

The Life Span Institute Annual Report 2011–2012

What we know Now

that we didn't know last year

KU THE UNIVERSITY OF
KANSAS
Life Span Institute

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 165 scientists who are affiliated with 20 academic departments to study human development from its genetic origins to the final stages of life through 135 research projects. These investigators are supported by 205 research and administrative staff members, including 48 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 post-doctoral 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. Dr. Schiefelbusch's 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.

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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 \$24 million in sponsored project support in FY 2011-12. Each state dollar brought in \$6.05 external dollars this fiscal year.

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From the Director

The Life Span Institute has long been an engine for intellectual progress in the behavioral and social sciences at KU, if not across the nation and the world. More than 20 years ago, former LSI Director Steve Schroeder emphasized the importance of behavior and environment in mediating gene expression and function. In the spring of this year, the Eunice Shriver National Institute of Child Health and Human Development convened a conference in Washington D.C. on the future of research in intellectual and developmental disabilities. As it turned out, gene-environment interactions and epigenetics took center stage. And, quite fittingly, Steve Schroeder was one of the keynote speakers.

In a word, progress is the theme of the 2011–12 LSI Annual Report. As this report so elegantly shows, we know much more today than we knew even one year ago, thanks to the efforts of LSI's scientists and staff. The yield of new knowledge represented here is a testament to the collaborative and interdisciplinary nature of the Institute, the breadth of its activities and the entrepreneurial spirit of the people who work here. Along with the feature articles that highlight specific projects, we've tried to tell this story in new and different ways in this report: we've included details on the different areas that our projects study, the types of activities that our projects cover (discovery, intervention/prevention, training, and service) and the extent to which our scientists collaborate within and beyond KU.

This report serves as a testament to how LSI continues to push the envelope and provide cutting-edge science and scholarship at KU. No matter how one chooses to measure it, the work done at LSI has tremendous impact within the scientific disciplines. Perhaps most importantly, the work here continues to make a difference in the lives of people all over the world.



John Colombo, Director
The Schiefelbusch Institute
for Life Span Studies

A handwritten signature in black ink that reads "John Colombo". The signature is written in a cursive style with a long horizontal line extending to the left.

A logo consisting of the numbers "365" in a stylized font. The "3" is blue, the "6" is white with a blue outline, and the "5" is yellow with a blue outline. A small blue dot is positioned below the "5".

What we know Now that we didn't know last year

Now we know that severe behavior disorders develop much earlier and in more complex ways

An international research team led by former Life Span Institute Director and Professor Emeritus Stephen Schroeder has found that severe behavior problems associated with neurodevelopmental disorders begin as young as four months and vary with age, diagnosis, gender, IQ, family income and education and other factors.

Schroeder and the interdisciplinary team of 15 researchers from KU, Texas Tech University, the Centers for Disease Control and Prevention and Peruvian colleagues at LSI's Centro Ann Sullivan del Perú conducted a study of the development of self-injurious behavior (SIB), aggression and stereotyped behavior among infants and toddlers in Peru.

"We haven't known a lot about how these behaviors develop so that we can decrease or eliminate the behaviors before they become deeply ingrained and intransigent in later life," Schroeder said.

This is one of the first such studies of its kind because of the young age of the 262 children (4-48 months, mean age 27 months) as well as the extensive evaluations they received under the guidance of the research team, including developmental-behavioral, genetic, nutrition and medical and social history.

Among the major findings to date:

More than 90 percent of the children exhibited some form of SIB, aggression, and stereotyped behavior at much earlier ages and in more complex patterns than previously known. Over half of them were already doing all of the behaviors by six months of age.

They also found interactions among age, diagnosis, gender, IQ and communication scores for the different aberrant behaviors. For instance, younger children with Down Syndrome and more stereotyped behaviors had lower IQs and tended to increase stereotyped behavior and SIB by the end of one year. But older children at risk for autism and more aggression tended to have higher IQs and mothers with more education and higher incomes. Their aggression decreased markedly over one year.

Schroeder and his colleagues are considering a long-term early intervention program to follow these children in Peru, as well a similar project to assess children of Hispanic and other ethnic origins in the U.S.

Funding: Eunice Kennedy Shriver National Institute of Child Health and Human Development and Fogarty International Center



Stephen R. Schroeder. Co-investigators on the project from KU: Nancy Brady, Merlin Butler, Janet Marquis, R. Matthew Reese. From Texas Tech University, David M. Richman; from Centro Ann Sullivan del Perú, Liliana Mayo-Ortega and Judith LeBlanc.

Now we know that pupil size and saliva measures might help doctors screen young children for autism spectrum disorders and may point to the brainstem being the seat of the disorder

The brainstem—the part of the brain that controls our most basic involuntary or autonomic responses including salivation and pupil response—is where researchers Christa Anderson and John Colombo are looking for biological characteristics and the neural basis of autism spectrum disorder.

They found two potential biological markers or biomarkers of ASD: larger resting pupil size and altered levels of a salivary enzyme associated with the neurotransmitter norepinephrine in children with the disorder.

The levels of the enzyme, salivary alpha-amylase (sAA) were higher in general across the day and much less variable for children with ASD compared to typically-developing children.



Christa Anderson, assistant research professor

“What this says is that the autonomic system of children with ASD is always on the same level,” said Anderson. “They are in overdrive.”

Collecting sAA levels with a small sponge swab under a child’s tongue and the measurement of pupil size are painless, non-invasive procedures that have the potential for pediatricians to screen children for ASD much earlier and with relatively little expense, said Anderson.

Beyond the exciting possibility of usefulness for early screening, the researchers see pupil size and sAA levels as possible physiological signatures of dysfunction in the autonomic nervous system.

“Many theories of autism propose that the disorder is due to deficits in higher-order brain areas,” said Colombo. “Our findings, however, suggest that the core deficits may lie in areas of the brain typically associated with more fundamental, vital functions.”

Both findings address the Centers for Disease Control’s urgent public health priority goals for ASD: to find biological indicators that can both help screen children earlier and lead to better understanding of how the nervous system develops and functions in the disorder.

Funding: National Institute of Mental Health and the Kansas Center for Autism Research and Training at the Life Span Institute

Now we know how to measure the communication of people with severe disabilities

Within weeks of a story in the *Advance for Speech-Language Pathologists and Audiologists* about a new communication scale for people with severe disabilities who use few or no spoken words, requests for the test came pouring in from clinicians across the country. The scale was developed by a team of researchers led by Nancy Brady that included Kandace Fleming, Kathy Thiemann-Bourque and Muriel Saunders at KU and researchers at the University of Washington. Within three months, the requests exceeded 300 including some from Australia, Canada and Turkey.

The Communications Complexity Scale (CCS) is a scale for researchers and clinicians to measure the communication development of children and adults with disabilities as diverse as autism spectrum disorders, deaf-blindness and cerebral palsy. The assessment is aimed at describing where an individual is on a communication continuum, which is helpful for initial assessment and monitoring intervention progress.

“Understanding the communication status of individuals with severe intellectual and developmental disabilities is difficult because they often communicate in ways that may not be readily recognized, even by clinicians,” said Brady.

The CCS is based on the well-established continuum of “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; and finally using “symbolic” communication—typically, spoken words. These developmental changes have also been documented for individuals with different types of disabilities, according to Brady, and were incorporated into the CCS.

“The CCS helps to quantify how an individual who might otherwise be described as untestable or nonverbal communicates with gestures, vocalizations and eye gaze,” said Brady. “These are important means of communication that need to be recognized and built upon in intervention.”

Brady says that the response by clinicians to the CCS speaks to the urgent need for better measures for the thousands of individuals who communicate nonverbally. Plans are underway to refine and improve the CSS further.

Funding: National Institutes of Health



Nancy Brady, assistant professor of speech, language, hearing sciences and disorders and associate research professor at the Life Span Institute. Other members of the University of Kansas team were Kandace Fleming, assistant scientist, Kathy Thiemann-Bourque, assistant research professor and Muriel Saunders, assistant research professor. The University of Washington team members were Lesley Olswang, professor of speech & hearing sciences and Patricia Dowden, clinical assistant professor of speech & hearing sciences.

Now we know more about differences in the immune system of children with autism

Among the LSI-affiliated researchers who made headway into understanding autism in the last year was a team that included geneticist and physician, Merlin Butler, who found differences in cytokines, the immune system's messengers and regulators, in children with autism disorder.



Merlin G. Butler, director, Division of Research; professor of psychiatry, behavioral sciences and pediatrics; ABMG certified clinical geneticist and clinical cytogeneticist, University of Kansas Medical Center

The researchers found that children with autistic disorder (AD) had lower plasma levels of several cytokines compared to those of children who had family members with autism spectrum disorders (ASD).

Both the immune system and genetic factors have been implicated in the biological basis for autism, Butler explained. "Our study further supports a disturbed immune system in children with classic autism that may be related to genetic factors, since cytokine proteins are coded by genes distributed among the human chromosomes."

Butler said that studies of families with autism have shown deletions and duplications of chromosomes and mutations or variants found in genes involved with brain development and function.

"The importance of identifying early immunological disturbances that may contribute to autism can potentially help us with identifying risk factors, diagnosis and possibly intervention, as cytokines may play a role in the function of the developing brain."

The study was one of the largest of its type so far, analyzing the plasma of 99 children with AD between five and ten years of age and that of 40 age and gender matched (unrelated) healthy siblings without AD.

Butler said that the direction of this research points toward linking the genes encoding immune-related proteins and cytokines to ASD along with identifying the sequence of events during critical periods of brain and neurological development.

Funding: Kansas Center for Autism Research and Training at the Life Span Institute and the Eunice Kennedy Shriver National Institute of Child Health and Human Development

Now we know that mothers who take DHA supplements while pregnant reduce the chances of their babies being born preterm and at a low birth weight

The first phase of a 10-year, double-blind randomized controlled trial to determine whether prenatal nutritional supplementation with the omega-3 fatty acid DHA benefits children's intelligence and school readiness has yielded results that greatly strengthen the case for the dietary supplement.

Infants whose mothers took 600 milligrams of DHA in the last half of gestation weighed more at birth and fewer of them were born before 34 weeks gestation than mothers who were given a placebo.

"A reduction in early preterm and very low birth weight delivery has clear clinical and public health significance," said Susan Carlson, who directed the study with John Colombo.

DHA (docosahexaenoic acid) occurs naturally in cell membranes with the highest levels in brain cells, but levels can be increased by diet or supplements. An infant obtains DHA from his or her mother in utero and postnatally from human milk, but the amount received depends upon the mother's DHA levels.

"U.S. women typically consume less DHA than women in most of the developed world," said Carlson.

The next phase of the study will continue to follow the children of the 350 mothers who were enrolled in the study during pregnancy. During the first five years of the study, all children received multiple developmental assessments through 18 months of age.

In the next five years, all children will receive twice-yearly assessments through six years of age. The researchers will measure developmental milestones that occur in later childhood and are linked to lifelong health and welfare.

Previous research has established the effects of postnatal feeding of DHA on infant cognitive and intellectual development, but DHA is accumulated most rapidly in the brain during pregnancy, said Colombo. "That's why we are so interested in the effects of DHA taken prenatally, because we will really be able to see how this nutrient affects development over the long term."

According to Carlson, the possibility that DHA may have long-term benefits for cognitive-intellectual development, particularly on measures that predict school achievement, would have enormous implications for public policy on prenatal nutrition.



John Colombo, Professor of Psychology and Director of the Life Span Institute and Susan Carlson, A. J. Rice Professor of Dietetics and Nutrition at the University of Kansas Medical Center.

Now we know more about children who get off to a good start in learning to read but begin to fall behind in later grades

Described as the “fourth-grade slump” by a researcher in 1983, there is relatively little known about those children who start out as apparently adequate or good readers, but begin to struggle in later grades.



Hugh Catts, professor and chair,
Speech-Language-Hearing: Sciences
& Disorders, Lawrence Campus

Now, in one of the largest and most extensive studies on the problem to date, Hugh Catts and his colleagues have found that more school-aged children than previously thought — 13 percent—have late-emerging reading problems, that these problems usually appear between the second and fourth grades—and persist thereafter.

Nearly half of the late-emerging poor readers had a history of language impairments in kindergarten, but language problems alone were not sufficient to identify which children would experience a fourth-grade slump, said Catts.

The study followed 493 children from kindergarten through tenth grade. The children were classified as good or poor readers on the basis of word reading or reading comprehension scores at second, fourth, eighth and tenth grades. Four reading classes were identified at each grade: good readers, poor readers with deficits in word reading, poor readers with deficits in comprehension or poor readers with deficits in both areas.

They then analyzed whether children stayed in the same class or changed classes over time. They found that about 32 percent of the children had reading problems at some point across grades. The majority of these children had difficulties in second grade that persisted across grades. But approximately 13 percent had late-emerging reading problems.

Catts and colleagues have begun a new longitudinal study designed to determine which factors can predict reading disabilities—including late-emerging reading problems.

“Until more is known,” Catts said, “educators need to be aware of this group of children and be prepared to assist children who initially appear to be reading well but begin to encounter difficulties.”

Funding: National Institute of Deafness and Other Communication Disorders

Now we know how technology can help bridge the gap between research and practice in parent training

With shocking cases of child abuse hitting the headlines regularly, it is clear why the Centers for Disease Control and Prevention fund child maltreatment prevention research. Kathleen Baggett is leading a three-year CDC-funded project that trains home visitors to coach parents in responsive, sensitive parenting to nurture infants' healthy social and emotional development.



Kathleen M. Baggett, associate research professor.

The project is groundbreaking because it addresses a major problem—while proven parent training has existed for years, getting it to at-risk parents has been problematic.

“We know that effective home visiting requires coaching that helps parents practice new skills with their babies during home visits,” said Baggett.

That has usually meant parent coaching by members of a research team—an expensive, time-consuming and ultimately limited proposition. But Baggett’s project gets this expertise rapidly and directly to families through a combination of technology and a partnership with the Kansas Children’s Service League, a highly respected agency whose staff of home visitors assists new parents in 13 Kansas counties.

The technology is netbooks loaded with the proven parent-training program, PALS (Play and Learning Strategies). The built-in eyeball camera is the real key to training since it captures video of home visitors coaching parents and parents interacting with their children. This way, the home visitor can show the parent his or her progress and the child’s progress over time.

The videos are also essential to the professional development of the home visitors who consult with KU research staff weekly. When the research project ends, home visitors will have 50 plus hours of continuing education credits; their agency will have those highly-skilled home visitors and the “Infant-Net” technology in place, and best of all, this top-flight parent training can continue to benefit Kansas parents and vulnerable children.

The videotaped sessions will also help answer the essential research question—can community home visitors deliver PALS faithfully?

“Researchers often get to the end of community intervention studies and have no idea if the intervention was delivered as intended and with high fidelity because these variables were not measured. This study is answering those questions,” said Baggett.

Funding: Centers for Disease Control and Prevention



Jomella Watson-Thompson, assistant professor of applied behavioral science



Kaston Anderson-Carpenter, doctoral student in applied behavioral science



Marvia Jones, doctoral student in applied behavioral science

Now we know how Kansas counties can reduce teen drinking

Teen drinking—including binge drinking—is a big community health problem for most Kansas counties, but now it is less of a problem thanks in part to a KU research group that helped 14 Kansas counties understand the process of reducing teen drinking.

Led by Jomella Watson-Thompson of the KU Work Group for Community Health and Development, the KU team was one of the partners in the five-year Kansas Strategic Prevention Framework-State Incentive Grant (SPF).

Today, in the 14 SPF counties, fewer sixth through twelfth-graders report having a drink in the previous 30 days, a decrease of 11 percentage points. Binge drinking, five or more alcoholic drinks in a row, fell seven percentage points.

But exactly how did the county coalitions achieve this? This is where the Work Group came in.

“A big piece of this is the Online Documentation and Support System,” said Margaret Perez, the former Finney County SPF-SIG director. “It allows us to graph data to show our stakeholders what’s going on.”

The ODSS allows county coalitions to record, code and graph their activities supporting strategies to reduce teen drinking in the areas of academic achievement, family functioning, social norms and enforcement, for example.

“The systematic categorization of activities allows coalitions to examine their contributions to changes in the environment and to understand what human resources, financial or material goods supported the change,” said Watson-Thompson.

The KU Work Group developed the ODSS to quantify the complex phenomena of community change. The KU team, which included Kaston Anderson-Carpenter and Marvia Jones, helps county coalitions make sense of the data of change.

Now that the grant is over, will the counties be able to sustain the reduction in teen drinking? Carpenter aims to find out. He will apply his \$2500 Friends of the Life Span Institute award to studying the sustainability of the approaches used in this project in a random sample of the counties as a component of his dissertation research.

Funding: Department of Social and Rehabilitation Services (now part of the Kansas Department of Aging and Disabilities Services) from the U.S. Department of Health and Human Services. More at: www.spfkansas.org

Now we know the community health issues of Douglas County, Kansas

Douglas County's recent comprehensive community health assessment included surveying, focus groups, interviews, a public health system assessment and a small area analysis using geo-mapping to pinpoint hotspots of emergency room use. Behind it all, including the final report, were Vicki Collie-Akers and Christina Holt of the Work Group for Community Health and Development, a World Health Organization (WHO) Collaborating Centre.

Key stakeholders in the assessment included the Lawrence-Douglas County Health Department, Community Health Improvement Partnership, Lawrence Memorial Hospital, Heartland Community Health Center, the Douglas County Community Foundation and the United Way of Douglas County.

What's driving the assessment and the upcoming community health improvement plan is the Lawrence-Douglas County Health Department's application for accreditation to the Public Health Accreditation Board, said Holt. "But more, it is the stakeholders' desire to impact public health issues collaboratively."

Key stakeholders pared down the findings of the assessment to five areas of concern slated for improvement in the next five years: lack of access to affordable healthy foods, insufficient access to health care, poverty or too few job opportunities, lack of access to mental health services and lack of physical activity.

Collie-Akers and Holt saw it as a step forward that poverty was included in the final five areas for improvement.

"Poverty is a social determinant of health," said Holt. "As a WHO Centre, we've studied how social determinants of health are correlated with health outcomes and work to build local capacity for taking action."

"We often refer to a question posed by WHO," said Holt, "why treat people's illnesses, without changing what made them sick in the first place?"

Report available at: www.ldchealth.org

Funding: Lawrence-Douglas County Health Department



Vicki Collie-Akers,
assistant research
professor



Christina M. Holt,
program specialist



Now we know that a classic psychology text about the inheritance of intelligence was based largely on myth

In 1912 eugenicist and psychologist Henry Herbert Goddard published his highly influential book, *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness*. While the book is now seen as pseudoscience, Goddard's chronicle of a family with two hereditary lines, one presented as a cavalcade of outstanding citizens and the other rife with criminals and the "feeble-minded," still resonates in culture, policy and science. In fact, the immutability of the inheritance of intelligence was an article of faith for much of the 20th century.

Now, 100 years later, Michael Wehmeyer and co-author J. David Smith have brought together evidence that disputes the very basis of Goddard's book, that a degenerate line descended from the progenitor Revolutionary War soldier's dalliance with a barmaid in *Good Blood, Bad Blood: Science, Nature, and the Myth of the Kallikaks*.

The pseudonymous Kallikak family so named by Goddard from the Greek *Kallos* (beauty) and *Kakos* (bad) was actually the Wolverton family, a fact discovered by a genealogist in the 1980s. With this genealogy, institutional records and interviews with Wolverton descendants, as well as other sources, the authors concluded that there was no "bad blood" at all.

"These were just poor people who lived in rural areas of New Jersey who were then cast into the quagmire of industrializing America at the turn of the 20th century," said Wehmeyer.

Goddard used the case of a young woman he called Deborah Kallikak (Emma Wolverton), who was an inmate at his Vineland State Training School, to justify his argument for the segregation and even sterilization of people deemed intellectually inferior.

Whether Emma even had an intellectual disability is up for debate, said Wehmeyer. She could read and write and became the nanny for the institution superintendent's children. She died at age 89, incarcerated for 81 of those years.

"It was time to tell this woman's story to reclaim some of her dignity as a person," said Wehmeyer. "The point of this book is that society makes decisions—it isn't just scientists. How society responds to, takes in, and what it does with that information matters. We need to be careful who gets to make the final decision."

Available through the American Association of Intellectual and Developmental Disabilities and Amazon



Michael L. Wehmeyer, professor of special education; director, KU Center on Developmental Disabilities and associate director, Beach Center on Disability.



Emma Wolverton, alias Deborah Kallikak

The Meaning of *Meaningful Differences*

This year the contribution of KU's Betty Hart and the late Todd Risley to understanding child language development received yet another honor: this time showcased as part of an 1800-square-foot exhibition, *The Wonder Years*, in the Science Museum of Minnesota in St. Paul.

Hart came to KU as a graduate student from the University of Washington in the mid-1960s along with Todd Risley, (her mentor and main collaborator), Montrose Wolf and Vance Hall. All were destined to move the science of behavior analysis into service of the problems of poor, urban neighborhoods and the University of Kansas to international acclaim.

But it is perhaps Hart and Risley's 1995 book, *Meaningful Differences*, that is the most recognizable benchmark of LSI's early years. The book was based on their seminal study of 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.

At the Friends of the Life Span 2012 annual dinner, Associate Research Professor Dale Walker highlighted the impact of Hart and Risley's work at the local, national and international levels. Walker, along with other LSI Juniper Gardens Children's Project researchers, followed the original Hart and Risley sample from kindergarten through the third grade and showed how the amount of language experienced by children predicted their later vocabulary development, early literacy and school performance. They then identified and tested practices that parents and childcare teachers could use to increase the amount of talk to children at home and in child care to improve infant-toddler outcomes.

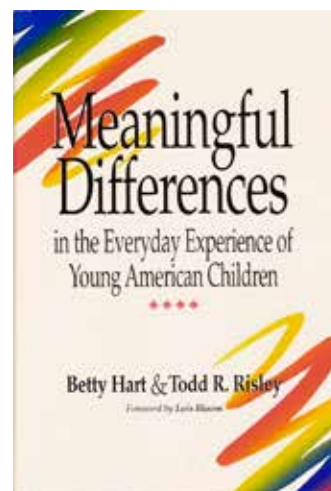
There are currently more than 3,000 citations to Hart and Risley's book and it continues to sell as well in 2012 as it did in 1995. Their work has influenced legislation and funding of early intervention and parenting education programs nationally and internationally.

Meaningful Differences has influenced technological innovation at KU in assessments documenting adult and child talk and progress monitoring of the communication of infants and toddlers. The LENA® system, developed by the LENA Research Foundation, uses digital software to capture and analyze utterances between adults and children.

The legacy of Hart and Risley's *Meaningful Differences* even includes national and international community change projects designed to increase parent-child interaction. One campaign, headed by *Washington Post* Pulitzer Prize-winning columnist William Raspberry, used lessons from *Meaningful Differences* to influence a Mississippi town to improve parenting skills. As described by KU Distinguished Professor Mabel Rice at the time of its publication, "This is scientific endeavor made real."



Betty Hart (left) and Dale Walker. Hart received the Council for Exceptional Children, Division for Early Childhood Service to the Field Award in 1999.



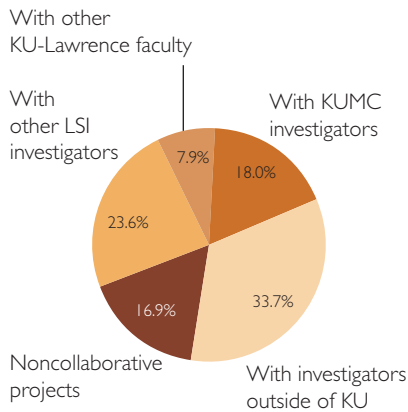
LSI by the Numbers

Collaboration

It is generally accepted that the cutting edge of science in all disciplines lies in collaborative research. Indeed, the word collaboration appears fifteen times in *Bold Aspirations*, KU's recent strategic planning document. When different scientists bring their perspectives and work together on a problem, solutions or approaches often emerge that might not have from the perspective of a single or lone investigator.

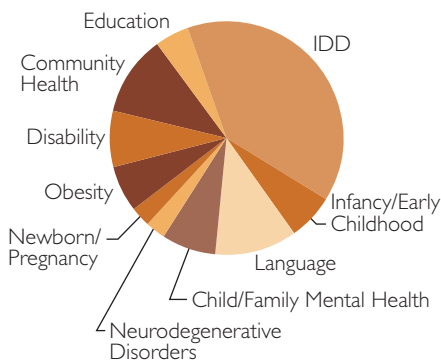
Among the charges of KU's designated research centers is to encourage, facilitate, engage and sustain such collaborative research endeavors, and the Life Span Institute has long met this charge.

For this annual report, we examined the currently funded research projects within the institute and found that **83 percent of our projects are collaborations among multiple investigators**. Nearly one in five involve collaborations across the Lawrence and KU Medical Center campuses, and include partners in the departments of Pediatrics, Molecular and Integrative Physiology, Dietetics and Nutrition, the Hogle Brain Imaging Center, the Center for Child Health and Development, the School of Medicine and the Landon Center on Aging. More than one-third of our research projects involve collaborations outside KU and include partners at Oregon University, UNC Chapel Hill, University of Nebraska-Lincoln, University of Texas Health Science Center, Columbia University, Virginia Commonwealth University, Kennedy Krieger Institute, Tulane University, University of Massachusetts-Boston, Cornell University and Vanderbilt University.



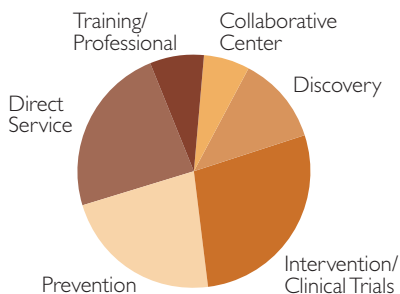
Project Topics

This figure shows the breadth of topics covered by Life Span Institute projects during FY2011-12. The largest number of projects involve intellectual and developmental disabilities (IDD) such as autism, Fragile X, Down Syndrome and other conditions, but other enduring strengths of the Institute in language, community health, early childhood and disability are also well-represented. Projects on emergent emphases in neurodegenerative disorders (e.g., Alzheimer's and Parkinson's Disease), obesity, and child/family mental health (e.g., projects on child maltreatment and neglect) show a broadening of the portfolio toward topics in human health and development.



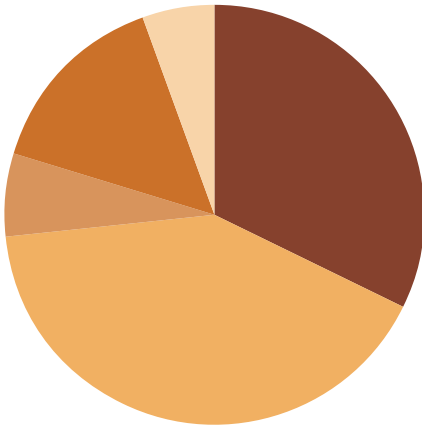
Project Types






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 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

Funding by Agency | Fiscal Year 2011



	National Institutes of Health	\$7,718,205	32.3%
	U.S. Department of Education	\$9,833,824	41.2%
	U.S. Health and Human Services	\$1,506,068	6.3%
	Kansas	\$3,529,540	14.8%
	Foundation/Industry/Other	\$1,289,813	5.4%

In 2012, LSI had 89 existing awards continued and 15 new awards for a total of 104 awards, totaling \$23.9 million.* This is a decrease of \$5 million from the 2011 total funding, although the actual loss to KU is only \$2.9 million (10 percent) due to \$2.1 million within the Center for Physical Activity and Weight Management (CPAWM) moving from Lawrence to KU Medical Center. In spite of this loss, this year's funding level still ranks as the fourth highest in LSI history.

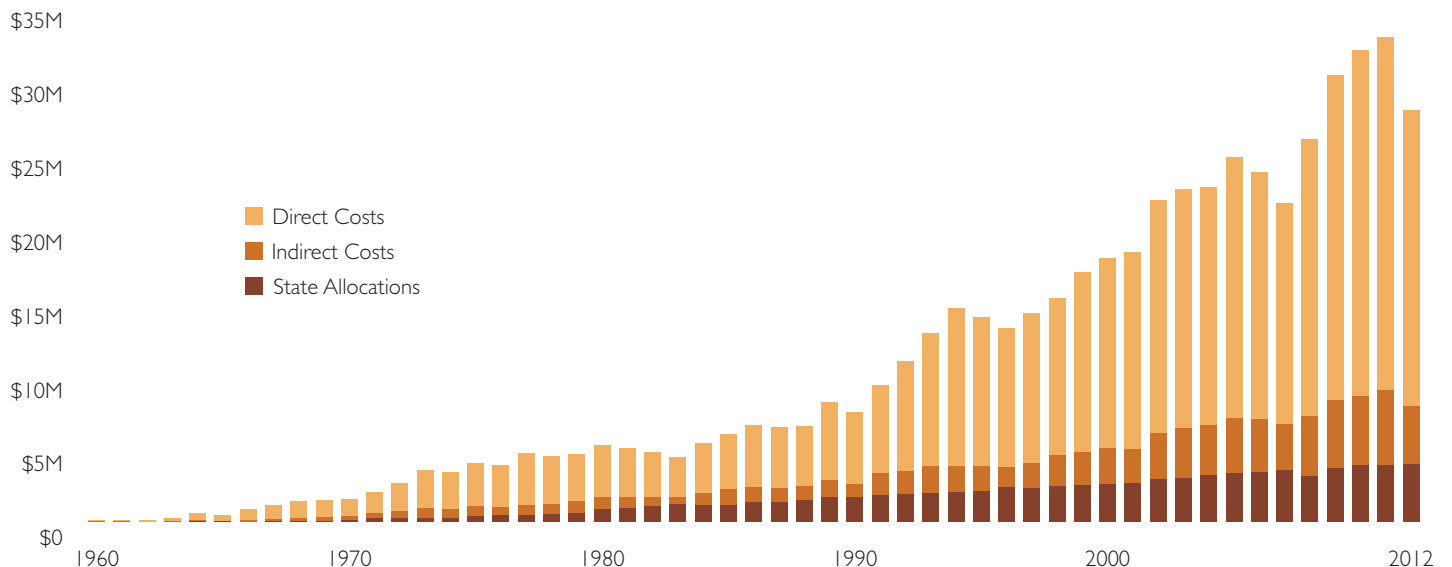
Federal awards continue to account for 80 percent of the Institute's overall external funding. Funding from the National Institutes of Health dropped from \$11.7 to \$7.7 million (this includes CPAWM's transfer to KUMC) with 33 awards (two of which were new). Awards from the U.S. Department of Education increased from \$9.6 to \$9.8 million with 27 total awards (six of which were new). Another \$1.5 million in funding was generated in awards from the U.S. Department of Health and Human Services.

State of Kansas contracts decreased from \$3.8 to \$3.5 million this past year with 21 awards, one of which was new. This level of state funding remained essentially unchanged in 2011-2012 despite major changes with a new state administration.

The 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 2012, every state of Kansas dollar invested in LSI yielded \$6.05 in external awards.

* This year, in keeping with KU Center for Research policy, funding amounts are reported without ARRA (American Recovery and Reinvestment Act of 2009) funds that were awarded to the Institute from 2008-2011.

Life Span Institute Funding History: State Allocations and Grant Dollars by Fiscal Year



The Life Span Institute Affiliated Centers*

*In order of year center founded or affiliated.

The Life Span Institute at Parsons 1956

For more than 50 years, the University of Kansas Life Span Institute at Parsons has partnered with national, state, regional and community partners to conduct research, develop model service programs and provide training for professionals involved in services to young children, youth and adults with disabilities and their families. Located in a rural community in southeast Kansas, the Parsons LSI includes the Kansas University Center on Excellence in Developmental Disabilities and the Parsons Research Center. Current research addresses early literacy and reading, language and communication, hearing assessment, health and obesity and maladaptive and challenging behavior. Additionally, the Parsons LSI provides significant service and training across the nation and state of Kansas on assistive technology needs, early intervention and early childhood, and training for community organizations and agencies serving persons with developmental disabilities.

David P. Lindeman, Ph.D., Director
Contact: 620 421-6550, ext. 1713, parsons.lsi.ku.edu

FY 2011–2012 Highlights

Assistive Technology for Kansans (ATK) was one of five state programs invited to present to the U.S. Department of Education staff and provided technical assistance regarding access to assistive technology to 21 states in 2011–2012.

Assistive Technology for Kansans staff collaborated with Kansas Rehabilitation Services staff and assisted 170 individuals with identifying and acquiring assistive technology devices for employment or job retraining. ATK and Kansas State University worked together to assist 103 farmers and ranchers who had been injured return to production agriculture.

The Kansas Inservice Training system provided training and technical assistance for all early intervention and early childhood special education programs in all counties of the state. This impacted 11,236 teachers, related service providers, administrators and family members.

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.

Think College Kansas developed a statewide strategic plan for implementing a sustainable and inclusive post-secondary education model for Kansans with intellectual and developmental disabilities.

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

The Family Care Treatment Project has been selected by the State of Kansas for replication. This program supports parents and caregivers of children with disruptive behaviors by providing an individualized, consumer-driven, home-based service.

Initial pilot work focusing on interventions in weight loss has transitioned to a randomized clinical trial with 160 adults with intellectual and developmental disabilities.

The Parsons LSI is collaborating with investigators at Columbia University and the University of Kansas School of Medicine at Wichita to identify the occurrence of epilepsy in children in southeast Kansas.

Pilot work with iPads to assess the functional vision of toddlers with cortical vision impairment has led to the development of a testable version of an iPad assessment application specifically for low vision and motor impaired toddlers. This work is in cooperation with the Kansas School for the Blind and utilizes the input of a McNair Scholar at KU.

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 2011–2012 Highlights

Drs. Abbott, Buzhardt, Greenwood, Walker, Carta and Wills reported their most recent procedures, plans, and techniques in advancing the use of Response to Intervention (RTI) progress monitoring and intervention decision making in early childhood programs and elementary schools

Buzhardt, J., Walker, D., Greenwood, C., & Heitzman-Powell (in press). Using technology to support progress monitoring and data-based intervention decision making in early childhood: Is there an App for that? *Focus on Exceptional Children*.

Buzhardt, J., Greenwood, C., Walker, D., Anderson, R., Howard, W., Carta, J. (2011). Effects of web-based support on early head start home visitors' use of evidence-based intervention decision making and growth in children's expressive communication. *NHSA Dialog: A Research-to-Practice Journal for the Early Childhood Field*, 14, 3, 121-146.

Abbott, M., Atwater, J., Lee, Y., & Edwards, L. (2011). A data-driven preschool PD model for literacy and oral language instruction. *NHSA Dialog*, 14(4), 229-245.

Abbott, M., & Wills, H. (2011). Improving the upside-down response-to-intervention triangle with a systematic, effective elementary school reading team. *Preventing School Failure*, 56(1), 37-46.

Effectiveness studies of the use of language and promoting strategies (Drs. Walker, Thiemann-Bourque, Atwater & Bigelow) continued in the Model Demonstration Center for Promoting Language and Literacy Readiness in Early Childhood in partnership with early intervention programs in Wyandotte County, Topeka and Olathe, Kan. Preliminary results were presented at the Association for Speech and Hearing Conference and the Division of Early Childhood Conference this past fall. Language-promoting strategies and study results were also disseminated during professional development events for local home visiting and early childhood programs.

Walker, D. (2011). Evidence-based practice in early childhood intervention. In C. Groark & L.A. Kaczmarek (Eds.), *Early Childhood Intervention: Shaping the Future for Children with Special Needs and their Families* (pp. 147-167). Santa Barbara, Calif.: Praeger.

Thiemann-Bourque, K. (2012). Peer-mediated intervention. In F. R. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders*. New York: Springer.

In collaboration with researchers at the Life Span Institute and the University of Washington, Dr. Kathy Thiemann-Bourque assisted in the development and testing of the Communication Complexity Scale (CCS). The goal of the CCS was to design a communication scale and summary score for interpretation that could be applied across populations of children and adults with limited (often presymbolic) communication forms. Comparison across other measures indicated significant correlations with standardized tests of language. The scale appears to be useful for describing a given individual's level of presymbolic or early symbolic communication. Development of the Communication Complexity Scale was published in the *American Journal of Speech Language Pathology* (Nancy C. Brady, Kandace Fleming, Kathy Thiemann-Bourque, Lesley Olswang, Patricia Dowden, Muriel D. Saunders, and Janet Marquis) (2011). The researchers received over 300 requests for more information on the CCS since the time of publication.

Thiemann-Bourque, K., Brady, N., & Fleming, K. (2011). Symbolic play of preschoolers with severe communication impairments with autism and other developmental delays: more similarities than differences. *Journal of Autism and Developmental Disorders*.

Thiemann-Bourque, K., Brady, N., & Fleming, K. (2012). Symbolic play of preschoolers with severe communication impairments with autism and other developmental delays: More similarities than differences. *Journal of Autism and Developmental Disorders*, 42(5), 863-873. doi: 10.1007/s10803-011-1317-7.

The focused research program at the JGCP-based Center for Response to Intervention in Early Childhood (CRTIEC: Carta, Greenwood, Atwater, Linas) continued development of measures and interventions for promoting language and early literacy skills of preschool children identified at risk for delays. The CRTIEC team, consisting of partners at the University of Minnesota, Ohio State University, Dynamic Measurement Group in Eugene, Ore., and JGCP, are developing a new generation of early literacy measures for screening and progress monitoring called Indicators of Growth and Development (IGDIs – 2.0). The editors of the *Journal of Early Intervention and Topics in Early Childhood Special Education* invited this team to contribute a paper to their joint, two-journal special edition recognizing the 25-year anniversary of PL-99-457. This policy established early intervention and early childhood as part of the IDEA. The team was invited to contribute an article describing the scientific advances made in developing universal screening and progress monitoring measures in the past 25 years (Greenwood, C. R., Carta, J. J., & McConnell, S. (2011). Advances in measurement for universal screening and individual progress monitoring of young children. *Journal of Early Intervention*, 33(4), 254-267) and a set of guidelines for authors contributing manuscripts and for peer reviewers.

Greenwood, C. R., & McConnell, S. R. (2011). JEl guidelines for manuscripts describing the development and testing of an assessment instrument or measure. *Journal of Early Intervention*, 33(3), 171-185.

CRTIEC is advancing what the field knows about the needs and benefits of a Response to Intervention (RTI) approach to language and early literacy instruction in preschool.

Greenwood, C. R., Carta, J. J., Atwater, J., Goldstein, H., Kaminski, R., & McConnell, S. R. (in press). Is a response to intervention (RTI) approach to preschool language and early literacy instruction needed? *Topics in Early Childhood Special Education*.

Carta, J., & Driscoll, C. (in press). Early literacy interventions for young children with special needs. In T. Shanahan & C. Lonigan (Eds.), *Literacy in preschool and kindergarten children: The National Early Literacy Panel and beyond*. Baltimore: Paul H. Brookes.

Articles also appeared reporting this team's research on the efficacy of a vocabulary and comprehension intervention for preschoolers with weak skills.

Spencer, E. J., Goldstein, H., & Kaminski, R. (2012). Teaching vocabulary in storybooks: Embedding explicit vocabulary instruction for young children. *Young Exceptional Children*, 15(1), 18-22.

Spencer, E. J., Goldstein, H., Sherman, A., Noe, S., Tabbah, R., Ziolkowski, R., & Schneider, N. (in press). Effects of an automated vocabulary and comprehension intervention: An early efficacy study. *Journal of Early Intervention*.

Greenwood, C. R., Carta, J. J., Spencer, E., Guerrero, G., Kong, N.Y., Atwater, J., & Goldstein, H. (submitted). The effects of a tier 2 vocabulary and comprehension storybook intervention on preschool children's early learning: A replication. *Journal of Early Intervention*.

CRTIEC is providing leadership to the field in preschool RTI among constituent audiences including researchers, practitioners, administrators and policy makers. The Third Annual RTI in Early Childhood Summit was held in Santa Ana Pueblo, N.M. on September 26 and 27, 2011, with 150 practitioners, researchers, policymakers, and higher education faculty in attendance. Attendees had the opportunity to find out about cutting edge work on new progress monitoring measures and interventions that can be used in multi-tiered systems of support. They also learned about programs successfully implementing RTI, networked with colleagues and helped direct the focus of future research.

The remote, point-of-care interventions work group continued their focus on using cell phones, notebook video technology, tablet devices, networking, internet and telemedicine technologies in homes, schools and clinics. Dr. Kathleen Baggett is evaluating the efficacy of in-home notebook video tools for point-of-care intervention by strengthening parent child-interactions. Dr. Baggett continued to direct projects, partnering with scientists at the Oregon Research Institute and the University of Texas Medical School to make evidence-based interventions more accessible to parents, childcare teachers and home visitors by developing and testing a series of web-based coaching and consultation programs. Streaming videos of caregiver-child interactions and in-home coaching have been used by research coaches to provide individualized phone and web consultation. This promotes caregiver responsiveness, reduces child maltreatment and improves infant social-emotional outcomes and has been tested with 12 home visitors serving families in 13 counties in Kansas, including many in rural areas. Dr. Bassett, along with Drs. Hannah Schertz (University of Indiana) and Samuel Odom (University of North Carolina) reported outcomes of a study of a parent-mediated intervention for improving social-communication outcomes for toddlers with

Autism Spectrum Disorders. In *Early Childhood Research Quarterly*, they reported that children who received the intervention, made significant pre-post-improvement in joint attention and on standardized measures of social communication. Dr. Baggett, with Drs. Schertz and Odom, received a new \$3.5 million grant from the U.S. Department of Education to test the effectiveness of this approach that targets pre-verbal social communication between toddlers younger than age two-and-a-half and their parents.

Schertz, H., Odom, S. L., & Baggett, K. M. (in press). Effects of Joint Attention Mediated Learning for Toddlers with ASD: An Initial Randomized Controlled Study. *Early Childhood Research Quarterly*.

Carta, J., Greenwood, C., Baggett, K., Buzhardt, J., & Walker, D. (2011). Research-based approaches for individualizing caregiving and educational interventions for infants and toddlers in poverty. In S.L Odom, E. Pungello, & N. Gardner-Neblett (Eds.). *Re-visioning the Beginning: The implications of developmental and health science for infant/toddler care and poverty*. New York: Guilford Press.

Kathleen Baggett received a National Institutes of Health Clinical Loan Repayment Award, funded by the National Institute of Child Health and Human Development (NICHD).

Drs. Judy Carta and Kathy Bigelow, along with partners at Notre Dame University, reported results at a meeting last winter at the Institute of Medicine's Forum on Global Violence Prevention. They announced significant follow-up effects for the children and families using an evidence-based parenting intervention with cell phone support as part of an in-home parenting intervention.

Drs. Linda Heitzman-Powell and Jay Buzhardt continued development and testing of content for their telemedicine approach to teach parenting skills to parents raising children with Autism Spectrum Disorder (ASD). An evaluation of their distance training program for parents of children with autism in geographically remote areas was presented at the National Association of Rehabilitation Research Training Centers Annual Conference in Bethesda, Md. Their program, the Online and Applied System for Intervention Skills (OASIS) is being translated into a Spanish version.

The behavior and autism work group at JGCP (Kamps, Co-PIs Linda Heitzman-Powell and Kathy Thiemann-Bourque), along with a partner at the University of Washington, is investigating how well children with ASD learn social and academic skills working in small groups (peer networks) with typically developing classmates in kindergarten and first grade. The classroom teachers have reported steady improvements in reciprocal social communicative interactions during the social networks. Participating children with ASD who are beginning readers also show improved literacy skills as a result of the peer networks intervention. Preliminary results were presented at the International Meeting for Autism Research in San Diego last fall and the Annual Convention of the Association for Behavior Analysis in Denver this spring.

In two related reports published in *Preventing School Failure* and *Journal of Positive Behavioral Interventions*, Drs. Kamps and Wills reported improved performance in a four-year long efficacy trial for students whose teachers used Class-wide Function related Intervention Teams (CW-FIT), a program including class-wide behavior management. The findings also indicated that both children with and without emotional and behavior disorders made significant improvements compared to groups not using these procedures. This work was presented at the meeting of the Council for Exceptional Children Conference in National Harbor, Md.

Kamps, D., Wills, H., Heitzman-Powell, L., Laylin, J., Szoke, C., Petrillo, T., & Culey, A. (2011). Class-Wide Function-Related Intervention Teams: Effects of group contingency programs in urban classrooms. *Journal of Positive Behavior Interventions*.

They have received new funding to replicate CW-FIT in a multi-site, four-year study with investigators at Vanderbilt University and Brigham Young University.

Drs. Wills and Kamps are also partners in the Center for Adolescent Research in Schools (CARS), which is conducting a large-scale evaluation of high-school-based behavioral and mental health interventions. In a related project, Wills and Kamps are developing I-Connect, an intervention for high school students that makes use of mobile devices such as smartphones to self-monitor and to connect with school and community mentors (see www.iwillgraduate.org).

The STICKS Project (Professional Development that is Systematic, focused on Teacher growth, Incorporates Coaching, collaboration, cohorts, and increased Knowledge to create Student Success) continued to develop coaching software to teach and promote effective behavioral interventions in the classroom.

Linas, M., Wills, H., Buzhardt, J., Dove, S., & Kamps, D. (May, 2012). Professional Development that STICKS: Meeting Teacher Learning Needs to Improve Student

Outcomes. Poster presentation at the Annual Association for Behavior Analysis conference. Seattle, Wash.

Linas, M., Wills, H., Buzhardt, J., Dove, S., & Kamps, D. (February, 2012). Professional Development that STICKS: Meeting Teacher Learning Needs to Improve Student Outcomes. Poster presented at the Annual Conference for the Midwest Symposium for Leadership in Behavior Disorders, Kansas City, Mo.

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, kiddrc.kumc.edu

FY 2011-2012 Highlights

Susan Carlson and John Colombo found that LCPUFA supplementation of infant formula fed during the first 12 months of life improves the quality of attention in infants across the first year (*Pediatric Research*, 2011).

Merlin Butler showed that children with autism have compromised immune systems (*International Journal of Developmental Neuroscience*, 2011). This is part of a larger program of work on the genes that encode immune-related proteins and cytokines, which are thought to have substantial impact on critical periods of brain development.

Nancy Brady described the development and use of the Communication Complexity Scale (*American Journal of Speech and Language Pathology*, 2012). The scale assesses children's early symbolic communication, and is currently being used in projects on children with Down syndrome and Fragile X.

Charles Greenwood and several Juniper Gardens colleagues replicated and extended the findings of Betty Hart and Todd Risley using automatic speech encoding technology (*Communications Disorders Quarterly*, 2011). The long-term goal of this work is to make the current approach to speech processing possible by researchers and clinicians working on a daily basis with families and young children.

Christa Anderson and John Colombo showed that children with autism have larger pupil sizes and that this dysregulated pupillary function is likely due to dysregulation of a brain system that involves the neurotransmitter norepinephrine (*Developmental Psychobiology*, 2012). These findings should establish the feasibility of these indicators for early detection of ASD.

Debra Kamps showed the effectiveness of the Class-Wide Function-related Intervention Teams program, a group contingency intervention for whole classes, and for students with disruptive behaviors who are at risk for emotional/behavioral disorders (*Journal of Positive Behavioral Intervention*, 2011).

Mike Soares published on the reorganization of uterine blood flow that takes place during pregnancy (*Proceedings of the National Academy of Sciences*, 2011). This reorganization is critical to normal fetal development, and understanding it is likely to lead to new strategies to prevent abnormalities that may put children at risk for developmental disabilities.

Kansas University Center on Developmental Disabilities 1973

Almost 40 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 KUCDD. These include clinics to diagnose and treat children with disabilities, a statewide project that provides assistive technology 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
Glen White, Ph.D., Associate Director
R. Matthew Reese, Director, KUCDD-Kansas City Site
David Lindeman, Ph.D., Director, KUCDD-Parsons Site
Michael L. Wehmeyer, Ph.D., Director, KUCDD-Lawrence Site
Wendy Parent, Ph.D., Assistant Director, KUCDD-Lawrence Site
Sara Sack, Ph.D., Director, Assistive Technology for Kansans Project
Rachel Freeman, Ph.D., Director, Kansas Institute for Positive Behavior Supports
Contact: 785 864-4295, kucdd.ku.edu

FY 2011-2012 Highlights

Faculty at the Center for Child Health and Development (CCHD) have combined efforts with the Kansas Instructional Support Network (KISN) to increase capacity in the state to screen and diagnose autism as well as other developmental disabilities. Autism Intervention Teams from school districts throughout Kansas trained through KISN have also been trained to collect autism diagnostic information. These teams and their parents are then linked to CCHD interdisciplinary medical providers through interactive TV. This year CCHD clinicians screened or evaluated 125 children with suspected autism using Interactive TV.

The Assistive Technology for Kansans project provided training on the availability and use of assistive devices and services to 956 people in Kansas and across the United States and provided direct technical assistance on the use of AT devices to 2,201 Kansans at multiple sites across the state. Staff at ATK responded to 3,833 people with developmental disabilities, families and professionals on AT devices through dissemination activities.

The Gateway to Self-Determination Project engaged in training and technical assistance on promoting and enhancing the self-determination of adults with intellectual and developmental disabilities.

KUCDD Parsons-site researchers have replicated a promising approach to weight loss for adults with intellectual and developmental disabilities with people who have mobility impairments.

The Kansas Inservice Training System provided intensive technical assistance to 32 early intervention and preschool programs that impacted 561 teachers, 82 administrators and 5,846 children.

KUCDD faculty in the Kansas Institute for Positive Behavior Supports trained 1,262 professionals on positive behavior supports and responded to more than 65,655 requests for technical assistance through the KIPBS website.

The Research and Training Center on Independent Living 1980

The Research and Training Center on Independent Living (RTC/IL) has a 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 meet 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 2011-12 Highlights

The RTC/IL received a five-year, \$4.25 million grant from the National Institute on Disability and Rehabilitation Research (NIDRR) to help people with disabilities live in and participate more fully in their communities. The new Research and Training Center on Community Living (RTC/CL) will develop evidence-based programs, policies and practices to further community living among people with disabilities.

Glen White trained more than 100 medical rehabilitation professionals in Perú to better care for people with spinal cord injuries (SCI) through trips to Lima in March and Arriquipa in July. KU Honors Program student Sam Ho assisted White on the first trip, and they presented information about health issues that are common to people with SCI to participants including physicians, physical therapists, occupational therapists, speech language therapists, psychologists and

physical therapy students. White will present one more training this fall in Chiclayo, Perú.

White has developed another international partnership in Asia. He is working with KU alumnae Kyung Mee Kim in South Korea and Chiaki Gonda Kotani in Japan to replicate research that has been conducted in the U.S. The comparative study analyzes the effectiveness of services offered to people with disabilities by centers for independent living.

Martha Hodgesmith and Amanda Reichard have been appointed to KanCare Workgroups that are tasked with helping redesign the Medicaid program in Kansas. Hodgesmith is serving on the Member Involvement and Protections group, and Reichard is on the Specialized Healthcare and Network Issues Workgroup.

Amanda Reichard's research on Medicaid and preventive healthcare for people with disabilities was included in the KU Chancellor's 2012 State of the University video. Reichard's research shows that preventive screenings and care for people with physical disabilities and cognitive limitations could help save money for Medicaid.

Amanda Reichard, Dot Nary and Cat Howland contributed modules to the first course about disability to be offered to nursing students at the KU Medical Center's School of Nursing. The curriculum was developed in collaboration with the Kansas Department of Health and Environment.

Amanda Reichard is lead author for "Quality of diabetes care for adults with physical disabilities in Kansas," which was published in *Disability and Health Journal* (Vol 5, No. 1, January 2012). Co-authors are Hayley Stolzle, Ana Carolina Sella and Theresa I. Shireman.

Martha Hodgesmith received the 2012 Chief Justice Kay McFarland Lifetime Achievement Award from the Women Attorneys Association of Topeka.

Dot Nary won the prestigious Switzer Fellowship from NIDRR. Her project is titled *Is there really no place like home?* "An exploratory study of the impact of non-visitable homes on wheelchair users."

The center's Living Well with a Disability program was one of five winners in a Voices of Health Equity Contest sponsored by the Center for Health Equity at Kansas Department of Health and Environment.

Glen White was appointed chair of the Kansas Rehabilitation Services Council in January. The Council advises Kansas Rehabilitation Services (KRS) on development of the State's rehabilitation plan and is comprised of consumers of vocational rehabilitation services, service providers, family members, advocates, employers and others interested in disability issues.

Amanda Reichard is serving on a National Institutes of Health Expert Panel on Adults with Chronic Health Care Needs. The goal of the panel is to provide the field with a new focal point for measurement, surveillance and service. They will craft a formal, population-level definition of adults with chronic health care needs, define key subgroups of this population, develop screening questions that will identify this population and its subgroups in national surveys and clinical settings, and disseminate the screening questions broadly for use by practitioners and policymakers alike.

Glen White made a presentation to the Kansas Commission on Disability Concerns on May 18. He provided information on the center's research, as well as the trainings he conducted in Peru and his ongoing collaboration with Delta Air Lines to improve air travel for people with disabilities.

Amanda Reichard presented an abstract at the 2012 Academy Health Meeting on June 23. The presentation, co-authored with Mike Fox, is titled "Using Population-Based Data to Examine the Relationship between Disability and Health among Dually Eligible (Medicare/Medicaid) Adults." On June 19 she presented a poster at the American Association on Intellectual and Developmental Disabilities conference, titled "What We Can Learn about Individuals with IDD from Medicaid Claims Data." Reichard was invited to present at the Kansas Quality of Care Project last fall, Learning Workshop on the ADA Standards, Resources and Questions Answered for Healthcare Practitioners, held October 14, 2011. She also made an oral presentation at the 2011 American Public Health Association annual conference on "Quality of Diabetes Care for Adults with Physical Disabilities."

Cat Howland presented "Best Practices to Level the Playing Field in Disasters for People with Disabilities" at the Pacific Rim International Conference on Disability and Diversity in April as both a poster and oral presentation.

Leslie Schille presented a poster at the annual conference of the Association on Higher Education and Disability (AHEAD) in July. The poster was titled "The Accommodations Model: A new tool for empowering students to request reasonable accommodations." Glen White and Jean Ann Summers are project investigators.

The center created new emergency preparedness resources for people with disabilities, including two new online trainings and four YouTube videos that provide concrete tips on preparing for natural and man-made disasters.

Child Language Doctoral Program 1983

The Child Language Doctoral Program 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 preschool children diagnosed as receptive/expressive specific language impaired. The Life Span Institute, the Language Acquisition Preschool and the clinical and research facilities of the Speech-Language-Hearing Clinic provide research sites and practica.

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

FY 2011-2012 Highlights

Alyson Abel will receive her Ph.D. in Fall 2012, and then begin a post-doctoral position at University of Texas at Dallas.

Leah Kapa is in the process of writing her thesis and Yi-Chih Chan is finishing his comprehensive exams.

Margaret Echelbarger is Coordinator for the Child Language Doctoral Proseminar

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 Marianna Beach for their long-standing efforts on behalf of families affected by disability and was inspired by the Turnbulls' son, Jay, who had several disabilities.

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

FY 2011-2012 Highlights

Beach Center investigators published 38 peer-reviewed articles, 20 chapters and 6 books in 2011-2012.

Developed, piloted and evaluated a model for preschool teachers and families to work in partnership to build foundational skills for self-determination for their children with disabilities.

Established a causal relationship between promoting self-determination for youth with disabilities and more positive self-determination, academic and transition goal attainment, and access to the general education curriculum outcomes.

Disseminated information about scaling up efforts to promote self-determination for adults with disabilities through employment, self-advocacy, health, wellness and community living activities.

Completed four years of school reform work in 15 Washington, D.C. schools with promising results, including inclusion of students with disabilities into the general education setting.

Developed, evaluated and piloted an online professional development program for practitioners in all Kansas early intervention programs, resulting in significant gains in knowledge and high levels of satisfaction with the training model.

Developed and piloted professional development to Kansas teachers for Tier 3 Literacy training to support targeted and intensive reading instruction to students with disabilities; delivered the training to more than 125 Kansas teachers.

Provided technical assistance to 16 school teams to develop and implement service plans for students with deaf-blindness, including transition support and customized employment plans for 8 students.

Developed a community mental health model for vulnerable families with results reporting high levels of family satisfaction and lower levels of family stress.

Completed a comprehensive policy analysis for the Department of Defense on the needs of military personnel with family members with special needs and guidelines for support across all service branches.

Developed, evaluated, and disseminated a Family Employment Awareness Training model throughout Kansas that resulted in higher family expectations for community employment for individuals with significant disabilities and significantly increased family knowledge on ways to access employment.

Developed, evaluated and piloted a training program, Roots to Resources, to guide Kansas school districts to analyze student data, identify causes of lower performance and develop a corrective action plan; delivered training and follow-up monitoring to 17 Kansas school districts.

Coordinated professional development to certify Kansas reading specialists as trainers for LETRS (Learning Essentials for Teachers of Reading and Spelling) to enhance knowledge for teaching reading and literacy skills; coordinated delivery of training to 1665 teachers in 32 Kansas school districts.

Participated with state Department of Education to create a comprehensive math essentials plan to provide professional development to Kansas teachers in teaching mathematics to students in special education.

Supported 25 Kansas families to complete online training on information and supports related to their child with deaf-blindness.

Developed nine online instructional modules providing knowledge and skills to teachers working with students with deaf-blindness.

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, <http://www2.ku.edu/~kugeron/>

FY 2011–2012 Highlights

In February, the Gerontology Center hosted Secretary Shawn Sullivan of the Kansas Department on Aging. In a presentation to the KU community, Secretary Sullivan outlined plans for KanCare, which will reform the state's Medicaid services.

In August, Susan Kemper gave the Sheffel Lecture at Brewster Place in Topeka on "Use It or Lose it," her popular talk on cognitive aging and anti-aging interventions. The Sheffel Lecture is supported by funds donated by Irv and Peggy Sheffel to provide a community lecture series.

David Johnson is Director of Neuropsychology at the new KU Alzheimer's Disease Center. Funded in August 2011, this center spans both campuses and is the newest of 29 National Institute on Aging designated Centers of Excellence that are foci of national funding and inter-institutional collaboration in the fight against Alzheimer's disease. Dr. Johnson plans and directs all cognitive assessments of the center's older adult volunteers.

Kristi Williams is working with colleagues at the new KU Alzheimer's Disease Center and the Alzheimer's Association to test how individualized professional feedback based on new video monitoring technology can support family caregivers at home. This project will utilize the Google Broadband network in Kansas City and was featured in the White House *U.S. Ignite* initiative report.

David Ekerdt and Keith Diaz Moore (School of Architecture) edited a special issue of the *Journal of Aging Studies* (August 2011) on *Age and the Cultivation of Place*. The articles in this issue explored ways that older adults make themselves at home and adapt in the residences, settings, and neighborhoods where they dwell.

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 2011–2012 Highlights

A special edition of the *Journal of Neurodevelopmental Disorders* focusing on epigenetics featured the papers resulting from the 2010 Merrill research conference in Tempe, Arizona. The special edition was published in December 2011.

The 16th annual Merrill Research Retreat was held July 18-20, 2012, at the Lied Lodge and Conference Center, Neb., on the theme, Information Systems as Infrastructure for University Research Now and in the Future. There were 22 participants at the invitation-only conference, including the keynote speaker Dr. David Shulenburg, Emeritus President for Academic Affairs at APLU; KU Provost Jeffrey Vitter, and research officers and researchers from KU, KUMC, Kansas State University, Iowa State University, the University of Nebraska-Lincoln and the University of Missouri.

A white paper from the 15th annual Research Retreat, on the topic of Behavioral and Social Sciences as Key Components in National Research Initiatives, was published and posted to the web site of the Merrill Advanced Studies Center: <http://www2.ku.edu/~masc/publications/2011whitepaper.pdf>

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 2011–2012 Highlights

Healthy Communities Study: The KU Work Group is a scientific partner in the 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.

Latino Health for All Project: Implementation of coalition-determined strategies for promoting physical activity (i.e., new soccer fields), healthy nutrition (i.e., community gardens) and access to health services (i.e., Celebrating Healthy Families).

The KU Work Group was funded by the CDC to address health disparities in Wyandotte County, Kan., as one of ten Racial and Ethnic Approaches to Community Health (REACH) CORE programs in the nation.

An evaluation of the U.S. State Department's Bureau for International Narcotics and Law Enforcement Affairs (INL) Coalition Training in Lima, Peru, is being conducted by the Work Group in partnership with Michigan State University.

Continued designation as a World Health Organization (WHO) Collaborating Centre.

The Community Tool Box (<http://ctb.ku.edu/>) partnered with the DHHS in supporting implementation of Healthy People 2020, the health objectives for the nation. The Community Tool Box is on a path to reach more than 1,000,000 unique users in 2012.

Biobehavioral Neurosciences in Communication Disorders Center 2002

The Center for Biobehavioral Neurosciences in Communication Disorders (BNCD) was founded in 2002 when the National Institute on Deafness and Other Communication Disorders awarded a core grant to establish the center. The BNCD is a natural outgrowth of the Life Span Institute's long-standing focus on communication and language development and intervention. The BNCD'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 language impairments, language intervention, the decline of working memory in old age as reflected in speech and more precise measures of hearing loss to aid cochlear implant design.

Mabel L. Rice, Ph.D., Director

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FY 2011-2012 Highlights

Seventeen investigators are affiliated with the BNCD with research interests in the areas of language and language impairments, phonological impairments, speech disorders, reading disorders, hearing impairments, infant cognitive and language development, language use and disability in aged humans, and language intervention.

The BNCD added four new investigators (Yolanda Jackson, Erik Lundquist, Hinrich Staecker and Kristi Williams) as part of the competing renewal recently submitted. Staecker and Lundquist are part of our interest in molecular biological bases of communication disorders as markers of growth in the nervous system implicated in the pathogenesis of genetically regulated infrastructure of speech/language/hearing impairments (Rice, Colombo, and likely to be developed by other investigators during the next funding cycle).

The other two new investigators, Williams and Jackson, share an interest in treatment of populations at risk for language impairments that in turn interact with treatment methods. The clinical trials research of Williams is highly relevant to possible language intervention methods for elderly persons with aphasia and Jackson is documenting language impairments in children in foster care, with relevance for studies of possible environmental effects on language impairments in children.

Common interests across this varied group of investigators include interests in the underlying biological and genetic bases of speech, language, and hearing disorders, and the way in which these processes and abilities play out over time, whether in the natural course of acquisition, age-related decline, trauma-induced decline or impairment or in behavioral intervention settings.

BNCD held its semi-annual meetings with investigators and Core personnel in fall 2011 and spring 2012.

Outreach newsletters are published by the PARC core three to four times annually, both in hard copy and on the BNCD website.

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.

Debra Kamps, Ph.D. Director
R. Matthew Reese, Ph.D., Co-Director
Contact: 913 897-8472, kcart.ku.edu

FY 2011-2012 Highlights

K-CART, through joint funding of KU and KUMC, has funded ten Discovery Grants since 2008 to advance the treatment and discovery of the causes of autism. Dr. Merlin Butler discovered that a disturbed immune system in children with classic autism may be related to genetic factors. His research showed cytokine levels related to T-helper cell immune system and the production of blood cells which affects antibody production were impacted for children with autism compared to healthy siblings. Brady and Anderson sought to validate eye-tracking as a method for the assessment of verbal comprehension by examining looking time and pupil responses to predetermined known and unknown receptive words in children with ASD and typically-developing controls. They found that eye-tracking measures did correspond with verbal comprehension. Anderson, Savage and Colombo examined pupil responses of 8-12 year old children with high-functioning ASD to human faces and toys. The ASD group had a decreased pupil response to the human faces only. Unlike their previous investigations, this older ASD group spent less time scanning the human faces than controls, indicating a possible developmental trend in looking behaviors. Based on the decreased pupil responses, they hypothesize that young children with ASD are not processing socially-relevant stimuli; therefore, they decrease the amount of looking time to such stimuli over time. Dr. Rene Jamison found that direct instruction of skills, video modeling and coaching by neuro-typical peers improved communication skills in community settings for adolescent girls with ASD. Dr. Kathy Thiemann-Bourque's research showed that typically developing preschoolers can be trained to use picture exchange systems and Voice Output devices to increase social and communication behaviors with young nonverbal children with autism.

Dr. Matt Reese, director of the Center for Child Health and Development (CCHD) at KUMC and co-director of K-CART, provided clinical services to more than 700 children with autism and 1,500 children overall. Outreach trainings

across the state have benefitted more than 2,000 professionals and family members. Eleven weekly clinics at KUMC have reduced the age of diagnoses from 4.5 to 3.5, dramatically increasing the likelihood of critical early intervention services. In 2010, K-CART and CCHD produced the first database in Kansas containing critical information about children suspected of autism. The CCHD database is a searchable resource that compiles family medical history, lifestyle and information on health issues that surface with autism (for example, sleep problems).

The Kansas Statewide Training for Autism Waiver Service Providers at K-CART received a new 5-year contract from the Kansas State Department of Social and Rehabilitation Services. Directed by Linda Heitzman-Powell and Training Director Jill Koertner, the Autism Training Program at K-CART has provided 37 local and statewide training sessions for 325 persons to provide intensive early intervention services. Drs. Heitzman-Powell and Jay Buzhardt have also developed and tested the Online and Applied System for Intervention Skills (OASIS) program, a training system for parents who live in rural or remote regions of the state.

In the past year, K-CART hosted follow-up sessions for one of 16 national sites of the Advancing Futures for Adults with Autism (AFAA) National Town Hall meeting held in November 2009. This community advocacy group addresses housing, employment and community life issues. It is also piloting the Systems Navigator program, a model of case management with seven young adults with ASD. Funding for the AFAA effort is provided by K-CART, the Bi-State Autism Initiative, Children's Mercy Hospital and Clinics, and donations from the Border Challenge event sponsored by Project Change (a corporate challenge groups with SFS Architects) and the Boulevard Brewery, all in Kansas City, Mo.

K-CART, in partnership with Johnson County Community College, facilitates the Autism Support Club on the JCCC Campus. This club brings JCCC students with ASD and same-age peer mentors together to learn from each other, gain social skills and gain community experience.

K-CART and the Life Span Institute joined the Johnson County Community College in Overland Park, Kan. to host a statewide conference, Beyond the Diagnosis: Autism Across the Life Span in October 2011.

Centro Ann Sullivan del Perú

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 serves 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 university faculty from the KU departments of Special Education and Applied Behavioral Science.

Liliana Mayo, Ph.D., Director
Contact: lilimayo@annsullivanperu.org

FY 2011-2012 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, Ministries of Health and Justice, universities and banks in Peru. One hundred are enrolled in regular schools.

The Government of Panama adopted the CASP model to teach children with autism in Panama. The President and First Lady of Panama inaugurated the Centro Ann Sullivan Panama (CASAPAN) May 31, 2012.

The CASP online Long Distance Education Program produced 27 conferences between 2008 and 2012 for more than 22,000 parents and professionals in the 24 states of Peru and 14 countries.

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 first results of the study have been published in the July 2012 *Journal of Mental Health Research in Intellectual Disabilities*.

Liliana Mayo received the order of Maria Ossa de Amador award from the government of Panamá for making the Center Ann Sullivan Panamá (CASAPAN) a reality.

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