rates of language delays than typical children and the anti-HIV medications had been suspected to be at the root of such delays.

For a woman who is HIV-positive and pregnant, recommended combination therapies treat the infection and greatly reduce the chance that the virus will spread to the fetus, Rice said. “Previous studies suggested that the drugs used to treat pregnant women might contribute to language delays in infants and toddlers, even those who remained HIV-negative.”

The researchers did conclude that one drug sometimes used in the combination treatments should be monitored. Children whose mothers received combination therapy containing the drug atazanavir were more likely to have language delays at one year of age than were the other children in the study. But these children appeared to catch up to their peers by age two.

“We continue to investigate the sources of risk for language delays in children exposed to HIV in the womb. In clinical practice it is prudent to monitor these children for signs of language delay,” said Rice.

Rice, an international authority on language disorders in children and the genetics of language acquisition, was the lead investigator in a previous study that found that children exposed to HIV at birth are at risk for language impairments.

The study is part of a national collaboration called the Pediatric HIV/AIDS Cohort Study.

Funding: The National Institutes of Health
CAN READING STORYBOOKS TO CHILDREN WITH SPECIFIC LANGUAGE IMPAIRMENT HELP THEM LEARN VOCABULARY WORDS?

Holly Storkel’s idea to help young children with Specific Language Impairment (SLI) learn vocabulary words through storybook reading is a newly funded clinical trial that will help answer a critical need.

The five-year study is aimed at developing an effective treatment for children with SLI, a subtle and often undiagnosed language impairment even though it is as common as ADHD—affecting about seven percent of children.

“Children with SLI have difficulty learning new words, which puts them at risk for later reading problems and academic failure,” said Storkel. Some research has found that children with SLI need to hear a word in context two to three times more often than their peers to learn them, she said.

Determining exactly how many more times children with SLI need to hear a word to learn it and the best way to expose kids to words could lead to the development of an effective treatment.

That treatment could be a modified version of interactive book reading, a research-based strategy in which an adult discusses vocabulary words in a storybook with children before, during and after reading the book by describing or defining the word and showing other ways to use it.

Once the researchers know the number of times children with SLI need to hear a word to learn it, they will test whether it is more effective to maximize the number of times children hear the word in a story book or the number of times they hear the book read.

This clinical trial will provide valuable information about the potential for optimizing interactive book reading as a possible SLI treatment and Storkel expects to be able to give general guidance to parents and others about how to help children with SLI learn words as a result.

Funding: National Institute on Deafness and Other Communication Disorders
CAN AN IPAD APP HELP PRESCHOOLERS WITH AUTISM TALK TO AND PLAY WITH THEIR CLASSMATES?

LSI scientist Kathy Thiemann-Bourque has approached the problem of the deficits in the social communication of children with autism from many directions. She developed and tested both peer training and teaching strategies to increase social communication between children with autism and their classmates.

In previous studies, she succeeded in training typically developing children to be responsive communication partners and to use the same communication system as their classmates with autism.

Now, she’s bringing these together with the help of a picture communication–voice output app on iPad in a newly funded $1.2 million grant.

So Much 2 Say© will be used as a speech-generating device that will be programmed to meet the individual needs of each child with autism.

The iPad app will allow children to quickly tap images or “cards” that the app verbalizes to express wants and needs, greet others and make comments typical of preschool communication. The images can even be personal photographs taken at a child’s home or school, for example.

“Many young children with autism have complex communication needs but do not develop functional speech,” said Thiemann-Bourque. “AAC—alternative and augmentative communication—can allow them to communicate independently, but most studies that report success involve communicating with adults, not with peers.”

The KU study will recruit 48 preschool children with autism who are nonverbal or minimally verbal, 48 early education school staff and 144 peers without disabilities (each child with autism will have three peer partners) from the greater Kansas City area and Lawrence school districts for the study, which began July 1. The intervention will be implemented for one school year.

The unique Communication Complexity Scale, that measures changes in communication by people who are non- or minimally verbal, unveiled by study co-director Nancy Brady in 2012, will measure changes in the complexity of children’s prelinguistic and early linguistic communication and play with their peers based on commonly used developmental play categories and behaviors.

The study will produce a manual for clinicians and videos for parents and teacher training.

Funding: National Institute on Deafness and Other Communication Disorders

Kathy Thiemann-Bourque, assistant research professor, the Life Span Institute, Juniper Gardens Children’s Project
DEVISE A FUN AND EFFECTIVE SYSTEM TO HELP ELEMENTARY SCHOOL TEACHERS MANAGE THEIR CLASSROOMS

What if a teacher could manage a class like clockwork—including those students with challenging behaviors—and even when teaching tough lessons? That’s the way CW-FIT (Class-wide Function-related Intervention Teams) works. What’s more, teachers do use clocks—actually timers—as part of the system’s game format.

Classes are divided into teams of two to five students. The teacher sets a timer to ring every two to three minutes. At the beep, the teacher awards a point on a chart to teams with everyone engaged in appropriate behaviors. At the end of the class, rewards are given to each team that meets a stated goal.

Students who need more support get booster sessions. They are the managers of their own behavior and are directed to award themselves points if they are behaving appropriately during the time interval.

Beginning in 2005, LSI behavioral scientists Howard Wills and Debra Kamps began testing their classroom management system to improve students’ engagement during academic instruction. Since then more than 1,600 students in culturally diverse urban communities in Kansas, Missouri, Tennessee and Utah have benefitted from the program.

“Our research showed that classes as a whole stayed on task better. Students with behavior issues decreased disruptive behaviors and also stayed on task more often,” said Kamps.

Students also reported that they liked the system. “One student even taught her family how it works,” said Wills.

Further, teachers found CW-FIT easy to use and very effective.

Wills and Kamps are now conducting a more extensive evaluation of CW-FIT with schools in Missouri, Tennessee and Utah. Nearly 3,000 children will participate in CW-FIT by 2015.

“Students with disabilities and at risk for emotional or behavioral disorders—between 3 and 6 percent of school-age children—have an alarming risk of failure in school,” said Wills. “The need for evidence-based interventions that improve classroom management and ameliorate or prevent severe problem behavior is of the utmost urgency.”

Funding: U.S. Department of Education
MEASURE THE COMMUNICATION ABILITY OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES WHO HAVE NO OR LIMITED SPEECH

Nancy Brady led the team that produced a beta version of the Communications Complexity Scale (CCS) in 2012. The CCS is a unique measure for researchers and clinicians to assess the communication status of children and adults with disabilities as diverse as autism spectrum disorders, Down syndrome, deaf-blindness and cerebral palsy, including those who are nonverbal or have very limited speech.

This year Brady received support from NIH to take the promising measure to the next level over five years. She will be collaborating with LSI assistant scientist Kandace Fleming, LSI assistant research professor Kathy Thiemann-Bourque and Connie Kasari, professor of psychological studies in education of the UCLA Center for Autism Research and Training to hone the validity of the CCS.

“With current measures, an intervention could make a big difference in an individual’s social communication, but that would never show up in the data if an individual wasn’t talking yet, said Brady. “The CCS may be able to show progress much earlier.”

The CCS is based on well-established “presymbolic” stages of communication development in typically developing children from birth, beginning with an infant crying or smiling, followed by eye gaze, gesturing and vocalizing directed at another person, to using “symbolic” communication, typically, spoken words.

Brady says that clinicians and family members sometimes give up on people who are nonverbal making any progress after early childhood. “But it is not unusual for someone to start doing new things as an adult when they have a need to communicate.”

The CCS may also be able to measure degeneration in communication as in the case of individuals with Down syndrome who start aging early.

“The CCS will help clinicians describe an individual’s current communication status, much like the Rancho Los Amigos Scale does for people with traumatic brain injury,” Brady said. “Then, appropriate therapies can be selected based on that level.”
In 1984, the Research and Training Center on Independent Living (RTC/IL) published the first edition of a brochure that has become a nationally known media resource for how to portray people with disabilities.

Now, almost 30 years later, the Center has published the eighth edition of Guidelines: How to Write and Report About People with Disabilities that reflects recommendations for current terminology from disability organizations across the country. A companion poster, Your Words, Our Image, highlights terms from the brochure.

“Journalists, public speakers, educators, human service providers and other communicators have a great influence on shaping society’s attitudes toward disability,” said RTC/IL Director Glen White. “These guidelines are a call to responsible and accurate portrayal that does not objectify or treat people with disabilities as mere human interest stories. Rather, they focus on the humanity of the individual and the fact that the experience of disability is a natural part of life.”

The Associated Press Stylebook, the Publication Manual of the American Psychological Association (6th edition) and the American Association for the Advancement of Science have all adopted some of the recommendations from previous editions of the RTC/IL’s Guidelines.

In the eighth edition, three new sections provide additional information about disability culture and related issues. Rosa’s Law and the Language of Bullying, Key Concepts in the Disability Community and A Few Exceptions expand the updated definitions of terms and give tips on portrayal.

The RTC/IL also used feedback from journalists for this edition in a first-time collaboration with the KU School of Journalism. Journalism Professor Tien-Tsung Lee used the Guidelines brochure and poster as a research project for students in a strategic communications research course. The students conducted a focus group and online survey of practicing journalists to gather responses to the publication. Val Renault, communications coordinator, was the editor of the new edition.

The brochure and poster are both available for free download at http://www.rtcil.org/guidelines.shtml. For more information or to order print copies, call or email the RTC/IL at 785-864-4095, rtcil@ku.edu.

Funding: Originally funded through the National Institute on Disability and Rehabilitation Research, now self-sustaining.
DEVELOP A LONG-DISTANCE TRAINING PROGRAM TO TEACH RURAL PARENTS EFFECTIVE TREATMENTS FOR AUTISM

In 2004, LSI scientists Linda Heitzman-Powell, a licensed psychologist and board certified behavior analyst, and Jay Buzhardt, a researcher who employs technology to help make evidence-based practices accessible to rural parents and others, had the bold idea of training parents of children with autism to use applied behavior analysis (ABA) to help them increase their children’s independent skills and reduce problem behaviors.

What’s more, the training would be rigorous and it would be long-distance: coaching via live interactive television along with online educational modules covering the concepts and principles of ABA, the most effective treatment currently available for children with autism.

“Autism Spectrum Disorders, now estimated to affect one in 50 children, are as common in rural America as they are in urban America,” said Heitzman-Powell, “but ABA-trained professionals are much rarer in rural communities.”

The initial evaluation of the Online and Applied System for Intervention Skills (OASIS) with close to 40 families across Kansas showed that parents learned and retained skills as precise as collecting and analyzing data and how to use it for making decisions.

“Pre- and post-test results on knowledge and using skills was impressive as was parent satisfaction, said Heitzman-Powell.

Best of all, OASIS will continue past the end of the research project: the Center for Child Health and Development at KUMC has begun offering OASIS as a clinical service.

Further, the KU team is translating and adapting OASIS for the Hispanic population and researchers from Poland and Italy have expressed interest in translating the training program.

The researchers are evaluating the short and long-term impact of the strategies parents learned through OASIS on their children’s language and social skill development. They will also assess the long-term effects on the families and children from their initial study.

As to the importance of OASIS, Heitzman-Powell notes that approximately half of children with ASD who are diagnosed early and receive appropriate treatment will mainstream in a public school setting without an aide. “But without appropriate treatment, only two percent will achieve this level of success,” she said.

Funding: U.S. Department of Education, National Institute on Disability and Rehabilitation Research
HELP STATES RAISE THE STANDARDS OF EARLY CHILDHOOD EDUCATION AND SERVICES FOR YOUNG CHILDREN WITH DISABILITIES

The Individuals with Disabilities Education Act (IDEA) of 1990 set in place guidance for states on providing education and related services to children with disabilities. But the realization of this law is still in process—particularly pre- and in-service preparation of professionals providing those services.

Eva Horn and David Lindeman are leaders for the Midwest region in a multi-university effort to support states in designing and implementing a comprehensive approach to professional development.

“The impetus for this effort was research that found that state training and standards for professionals vary widely,” said Lindeman.

KU’s Horn and Lindeman, along with project coordinator Stephanie Parks, are collaborating with the Universities of Connecticut, Oregon and Florida State in the five-year Early Childhood Personnel Center.

The center researchers will collect data on standards in every state and some territories and look at strengths and challenges in the preparation and training standards for each discipline, said Horn.

“We will compare state standards for individual disciplines and analyze how current professional standards align with the nationally recommended standards of the major professional organization for each discipline,” she said.

The researchers will also look at how required knowledge and skills conform with and lead to the attainment of each state’s early learning standards for children with disabilities.

Lindeman’s long experience as director of Kansas’ in-service training for early childhood special educators and Horn’s national recognition for curriculum development as an expert in pre-service personnel preparation in early childhood and special education, should serve them well in working with professional counterparts and agencies in targeted states.

Lindeman said that what they’ll learn from the center’s work should have an even broader impact. “We hope that what we find out can help with personnel training and systems for early educators working with typical kids, too.”

Funding: U.S. Department of Education
BETTY HART, 1927-2012

Associate Professor Emeritus Betty Hart died on September 28, 2012, at the age of 85. The modest and unassuming Hart was a meticulous scientist who was catapulted to fame as co-author of *Meaningful Differences*, the seminal study on early experience and language acquisition by children at home that showed a stunning 30-million-word difference between the number of words children from the least and most affluent homes heard by age 3. She tirelessly pursued her research interests even after retirement and was working on her latest book up to the night before her death.

LSI BY THE NUMBERS

Collaboration

LSI is an inherently collaborative organization. Of the currently funded research projects within LSI, 87 percent are attributable to collaborations among multiple investigators. Nearly one in four (23 percent) of LSI awards involve collaborations across the Lawrence and KU Medical Center campuses. These projects involve partners in the departments of Pediatrics, Molecular and Integrative Physiology, Dieterics and Nutrition, the Hoglund Brain Imaging Center, the Center for Child Health and Development, the School of Medicine and the Landon Center on Aging.

Furthermore, 37 percent of LSI awards involve collaborations beyond KU. Our partners include:

Other universities and medical centers
Arizona State University
Australian National University
Brigham Young University
Columbia University
Drake University
Florida State University
Lehigh University
Ohio State University
Oregon Health Sciences University
Tulane University
University of Connecticut Health Center
University of Indiana
University of Massachusetts Medical Center
University of Minnesota
University of Montana
University of Nebraska Medical Center
University of New Hampshire
University of New Mexico
University of North Carolina – Chapel Hill
University of North Carolina – Charlotte
University of Oregon
University of South Carolina
University of South Florida
University of Texas Health Sciences Center
Vanderbilt University
Washington University of Saint Louis

Free-standing research entities
Dynamic Measurement Group
Kennedy Kreiger Research Institute
Oregon Research Institute

Regional hospitals
Overland Park Regional Medical Center
Stormont Vail Regional Hospital

State agencies
Kansas Department of Health and Environment

Non-profit organizations
Council of Chief State School Officers
Maryland Coalition for Inclusive Education
National Association of State Directors of Special Education
TASH

Project Topics And Types

The breadth of topics covered by Life Span Institute projects during FY2012-13 is shown in this figure. In keeping with our history, the largest number of projects involve intellectual and developmental disabilities (autism, Fragile X, Down Syndrome and other conditions), but the table also reflects other strengths of the Institute in language, community health, infancy/early childhood and disability policy and service.

This figure shows the distribution of the types of projects in the LSI portfolio. The plurality of projects involve interventions and clinical trials designed to address or ameliorate existing human conditions while a good proportion of projects are devoted to prevention that seeks to keep disadvantageous conditions from developing in various populations. A growing proportion of projects are involved in basic discovery—those projects that seek clues about the underlying causes or strive to develop a complete description of the symptoms and correlates of various conditions or disorders. These research projects are complemented by activities designed to provide direct services to people in the state and nation, by those that bring scientists together in centers devoted to particular research emphases and projects that train the next generation of scientists.
Funding

LSI had a strong bounce-back year, attaining a total $29.5 million in 2013*, a $5.5 million (23 percent) increase in external awards over 2012. This total exceeds the external awards generated in our previous record-high year of 2011, when funds from the 2009-2011 ARRA (American Recovery and Reinvestment Act of 2009) program are excluded. LSI saw 27 new awards, and coupled with the continuation of previous awards, held a total of 93 awards. As in 2012, the majority of external awards came from the U.S. Department of Education.

Federal awards still account for the vast majority (77 percent) of LSI awards. Funding from the National Institutes of Health dropped from $7.7 million to $6.4 million with 30 awards (seven of which were new); awards from the U.S. Department of Education increased from $9.8 million to $14.7 million with 27 total awards (six new). Another $1.4 million was generated in awards from the U.S. Department of Health and Human Services with nine awards (five of which were new).

State of Kansas contracts increased from $3.5 million to $5.5 million this past year with 15 awards, two of which were new. Finally, awards from foundation/industry sources remained level with $1.3 million from 12 awards (six new).

Although the number of awards to LSI is decreasing, we are seeing a clear trend toward increased award totals. Over the past ten years, the average total annual award has increased from $185 thousand per project to $316 thousand per project, an increase of more than 70 percent per project. The average indirect costs generated by awards has also increased from $32 thousand per award to $49 thousand.

LSI continues to leverage external funding at an impressive rate. In 1990, LSI returned $3.30 on every dollar the state of Kansas invested in the Institute. In 2013, every state of Kansas dollar invested in LSI yielded $7.28 in external awards.

* This year, in keeping with University of Kansas Center for Research, Inc. policy, funding amounts are reported without reference to ARRA funds that were awarded from 2008-2013.
ATK annually hosts an AT Conference and EXPO that brings approximately 90 vendors from 13 different states to Kansas to showcase the latest technology. In addition to being able to see and try out the newest technologies, more than 700 attendees will gain new ideas and develop skills in the field of assistive technology.

The Kansas In-service Training System (KITS), the state’s in-service training program for early childhood special education professionals, provided training and technical assistance for all early intervention and early childhood special education programs in all counties of the state. This training reached 16,586 teachers and related service providers, administrators, and family members.

KITS held its 20th Annual Summer Institute that focuses on recommended practices in early intervention and early childhood special education. Participants enroll for college credit from any of six participating universities in Kansas.

Faculty from the LSI/Lawrence and LSI/Parsons are currently working together in the identification of standards for personnel development in early childhood and linking those standards to professional organizations standards with an outcome of supporting states’ professional development plans and aligning pre-service and in-service programs. KU is one of four partnering universities in this National Early Childhood Personnel Center.

LSI/Parsons staff are currently working with the Kansas Department of Education to develop a framework for the establishment of a statewide early childhood data management system.

LSI/Parsons staff are currently working with the KU Department of Social Welfare to develop strategies for early identification and studying the benefits of intervening to reduce the effects of toxic stress on young children and families.

LSI/Parsons, Lawrence, and KU Medical Center researchers are studying the effects of propranolol in reducing self-injury and aggression induced by activity transitions in children with autism spectrum disorder. Propranolol is a blood pressure and heart rate controlling drug that also has anti-anxiety effects.

Many children with hearing impairments and other disabilities require numerous teaching sessions to learn to respond to the tones used in hearing evaluations. The time required for this training is seldom available in the audiology clinic. A newly funded project from the Office of Special Education Programs will develop training procedures to prepare children for testing before they arrive at the clinic.

LSI/Parsons researchers are collaborating with investigators at Johns Hopkins University and University of Massachusetts Medical Center on an NIH-funded research program designed to understand and develop level treatments for self-injurious and aggressive behavior in individuals with developmental disabilities.

LSI/Parsons researchers are collaborating with LSI/Lawrence researchers in a study combining behavioral and neuroscience methods to understand the mechanisms by which transitions between activities elicit problem behaviors in young children with autism spectrum disorder.

LSI/Parsons and LSI/Lawrence researchers are collaborating on translational research to develop a novel animal model of aggression and disruptive behaviors seen in persons with autism and other developmental disabilities. They are currently examining medications such as benzodiazepines (e.g., Valium) with known behavioral effects to better understand the neurobehavioral mechanisms of the model.

Due to the program’s success in 12 counties in southeast Kansas, the Family Care Treatment Project will be expanded statewide through training to Kansas’ new mental health resource hubs. This program supports parents and caregivers of children with disruptive behaviors by providing an individualized, consumer-driven, and home-based service.

Juniper Gardens Children’s Project 1964

The Juniper Gardens Children’s Project (JGCP) began in 1964 when citizens from northeast Kansas City, Kansas, joined with faculty from the University of Kansas to devise solutions to specific problems in educational achievement and parenting in that low-income community. The JGCP has grown over the years from a small, community-based research initiative housed in the basement of a liquor store to a unique, internationally recognized research center which includes local and national community sites in projects and investigations housed at the Children’s Campus of Kansas City, four blocks from where it began. The Children’s Campus of Kansas City is a joint community initiative in Kansas City, Kansas—an effort that the JGCP has been supporting for the past decade. The JGCP is particularly recognized for its contributions to the development of effective approaches for accelerating learning and reducing classroom conduct problems in both special and general education. In 1996, the JGCP was awarded the Research Award of the International Council for Exceptional Children in recognition of its outstanding research contributions.

Charles R. Greenwood, Ph.D., Director
Debra Kamps, Ph.D., Associate Director
Barbara Terry, Ph.D., Director of Community Relations

Contact: 913 321-3143, jgcp.ku.edu

FY 2012-2013 Highlights

Awards/Honors

Jenne Bryant, JGCP Finance and Administration received the January KU Employee of the Month award
Mary Abbott, Judith Carta, Kathleen Baggett, Charles Greenwood, Debra Kamps, Maura Linas and Dale Walker received 2012 KU Leading Light Awards for Research Accomplishment
Kathleen Baggett received two competitive renewal awards from the National Institutes of Health Loan Repayment Program for Clinical Scientists

Key Areas of Mission

Interventions Supporting Child Development

Promoting Language and Communication

Kathy Thiemann-Bourque received a $1.2 million grant from the National Institute on Deafness and Other Communication Disorders, Communication Intervention for Preschoolers Learning to use AAC (CI-PAAC) to develop and investigate the effects of an iPad voice output app to determine whether the technology can improve the deficits in communication, social reciprocity and play skills that are typical of children on the autism spectrum.

Kathleen Baggett and colleagues received a $3.5 million grant from the U.S. Department of Education to test the effects of a parent mediated intervention for children with autism that directly targets foundational pre-verbal social communication
competencies from within the parent-child relationship prior to child age of 30 months.

Web-Based Parenting Intervention for Mothers of Infants At Risk for Maltreatment
Kathleen Baggett and colleagues completed the third year of a multi-site, randomized control trial, funded by the National Institute of Health, to test the effects of web-based program for improving parenting among English and Spanish-speaking parents of infants at risk for child maltreatment. Key findings to date include high parent engagement and program completion as compared to traditional home visiting programs. Effects of the program on parent responsiveness and infant social-emotional engagement with their mothers will be examined during the final year of the grant.

Center for Promoting Language & Literacy Readiness in Early Childhood: Model Demonstration Center
Dale Walker, Kathryn Bigelow, Jane Atwater and colleagues conducted a series of studies documenting the use of naturalistic communication interventions by parents and early educators to promote the communication of infants and toddlers. This group is translating language intervention research with infants and toddlers with special needs into practice so that it can be readily used by parents, teachers and interventionists in homes and community-based early education programs. This work was reported in the 2012 Winter KITS Kansas Inservice Training Service Newsletter.

The Effects of Online Decision Making Support (The MOD) For Home Visitors Using An RTI Approach To Promoting The Language Development Of At-Risk Infants And Toddlers
Jay Buzhardt, Dale Walker and Charles Greenwood are investigating the effects of online decision-making support (the MOD) for home visitors using a Response to Intervention approach to promote the language development of at-risk infants and toddlers in a randomized trial funded by the National Special Education Center at IES involving eleven Early Head Start centers in Kansas, Ohio, Iowa and Minnesota. Last year they trained and certified more than 100 home visitors in these states to use the Early Communication Indicator (ECI) to monitor children's communication outcomes. To date these home visitors have administered 578 ECI assessments to 352 children.

Project Engage: Building Parents’ Capacity to Improve Child Language Outcomes
Kathy Bigelow and Dale Walker received a three-year, $900,000 grant from the Health Resources and Services Administration, as part of the Maternal, Infant, and Early Childhood Home Visiting research program to examine how cellular phones can enhance parent engagement and use of naturalistic communication promoting strategies in Early Head Start home visiting programs. The research team will collaborate with Early Head Start home-based programs in Wyandotte and Montgomery counties in Kansas that will recruit 180 families to participate in Project Engage.

Promoting Parent-Child Interaction
Connie Beecher, a current JGCP post-doctoral associate, along with Jay Buzhardt and Judy Carta, will develop a mobile app for teachers and families of preschool children to facilitate richer communication between teachers and family members about activities at school and home, particularly those related to the child’s curriculum, with the ultimate goal of improving students and parents school readiness. The project is funded by the Schumaker Family Foundation.

Preventing Maltreatment
Judith Carta, Kathryn Bigelow and colleagues found that in a randomized trial, mothers who received a cell phone-enhanced parenting intervention used their newly learned parenting strategies more often, had reduced depression and stress and their children were more likely to engage in positive behaviors than control groups. (Pediatrics, in press).

Strategies for School Success
Promoting Early Reading and Writing
Charles Greenwood, Judith Carta, Jane Atwater and colleagues: Tier 2 and 3 language and early literacy interventions for preschoolers with weak and very weak skills developed by the Center for Response to Intervention in Early Childhood are moving from development to efficacy stage research. Initial reports were published in the Journal of Early Intervention, Topics in Early Childhood Special Education and are in review at Early Childhood Research Quarterly.

Peer Networks Intervention: Improving Social Communication, Literacy and Adaptive Behaviors for Young Children with Autism Spectrum Disorder
Debra Kamps, Linda Heitzman-Powell, Kathy Thiemann-Bourque: The Autism Peer Networks Project randomized trial provided essential social and reading interventions to 50 kindergarten and first grade children with autism in 13 school districts and 51 interventionists in Kansas, Missouri and Washington State. More than 350 peers have participated in social networks and 100+ peers participated in reading networks with their classmates with autism. More than 150 school staff were trained to implement Peer Networks with high fidelity. Children with autism showed steady improvements in social communication with peers and teachers rated social skills as significantly improved. Most students showed steady reading gains and teachers' feedback was generally positive about the Literacy Peer Network groups.

Debra Kamps, Kathy Thiemann-Bourque, Linda Heitzman-Powell, Schwartz, and colleagues reported that a Social Peer Networks intervention used by a randomized sample of children with autism who participated with typically developing classmates three times per week had significantly higher ratings on social and communication skills by kindergarten and first grade teachers than children in a comparison group and showed significant increases in social communication with peers over time. (Journal of Autism and Developmental Disorders, under review).

Social and Behavioral Context for Academic Learning
Preventing School Conduct Problems: A Multi-Site Efficacy Trial of the Class-wide Function-related Intervention Teams “CW-FIT”- A Research-to-Practice Agenda for Students with and At Risk for Emotional and Behavioral Disorders
Howard Wills, Debra Kamps: CW-FIT is the second efficacy trial of this group contingency intervention for which KU is collaborating with Vanderbilt and Brigham Young Universities. Year 1 was recently completed with five elementary schools in three states: Florida, Missouri and Pennsylvania. The CW-FIT intervention classes improved on-task behavior; on-task behavior increased for students with social and behavioral disorders (SBD) and disruptive behaviors decreased dramatically for the CW-FIT students.

Kamps and Wills reported that when a randomized sample of teachers used CW-FIT, class-wide and student-level on-task behavior significantly increased, as did teacher praise, and disruptive behaviors by students at risk for SBD decreased. (Journal of School Psychology, under review).

I-Connect: Solutions for Self-management and Support Connections for High School Students with Learning or Emotional/Behavioral Disorders
Howard Wills and Benjamin Mason have developed and tested an application for high-school students with disabilities to monitor their engagement in class using cell phones or tablets and have three studies demonstrating strong outcomes currently under review www.iwillgraduate.org.

Professional Development and Technical Assistance that Achieves Implementation of Evidence-based Practices
Development of Distance (Deaf-Blind) Mentorship Program to Improve Services for Children with Deaf-Blindness (DMP)
Jay Buzhardt and Jean Ann Summers (Beach Center on Disability) continued their development and evaluation of the Distance Mentorship Program (DMP), a model for providing distance coaching and technical assistance for teachers working with students with Deaf-Blindness. Working with the National Consortium on Deaf-Blindness and the Kansas State School for the Blind, they are developing tools (e.g., web-based wikis) to facilitate ongoing distance collaboration between teachers, coaches, and family for live distance consultation and a guide to support replication of the DMP. Through the efforts of Sunday Dove and Susan Higgins, they recently completed development of 12 online modules and assessments for teachers (see training distance mentoring.org).

Linda Heitzman-Powell and Jay Buzhardt are evaluating an adaption of the existing OASIS training program for use with Hispanic families. Findings from their research indicates overall increases in parent knowledge and skill fluency using behavioral techniques with their child (Focus on Autism and Other Developmental Disabilities, 2013; in press.) The group’s video poster, Longitudinal Evaluation of the OASIS Distance Training Program for Parents of Children with Autism in Geographically Remote Areas, is being used as a model on the Association for Behavior Analysis’s website.

Child Care Provider Web
Kathleen Baggett and colleagues recently completed a development and pilot study funded by the NIH to test the effects of a web-based professional development program for strengthening teacher sensitivity and responsiveness. Results showed high teacher engagement and program completion as well as significant post-program improvement in teacher knowledge of infant social-emotional development and strategies for promoting it. Teachers also showed significant improvement in responsive behaviors toward infants during classroom-based interactions and infants showed significant increases in social engagement with their teachers in the classroom.

Kansas Maternal, Infant and Early Childhood Home Visiting Program
Kathryn Bigelow and Dale Walker: A provision of the federal Maternal, Infant and Early Childhood Home Visiting Program to examine how cellular phones or tablets and have three studies demonstrating strong outcomes currently under review www.iwillgraduate.org.

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National Research and Development Center on Serious Behavior Disorders at the Secondary Level (CARS)
Howard Wills, Debra Kamps and Wendy Iwazuk have examined high school interventions for students at-risk of dropping out as partners in the Center for Adolescent Research in Schools (www.ies-cars.org) and among their findings have demonstrated the effects of strong mentors on students classroom success.

Advancing Measurement and Technology for Intervention
Work was completed on preschool classroom observational software (CIRCLE) for tablet devices enabling unobtrusive teacher and student observation.

Refinements to the Infant-Toddler IGDI (Indicators of Individual Growth and Development for Infants and Toddlers) website to support greater scalability and usability. Improvements included updated norms for the Early Communication Indicator.

Greenwood, Walker, Buzhardt and colleagues reported that the key skill trajectories in the Early Communication Indicator reflect a continuum of foundation skills and that the measure used in two different samples of Early Head Start children produced equivalent estimates that further enhance the validity of the measure (Early Childhood Research Quarterly, 2012; in press).

Research Preparation
20 graduate students were mentored and received support.

Four IES supported Post-doctoral associates are working to complete research training at JGCP.

Kansas Intellectual and Developmental Disabilities Research Center 1967
The Kansas Intellectual and Developmental Disabilities Research Center (KIDDRC) has been funded by the National Institute of Health and Human Development for the past 45 years. Throughout its history, the KIDDRC has played a major role in elucidating the causes, prevention and treatment of intellectual disabilities and related secondary conditions. The center brings together researchers from the KU-Lawrence and Kansas University Medical Center campuses, as well as from the Juniper Gardens Children’s Project at the Children’s Campus of Kansas City. Over the past four decades, the KIDDRC has served as a model of interdisciplinary collaboration across campuses and disciplines. More than 80 percent of KIDDRC investigators collaborate with one another on funded projects, and half of these represent collaborations across the three Center sites. Another 30 percent of KIDDRC investigators collaborate with investigators at other IDDRCs at Vanderbilt, UNC-Chapel Hill, the University of Washington, the University of Wisconsin, Washington University of St. Louis, and Johns Hopkins University/ Kennedy Krieger.

John Colombo, Ph.D., Director
Peter Smith, Ph.D., Co-Director
Contact: 785 864-4295, kiddrk.kumc.edu
FY 2012–2013 Highlights
KIDDRC Director John Colombo and KIDDRC member Susan Carlson reported results from their ten-year clinical study of prenatal DHA supplementation in the American Journal of Clinical Nutrition, showing that supplementing pregnant women with 600 mg of DHA a day for their entire pregnancies, resulted in a significantly longer gestation and higher birth weight, both of which have implications for improving neurodevelopment outcomes as well as preventing hospitalizations for preterm birth and resulting medical cost savings.

KIDDRC Co-Director Peter Smith and colleagues, including KIDDRC member Hinrich Staecker, published in the January 2013 Journal of Neuroscience that bone morphogenetic protein 4 (BMP4) is a critical mediator of adult physiological plasticity as well. Altered BMP4 expression may therefore contribute to sensory hyperinnervation, a hallmark of several pain disorders, including vulvodynia.

Paul Cheney, and former KIDDRC co-director, was invested as the recipient of the Kathleen M. Osborn Chair in Molecular and Integrative Physiology September 26 at the KU Medical Center. Cheney’s research interests encompass brain mechanisms underlying the control of voluntary movements, and recovery of motor function following brain injury.

Mabel Rice’s invited keynote address to the Speech Pathology Australia National Conference was published in the 2013 International Journal of Speech-Language Pathology. The paper elaborated on the need for new developmental perspectives to inform language interventions and highlighted the potential contribution of epigenetic approaches.

Steven Walker was a principal investigator for research and graduate student studies and former KIDDRC and Life Span Institute director, was named the 2013 Edgar Doll Award winner by the Awards Committee of Division 33 of the American Psychological Association. The Doll Award is the Division’s highest recognition of outstanding scientific contributions to the field of intellectual and developmental disabilities.

Kathryn (Kate) Saunders, senior scientist at the Life Span Institute at Parsons, was appointed Fellow of the Association for Behavior Analysis International’s (ABAI) and recognized at the 39th Annual Convention in Minneapolis on May 27. The Fellow designation recognizes the outstanding contributions of the ABAI’s most distinguished members and cited her research on stimulus control that has contributed substantially to individuals with intellectual disabilities.

Kansas University Center on Developmental Disabilities 1973
Forty years ago, as the Life Span Institute’s research on developmental disabilities took root, efforts began to translate this research into practice through what is now known as the Kansas University Center on Developmental Disabilities (KUCDD). Virtually all of the Life Span Institute’s direct service, technical assistance and post-doctoral, pre- and in-service training are associated with the KUCDD. These clinics include clinics to diagnose and treat children with disabilities, a statewide project that provides assistance to people with disabilities and their families, and training childcare providers and social workers to support individuals with disabilities. In addition, investigators affiliated with the KUCDD conduct research that has state, national and international impact in areas like self-determination, positive behavior supports, inclusive educational practices, early childhood education, community and workplace supports, family systems and supports and other areas critical to the lives of people with developmental disabilities and their families.

Michael L. Wehmeyer, Ph.D., Executive Director
Karrie A. Shogren, Ph.D., Associate Director
Glen White, Ph.D., Associate Director
G. Denise Lance, Ph.D., Consumer Activities Coordinator
R. Matthew Reese, Director, KUCDD-Kansas City Site and KUMC Center for Child Health and Development
David Lindeman, Ph.D., Director, KUCDD-Parsons Site

FY 2012–2013 Highlights
Faculty at the Center for Child Health and Development (CHCD) at the University of Kansas Medical Center, affiliated with the KUCDD-Kansas City site, provided early identification and intervention development through health care screening and evaluation of autism diagnosis and screening to 150 families and children throughout Kansas via the Autism Referral Evaluation Telemedicine clinics. The mean distance from KUMC that families lived and were served over telemedicine was 180 miles. Through the Rural Outreach Clinics operated by the CHCD and the Kansas Children with Special Health Care Needs project, the KUCDD Kansas City site faculty provided rural outreach clinics in five communities, serving more than 60 families who would not otherwise have had access to such services.

Faculty at KUCDD engaged in activities to train Certified Employment Support Professionals to meet the need to support people with disabilities to get and retain meaningful jobs, resulting in 500 people certified. Further, KUCDD faculty disseminated information about Employment First policies and practices to more than 3,200 people nationwide.
The Research and Training Center on Independent Living 1980

The Research and Training Center on Independent Living (RTC/IL) has a more than 30-year history of conducting disability research, providing training and transferring knowledge to practice. The Center furthers independent living for people with disabilities through the use of scientifically sound, theoretically driven sustainable interventions and measures that lead to effective community living solutions and policy change. Center researchers work closely with consumers and service providers to develop research and products that address their critical needs. The Center also partners with other universities and agencies to design and implement projects that improve the health and participation of people with disabilities in the community.

Glen W. White, Ph.D., Director
Contact: 785 864-4095, rtcil.org

FY 2012–13 Highlights

The Research and Training Center on Community Living (RTC/CL) hosted an innovative Bridging Meeting to build connections between researchers, practitioners, and federal policymakers who are involved in community living for people with disabilities. The meeting represented a new approach to knowledge translation by bringing stakeholders together while the center’s work is still in process rather than waiting until all projects are completed. Presenters used a novel six-minute presentation technique that KU has also used in interdisciplinary research sharing sessions.

An infographic and two fact sheets produced by the RTC/CL were submitted to the U.S. Senate committee on Health, Education, Labor, and Pensions by the National Institute on Disability and Rehabilitation Research, which funds the KU research center. The lawmakers had requested examples of succinct and easily understandable knowledge translation materials.

A free training for college students with disabilities is now available online. The project was funded by a grant from the National Institute on Disability and Rehabilitation Research. Glen White, Jean Ann Summers, Leslie Schnnille and Alice Zhang created Access to Success (www.access2success.ku.edu) to improve students’ self-advocacy skills and knowledge about their legal rights and responsibilities under the Americans with Disabilities Act.

Center staff have published and presented their research at national and local conferences, including these highlights:

- Glen White published “Participatory Action Research Designs in Applied Disability and Rehabilitation Science: Protecting Against Threats to Social Validity” (with Tom Seekins) in Archives of Physical Medicine and Rehabilitation. White discussed his continuing work in Peru with people with disabilities at the State of the Science of Prevention and Management of Secondary Health Conditions in People after Spinal Cord Injury. As part of his service on Delta Air Lines’ Advisory Board on Disability, White presented a keynote address on “Disability and Cultural Competence” at a Delta vendor meeting.
- Amanda Reichard published “Using population-based data to examine preventive services by disability type among dually eligible (Medicare/Medicaid) adults” (with Michael Fox) in Disability and Health Journal. She made two poster presentations at the American Public Health Association conference, one on Multiple Chronic Conditions and Health Disparities among People with Disabilities Compared to People without Disabilities, the other on Weight Loss Intervention for Adults with Physical Disabilities. Reichard also presented her work at KU’s Red Hot Research interdisciplinary sharing sessions, where she distinguished disability from chronic disease and emphasized that people with disabilities can be healthy.
- Amalia Monroe-Gulick, Megan O’Brien and Glen White published “Librarians as Partners: Moving from Research Supporters to Research Partners” in the Association of College and Research Libraries annual conference proceedings. Monroe-Gulick and O’Brien also presented in the Embedded Librarian Series for the University of Kansas Libraries staff, discussing their collaboration on two systematic scoping reviews for the RTC/CL.

Dorothy Nary presented her research on the impact of in-visit able homes on wheelchair users at three KU events. For the Red Hot Research interdisciplinary forum, she spoke on Accessibility and Social Connectedness: The Problem with U.S. Housing Stock. She presented In-Visit able Homes: How They Complicate Aging in Place to the Gerontology Faculty Colloquium, and made a public presentation on the same topic as part of the Community Conversation series sponsored by the Life Span Institute.

Center staff have also provided service and received awards for their work:
- Glen White is chair of the Kansas Rehabilitation Services (KRS) Council, which advises KRS on development of the State’s rehabilitation plan. He was elected as Secretary of the United States International Council on Disabilities, and is now Chair of Delta Air Lines’ National Advisory Board on Disability.
- Martha Hodgesmith has been appointed to the Aging and Disability Resource Centers Advisory Council in Kansas. The ADRCs in Kansas contract with the Area Agencies on Aging to coordinate services and provide assessment, information, case management and numerous other services for seniors and people with disabilities in all 105 counties of Kansas.
- Amanda Reichard is serving on a National Institutes of Health Expert Panel on Adults with Chronic Health Care Needs, whose purpose is to provide the field with a new focal point for measurement, surveillance and service.
- Dorothy Nary received KU’s Ann Eversole Advisor of the Year Award in Apr. 2013 from the Student Involvement Leadership Center. The award recognizes her service as advisor to AbleHawks and Allies, a student group that raises awareness of disability issues at KU.
- The center hosted Kwancheol Koh as an International Visiting Scholar from Seoul, South Korea for 2012-13. Koh established the Korean Federation on Independent Living and was director of several centers for independent living (CILs) in South Korea. He has experience in developing, managing and overseeing peer counseling at Korean CILs. While in the U.S., he has been researching peer support systems.

Child Language Doctoral Program 1983

The Child Language Doctoral Program (CLP) was established in 1983 as the first specialized degree program in the emerging field of child language acquisition. The program focuses on the interdisciplinary academic preparation and research training of child language specialists. The internationally recognized faculty brings diverse approaches to the study of how children communicate and speak. The program offers students a wide choice of research tools, facilities and field sites including the Child Language Acquisition Studies Lab that has the largest known archive of transcribed spontaneous samples from a longitudinal study of preschool children diagnosed as specific language impaired (SLI). The Life Span Institute, the Language Acquisition Preschool and the clinical and research facilities of the Speech-Language-Hearing Clinic provide research sites and practice.

Mabel L. Rice, Ph.D., Director
Contact: 785 864-4570, clp.ku.edu

FY 2012–2013 Highlights

In 2013-14, the CLP will be searching to fill a new faculty position in the area of neuropsychology of language acquisition. Student progress in 2012-13 was strong. Yi-Chih Chan, Megan Blossom Prentice and Leah Kapa completed their Comprehensive Oral Exams for Doctorate. Leah Kapa also completed her Final Exam for Doctorate and will move to a post-doctoral position at the University of Arizona. Margaret Echelbarger completed her Master’s Exam/Thesis. Yi-Chih Chan is organizing the Child Language Proseminar series for the fall semester, 2013.

Beach Center on Disability 1988

Through excellence in research, training, technical assistance and public service in Kansas, the nation and the world, the Beach Center on Disability seeks to make a significant and sustainable difference in the quality of life of families and individuals affected by disability. Research focuses on access to the general curriculum, assistive technology, deaf-blindness, disability policy, employment, family supports and services in early childhood, family quality of life, individual control of funding, positive behavior support and self-determination. Founded in 1988 by KU Distinguished Professors Ann and Rud Turnbull, the Beach Center honors Ross and Marriana Beach for their long-standing efforts on behalf of families affected by disability and was inspired by the Turnbells’ son, Jay, who had several disabilities.

H. Rutherford Turnbull, III, L.I.B./J.D., L.L.M., Co-Director
Ann P. Turnbull, Ed.D., Co-Director
Michael L. Wehmeyer, Ph.D., Associate Director
Wayne Sailor, Ph.D., Associate Director
Jean Ann Summers, Ph.D., Associate Director
Contact: 785 864-7600, beachcenter.org

FY 2012–2013 Highlights

Published 38 peer-reviewed articles, 20 chapters, and six books.
Made 10 international presentations, 42 national presentations, and 17 state/local presentations.
Taught 10 courses.
Awarded a five-year, $24.5 million grant to develop a national center to assist schools nationally to implement a model for educating all students (e.g., students with needs for pervasive educational support, typical students, students who are gifted, students who are learning English as a second language) together in order to improve academic, behavioral, and social outcomes – Schoolwide Integrated Framework for Transformation – SWIFT (www.swiftschools.org).
Selected six exemplary inclusive schools from a national sample and conducted two rounds of research visits at each of the schools in order to document their successful administrative, instructional, and partnership strategies.
Conducted the inaugural SWIFT Professional Learning Institute for over 200 representatives from schools, districts, and states to launch technical assistance for the Schoolwide integrated Framework for Transformation.
Developed a plan to provide technical assistance in 64 schools across five states to integrate special education and general education resources to meet...
the academic, social, and behavioral needs of all students.

Provided intensive training to support effective co-teaching to Kansas educators in 32 schools across 14 districts.

Created effective training for intereners, who are para-educators assigned to help students who are deaf and blind, and developed online training and practicum supervision for para-educators assigned to support students who are deaf and blind.

Developed a model to support long-distance coaching for school teams serving students who experience deaf-blindness.

Completed data analysis and developed a Facilitator’s Manual for supporting teachers and families of preschool children with disabilities to work together to develop children’s self-regulation and engagement.

Received a new Institute for Educational Sciences project to develop a measure of self-determination for students with and without disabilities.

Published two studies establishing causal evidence for the impact of instruction to promote student self-determination on self-determination and positive school and adult-related outcomes.

Published research establishing the Self-Determined Learning Model of Instruction as an evidence-based practice to support youth with intellectual and developmental disabilities, as well as learning disabilities.

Documented that the Beyond High School model for youth with intellectual and developmental disabilities ages 18 to 21 promoted student involvement in transition planning and transition empowerment.

Developed three online modules, constituting approximately 20 hours of instruction, for early intervention practitioners which will be used throughout the 37 early intervention programs in Kansas.

Completed a policy analysis on family support for the Department of Defense that will potentially impact all military personnel on active, reserve, and National Guard duty who have family members with disabilities.

Mentored five graduate students to complete their dissertations and receive their Ph.D. with four of the students now employed at Research I universities.

Susan Palmer elected as national Vice-President of the American Association on Intellectual and Developmental Disabilities.

Wayne Sailor received the Gretchen and Gene Budig Distinguished Teaching Award from the School of Education.

Rud Turnbull and Mike Wehmeyer, respectively, received the 2012 and 2013 Distinguished Research Award from The Arc of the U.S.

Mike Wehmeyer inducted into Phi Beta Kappa as a distinguished alumnus at the University of Tulsa.


Work Group for Community Health and Development 1990

The mission of the KU Work Group is to promote community health and development through collaborative research, teaching and public service. Established in 1975, the KU Work Group joined the Life Span Institute as a distinct center in 1990. The Work Group has developed widely used capabilities for community-based participatory research (including its Online Documentation and Support System) and for building capacity for community work (including the Community Tool Box). Recognition of these capabilities led to official designation in 2004 as a World Health Organization Collaborating Centre. Stephen B. Fawcett, Ph.D., Director Jerry A. Schultz, Ph.D., Co-Director. Contact: 785.864.0533, http://communityhealth.ku.edu

FY 2012–2013 Highlights

The KU Work Group was selected to serve as the national evaluators for the Bristol-Myers Squibb Foundation’s Together on Diabetes initiative, a $100 million, five-year initiative targeting adults in the United States disproportionately affected by type 2 diabetes.

The KU Work Group and the Lawrence-Douglas County Health Department have launched an Academic Health Department, the first in Kansas and one of only a few in the country.

The KU Work Group continued work as a scientific partner in the Healthy Communities Study, a national study of childhood obesity prevention that involves over 275 communities. Funded by several NIH Institutes, the CDC and the Robert Wood Johnson Foundation, this five-year study is examining what works in community-level efforts to prevent childhood obesity.

The KU Work Group was funded by the CDC to expand the Latino Health for All Model to further address health disparities in Wyandotte County, Kan. This is one of ten Racial and Ethnic Approaches to Community Health (REACH) CORE programs in the nation.

The Community Tool Box garnered three national awards in 2013. The Division of the Civilian Volunteer Medical Reserve Corps awarded the Community Tool Box, http://ctb.ku.edu, with the Medical Corps Reserve Partnership Organization Award. The Society for Community Research and Action, Division 27 of the American Psychological Association awarded the Community Tool Box the John Kalafat Community Program Award for global contribution to the field and the Don Klein Publication Award to Advance Community Psychology Practice 2013 Award. The Community Tool Box now reaches more than 3.4 million unique visitors annually in 231 countries around the world.

The University of Kansas’ Work Group for Community Health and Development has been redesignated as an official World Health Organization Collaborating Centre for Community Health and Development for another four years. The WHO Centre will continue its work with WHO Regional Offices (e.g., in the Americas, Africa) to expand the evidence base and build capacity for collaborative action to promote health and health equity.

The Merrill Advanced Studies Center 1990

The Merrill Advanced Studies Center, established in 1990 with an endowment from Virginia Urban Merrill and Fred Merrill, is a catalyst for scholarship on disabilities and policies that shape university research. Merrill conferences and publications establish new directions and build collaborative projects in both science and policy. World-class experts often meet as a group for the first time at Merrill conferences and go on to develop national projects that answer key questions in science. The Center publishes books on topics relevant to developmental disabilities and makes policy papers available online and in print. The Merrill web site at KU has fact sheets and discussions on science and policy for the general public.

Mabel L. Rice, Ph.D., Director Contact: 785.864.4570, merrill.ku.edu

FY 2012–2013 Highlights

The 17th annual Merrill Research Retreat was held July 17-19, 2013, at the Lied Lodge and Conference Center, Neb., on the theme Planning for Research Excellence in the Era of Analytics. There were 21 participants at the invitation-only conference, including keynote speaker Dr. Joseph deNeffe, Executive Vice President and Provost, The Ohio State University; KU Vice Chancellor for Research and Graduate Studies Steven Warren and research officers and researchers from the University of Kansas, University of Kansas Medical Center, Kansas State University, Iowa State University, the University of Nebraska-Lincoln and the University of Missouri. A white paper from the 16th annual Research Retreat, on the topic of Information Systems Infrastructure for University Research Now and in the Future was published and posted to the web site of the Merrill Advanced Studies Center: http://www2.ku.edu/~masc/PDFfiles/2012whitepaper.pdf

Gerontology Center 1990

The Gerontology Center’s affiliation with the Bureau of Child Research in 1990 paved the way for an extended research agenda of the newly formed Life Span Institute. Center researchers are interested in all areas of aging but are distinguished by seminal research in cognition, communication and aging, long-term health care and housing alternatives and decision making in later life. The Center coordinates a multidisciplinary graduate program that offers both masters and doctoral degrees in gerontology, as well as dual-title doctoral degrees that combine training in gerontology with certain social and behavioral sciences.

David J. Ekerdt, Ph.D., Director Contact: 785 864-4130, gerontology.ku.edu/

FY 2012–2013 Highlights

The Center is hosting three Strategic Initiative Grants (Level II), which are intramural investments to enhance KU’s research capability. One is led by Keith Diz Moore, Resilient Lifestyles for Older Adults: Seeding a Center on Sustainable Longevity. David Johnson is leading Neuroimaging of TBI-associated Alzheimer’s Disease in the KU Wounded Warrior Program. Dennis Domer, along with Susan Kemper and David Ekerdt, is conducting the I-70 Interdisciplinary Aging Research Network among regional universities. All of these strategic initiative projects involve faculty members from the KU and KUMC campuses and will lead to the submission of multiple research grant proposals.

David Johnson was funded for an NIH Fogarty International Research Grant to extend the clinical research infrastructure of the University of Kansas’ Alzheimer and Memory Program to the Costa Rican healthcare system and build Costa Rican clinical research expertise for the assessment and treatment of Alzheimer’s disease.

Ellen Rozek successfully defended her dissertation to become the first KU student awarded a dual-title Ph.D. degree in Psychology and Gerontology. Dr. Rozek conducted her research on the effects of loneliness on executive function in young and older adults. She has taken a tenure-track position at the University of Wisconsin-La Crosse.

David Ekerdt is one of an international team of six sociologists and psychologists funded by the Volkswagen Foundation to study cultural differences in the way that older people engage with the future. This three-year project will use mixed methods to compare people’s conception of Blogging and time in Germany, Hong Kong, and the U.S.

The Center organized an event for the Bold Aspirations Visitor and Lecture Series, which is
supported by the Office of the Provost and features presentations on KU’s strategic initiative themes by eminent guests. Anne Basting, Professor of Theatre at the University of Wisconsin-Milwaukee, promoted the potential of the arts and humanities for improving the quality of later life and for inspiring gerontological research.

Biobehavioral Neurosciences in Communication Disorders Center 2002

The Center for Biobehavioral Neurosciences in Communication Disorders (BNCND) was founded in 2002 when the National Institute on Deafness and Other Communication Disorders awarded a core grant to establish the center. The BNCND is a natural outgrowth of the Life Span Institute’s long-standing focus on communication and language development and intervention. The BNCND’s research spans a wide range of issues relevant to the causes and treatment of communication disorders from infancy to old age including studies on infant attention, the genetics of communication disorders from infancy to old age, and early autism intervention services. This past year, the Autism Training Program trained 151 individuals, now totaling more than 465 trained since the inception.

The Kansas Center for Autism Research and Training 2008

The Kansas Center for Autism Research and Training (K-CART), 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.

The Center for Biobehavioral Neurosciences in Communication Disorders

Mabel L. Rice, Ph.D., Director

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FY 2012-2013 Highlights

Eighteen investigators are affiliated with the BNCND with research interests which include the underlying biological and genetic bases of speech, language, and hearing disorders, and the decline in working memory in old age as reflected in speech and more precise measures of hearing loss to aid cochlear implant design.

The BNCND added a new investigator with an NIDCD-funded R01 award (Kathy Thiemann-Bourque) and two affiliated investigators with NIDCD-funded R03 awards (Jonathan Brumberg and Kostas Kokkinakis). Thiemann-Bourque is a behavioral scientist who carries out training studies of children using augmentative communication devices. Brumberg is a speech scientist who investigates how the brain controls speech movements. Kokkinakis is a hearing scientist who studies speech and sound perception in persons with cochlear implants. In addition, we invited another junior investigator to join the Center, Janet Choy-Hubbard, who is an unfunded entry-level assistant professor of SPLH with expertise in language disorders of persons with aphasia.

BNCND held its semi-annual meetings with investigators and Core personnel in fall 2012. Outreach newsletters are published by the PARC core three to four times annually, both in hard copy and on the BNCND website.

The Kansas Center for Autism Research and Training - 2008

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Debra Kamps, Ph.D. Director

R. Matthew Reeve, Ph.D., Co-Director

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FY 2012–2013 Highlights

K-CART continues to promote research and training on evidence-based practices by training professionals, practitioners and families to serve individuals with autism. K-CART sponsors: Pilot Studies: an internal research funding source for investigators to conduct initial studies to provide pilot data for grant applications. Ten projects have been funded in bio-behavioral assessments and interventions for persons with Autism Spectrum Disorders.

K-CART, in partnership with Johnson County Community College, hosts an annual conference: Beyond the Diagnosis: Autism Across the Life Span. More than 200 attendees registered for this conference every year to receive information directly from KU researchers and invited community experts.

The Autism Training Program: an intensive training program designed for individuals wanting to provide early autism intervention services. This past year, the Autism Training Program trained 151 individuals, now totaling more than 465 trained since the inception.

The Center for Child Health and Development (CHHD) provides important clinical evaluations, diagnostic and intervention services to children and youth with autism seen in 11 weekly clinics. The age of children seen in the research has recently transitioned into a clinical service at the Center for Child Health and Development at KU Medical Center.

Bridge Clinic: A first step in treatment for children recently diagnosed with autism. The clinic provides short-term behavioral intervention services until the child has the opportunity to begin services with a community provider.

Functional Analysis Clinic: A service designed to determine how environmental events may affect children’s challenging behaviors. The clinic develops personalized treatment plans to help reduce these behaviors and teaches parents how to interpret environmental cues and better implement behavior management strategies.

The Center for Child Health and Development (CHHD) provides important clinical evaluations, diagnostics and services. Under the guidance of Dr. Matt Reese, K-CART co-director, approximately 1,500 children are seen annually with more than 700 with autism seen in 11 weekly clinics. The age of diagnosis has been reduced at CCHD from 4.5 to 3.5 years of age in the last two years, dramatically increasing the likelihood of critical early intervention services. In 2012 the CCHD purchased the PLR 2000 pupillometer, a hand-held digital device that can be used to measure pupil size in clinical settings, as we have found in several studies for pupil size to distinguish children with ASD from controls. The incorporation of this device into the data that the CCHD is currently collecting will allow us to assess the clinical utility of this device and obtain prospective data. A K-CART Discovery Grant funded the initial research in pupil size that led to this clinical application.

Additionally, the CCHD has been developing its capacity to be a leader in bio-informatics for people with autism. Since 2009 the CCHD has been using the Comprehensive Research Information System (CRIS) to track all intakes into the CCHD. In 2010 a patient portal was implemented, allowing families to fill out their child’s diagnostic history on-line. This means that as of 2013 CCHD has a searchable database of more than 2400 patients, including more than 400 data items regarding medical and diagnostic history.

Centro Ann Sullivan del Perú 1990

Centro Ann Sullivan del Perú (CASP) is a nonprofit educational institution that serves children and adults with intellectual disabilities, autism and behavioral problems, as well as their families and professionals from Peru and other parts of the world. Under the direction of its founder, Liliana Mayo, Ph.D., CASP is recognized and honored worldwide for its contributions as a model research, demonstration and training center. Mayo has been supported by a steady stream of her KU colleagues who have volunteered as consultants, trainers, administrators and fundraisers; notably, Judith Le Blanc, who has served as CASP research director for more than 30 years, and retired Life Span Director Stephen Schroeder and Carolyn Schroeder. CASP has a formal agreement with the Life Span Institute and receives much of its staff education through unpaid faculty from the KU departments of Special Education and Applied Behavioral Science.

Liliana Mayo, Ph.D., Director

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FY 2012–2013 Highlights

CASP continues to educate more than 450 people with different abilities and their families. Teamwork between the staff and families continues to prepare students for inclusion and work in real jobs for real pay: more than 110 individuals currently hold positions in small and large companies, the Ministries of Health and Justice, universities and banks in Peru. More than 60 percent are the primary economic support for their families. One hundred student are included in 53 regular schools.

CASP continues to work with the Government of Panama that adopted the CASP model to teach children with different abilities in Panama. Panama now has a Centro Ann Sullivan de Panamá that was always the dream of the First Lady of Panamá, Martha Linares de Martínez.

CASP signed an agreement of cooperation with the Government of the Dominican Republic on the July 26, 2013. The First Lady of the Dominican Republic, Candida Montilla de Medina, went to Peru to sign this agreement with CASP. The President and First Lady of the Dominican Republic will be inaugurating the Center for Integral Services for the Children with Disabilities (CAID) that is the first center of its kind in the Dominican Republic. CASP will be training their staff and families.

The CASP online Long Distance Education Program produced 32 conferences between 2008 and 2013 for more than 25,450 parents and professionals in the 24 states of Peru and 15 countries: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Germany, Guatemala, Italy, México, Nicaragua, Panama, Spain, the U.S. and Peru.

A National Institutes of Health Fogarty International Research Program grant funded a very successful pilot study in which 262 infants and toddlers at risk for severe behavior disorders were screened and evaluated. The grant resulted in seven presentations at international meetings, four published papers and ten more are in progress.

Janet Marquis, Judith LeBlanc and the staff of CASP are developing a recording methodology for demonstrating the improvement of CASP students as well as for aggregating the longitudinal data for analysis.

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