Investigators, research and administrative staff, graduate and postdoctoral students

The LSI brings together 154 scientists who are affiliated with several academic departments to study human development from its genetic origins to the final stages of life through 114 research projects. These investigators are supported by 196 research and administrative staff members, including 52 graduate research assistants and 43 student hourlies.

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 13 centers and Peruvian affiliate currently have 114 active programs and projects that constitute basic and translational research, training, direct services, consultation and technical assistance. Last year, thousands of Kansans benefited from the Institute’s direct services, training and technical assistance.

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 other research groups to form one of the premier research institutes in the world on human and community development and disability. Richard L. Schiefelbusch, for whom the Institute is named, directed the Bureau for 35 years. His appointment to lead the Bureau in 1956 was the beginning of its modern era.

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

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.

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 $28.2 million in sponsored project support in FY 2016. Each state dollar brought in $7.77 external dollars this fiscal year.
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Welcome to the 2016 Annual Report. As always, it is an informative—if not a wholly inspiring—experience to collect the stories of our scientists’ achievements and accomplishments over the past year. We are preparing this year’s report as the Life Span Institute is about to undergo a periodic review by the university. Thus, as I write this, my perspective is perhaps focused more deeply on the long-range view of the success that LSI has seen over this decade. In retrospect, what’s striking is that LSI’s achievements have been attained while working in remarkably precarious environments. The volatility of the federal and state funding base for research and service has been unprecedented, and we have seen significant changes at all administrative levels here at the University of Kansas over the past decade: three provosts, four deans of the College of Liberal Arts and Sciences, and three vice chancellors for research. Although we’ve had only one chancellor, Bernadette Gray-Little has recently announced her retirement effective at the end of this academic year.

This volatility is plainly reflected in our productivity across the last several years: starting with 2011, we have seen a pattern in which LSI alternates between drops in funding, only to roar back the next year and set a new record. Through all of this, however, the productivity of our scientists has been truly outstanding—from 2010–2016, our scientists published more than 1000 articles, chapters and books, and they are responsible for nearly $200 million in awards. I can confidently attribute this level of accomplishment to the perseverance of LSI’s longstanding traditions of competitiveness and entrepreneurship.

These traditions, however, are driven by our scientists’ commitment to core values: LSI investigators truly believe that their research makes a difference in the lives of individuals, and their emphasis is on making that difference for those individuals who may need it most—individuals with intellectual, developmental, or physical disabilities, children and families living in poverty, and individuals at risk for delay, deficit, or decline in their quality of life. The record shows that this key commitment continues to sustain and motivate our investigators in the face of change and upheaval.

"LSI investigators truly believe that their research makes a difference in the lives of individuals...with intellectual, developmental, or physical disabilities, children and families living in poverty, and individuals at risk for delay, deficit, or decline in their quality of life."
A gene on a “fragile” site of the X chromosome is the most common cause of inherited developmental disability and the leading genetic cause of autism. Fragile X Syndrome impacts not just individuals but families through generations. A mutation in the FMR1 gene occurring in one individual can result in descendants who are increasingly affected. A segment on the gene called a CGG triplet lengthens from the normal 5 to 40 repeats to more than 200 in people with full mutation FXS. Then the gene shuts down and prevents the production of a protein crucial to neural development. But even those with fewer repeats—both males and female carriers—are at risk for disorders later in life.

This is the background of one of the most important studies of this population to date. University Distinguished Professor Steven Warren and Associate Professor Nancy Brady, were awarded a five-year, $2.4 million grant from the Eunice Kennedy Shriver National Institute of Child Health and Human Development to continue their 10-year longitudinal study of the effect of parenting on 55 children with FXS, now adolescents, and their mothers.

“Because this is one of the longest studies ever on individuals with FXS, we can ask fundamental questions about the relationships between environment and development over time,” Warren said.

Those questions include how parenting behaviors, measured across early and middle childhood, influence the adolescents’ developmental trajectories and how these trajectories vary based on child gender, autism status and molecular measures of genetics.

Mothers are of particular interest in this study because female carriers of the mutation in the FMR1 gene often start showing some symptoms of the disorder such as anxiety and depression in their 40s and 50s when their children become adolescents.

The study will also examine the extent to which the parenting that the researchers observed in early and middle childhood predicts differences in adolescent behavior and development. The researchers saw the powerful effects of parenting on early vocabulary acquisition for which they found evidence even years later, as well as on cognition and adaptive behaviors.

“There is a lot of research on the biology of FXS, but much less on the environment’s effect over time,” Warren said. “Parents are usually a daily constant in their child’s lives, and their interactions have both short-term and cumulative effects on their children’s development and behavior. Consequently, they represent a nearly ideal environmental measure.”

Collaborators: Elizabeth Berry-Kravis, professor of pediatrics, neurological sciences and biochemistry at the Rush University Medical Center in Chicago; Leann Smith, assistant clinical professor and senior scientist at the University of Wisconsin Waisman Center in Madison and Kandace Fleming, associate scientist at the University of Kansas Life Span Institute.
Sophisticated analyses of two clinical trials—one in the U.S. directed by University of Kansas researchers John Colombo and Susan Carlson, and the other in Australia—suggest that thousands of risky early preterm births could be prevented if pregnant women took daily docosahexaenoic acid (DHA) supplements.

The two randomized controlled trials, in which pregnant women took daily DHA supplements, independently found statistically significant reductions in early preterm birth. The statistical model examined low, moderate and high risk preterm births from mothers supplemented with DHA during pregnancy as compared to placebo controls. The analysis estimated that more than 106,000 high-risk early preterm births could be avoided in the U.S. and about 1,100 could be prevented in Australia each year if pregnant women took daily supplements of the omega fatty acid.

Infants born very preterm—those at or before 34 weeks' gestation—often require lifesaving treatments and longer hospitalizations at birth and are at increased risk for additional hospitalizations in the first year of life, said Colombo, University of Kansas professor of psychology and director of the Life Span Institute. “Further, these infants are at risk for serious disability or death the earlier they are born.”

“At present there is no effective method to prevent spontaneous early preterm birth,” said Susan Carlson, A.J. Rice Professor of Nutrition at the University of Kansas Medical Center. “Our recent studies suggest that DHA could be a promising agent for reducing this critical public health problem.”

Both the KUDOS (Kansas DHA Outcome Study) and the Australian study, DOMInO (DHA to Optimize Mother Infant Outcome), saw a small overall increase in the length of gestation, but this increase was found to be related to the decrease in deliveries at higher risk for early preterm birth.

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 status, said Carlson. “U.S. women typically consume less DHA than women in most of the developed world. The intake of DHA in both the U.S. and Australia is well below that reported by Japanese women.”

KUDOS was supported by a grant from the Eunice Kennedy Shriver National Institute of Child Health and Human Development. The DOMInO trial was supported by the Australian National Health and Medical Research Council and was directed by Maria Makrides, professor of human nutrition and Healthy Mothers, Babies and Children Theme Leader for the South Australian Health & Medical Research Institute, and Robert Gibson, professor of functional food science at the University of Adelaide.
Cognitive science cannot yet explain how we are able to understand speech under a variety of conditions. The acoustics of a spoken message depend on the speaker, their dialect, the rate of speech and background noise, among other things, according to Navin Viswanathan, associate professor of Speech-Language-Hearing.

Despite this variability, human listeners reliably perceive speech seemingly effortlessly especially compared to contemporary speech recognition systems, he said. Take Apple’s Siri: It often seems that a user of the system gets trained to use Siri, instead of the other way around, said Viswanathan.

Viswanathan and his collaborators, Laura Dilley, assistant professor of communicative sciences and disorders at Michigan State University and Lisa Sanders, associate professor of psychological and brain sciences at the University of Massachusetts, Amherst, are bringing their combined expertise in cognitive psychology and cognitive neuroscience to try and answer the question of speech variability. Their project is tantalizingly titled, Making Words Disappear or Appear: A Neurocognitive and Behavioral Investigation of Effects of Speech Rate on Spoken Word Recognition. The grant is supported by the National Science Foundation.

For example, in the sentence, “Deana doesn’t have any leisure time,” their past research found that by changing the rate of speech that comes before “leisure time,” listeners hear either “leisure time” or “leisure or time.” Viswanathan said this offers clues on how we perceive speech.

“If we do similar things to the context part of the sentence, can we change both the number of words that are perceived as well as the phonetic properties of those words? That’s what we’re trying to figure out.”

There are more and more voice-activated systems that interact using human speech, but how well they solve the variability problem is going to be increasingly crucial, according to Viswanathan. Systems like caregiving robots for seniors that fulfill social functions will need to speak to and understand humans, including those with motor speech disorders caused by stroke or diseases such as ALS or Parkinson’s disease.

Beyond technological applications, there are clear clinical applications to understand how it is that we perceive speech. “It seems relatively effortless to understand speech, but it is not for everybody, and when things go wrong, if we understand how the basic mechanism that supports the perception of speech works, we can try to fashion interventions appropriately.”
The Life Span Institute’s Work Group for Community Health and Development has been re-designated as an official World Health Organization Collaborating Centre for Community Health and Development for another four years (2016-2020).

Vincent Francisco and Stephen Fawcett will co-direct the center that was initially designated by the WHO Director-General in 2004 to be part of an international collaborative network to carry out activities in support of WHO’s mandate for promoting health and health equity.

The KU Work Group will continue to work closely with the Pan American Health Organization (PAHO), one of WHO’s six regional offices. The center expanded the evidence base for health promotion efforts and built capacity for community health and development globally using the resources of the KU Work Group’s online Community Tool Box (CTB) at ctb.ku.edu, said Francisco.

In collaboration with PAHO, the CTB was made available in Spanish at ctb.ku.edu/es to help build capacity among Spanish-speaking peoples in the Americas. Site users can access in-depth support for developing a strategic plan or evaluation and can read case examples of culturally grounded work on issues such as promoting maternal and child health, nutrition, physical activity, sanitation and water quality.

The KU center has also worked with the WHO Regional Office for Africa in Brazzaville, Republic of Congo, for the last five years. Beginning in 2013, their work shifted to the Ebola epidemic, said Fawcett. “In particular, they asked us to help monitor and evaluate the response to the outbreaks in Liberia.”

One of the results of this collaboration with the African Region was a toolkit aimed at helping both health and non-health professionals to better address the root causes of what makes people sick or healthy, said Fawcett. The toolkit drew on the resources of KU’s CTB that reached over 5.8 million unique users last year. The Action Toolkit for Social Determinants of Health in the African Region at sdhaction-afro.org aims to strengthen learning and problem-solving skills to address a wide range of public health concerns.

“The Toolkit is being introduced as a just-in-time resource for policy makers, NGOs, academics and communities to be able to respond to any public health issue using learning and problem-solving skills contained in the framework,” said Fawcett.
What is the KU experience? For most it is an exciting and challenging
time of learning, friendships and fun that paves the way to the adult
world and employment. Now this will also be true for students
who might not otherwise go to college through the KU Transition
to Postsecondary Education for Youth with Intellectual Disabilities
program (KU-TPE), funded by a five-year grant from the U.S.
Department of Education.

The first group of students was accepted into the program for the fall
2016 semester. Those who complete the two-year program will leave
with a non-degree undergraduate career development certificate after
completing 24 credit hours. Ten more students will enter the program
in Fall 2017. The students pay tuition like every other KU student.

“The program will be of tremendous benefit to these students because
they will leave with credentials,” said Mary Morningstar, associate
professor of special education, who directs the program at the Beach
Center on Disability. “Our expectation is that they will complete the
program with improved skills and opportunities around adult roles
and responsibilities with a clear path to integrated paid employment.”

But KU will benefit as well, said Morningstar. With KU consistently
rated as one of the top special education programs in the nation, KU-
TPE will offer research opportunities as well as first-hand experience
to undergraduate and graduate students. And the program has also
connected to faculty and students in other fields, including social
welfare and pre-med.

“We see this as an opportunity for students to experience disability
from a much more personalized and inclusive approach than the
medical or the special education model,” said Morningstar.

KU students are also involved in KU-TPE as mentors offering
academic support and social involvement. Further, the residents of
Margaret Amini Scholarship Hall engage KU-TPE students in hall and
campus events.

Working with KU faculty to determine strategies for learning has been
“amazing” said Morningstar. “We have found faculty and instructors
to be creative problem-solvers to ensure that KU-TPE students are
fully included in class.”

Now nearly three months in, KU-TPE is proving to be successful.
“The students have all grown comfortable with getting around
campus, setting up transportation, developing a weekly schedule, and
managing and balancing their academic priorities with student life
and campus involvement commitments,” said Amber Grant, program
coordinator. “They are rockin’ it.”
The Kansas Intellectual and Developmental Disabilities Research Center (KIDDRC) has been awarded a five-year $5.40 million cooperative agreement from the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

The award provides support for administrative, statistical, participant recruitment, measurement methodology and various preclinical services to support the work of 43 scientists who hold 51 externally funded basic and applied research grants on the topic of intellectual and developmental disabilities at the Lawrence and Medical Center campuses, as well as at the Children’s Campus of Kansas City.

It also supports a research project that examines the efficacy of an intervention to improve spoken word production in minimally verbal school-age children with autism spectrum disorder. The research addresses an unmet need to promote spoken word production in children who remain essentially nonverbal well past the ages associated with speech acquisition.

The KIDDRC is one of only 14 nationally designated centers that seek to advance the diagnosis, prevention, treatment and amelioration of intellectual and developmental disabilities and has been funded since 1966 by the National Institutes of Health.

The bi-campus KIDDRC is directed by John Colombo, director of the Life Span Institute and professor of psychology at the University of Kansas main Lawrence campus, and co-directed by Peter Smith, senior associate dean for research and professor of molecular and integrative physiology at the University of Kansas Medical Center.

“This award was well-earned” said Colombo. “KU competed successfully in a pool against Harvard University, the University of Wisconsin, Children’s Hospital of Philadelphia and the Children’s National Medical Center in Washington, D.C. The agreement is an acknowledgement that the scientists at KU and KUMC who are doing research on intellectual and developmental disabilities are among the best in the nation.”

“The KIDDRC remains vibrant and relevant, continuing to serve vital research needs of the intellectual and developmental disabilities research community,” Smith noted. “It brings together cutting-edge technology so that teams of investigators can rapidly improve our ability to diagnose and treat developmental disorders.”

This award represents the continuation of a program envisioned by President John F. Kennedy in 1963 to promote and facilitate research on intellectual and developmental impairments.
The goal of HAIL is to empower consumers by giving them knowledge and skills to manage their own health and health care.

“HAIL addresses the fact that people with disabilities are often less healthy than people without disabilities and more likely to have a chronic condition like diabetes,” said Jean Ann Summers, research professor. “People with disabilities can be healthy, though, if they have equal access to health information and health-promoting activities.”

“The goal of HAIL is to empower consumers by giving them knowledge and skills to manage their own health and health care,” said Dot Nary, assistant research professor. “Since CILs are trusted advisors for people with disabilities, they are a perfect partner for our work.”

The HAIL team of Summers, Nary, Aruna Subramaniam and Alice Zhang built an online database that provides users with options for treating common health problems, plus information on skills for managing one’s health care, such as talking to a doctor (see hail.ku.edu). Then the research team trained CIL staff members to use the HAIL process with consumers who learned to set short- and long-term health goals.

For the participants in this pilot project, HAIL netted measurable results. Maria reached her goal of standing briefly and dressing herself. Bradley reduced his use of pain medications and exercised more. The experience empowered another consumer to say, “HAIL gave me the motivation. Now if I feel I’ve hit a plateau, I have the confidence to go back and find new ideas.”

Just as important, CIL staff members who took part in the research were able to integrate health information into the support they already provide consumers. A staff member from the Three Rivers CIL in Wamego, Kansas commented, “This is going to go well with people with disabilities who will want to stay home instead of entering an institution.”

—Val Renault, RTC/IL communications coordinator

Front row from left: Alice Zhang; Dot Nary; back row: Jean Ann Summers; Aruna Subramaniam

Learning how to improve health empowers people with disabilities

Maria* was critically injured in an act of domestic violence. Bradley,* a veteran, returned from Iraq with spinal cord and traumatic brain injuries.

Both turned to their local Center for Independent Living (CIL) for help navigating the world. Nonprofit CILs provide advocacy and services for people with disabilities, who are considered “consumers” of those services.

Through their CIL, Maria and Bradley joined a research intervention conducted by the Research and Training Center on Independent Living called Health Access for Independent Living (HAIL) funded by the National Institute on Disability, Independent Living and Rehabilitation Research.

*Names have been changed.
A clinical trial of book reading to help kindergarten children with Specific Language Impairment learn words has determined the number of times a child with SLI needs to hear a word to learn it. That would be 36 times or “exposures” compared to 12 times for typically developing children.

This is the first piece of evidence that could lead to the development of an effective treatment for children with SLI, something that Holly Storkel, who directed the trial, says is a critical need.

SLI is a subtle and often undiagnosed language impairment even though it is as common as ADHD—affecting about seven percent of children.

“Children with SLI have difficulty learning new words which puts them at risk for later reading problems and academic failure,” said Storkel, professor and chair of KU’s highly ranked Speech-Language-Hearing: Sciences and Disorders department.

The trial was a version of interactive book reading, a research-based strategy in which an adult discusses vocabulary words in a storybook with children before, during and after reading the book by describing or defining the word and showing other ways to use it. Although the average child learned only five words over the course of the trial, others learned as many as 12 to 14 words.

Now, in an ongoing study, Storkel is adjusting the treatment for children with SLI to increase the number of words learned. The aim is to determine if it is better for a child to hear a word many times in one reading and practice the book on fewer occasions; or to hear the word fewer times in one reading but practice the book on many different occasions.

One of the promising aspects of developing a treatment based on book reading is that it could be administered by parents and teachers with minimal training, said Storkel.

“For now, parents of children with SLI should realize that their children need to practice a new word often to be able to learn and remember it,” said Storkel. “When you notice that there is a word your child doesn’t know, try to find ways to work that word into everyday activities, conversations and book reading, and realize that this will need to be done over many weeks.”
Neuroscientist Jonathan Brumberg was awarded a New Century Scholars Research Grant by the American Speech-Language-Hearing Foundation to develop and test a brain-computer interface (BCI) that will directly control commercially available augmentative and alternative communication (AAC) devices for individuals with profound speech and motor disorders.

AAC devices, such as speech-generating devices, are widely used by those who would otherwise be unable to verbally communicate, including those who can only move their eyes. However, some individuals cannot even voluntarily move their eyes because of neurogenerative disorders such as advanced amyotrophic lateral sclerosis (ALS), brain trauma or brainstem stroke, said Brumberg, assistant professor of speech-language-hearing.

The BCI under development by Brumberg, who holds appointments in the speech-language-hearing department and electrical engineering and computer science, records the electrical activity of the brain from electrodes placed on the scalp and then uses those signals to directly interact with communication devices.

"If we’re able to elicit set patterns of activity, as long as the patterns are reliable, we can translate them into computer control signals—something that could select letters or symbols on a screen or even move a mouse cursor and click," Brumberg said.

With ALS, said Brumberg, the disease progresses from being able to walk and talk to being confined to a wheelchair and often losing the ability to speak.

Brumberg explained that they plan to teach individuals with ALS who are already using an AAC device how to use a BCI to control it while they still have enough cognitive ability and attention. This way they don’t have to learn something completely new if and when they lose their remaining motor activity.

"We want to make sure that we’re using their AAC device with the BCI because the BCI is hard enough to learn without learning a whole new communication system."

The study, which will have four participants with neuromotor impairment, will quantify the effectiveness of the integrated BCI-AAC device over an eight-week training period and identify both longitudinal performance and what, if any, neurological changes occur from learning how to control the BCI-AAC device.

The findings of this study will support Brumberg’s long-term goal of translating advances in BCI technology to clinical practice, including the adoption of BCI as an input access by manufacturers of AAC systems.
Judith (Judy) Carta, professor of special education and LSI senior scientist at the Life Span Institute’s Juniper Gardens Children’s Project, is the 2016 recipient of the Irvin E. Youngberg Award in the Applied Sciences. The award is one of the four Research Achievement Awards given each year that recognize research accomplishments of researchers at Kansas Board of Regents institutions. The prestigious awards were established in 1981 through the KU Endowment Association by the late Takeru Higuchi, Regents Distinguished Professor of Chemistry and Pharmacy, and his wife, Aya. Each $10,000 award supports the recipient’s research program.

Carta’s nominators noted her seminal contributions to the fields of early intervention and early childhood special education that have influenced changes in social policy and improved the quality of services that children and family receive across the state and nation. Since 2014, she has been the director of the Bridging the Word Gap National Research Network, made up of more than 100 nationally recognized researchers, practitioners, policymakers and funders working together to develop and push forward a coordinated national research agenda to reduce the number of children who enter school with delays in language and literacy.

The Irvin Youngberg Research Award is given in recognition of research achievement in the applied sciences “to an individual who may be described as having had a major and substantial impact and whose work has been of significant relevance to the State of Kansas. This individual’s research should be characterized either as profoundly seminal in nature or as representing a productive record of significant research.”

Michael L. Wehmeyer, Ross and Marianna Beach Distinguished Professor of Special Education, director and senior scientist at the Life Span Institute’s Beach Center on Disability and co-director at the LSI’s Kansas University Center on Developmental Disabilities, received the 2015 Balfour Jeffrey Research Award in the field of the Humanities and Social Sciences.

Wehmeyer was described by his nominators as “the foremost researcher in the world in an area of study in education and psychology known as self-determination. He has focused primarily on its application to adolescents and adults, especially those with intellectual and developmental disabilities.”

The Balfour Jeffrey Research Award recognizes research achievement in the humanities and social sciences that has had “major and substantial impact.” Further, the “individual’s research should be characterized either as profoundly seminal in nature or as representing a productive record of significant research and expanding intellectual or societal insights.”
As a newly minted Ph.D. in the late 1960s, Professor Emeritus Stephen Schroeder received dozens of small grants before grabbing the academic equivalent of the brass ring—a major grant from a federal agency. The time and effort it took left an impression.

Now, after a long and distinguished career in biobehavioral science, including 11 years as the first director of the Life Span Institute, Schroeder, and his wife, Carolyn, have stepped forward to help young LSI investigators conduct pilot research that can lead to federal funding earlier in their careers.

Through a major gift to the KU Endowment Association, the Schroeders have established the Stephen and Carolyn Schroeder Young Investigator Award for Research in Neurodevelopmental Disorders. The endowed fund will support one or more awards annually to a graduate student, postdoctoral fellow or junior faculty member affiliated with LSI who plans to conduct basic or applied research, preferably biobehavioral, in neurodevelopmental disorders. This would include research in autism spectrum disorder, developmental disabilities, intellectual disabilities or neuroscience.

The award will enable investigators to complete pilot research, learn competent grantsmanship and improve their eligibility for funding from the National Institutes of Health, the National Science Foundation and related agencies. Senior LSI scientists will select recipients in a peer-review process using the criteria of the targeted federal agency. “This will help new investigators receive helpful feedback from experienced reviewers at LSI and to be successful earlier in their careers,” said Schroeder.

“We are honored by this gift from Steve and Carolyn,” said John Colombo, LSI director. This will allow us to sustain and support junior faculty working in neurodevelopmental disabilities. The gift is especially meaningful to me personally, as I consider Steve to be a mentor for many aspects of my own work in intellectual and developmental disabilities.”

Schroeder earned his Ph.D. in experimental psychology at the University of Pittsburgh and became one of the nation’s preeminent researchers in experimental psychology and pharmacology, focusing on biobehavioral approaches to help people with intellectual disability and self-injurious behavior.

Carolyn Schroeder, an adjunct faculty member in the Department of Clinical Child Psychology, is widely recognized for the establishment of a model for psychologists’ participation in primary care pediatrics.

The Schroeders have also established the Carolyn and Stephen Schroeder Practice-Informed Research Award, an endowed fund for the benefit of clinical child psychology at KU.

The first Stephen and Carolyn Schroeder Young Investigator awards will be announced in spring 2017.

—Mary-Margaret Simpson

“"The gift is especially meaningful to me personally, as I consider Steve to be a mentor for many aspects of my own work in intellectual and developmental disabilities.""
During the 2016 fiscal year, the Life Span Institute generated $28.2 million in awards. Although this amount is down from $32.8 million in the previous year, 2015 was the highest year for generation of external awards in LSI’s long history. In 2016, LSI held a total of 113 awards, with 103 continuing awards and 10 new ones.

Federal awards still account for the vast majority (84 percent) of LSI funding at $23.7 million. Other sources contributing to the overall total include the state of Kansas at $2.5 million (9 percent), private foundations at $0.8 million (3 percent), other state agencies at $0.5 million (2 percent), and industry/other funding sources at $0.6 million (2 percent). Awards from the National Institutes of Health accounted for $6 million; awards from the U.S. Department of Education accounted for $13 million. Another $4.2 million in funding was generated by awards from the U.S. Department of Health and Human Services. An additional $0.4 million was generated from the National Science Foundation, Federal Communication Commission and the U.S. Department of Homeland Security.

The LSI represents a high return on investment. In 1990, LSI returned $3.30 on every dollar the state of Kansas invested in the Institute. In 2016, every state of Kansas dollar invested in LSI yielded $7.77 in external awards.

In keeping with KU Center for Research reporting policy, funding to LSI from 2008 to 2011 that is attributable to the American Recovery and Reinvestment Act of 2009 is not included here.
The Life Span Institute Affiliated Centers

Beach Center on Disability

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. Founded in 1988 by KU Distinguished Professors Emeriti 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.

Michael L. Wehmeyer, Ph.D., Director
Karrie A. Shogren, Ph.D., Associate Director
Jean Ann Summers, Ph.D., Associate Director and Coordinator, Family Programs
Mary Morningstar, Ph.D., Director, Transition Coalition
Kathleen Lane, Ph.D., Director, CI3T Projects
Contact: 785 864-7600, beachcenter.org

FY 2015–2016 Highlights

The Beach Center on Disability is home to multiple investigators and researchers who focus on research to improve the lives of people with intellectual and developmental disabilities. Director Michael Wehmeyer and Associate Director Karrie Shogren, along with Susan Palmer, have multiple projects on developing assessments of self-determination, measures to promote the design of supports related to supported decision-making, and research on interventions to promote the self-determination of youth and adults with intellectual and developmental disabilities. In January 2016 James Thompson joined the Beach Center staff as professor and senior scientist. Thompson, Shogren, and Wehmeyer focus their research on the measurement and impact of supports and support needs for people with intellectual and developmental disabilities.

The Beach Center’s Kansas Institute on Positive Behavior Supports, headed by Jennifer Kurth, principal investigator, and Matt Enyart, project director, conducts training around the state and supports web-based materials pertaining to PBIS.

The Comprehensive, Integrated, Three-Tiered (CI3T) Prevention Research Project team, led by Kathleen Lane, works with schools in Lawrence and around the country to implement high-quality multi-tiered systems of supports (MTSS).

The Transition Coalition, led by Mary Morningstar with Dana Lattin, provides online information, support and professional development on topics related to the transition from school to adult life for youth with disabilities. This is accomplished by designing training that leads to change and supporting school and community teams as they learn research-based effective practices. The team has developed a combination of face-to-face and online training as a hybrid approach to technical assistance. A core focus of the team’s professional development is incorporating self-assessment, learner-centered hybrid learning, communities of practice, social networking and ongoing technical assistance and support. Among the highlights of the year was the receipt of a new grant to develop a post-secondary education program for young adults with intellectual disability at KU.

Judith Cross directs the Beach Center Family Employment Awareness Training project, which promotes awareness of employment options among parents and family members with intellectual and developmental disabilities.

Jean Ann Summers and Martha Blue-Banning are long-time Beach Center investigators, furthering the Center’s focus on families.

The Beach Center is the academic home for a number of doctoral students in the KU Department of Special Education, the top-ranked special education graduate program in the country. Kurth, Lane, Morningstar, Shogren, Thompson and Wehmeyer hold faculty appointments in the department and host several visiting scholars and doctoral students throughout the year.

This year Evan Dean served as the Borchardt Family Post-Doctoral Fellow, working with Shogren and Wehmeyer on activities to increase participation in life by people with intellectual disability. The fellowship is generously supported by the Borchardt Family through the KU Endowment Association.

Biobehavioral Neurosciences in Communication Disorders Center

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
Contact: 785 864-4570, bncd.ku.edu

FY 2015–16 Highlights

Fifteen investigators are affiliated with the BNCD with research interests that include 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.

Center for Research on Learning

The Center for Research on Learning (CRL) was established in 1978 as the Institute for Research in Learning Disabilities and currently includes 38 researchers and support staff dedicated to the Center’s four-fold mission of research, product development, dissemination/system change and professional learning. Researchers study problems in education and work to place solutions that make a difference into the hands of educators, learners, employers and policy makers.

Michael Hock, Ph.D., Director
Contact: 785 864-4780, crl@ku.edu

FY 2015-2016 Project Highlights

The Center’s research teams and their focus are as follows.

- ALTEC, guided by Marilyn Ault, Jana Craig-Hare and Amber Rowland, designs, develops and evaluates effective use of educational technologies in K-12 instruction and uses technologies to engage learners.
- The Center on Online Learning and Students with Disabilities, led by Sean Smith, Jamie Basham and Daryl Mellard, conducts research on how online learning can be made more accessible, engaging and effective for K-12 learners with disabilities.
- The e-Learning Collaborative, led by Mellard, studies and develops new uses of technology to improve online learning environments and pedagogies.
- The Institute for Research in Adolescent Learning, co-directed by Irma Brasseur-Hock and Michael Hock, designs and validates instructional practices, strategies and programs that enhance the achievement of adolescents who struggle with learning.
- The Kansas Coaching Project, led by James Knight, conducts research on instructional coaching (including virtual coaching) and professional development intended to teach educators how to use proven instructional methods.
- The Professional Development Research Institute, directed by Patty Graner, studies ways to design and deliver quality professional learning opportunities and support to teachers with the ultimate goal of improving student achievement.
- The Research Collaboration, co-directed by Amy Gaumer-Erickson and Pattie Noonan, provides professional development and evaluation for numerous diverse education projects.
Activities for the year include:

- Brasseur-Hock’s online course “Blended Instructional Design” was presented at the Flipped Learning Network, the SIM conference and the KU TechEd camp. She launched and continues to study the Fusion Reading program (Brasseur-Hock, Deshler, Hock, 2012) in Virginia, North Carolina, Minnesota, Iowa and New York. She also is leading efforts in Virginia to study how blended professional development can impact teacher fidelity of implementation and student outcomes.

- Craig-Hare strengthens research-practitioner partnerships through her work with K-12 districts and schools. She was recently selected as a fellow by the Research-Practitioner Collaboratory, funded by the National Science Foundation (NSF). She also received the International Society of Technology in Education Making IT Happen Award for her contributions to helping teachers integrate technology.

- Rowland continues as co-principal investigator for the NSF grant “Enhancing Argumentation with Social Media: Supporting Teacher Professional Learning and Student Science Practice,” which is studying how social media can support teacher professional learning and student practice of scientific argumentation in high school biology classrooms. She also is project director of a U.S. Department of Education, Office of Special Education Programs Stepping Up grant with Smith.

- Ault, Craig-Hare and Rowland were designated by the KU Emily Taylor Center for Women and Gender Equity as women innovators who are advancing learning through technology. The group is featured in the KU Women of Distinction 2016-17 calendar, which celebrates women who serve as role models, mentors and leaders, challenging stereotypes and inspiring others to promote women’s access, opportunities and equity.

- Janis Bulgren is the principal investigator on a subcontract for an i3 (Investing In Innovation) Development Grant: “Redesign of Secondary Courses to Improve Academic Outcomes for Students with Disabilities and Other Underperforming Students with Mobile Technologies.”

- Noonan and Gaumer-Erickson continue to lead the Kansas TASN evaluation. This five-year evaluation project provides a comprehensive evaluation of educators’ acquisition of knowledge and skills and the implementation of evidence-based practices that address the current Kansas State Department of Education statewide priorities.

- Mellard, Smith and Basham recently wrote a report for the Equity Matters series published by the Center on Online Learning and Students with Disabilities. The report is available at http://centerononlinelearning.org/publications/annual-publication-2015/

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**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 Perú 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 research, demonstration and training center and for its Function-Natural Curriculum developed by Judith LeBlanc and the staff of CASP. Mayo has been supported by a steady stream of KU colleagues who have volunteered as consultants, trainers and fundraisers; notably, LeBlanc, who has served as CASP research director for more than 35 years, retired Life Span Director Stephen Schroeder and his wife, Carolyn Schroeder. CASP has a formal agreement with LSI and receives much of its staff education through faculty from the special education and applied behavioral science departments at KU.

- Liliana Mayo, Ph.D., Director

  Contact: limayo@annsullivanperu.org

**FY 2015-16 Highlights**

CASP educates more than 450 people with different abilities and their families annually. Teamwork between the staff and families prepares students for inclusion in life, school and work. More than 110 individuals currently hold positions in real jobs for real pay in small and large companies, in the Ministries of Health and Justice, and in universities and banks in Perú. This year marked a historic event in Perú and a first for CASP: six students with different abilities were hired to work in the Congress of Perú. Sixty percent of CASP students who are working are the primary economic support for their families and 100 students are included in 53 regular schools.

In August CASP was asked by the National Bank of Perú to train more than 600 employees in order to improve the treatment of clients with different abilities. Through this simulation workshop, I Am A Client, Too, participants experienced motor problems, used a wheelchair, and learned what it was like to be non-verbal and visually impaired. It was the first time in Perú that a private sector business requested this kind of training.

Through the Long Distance Education Program, CASP conducted 44 conferences for more than 33,394 parents and professionals in the 24 states of Perú and in 15 other countries: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Germany, Guatemala, Honduras, Italy, México, Nicaragua, Panama, Spain and the United States.

This year Delta Airlines will complete its fourth simulated travel experience at CASP to allow students to experience all the steps involved in airline travel. A complete simulated airport is built at CASP with check-in counters, security, boarding gate and the cabin of an airplane. Last October more than 200 students participated in a simulated flight from Lima to Atlanta. This year students will “travel” from Lima to Los Angeles and back to Lima. The project earned Delta Commercial Manager Delia Ortega the 2016 Advisory Board Award for unique innovation.

This year marks the second “Mother-to-Mother” project, which trains families and professionals throughout Perú. Ten teams comprising a mother and child with different abilities and two CASP professionals travel to 10 cities to train more than 100 families in each location. Peruvian Airlines donated 42 airline tickets. This year students from two Peruvian Universities also will participate.

With the Australian embassy, CASP launched “Garden and Healthy Cooking for People with Different Abilities: Pilot Project in Perú.” The project includes a garden on the grounds of CASP and a fully equipped kitchen. The purpose is for CASP students to learn skills for growing and caring for plants and to use what is harvested for preparing meals, desserts and healthy drinks. This project, part of the Functional-Natural Curriculum at CASP, provides opportunities to teach a wide range of skills.

With the support of funding by benefactors, CASP continues to follow 50 children from the 2013 R21 project, Early Prevention of Neurodevelopmental Behavior Disorders among Young At-Risk Children in Perú. With adequate funding, CASP hopes to follow these children into adulthood. Steve Schroeder and Erin Atwood, both affiliated with KU, visit CASP each year to follow student outcomes and interview families.

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**Child Language Doctoral Program**

The Child Language Doctoral Program (CLDP) 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 bring diverse approaches to the study of how children communicate and speak. The program offers students a wide choice of research tools, facilities and affiliated research labs, including large-scale longitudinal studies of children with language impairments, genetics of speech and language impairments and language intervention studies of children with a wide range of language impairments including those using communication devices. LSI, the Language Acquisition Preschool and the clinical and research facilities of the Speech-Language-Hearing Clinic provide research sites and practical experiences.

- Mabel L. Rice, Ph.D., Director

  Contact: 785 864-4570, cldp.ku.edu

**FY 2015-16 Highlights**

The CLDP is affiliated with the departments of applied behavioral sciences, clinical child psychology, linguistics,
molecular biosciences, psychology and speech, language and hearing. Over the last year the collaborative structure of the CLDP has expanded to establish the CLDP as an entity that provides faculty appointments and new course development that complements those of the affiliated departments. Lesa Hoffman, Ph.D., was the first direct faculty appointment in the CLDP. She has a split appointment as professor in the CLDP and as the scientific director of the Research and Design and Analysis unit within LSI. She is an outstanding quantitative scholar with multiple projects funded by the National Institutes of Health. She also is well known as a teacher and consultant and is the sole author of a textbook on longitudinal analyses. She teaches new advanced coursework on modeling methods for longitudinal and multivariate studies of children’s development. Her courses include Latent Trait Measurement and Structural Equation Models and Advanced Multilevel Models, Multilevel Models for Longitudinal and Repeated Measures Data.

The second faculty member in the CLDP is M. Hashim Raza, a research geneticist who worked at an internal research lab at the National Institute of Deafness and Other Communicative Disorders. Raza joined the CLDP as an assistant professor in 2015. He is an expert in pedigree-based genetic analyses that have led to the identification of candidate genes for stuttering. He is moving into genetic studies of families with language impairments. Raza developed three new doctoral-level courses in genetics of speech and language impairments: Concepts in Human Molecular Genetics, Principles to Study Human Genetic Disorders, and Behavioral and Cognitive Genetics. One of the new courses will be offered in a collaborative format with Mabel Rice in order to bridge the scope of genetics investigations, from molecular biology to behavioral phenotyping of speech and language impairments. Students currently enrolled in the CLDP are Claire Selin, Teresa Giralomo, Heather Fielding, Erin Andres and Lindsay Williams.

Juniper Gardens Children's Project

The Juniper Gardens Children's Project (JGCP) began in 1964 when citizens from northeast Kansas City, Kan., 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 that collaborates with local and national community sites developing projects and investigations. JGCP is currently located at the Children’s Campus of Kansas City, four blocks from the original JGCP site. The CCKC is a state-of-the-art facility where JGCP researchers are located with a model educational center and social service agencies serving low-income families and children. This research-program partnership was developed to address issues of children and families in poverty and serves as a center for training and technical assistance in the Kansas City metropolitan area.

JGCP is particularly recognized for its contributions to the development of effective approaches for accelerating learning and reducing classroom conduct problems in special and general education and for developing innovative approaches to reduce the achievement gap. JGCP has received the Research Award of the International Council for Exceptional Children in recognition of its outstanding research contributions to the field. In recognition of its 50 years of service, November 7, 2015 was proclaimed Juniper Gardens Children’s Project Day in Wyandotte County/Kansas City, Kan. by the Honorable Mark R. Holland, Mayor/CEO, Unified Government of Wyandotte County/Kansas City, Kan.

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 2015–2016 Highlights (50th Anniversary Year)


JGCP continues its research that is focused on school-age children, including those with challenging behavior and severe emotional and behavior problems. Work in the schools focuses on the researcher/practitioner partnership with paraprofessionals trained to use evidence-based practices via local research-practice partnerships (Mason).

Behavioral self-management is developing online modules and telecoaching studies for teens (I-Connect [Wills]) and young adults with ASD (I-CONNECT Plus [Wills]). Peer networks are changing the social well being of students with ASD (Kamps, Thiemann-Bourque, Heitzman-Powell).

JGCP is a leader in developing digital applications that support community-engaged research and practice. Mobile phones and tablet devices running Android and Apple OS are used to support intervention implementation, providing real-time practitioner advice and data-based feedback and support. JGCP continues to serve as a leader in cell phone texting and contacting to reduce attrition from interventions serving high-risk mothers (Carta, Bigelow), recently extending to help Early Head Start program parents implement communication interventions at home with their infants and toddlers (Bigelow, Walker). An app to increase parents’ talk to their infants when in community settings was selected as a finalist in the Bridging the Word Gap Challenge prize (Talk Around Town [Bigelow & Irvin]) sponsored by the Health Resources and Services Administration. Advances in automated behavioral imaging were made by merging two digital sensors (LENA & Ubisense) to portray Who is Talking to Whom and Where in the preschool classroom using heat map displays (Irvin & Greenwood). The Individual Growth and Development Indicators (IGDIs) online data system, now 11 years old, helps guide practitioners’ intervention decisions with at-risk infants and toddlers. It has been enhanced in a revised website, a hand-held support app, and improved benchmarks for cognitive problem solving and movement IGDIs (Buzhardt, Walker, & Greenwood). The Distance Mentorship Program (Buzhardt & Summers), a cloud-based tool that supports K-12 teachers working with students who are deaf-blind, teaches specific classroom strategies for technical assistance providers to deliver distance coaching to rural and remote schools.

Kansas Center for Autism Research and Training

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
Kathryn Ellerbeck, M.D., Co-Director
Contact: 913 897-8472, kcart.ku.edu

FY 2015–2016 Highlights

K-CART promotes research and train on evidence-based practices by training professionals, practitioners and families to serve individuals with autism. Ten pilot studies were originally funded and findings from these grants supported new research initiatives. Among these was I-CONNECT Plus, which developed instructional modules, tele-coaching and self-management to support adolescents and young adults on the spectrum (Kamps, Wills, Mason). Another was a study by Kathy Thiemann-Bourque on the use of I-Pads to increase social-communication skills for non-verbal preschoolers with autism and their peers.

In 2015 funding from the KU Strategic Initiative enabled a critical expansion for K-CART to address the neuroscience
and neurocognitive aspects of autism. A nationally known researcher, Matthew Mosconi, was recruited to lead this effort. A psychologist and neuroscientist in ASD previously at the University of Texas Southwestern, Mosconi is expected to increase the national profile of KU in the field of ASD. He is serving as Director of Clinical Translational Research for K-CART.

The Autism Training Program (ATP), designed for individuals wanting to provide early autism intervention services and funded by the Kansas Department of Children and Families, has conducted 86 trainings and trained 1,139 individuals since its inception. The OASIS Parent Training Program is assessing the training of parents of children with autism on how to implement behavioral techniques with their child. Findings from this research were published in Advances in Medicine (2013). This research recently transitioned into a clinical service at the Center for Child Health and Development (CCHD) at the KU Medical Center. Recent funding from National Institute on Disability, Independent Living and Related Research will enable the dissemination of the intervention for broader use. Anticipated outcomes include fully trained OASIS coaches at key agencies serving children with autism and structures for successful reimbursement, ultimately resulting in improved parenting behaviors with a beneficial impact on child outcomes.

The Bridge Clinic, which is for children recently diagnosed with autism, provides short-term behavioral intervention until services can begin with a community provider.

CCHD provides clinical evaluations, diagnostics and services. Guided by Kathryn Ellerbeck, K-CART co-director, approximately 1,200 children are seen annually, more than 700 with autism. To better serve rural populations in Kansas, CCHD has 20 telemedicine clinic slots per month and has pioneered diagnosis and treatment via telemedicine. Ellerbeck was recently awarded a LEND grant for five years of renewed funding to provide high-quality interdisciplinary graduate-level education to long-term trainees, engage university faculty from a variety of disciplines to encourage interdisciplinary training, and ensure that the CCHD LEND programs are engaged in the national LEND network to foster collaboration.

CCHD has developed its leadership capacity in bioinformatics for people with autism. Since 2009 CCHD has used the Comprehensive Research Information System to track all intakes. For the 2016 CCHD transitioned to a Redcap system to collect clinical, assessment and research data. This includes a patient portal, allowing families to complete their child’s diagnostic history online. CCHD now has a searchable database of more than 6,000 patients, including more than 300 data items regarding medical and diagnostic history. The Kansas Intellectual and Developmental Disabilities Research Center supports work on the database.

K-CART continues to offer an Autism Resource Center at KU Edwards Campus, designed to meet the needs of families who need assistance locating community resources and identifying evidence-based interventions and treatments. K-CART, in partnership with Johnson County Community College, hosts an annual conference on “Beyond the Diagnosis: Autism Across the Life Span.” The 2017 conference will be held March 3. The partnership also includes an on-campus ASD Support Club for JCCC students.

**Kansas Intellectual and Developmental Disabilities Research Center**

The Kansas Intellectual and Developmental Disabilities Research Center (KIDDRC) serves as the predominant focus for intellectual and developmental disabilities (IDD) research at the University of Kansas by supporting basic research on various neurodevelopmental disorders and early interventions that improve cognitive, language and social outcomes in typically developing children and children with disabilities. In 2016 KIDDRC was renewed for the first time as a cooperative agreement (U54) with the Eunice Kennedy Shriver National Institute for Child Health and Human Development. The renewed Center provides investigators with administrative, preclinical, clinical-translational, measurement and statistical/bioinformatics services, and it also supports a randomized clinical trial on an intervention for improving communication in extremely low-verbal children with autism spectrum disorder.

The Center provides a focus for the development of new investigators in IDD; significant numbers of junior scientists are mentored within KIDDRC-associated training grants. In 2016 KIDDRC had 43 investigators and co-investigators, including four new junior principal investigators (PIs). KIDDRC’s portfolio currently contains 51 projects, most funded by the National Institutes of Health or awarded through NIH-equivalent peer review. KIDDRC PIs routinely collaborate with other KIDDRC scientists within the institution, and more than one-third of our investigators collaborate with KIDDRC investigators across the three Center sites. This culture of collaboration extends to interactions with other IDDRCs: many of our PIs collaborate with IDDRCs at other universities, including Vanderbilt, University of North Carolina-Chapel Hill, University of Washington, University of Wisconsin, Washington University (St. Louis) and Johns Hopkins/Kennedy Krieger.

Over the past five years, the KIDDRC has recruited 35 new investigators to research in IDD, and has generated 443 publications; over that very short period, these publications have generated 5,807 citations (an average of 13.1 citations per paper), and the collective h-index derived for the KIDDRC from this collection of publications is 36.

**Kansas University Center on Developmental Disabilities**

More than 45 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 LSIs 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 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., Co-Director
Karrie A. Shogren, Ph.D., Co-Director
James R. Thompson, Ph.D., Associate Director for Consumer Activities
Susan B. Palmer, Ph.D., Associate Director for Applied and Translational Research
Kathy Ellerbeck, M.D., Director, KUCDD-Kansas City Site
David Lindeman, Ph.D., Director, KUCDD-Parsons Site
Sara Sack, Ph.D., Director, Assistive Technology for Kansans Project
Jennifer Kurth, Ph.D., PI, Kansas Institute for Positive Behavior Supports
Contact: 785 864-4295, www.kucdd.org

FY 2015–2016 Highlights

Faculty at the Center for Child Health and Development (CCHD) at the University of Kansas Medical Center, affiliated with the KUCDD Kansas City site, provided early identification and intervention development through healthcare screening and evaluation of autism diagnosis and screening to 64 families and children throughout Kansas via the Autism Referral Evaluation telemedicine clinics. Families who were served by telemedicine lived an average of 180 miles from KUMC. Through the Rural Outreach Clinics operated by the CCHD and the Kansas Children with Special Health Care Needs project, KUCDD Kansas City-site faculty provided rural outreach clinics in four communities, serving almost 48 families who would not otherwise have had access to such services. Further, special arrangements were made to serve military families at Kansas bases, including Ft. Riley and Ft. Leavenworth.

The Assistive Technology for Kansans (ATK) project, operated by the KUCDD-Parsons site, provided training on the availability and use of assistive devices and services to 475 people in Kansas and across the United States, and direct technical assistance on the use of AT devices to 426 Kansans at multiple sites across the state. Further, ATK lent devices to 501 people with disabilities for them to try out in their homes, schools, work places or communities.

The Gateway to Self-Determination Project operated by KUCDD Lawrence-site faculty engaged in training and technical assistance on promoting and enhancing the self-determination of adults with intellectual and developmental disabilities. The project also conducted training and technical assistance activities to support efforts to promote the self-determination of people with intellectual and developmental disabilities across Kansas and the United States.

The Kansas Inservice Training System (KITS) developed and implemented 17 technical assistance (TA) plans for early intervention providers or preschool special educators in Kansas. These TAs are highly intensive with written plans identifying outcomes, needed resources, persons responsible, evaluation methods and goal attainment scales. This current year, TA plans had an impact on 29 administrators, 256 professionals and 7,008 children.

Life Span Institute at Parsons

As the founding Center of the Schiefelbusch Institute for Life Span Studies, LSI at Parsons has worked with national, state, regional and community partners to conduct research, develop model service programs and provide training for professionals involved in services for individuals of all ages with disabilities and their families. Located in southeast Kansas, the Center includes a component of the Kansas University Center on Developmental Disabilities and the Parsons Research Center.

David P. Lindeman, Ph.D., Director
Contact: 620 421-6550, ext. 1713, parsonslsi.ku.edu
FY 2015–2016 Highlights

Faculty and staff provided training or technical assistance to 8,809 Kansans in all 105 Kansas counties and 727 individuals at national conferences.

Faculty and staff provided training and technical assistance through the Kansas Inservice Training System (KITS) to 256 teachers and service providers and 29 administrators through individualized technical assistance plans, resulting in a potential impact on 7,008 children and families. In addition, 1,920 professionals were engaged in other training and professional development events.

An LSI Parsons investigator partnered with Kansas Child Care Training Opportunities, Inc., to initiate a new statewide training and technical assistance project for childcare providers who deliver services to infants, toddlers and their families. This project is designed to increase the access to and quality of services.

LSI Parsons served 3,168 Kansans with disabilities and chronic health conditions at six sites where individuals accessed more than 5,172 assistive technology (AT) services and acquired nearly 2,000 AT devices valued at more than $1.5 million.

The following Kansans received AT services from LSI Parsons in 2015-16:

• 122 infants and toddlers with disabilities and their families

• 311 adults with disabilities who were retraining or obtaining employment

• 88 farmers, ranchers and other agricultural workers

• 1,956 seniors needing services to stay in their homes or be active in their community

• 1,363 who received training on the use and maintenance of an assistive device

Assistive Technology for Kansans (ATK) was one of four state programs invited to present to the U.S. Department of Education. ATK provided technical assistance in 14 states.

ATK provided services to 83 individuals during the second year of operating the iKAN Connect advanced telecommunication grant for individuals who are deaf and blind as part of the National Deaf Blind Equipment Distribution Network.

Faculty and staff supported 75 individuals with disabilities who participated in the ATK project focused on developing basic technology skills, “Achieving Employment and Health Goals with Digital Technology.” Thirty-four of the 75 participants found employment using their new digital technology skills and 13 individuals made it to the interview stage.

LSI Parsons collaborated with Kansas State University to operate the AgrAbility project to assist injured farmers and ranchers in acquiring technology and modifying production activities to support returning to agricultural employment.

LSI Parsons also operated the Telecommunication Access Program (TAP) and the Dual Party Relay System. TAP provides telecommunications equipment to individuals earning $55,000 a year or less who have trouble using traditional telecommunications due to vision, hearing, motor, cognitive or speech difficulties.

With a KU Strategic-Initiative Grant, a cross-departmental team headed by a Parsons researcher is developing a computerized assessment of early reading skills, including phonemic awareness and the alphabetic principle. The assessment does not require spoken responses and will fill a critical need for assessments suitable for children with speech impairments.

LSI Parsons investigators are collaborating with KU colleagues to assess the incidence of problematic activity transitions in different populations of individuals with IDD including autism spectrum disorder and Fragile X.

LSI Parsons investigators are developing procedures to assess genetic rodent models of IDD to determine if variables that trigger self-injurious and aggressive behaviors in patients also trigger maladaptive behaviors in rodent models.

With funding from the National Institutes of Health (NIH), LSI Parsons researchers collaborated with Johns Hopkins and the University of Massachusetts Medical Center to examine novel mechanisms controlling self-injurious and aggressive behavior in people with IDD and assess potential new treatments.
With funding from the Office of Special Education Programs, LSI Parsons developed specialized computer assisted training procedures for teachers to prepare children for hearing assessments who do not follow verbal instruction.

**Merrill Advanced Studies Center**

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

**Research and Training Center on Independent Living (RTC/IL)**

FY 2015-2016 Highlights

In the past year, RTC/IL researchers have been completing projects to enhance community living and participation for people with disabilities, funded by a five-year grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR). Glen White directs the intervention “Building Capacity for Full Community Participation,” partnering with KU’s Work Group on Community Health and Development. Jean Ann Summers leads “Health Access for Independent Living.” (See page 8.)

In June 2016 White shared his insights on community living as a panelist for the National Academies of Science, Engineering and Medicine’s Forum on Aging, Disability and Independence.

The Center awarded its inaugural Community Living Research Award to graduate student Marren Leon-Barajas, who studied weight loss and community participation for individuals with intellectual disabilities.

Our research and training portfolio also includes “Access to Success,” in which Summers and White are training college students with disabilities how to request accommodations and advocate for themselves. Summers and Dot Nary are partnering on “Resilience in Community Participation” with the University of Montana, and Nary, Martha Hodgesmith and Val Renault are developing training for a new Medicaid Home and Community-Based Services functional assessment for the state of Kansas.

**Benefiting Consumers**

Through ongoing dissemination of information, the RTC has established connections with organizations and agencies that may translate our research findings into programs, practices and policies that benefit consumers.

In November 2015 White and Jessica Dashner, partner from Washington University in St. Louis, presented information on the Community Health Environment Checklist (CHEC) to the Centers for Medicare and Medicaid Services (CMS) as part of a “Listening Session on Adding Accessibility Information to Physician Compare,” an online resource.

White and graduate research assistants E (Alice) Zhang and Kelsey Shinnick presented research on parking access to the Kansas Commission on Disability Concerns (KCDC) in November 2015. As a result, KCDC has endorsed a Center brochure about accessible parking etiquette, and the Kansas Department of Revenue plans to give the brochure to people who receive accessible parking placards and licenses.

White also is directing studies by Shinnick and Zhang to continue this line of research with a $25,500 GE Research Grant, awarded as part of the KU Dole Institute of Politics’ 2015 “commemorateADA” initiative.

This year, the Center also published a Spanish translation of its internationally known “Guidelines: How to Write and Report About People with Disabilities.”

**Research Collaborations**

RTC staff collaborated with three other KU research centers to form the Work Group on Community Living. In November the Work Group hosted an invited symposium titled “Experience of Aging for People with Long-Term Disabilities: Opportunities to Further Research.”

Hodgesmith collaborated with the Spaulding-Harvard Traumatic Brain Injury (TBI) Model System to plan its “Severe TBI Stakeholder Summit” in May 2016. She delivered the opening presentation and facilitated the invitational summit.

**Service**

White has been named to NIDILRR’s Disability, Independent Living and Rehabilitation Research Advisory Board. NIDILRR is an agency within the Administration for Community Living, U.S. Department of Health and Human Services, and funds our Center’s work.

Hodgesmith has been appointed by the U.S. Commission on Civil Rights as a member of its Kansas Advisory Committee.

**Recognition**

E (Alice) Zhang received the 2015 Early Stage Graduate Award from the Friends of the Life Span Institute.

The University of Kansas recognized Center staff Jean Ann Summers and Martha Hodgesmith and KU alumnae Ranita Wilks and Katerina Birge as Women of Distinction at an August 2015 ceremony. They were acknowledged for their disability research and advocacy.

**SWIFT (Schoolwide Integrated Framework for Transformation) Education Center**

The SWIFT Education Center provides technical assistance to states, local educational agencies and schools. With these partnerships, SWIFT works to transform education so it benefits all students, their families and communities. SWIFT approaches this vision by helping whole education systems build their own capacity to provide academic and behavioral support to improve outcomes for all students – including students with disabilities who require even the most extensive supports and services – through equity-based inclusion.

Wayne Sailor, Ph.D., Director
Amy McCart, Ph.D., Co-Director
Contact: 785 864-6844, swift@ku.edu

FY 2015-2016 Highlights

A new partnership with the State of California, supported by $30 million in state funding, will bring SWIFT features to 300 schools. SWIFT is collaborating with the Orange County Department of Education and Butte County Office of Education to create a framework for the Scale Up MTSS Statewide (SUMS) initiative. SUMS will weave together several initiatives into a comprehensive Multi-Tiered System of Support (MTSS) to improve students’ academic,
behavioral and social-emotional outcomes across the state’s pre-K-12 educational system of more than 10,000 schools.

SWIFT is continuing the fourth year of its technical assistance partnerships with Maryland, Mississippi, New Hampshire, Oregon and Vermont through funding by the U.S. Department of Education, Office of Special Education Programs. Work with these partners has emphasized improving all students’ academic and behavior outcomes through integrated organizational structures and MTSS, and the scaling up of SWIFT to additional districts and schools.

SWIFT hosted a national professional learning institute in Arlington, Va., with approximately 500 participants from partner states and other stakeholders. Presentations were led by individuals from every SWIFT partner state and experts in the field.


The SWIFT Field Guide continues to provide curated resources that support learning about and practicing SWIFT content (guide.swiftschools.org).

SWIFT expanded its national knowledge bank of resources on swiftschools.org/shelf to include:

- “Together,” a 24-minute film on the Integrated Educational Framework, showing how partner schools include students with extensive support needs in general education (also available on YouTube)
- “Whatever It Takes,” a 22-minute film on Inclusive Academic Instruction, showing how partner schools use MTSS, co-teaching, peer learning and more to improve outcomes for all students (also available on YouTube)
- “SWIFT Unscripted” podcasts joined the continuing series of SWIFT Talk blogs in telling the story of equity-based inclusive education (also available on iTunes)
- SWIFT’s webinar series was launched with presentations on such topics as strategies for including all students, universal design for learning and differentiated instruction, MTSS, using data to improve student outcomes and promoting equity in urban schools.
- New Research to Practice Briefs joined our Issue and Technical Assistance Briefs and White Papers.
- One- and two-page Family and Community Resources in English and Spanish are now available to support schools as they communicate about SWIFT and engage important stakeholders in the work.

SWIFT leaders presented at national conferences and published in the following peer-reviewed journals:


Work Group for Community Health and Development

The mission of the KU Work Group is to support community health and development through collaborative research and evaluation, teaching and training, and technical support and capacity building. Established in 1975, the KU Work Group joined the Life Span Institute in 1990 and has developed widely used capabilities for community-based participatory research and building capacity for community work. It was designated as a World Health Organization Collaborating Centre for Community Health and Development in 2004.

Vincent T. Francisco, Ph.D., Co-Director
Jerry A. Schultz, Ph.D., Co-Director
Contact: 785 864-0533, communityhealth.ku.edu

FY 2015-16 Highlights

Vincent Francisco is co-director of the Center and of the World Health Organization Collaborating Centre for Community Health and Development at KU. He also is the Kansas Health Foundation Professor of Community Leadership in the Department of Applied Behavioral Science and is leading a project funded by the Robert Wood Johnson Foundation to study benchmarks of successful community initiatives.

Work Group Associate Director Jomella Watson-Thompson received tenure this year. Additionally, she was recognized by the KU Center for Civic and Social Responsibility for Faculty Excellence in Service Learning.

The Work Group completed the community measurement aspect of the National Heart, Lung and Blood Institute/ National Institutes of Health National Healthy Communities Study examining how community programs and policies shape physical activity, nutrition and healthy weight of children. Engaging 130 communities and 5,000 children, the study was the largest of its kind.

The Academic Health Department partnership is building a shared research program and enhancing the capacity of Lawrence-Douglas County Health Department staff, KU students and Work Group staff to implement core functions and essential services of public health in Douglas County.

A long-term research partnership with the Latino Health for All Coalition in Kansas City, Kan., continues with the mission of reducing the risk for diabetes and cardiovascular diseases by promoting physical activity, healthy nutrition and access to health services for the Latino community. With funding from NIH, CDC REACH and local foundations, the coalition continues to improve conditions for health and health equity.

As evaluation partner for the national Together on Diabetes initiative to reduce health disparities, the Work Group supports data collection and development of empirical case studies in a $20 million initiative funded by the Bristol-Myers Squibb Foundation.

Nearly 5.7 million users from 237 countries accessed the Community Tool Box this year. The Community Tool Box was featured at an exhibit at the World Bank Group’s Global Leadership Forum in Washington D.C. with attendees from around the world. The Community Tool Box partnered with the Peace Corps’ Office of Global Health and HIV on a “Peace Corps Community Tool Box” to support capacity-building efforts among Peace Corps staff, volunteers, and community counterparts, and is partnering with the National Democratic Institute to build resources for youth change-makers.

Publications


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