Discovery in the service of human health and development

Investigators, research and administrative staff, graduate and postdoctoral students
The LSI brings together 177 scientists who are affiliated with 20 academic departments to study human development from its genetic origins to the final stages of life through 102 research projects. These investigators are supported by 182 research and administrative staff members, including 47 graduate research assistants.

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

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 102 active programs and projects that constitute basic and translational research, training, direct services, consultation and technical assistance. Last year, more than 30,300 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 the Gerontology Center and other new research groups to form one of the premier research institutes in the world on human and community development, disabilities and aging. The Bureau was directed for 35 years by Richard L. Schiefelbusch for whom the Institute is named. His appointment to lead the Bureau in 1956 was the beginning of its modern era.

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

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 $23.4 million in sponsored project support in FY 2013-14. Each state dollar brought in $8.63 external dollars this fiscal year.
FROM THE DIRECTOR

The numbers tell us that this has been a tough year for anyone who works in the sector of research represented by the investigators of the Life Span Institute. We are still feeling the effects of the federal sequester and those effects were compounded by the Institute of Education Science’s decision to forego competitions for special education grants in 2014. I’m not discouraged by any of this, however, and I am confident that LSI will recover next year. It’s worth noting that, even in all of this, LSI still posted its fifth best year on record. In addition, next year’s recovery will reflect the addition of a new center to the fold: in July of 2014, the Center for Research on Learning (CRL) joined with LSI. Although we will not integrate CRL’s numbers into our financial report until next year, we’re pleased to welcome these investigators and interim director Mike Hock (all of whom are, for this year, listed in a separate section on the back page and introduced in a feature article on page 9).

All this aside, it’s important to look back at the things that really matter—the research that gets done by our investigators. When I arrived as a postdoc at the University of Kansas in 1982, I began work in the Bureau of Child Research (the organization that would eventually evolve into the LSI), and I repeatedly heard a phrase spoken by its scientists: “Our research makes a difference.” The nature of our work is what sustains our investigators and motivates them to continue on, even under the many difficult periods we’ve faced in the past (including, by the way, the early 1980s when I first arrived). I’m proud to say that after my 32 years at KU, I know that this isn’t just an empty slogan. This work has always made a difference and LSI research has always offered a meaningful or useful “takeaway” for its constituents and the communities it serves. As a result, we’ve organized this year’s annual report around this takeaway theme. I hope this gives you a sense of why our investigators do what they do, and what keeps them going in even the toughest of times.

John Colombo, Director
The Schiefelbusch Institute for Life Span Studies (The Life Span Institute)

OUR RESEARCH makes a difference
On October 17, a grant award was announced at a White House event that recognized the decades of leadership by the University of Kansas Life Span Institute in discovering and addressing the so-called “30 million word gap,” referring to the vast difference in the number of words that some children from poverty backgrounds hear by age four compared to those of children from more affluent homes.

First identified by the seminal research of Betty Hart and Todd Risley, this early difference in the amount and quality of talk to which infants and toddlers are exposed often leads to an ever-widening disparity in children’s vocabulary and early literacy skills once they are in school.

Judith Carta, Charles Greenwood and Dale Walker will direct the national network of experts in language and literacy development called the Bridging the Word Gap Network. Like Hart and Risley before them, they are research scientists at the Juniper Gardens Children’s Project, which Greenwood directs, located in a low-income Kansas City, Kansas neighborhood.

“We have learned valuable lessons about how to address this gap using evidence-based interventions for improving children’s language learning environments, but many children are still not reaping the benefits from our research,” said Carta. “It is time to bring these lessons to scale and to more fully integrate them into a forward-looking agenda of research and practice.”

The network is part of a larger Bridging the Word Gap effort endorsed by the White House and coordinated by the Departments of Education and Health and Human Services and the Institute of Museum and Library Services.

As more communities around the country are mounting city- and state-wide efforts to work with parents and childcare providers to bridge the word gap, the research network will help researchers learn the most effective ways to address this urgent issue, Walker said. “Our aim is to reduce the number of children entering school with delays in language and early literacy.”

Members of the Bridging the Word Gap Research Network: Ann Kaiser, Vanderbilt University; Howard Goldstein, University of South Florida; Scott McConnell, University of Minnesota; Dana Suskind, Thirty Million Words Initiative, University of Chicago; Meagan Bair-Merritt, Boston Medical Center; Margaret Burchinal, University of North Carolina at Chapel Hill; Kathy Hirsh-Pasek, Temple University and Roberta Golinkoff, University of Delaware.

Funding: Department of Health and Human Services

Professor of Special Education and Senior Scientist Judith Carta, Kansas City, Missouri
Mayor Sly James, Associate Research Professor Dale Walker and Professor of Applied Behavioral Science and Senior Scientist Charles Greenwood.

Mayor James and a representative from Kansas City, Kansas Mayor Mark Holland’s office were among the community leaders attending the White House event from the KC Metro area. Mayor James expanded the Talk Read Play initiative this year that was created through a collaborative effort of the Children’s Campus of Kansas City and community partners from the KC Metropolitan area in 2013. Credit: Julie Holland
In the first randomized trial on the effects of cell phone use, University of Kansas and Notre Dame researchers found that when parenting coaches texted and called mothers who had participated in a home-based parenting program, they were much more likely than the other mothers in the study to learn and use positive parenting strategies—both immediately following and six months after the program ended.

The study is also the first to test the effectiveness of cell phones as a way of increasing parents’ engagement in home-based parenting programs and keeping them from dropping out, said Judith Carta, who directed the study.

“Parents who most need to learn positive ways to interact with their children are often the most likely to drop out of parenting programs,” she said. “Ultimately, this is about preventing child maltreatment by showing parents a different, more positive way to interact with their children.”

The intervention used in the study, Planned Activities Training (PAT), is a brief program—five 90-minute home-based sessions—aimed at preventing children’s challenging behavior by giving parents strategies to use in everyday routines such as getting ready for school and bedtime, and eating dinner.

Parent coaches, known as home visitors, texted mothers twice a day five days a week, as well as calling them at least once a week, with reminders from the PAT program along with words of encouragement and suggestions for free activities available in the community that they could do with their children.

“The cell phone allowed the mother and the home visitor to become more connected,” said Kathryn Bigelow, who co-directed the study. “The texts and calls extended the home visits outside of the home.”

With the addition of the cell phone, this relatively short intervention had big effects on parenting, said Bigelow, and since the dropout rate was half of what it was for the group that didn’t have the cell phone component, the model is cost efficient and very feasible, she said.

Further, said Carta, parents typically miss about one out of three scheduled home visits and this is expensive for home visiting programs,” said Carta, “The cost benefit of including cell phones is clear.”

Home visiting is part of the Affordable Health Care Act, said Carta. “That’s given states a whole new impetus to identify evidence-based home visiting programs. Our study will become part of that evidence base.”

Additional study collaborators: Steven F. Warren, professor of speech, language, hearing and senior scientist, University of Kansas; John Borkowski, professor of psychology, and Jennifer Burke Lefever, assistant professor of psychology, University of Notre Dame.

Funding: Injury Prevention Branch of the U.S. Centers for Disease Control and Prevention, the CDC Foundation, the Doris Duke Charitable Foundation, the Health Care Foundation of Greater Kansas City, the AT&T Foundation and the Sprint Foundation.
SEVERITY, NOT FREQUENCY, OF ABUSE MAY PREDICT CHILDREN’S MENTAL HEALTH OUTCOMES

Yo Jackson and her team are analyzing data from one the largest longitudinal studies of foster children ever undertaken. “We know so much more about these children than most research efforts in the past and we are in a great position to tell their stories,” she said.

One of the first findings from the study, that seeks to determine why some children who suffer child maltreatment are more resilient than others, was that how severely children are abused or neglected, rather than how frequently, appears to predict which children will suffer serious mental health outcomes.

“If your goal is to understand what about a child’s life really speaks to his mental health or illness, so far the data is telling us that it would be how bad or injurious the abuse was—and it would only have to happen once,” said Jackson.

However, she says, even in cases of severity it is rarely the one time. The threshold for foster care does require severity but more often than not requires frequency.

“That is the rubric that by and large our systems of care use. Even if you have hurt your child significantly, you will likely get a lot of chances to get your children back if you want them. What that means, however, is that a lot of kids will be in and out of foster care before the environment at home is safe again.”

While Jackson strongly cautioned that the study is not saying that children who experience frequent, but milder kinds of maltreatment should not be in foster care, it does suggest that kids who have been abused and in foster care are not all the same.

“There’s really a range of kids and that range is important for us to understand and think about how we are going to intervene,” she said.

Do the study results generalize to the rest of us? Jackson says that they do. “They generalize in the sense that these kids are in the general population. Your kids go to school and play soccer with them and their numbers are growing.”

The results could also have some implications for other kinds of trauma that all kids experience. “We hope the model of the relation between trauma experiences like child maltreatment and mental health could inform other models of how traumatic events in the general population operate to predict outcomes.”

Jackson said that future analyses would determine how childhood experiences of maltreatment and other stressors impact both adjustment and maladjustment in youth.

Study co-authors: Joy Gabrielli, KU doctoral student in clinical child psychology, Kandace Fleming, KU associate scientist, P. Kalani Makanui, KU postdoctoral researcher and Angela M. Tunno, KU doctoral student in clinical child psychology.

Funding: National Institute of Mental Health
Howard Wills is putting high school students with emotional and behavioral problems in charge of themselves. Wills directed the development of a web-based application called I-Connect with Ben Mason that lets teens monitor and manage their behavior and set and achieve academic goals—all through wireless devices like smart phones and tablets.

“Schools have a great need for evidence-based interventions that can lead to students staying in and succeeding in school,” said Wills. “The I-Connect Intervention and Self-Monitoring application fills an important void in supporting high school students most at risk for school failure.”

During the two-year development, 20 high school students in Lawrence and Kansas City used I-Connect to connect with their support systems—school and community mentors and parents—who encouraged them to improve attendance, set goals, complete assignments and evaluate their progress, among other goals.

I-Connect eliminates paper and pencil forms, something any school psychologist or special educator who has had to sift through folders full of self-monitoring sheets that were never entered into a central database will appreciate, said Wills.

Mentoring is very structured and efficient in the I-Connect model, said Wills. Mentors can assess students’ academic and behavioral progress along with the self-monitoring data uploaded from the student’s device to a server.

“Reducing paperwork while adding to the richness of the data the mentor can use to problem-solve is the goal of the program.”

Another advantage to I-Connect is that students can monitor themselves unobtrusively. “This is a rare intervention that works without being apparent to peers why it works,” said Mason. “This is valuable for schools that are trying to integrate students with disabilities into general education classrooms but still want to provide supports.”

Self-monitoring has the longest track record of success of any intervention, according to Wills. “Even Benjamin Franklin wrote about it and most of us have used the same principles to meet career and fitness goals.”

The results of pilot studies have been very positive, said Wills. For example, two high school students’ on-task behavior increased from 51 to 95 percent and from 18 to 91 percent respectively during science class.

Wills and Mason will continue the development and testing of the I-Connect self-monitoring application in different settings and with additional populations such as students and young adults with autism.

Study collaborators: Ben Mason, post-doctoral researcher, Juniper Gardens Children’s Project; Linda Garrison-Kane, professor of education, Missouri State University, and Shye Hou-Reynolds, software engineer, and Nick Tallmon, web and mobile application engineer, Juniper Gardens Children’s Project.

Funding: U.S. Department of Education
It all started when Kat Stremel-Thomas, a researcher who was studying language development in children with cochlear implants, told Kate Saunders and Dean Williams that even though many children with developmental disabilities were getting $90,000 per ear cochlear implants, audiologists were having trouble adjusting them. She suggested that, as behavioral scientists with decades of experience studying learning difficulties of people with intellectual disability, they should apply for a grant to support the development of a technology to train kids to take a hearing test.

Those would be the kids who, because of autism, intellectual or developmental disability, have difficulty following spoken instructions and communicating to audiologists that they hear tones during a hearing test. It can take multiple teaching sessions to learn this skill—too much time for the clinic setting.

The researchers are developing and testing a software program designed to enable teachers, therapists and paraprofessionals to shape a child’s behavior to respond to audio tones.

The program records everything that occurs during a teaching session, including whether the child presses a button during tone presentations and does not press the button when the tone is off.

“If a child responds when there is a tone, the program signals the trainer to deliver a reinforcer,” explained Williams. “The program can even operate toys—like a jumping dog—but usually, rewards are enthusiastic praise, treats or tokens.”

A large percentage of people with profound hearing loss also have a second or third disability, said Williams. “The most common is intellectual disability or autism.”

Although enabling children to benefit from expensive cochlear implants helped persuade the U.S. Department of Education to fund the development of the prototype, in practice, said Saunders, there are many more children who simply need a valid assessment of their hearing.

“This technology is based on shaping and reinforcement procedures to teach children what to do during a hearing assessment,” said Saunders. “If a loss is detected and remediated, that opens up the path to communication—and that’s a game changer.”

Study collaborators: Yusuke Hayashi, assistant research professor and project coordinator (now assistant professor of psychology, Penn State-Hazelton); Tiffany Johnson, associate professor of hearing and speech, KU Medical Center, and Carol Cummings, graduate research assistant, applied behavioral sciences.

Funding: U.S. Department of Education
Michael Wehmeyer and Karrie Shogren are two of the leading scientific explorers on the frontiers of disability. Both are internationally known for applying the concept of self-determination to the context of disability and special education, conducting research and developing interventions that show that people with intellectual and other disabilities can and should determine how they live their lives.

As editor and contributor, respectively, of the 2013 Oxford Handbook of Positive Psychology and Disability, Wehmeyer and Shogren argue that the expanding field of positive psychology, with its focus on strengths rather than deficits, has the potential to change how disability is understood and discussed.

In 1990, Wehmeyer looked at the outcomes for youth with disabilities, 15 years post IDEA (Individuals with Disabilities Education Act), and saw that young people weren’t doing as well as they should be in terms of employment, education and community participation because they weren’t involved in planning or determining their own lives.

Since then much progress has been made in practices and expectations for people with and without disability influenced by positive psychology and the social ecological model of disability—that the gap between a person’s capacity and the demands of the environment can become irrelevant with the right supports.

Wehmeyer and Shogren are developing an assessment, the Self-Determination Inventory System (SDIS), based on their research in self-determination and concepts in positive psychology that will enable researchers to measure the self-determination of students with and without disabilities.

They are developing and validating the Self-Determination Inventory-Self-Report version with 3,600 students, ages 13 to 22, with and without disabilities. Another 1,600 parents, teachers and adult caregivers will complete an adult-report version.

In practice, teachers would use the SDIS assessment scores to target instructional interventions and assess students on an ongoing basis to monitor progress, said Shogren. The Self-Determined Learning Model of Instruction, developed by Wehmeyer and colleagues, for example, was designed to enable teachers to teach students to teach themselves. Although it was developed for students with disabilities, the focus on self-regulation, problem-solving and goal-setting is relevant for all students, she said.

“This is a seamless system,” said Wehmeyer, “that meets the demands of the 21st century classroom, workplace and community.”

Funding: U.S. Department of Education
When Debra Kamps first began researching how to improve the social and communication skills of children with autism in natural settings like school in the 1970s, it was hard to find children with ASD who were in classrooms with their typically developing peers.

Today, Kamps and her colleagues from KU and other universities can say with certainty that they know how teachers, speech therapists and others can teach social and communication skills to kids with ASD and their peers in the classroom, at lunch and even at recess. Kamps-led studies have been cited in national references and reports, including one by the National Research Council.

“We know how to do this and our research has shown us that it is not hard to teach people how to do it,” she said.

Recently, Kamps and her collaborators completed a large randomized control study that involved 95 students with ASD in Kansas and Washington. Of that group, 56 children participated in a two-year intervention from kindergarten through first grade in which each child was grouped with two to three typically developing classmates in a peer network, while the remaining 39 were the control group. The social peer network focused on teaching social communication skills such as requesting, commenting and saying “niceties” such as please and thank you, while playing with toys and board games.

To find out if the children were continuing to use social skills, the researchers followed up with “probes” outside of the intervention sessions at four points in time.

“We found that the children who participated in the social network not only made significant progress in social communication during the intervention, but also made many more initiations to their peers in general,” said Kamps. “Teachers also reported that children in the intervention were more social and had better classroom behavior.”

Although peer networks are still not used routinely in schools, often due to lack of resources, Kamps hopes that the promising results from larger studies will change that. “Seeing the expression on the faces of the children when their peer buddies come to class—that’s what’s kept me going all these years.”

Video from the study: autismconnections.drupal.ku.edu/connecting-kids/play-tips

Study collaborators: University of Kansas: Kathy Bourque, associate research professor, Juniper Gardens Children’s Project; Linda Heitzman-Powell, assistant research professor, University of Kansas Medical Center; Rose Mason, assistant research professor and Suzanne Cox, project coordinator, Juniper Gardens Children’s Project. University of Washington-Seattle: Ilene Schwartz, chair and professor, Special Education Department; Nancy Rosenberg, project coordinator, Special Education Department.

Funding: U.S. Department of Education
With a common philosophical “ancestor”—Richard Schiefelbusch—the Center for Research on Learning was a natural to become the Life Span Institute’s newest affiliated center when it joined LSI on July 1, 2014.

Schiefelbusch, director and professor emeritus of the Schiefelbusch Institute for Life Span Studies (Life Span Institute) and Ed Meyen, professor of special education, along with Donald Deshler, Williamson Family Distinguished Professor of Special Education, founded the Institute for Research on Learning in 1978 that later became CRL.

Initially the center was funded by the U.S. Department of Education to study adolescents with learning disabilities (LD). “At the time, this was a new category of students who struggled with learning,” said Mike Hock, CRL interim director. The center, one of five nationally funded centers, was the only one to concentrate on adolescents with LD.

Today CRL is an internationally recognized research and development organization known for innovative solutions to problems that limit individuals’ ability to learn and perform in school, work or in the community.

Among the most impactful contributions of CRL is the Strategic Instruction Model or SIM, which has been widely adopted across the U.S. with more than 800 active members in the SIM professional development network. SIM gives teachers tools to present content to diverse classrooms as well as giving students with learning disabilities tools to help them acquire and express information.

CRL is also noted for developing effective professional development instructional coaching models so that teachers can learn to use interventions effectively in classrooms. Recently, the CRL has begun to introduce the use of technology in its instructional work.

CRL has created many products for teachers based on successful interventions for adults and adolescents with learning differences. “Now, for example, we are exploring the use of technology to enhance database individuation,” said Hock. “This will allow us to get formative assessment information into the hands of teachers and students almost immediately.”

CRL is also investigating if “flipped” learning is effective for students with learning disabilities. Flipped learning means that students may watch a video of a teacher’s classroom lecture online outside of class. Then, during class, the teacher will spend more time helping students with assignments related to the video so they get individual instruction and feedback during class time.

Besides complementing the Life Span Institute’s early development and literacy work, CRL and LSI share a common interest in disability policy research. The CRL’s Institute for Health and Disability Policy Studies is a national leader in disability policy issues that support access to quality care for those with disabilities.

“I’m really looking forward to working with CRL,” said LSI Director John Colombo, “They have great people and there is a clear synergy of their mission with the LSI.”
Advanced Learning Technologies (ALTEC), directed by Marilyn Ault, designs, develops and evaluates the effective use of educational technologies in K-12 instruction and uses evolving telecommunication technologies to connect and engage learners.

The Division of Adult Studies, directed by Daryl Mellard, conducts research, evaluates programs and projects, disseminates findings, and provides assistance to individuals or organizations that seek to improve services for people with disabilities or disadvantages.

The E-Learning Design Lab, directed by Ed Meyen and James Miller, explores new uses of technology to enhance learning environments that meet the educational and training needs of society.

The Institute for Research on Adolescent Learning, directed by Mike Hock, develops and researches instructional practices, strategies and programs that significantly enhance the achievement of adolescents who struggle with learning.

The Kansas Coaching Project, directed by Jim Knight, conducts research on instructional coaching and provides on-site professional development to teach educators how to use proven instructional methods.

The Professional Development Research Institute, directed by Patricia Garner, seeks new ways to deliver quality learning opportunities, conceptualize models of professional development and provide support to teachers and other school personnel.

The Transition Coalition, directed by Mary Morningstar, develops and offers online and in-person information, resources and professional development on topics related to the transition from school to adult life for youth with disabilities.
The Life Span Institute is a center of centers with a core of exceptional resources for University of Kansas researchers, notably, the Research Design and Analysis (RDA) unit. Established in 1994, the RDA is an essential component of the scientific mission of the Life Span Institute, offering comprehensive support for conducting rigorous quantitative research, including data collection and management services, supporting the development of research proposals and conducting advanced statistical analyses.

In the last two years alone, RDA scientists Kandace Fleming, RDA general director, and Rebecca Swinburne Romine, have contributed to the proposals of five different LSI research teams bringing a total of $5.2 million in grant dollars to the University of Kansas. Since 2012, Fleming and Swinburne Romine (along with now-retired RDA scientist Janet Marquis) have co-authored 22 peer-reviewed publications and six technical reports with 15 different LSI research teams.

In addition to statistical support, the RDA unit provides innovative resources for the collection, storage and presentation of data. The RDA manages a HIPAA-compliant, encrypted, secure web server for online data collection and a HIPAA-compliant database server for data storage. Database manager Lisa Hallberg also designs custom web-based data capture systems. For researchers using traditional paper-and-pencil forms, optical capture software is available to replace manual data entry, as are custom software programs to automate data validation and scoring, greatly reducing human error. “Using the right technologies can improve upon the very measures themselves,” said Hallberg.

RDA also offers services to disseminate research findings. An RDA member since 1998, graphic designer Chris Lorenzen’s creative skills include designing logos, pamphlets and conference posters that are now available in a new cloth format for easier transport and greater durability. Program assistant Lisa Love provides critical administrative assistance in keeping projects running smoothly.

Together RDA members offer investigators a stable and continuous relationship over the life cycle of a study. “We become part of your research team,” said Fleming.

An example of the RDA’s strategy of comprehensive collaboration throughout the research process can be found in the development of the Communication Complexity Scale (CCS), a new instrument designed to measure the communication status of individuals with no or limited speech and intellectual and developmental disabilities. Fleming assisted Nancy Brady, principal investigator, secure funding from the National Institutes of Health and served as co-investigator. Hallberg built custom web-based data collection forms for use with desktop or tablet computers to facilitate flexible, fast and accurate data collection in schools, homes and other facilities, and designed a website used to...
recruit subjects and enhance the visibility of the project that features logos designed by Lorenzen. Fleming and Swinburne Romine have begun preliminary data analyses that will continue as data collection progresses.

The RDA has continued to expand its capabilities through the July 2013 addition of Associate Professor and Associate Scientist Lesa Hoffman. In addition to supplementing ongoing efforts in proposal development and statistical analysis, Hoffman seeks to facilitate the methodological development of RDA scientists and LSI investigators. “I’m interested in finding new ways to use statistical models,” said Hoffman, “and to be a translator of statistical methods for those who could really benefit from them if they only knew about them.”

Together the RDA team is well-poised to continue its long-standing tradition of joining other LSI scientists in their efforts toward cutting-edge empirical research.

“We have a lot of experience working with real data and real people,” said Hoffman, “and we are at the intersection of how modern quantitative methods can solve practical problems.”

More information about the Research Design and Analysis Unit at the Life Span Institute is available at lsi.ku.edu/resources/rda.shtml.
LSI BY THE NUMBERS

COLLABORATION

The Life Span Institute has always been an interdisciplinary, multidisciplinary and collaborative organization, and in many ways the LSI can be perceived as a forerunner of the organizational and strategic themes seen in the strategic and organizational plans put forth for KU in Bold Aspirations and Changing for Excellence beginning in 2012. A quantitative analysis of the LSI’s current projects indicates that these characteristics continue to facilitate success and productivity.

Of the 102 funded projects held by LSI, 82 percent reflect active collaborations among our investigators. Of these collaborations, 54 percent involve other faculty members or scientists at KU, 10 percent involve faculty members at the KU Medical Center and nearly 20 percent involve partnerships with investigators outside of KU. Those outside collaborations involve other academic institutions in the United States (University of Oregon, Indiana University, Boston University, University of Nebraska, University of Chicago, The Ohio State University, Tulane University, Kennedy-Kreiger Institute/Johns Hopkins University, Queens College, Washington University at St. Louis and the University of Missouri at Kansas City) and abroad (University of Costa Rica, Macquarie University) and various partners from industry and non-profit organizations (Ellenson Integration Enterprises, The Hartford, The Via Institute, Bristol-Meyers-Squibb and Mead Johnson Nutrition).

PROJECT TOPICS

The portfolio of topics covered by LSI projects remains fairly consistent from previous years, with the majority of work being devoted to intellectual and developmental disabilities. Infancy, early childhood and language also remain as major themes among the projects, although with an increasing influence of clinical child psychology, the LSI is experiencing a new and growing emphasis on child and family mental health. Research on education, obesity, community health and independent living for persons with disabilities round out the other mainstays of the LSI’s portfolio over the years.

TYPES OF PROJECTS

This figure shows the distribution of project types at the LSI. The number of projects that can be classified as being devoted to discovery (basic research) shows an increase, while keeping with the tradition of making a difference, nearly half of the projects involve interventions/clinical trials and direct service to constituents. The remaining quarter of projects is evenly divided among prevention/program evaluation, training grants and collaborative centers that provide research infrastructure for this sector of the KU research community.
Due to the continuing effects of the 2011 sequestration for all federal funding agencies and the new effects of suspended grant competitions at the Institute of Education Sciences, the Life Span Institute saw a decline in funding of $6 million in fiscal year 2014, down to $23.4 million from the previous year’s record of $29.4 million. LSI held a total of 102 awards, with 88 continuing awards and 14 new ones.

Federal awards still account for the vast majority (79.5 percent) of LSI funding at $18.5 million, with other sources, including the state of Kansas, at $2.8 million (11.9 percent), private foundations at $1.7 million (7.6 percent) and industry $192 thousand (one percent) comprising the rest. Funding from the National Institutes of Health increased to $7.6 million from $6.4 million, but awards from the U.S. Department of Education dropped from $14.7 million to $5.1 million. Another $766 thousand in funding was generated by awards from the U.S. Department of Health and Human Services.

Despite the drop in funding over this fiscal year, 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 2014, every state of Kansas dollar invested in LSI yielded $8.63 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 at Parsons 1956

As the founding center of the Schiefelbusch Institute for Life Span Studies (Life Span Institute), 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 a component of the Kansas University Center on Excellence in Developmental Disabilities and the Parsons Research Center. Current research focuses on individuals with autism, novel intervention strategies for challenging behavior, hearing assessment with individuals who are difficult to test, effects of toxic stress on children and families, and maladaptive and challenging behavior. Additionally, the Parsons LSI provides significant service and training across the nation and state of Kansas on assistive technology, 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, parsonslsi@ku.edu

FY 2013–2014 Highlights

Faculty and staff of the LSI Parsons have provided training or technical assistance to 14,077 Kansans, in all 105 counties, and 2,630 individuals at national conferences and/or audiences in the past year.

Faculty and staff of the LSI Parsons produced six peer-reviewed publications and 126 conference presentations and/or training events.

Faculty and staff of the LSI Parsons serve on two national boards, two state boards, seven journal review boards, seven grant review panels and received awards from the Kansas Division for Early Childhood, Association for Behavior Analysis International and Leading Light Awards from the University of Kansas.

Of the 56 assistive technology programs in the U.S. and territories, the program at KU, Assistive Technology for Kansans (ATK), was one of four state programs invited to present to the U.S. Department of Education staff. ATK provided technical assistance regarding access to assistive technology to 14 states and served on three federal grant review panels in 2013-2014.

The 23 ATK program staff from the six assistive technology access sites provided services to 2,214 Kansans with disabilities and chronic health conditions and/or service providers. ATK staff provided Kansans with more than 5,000 assistive technology (AT) services in 2013.

ATK assisted Kansans in acquiring almost 2,000 assistive technology devices valued at more than $1.5 million.

Specific Kansas populations receiving AT services in 2013:

- 57 Infants and toddlers with disabilities and their family members
- 272 Adults with disabilities who were retraining or obtaining part-time or full-time employment
- 114 Farmers, ranchers and other agricultural workers with disabilities
- 754 Seniors needing services to stay in their homes and/or to be active in their community
- 830 Kansans received hands-on training on use and maintenance of an AT device

KU and Kansas State University work together to operate the AgrAbility project to assist farmers and ranchers who have been injured acquire the technology and modify agricultural-production activities to support them in returning to agricultural related employment. Through this collaborative effort, ATK and KSU assisted 114 farmers and ranchers return to production agriculture. So thank a farmer for your food, and thank ATK (and KU) for helping farmers who have been injured to provide that food.

During the second year of operating the iKAN Connect advanced telecommunication grant for individuals who are deaf and blind, ATK provided services to 51 individuals. As part of the National Deaf Blind Equipment Distribution Network, ATK provided assessment and training to support deaf blind Kansans across the state.

In the spring of 2014, ATK assumed responsibility for the Telecommunication Access Program (TAP) and the Dual Party Relay System. TAP provides telecommunications equipment to individuals who earn $55,000 a year or less and who have trouble using telecommunications through traditional means due to vision, hearing, motor, cognitive or speech difficulties. In operating this program, ATK expects to improve the telecommunication experiences of more than 1,200 Kansans each year.

A few examples of the impact that services provided by ATK has had on Kansans over this past year:

- A young man with Down syndrome wanted to be promoted to waiter at the local Pizza Hut. Because he had trouble writing down orders quickly, ATK staff demonstrated several devices that would let him record orders. After trial use of the LivescribeTM pen, the iPad mini®, and the iPad®, he chose the iPad®. He got the promotion.
- A student who is unable to speak and has no consistent movement needed an access method. Working with her school team, ATK staff arranged for lease or loan of all commercially available head array and eye-gaze systems. The identified technology was acquired through a funding justification submitted to KanCare, the Kansas Medicaid program. The student now initiates her own communication messages and responds to others.
- A man who is legally blind and has a significant hearing loss wanted to be more involved in his community. ATK staff demonstrated handheld magnifiers and digital devices to read print materials and to...
use the Internet and email. With instructional support, he learned to use the accessible features of these devices. Now he volunteers at the local senior center, demonstrates his favorite technology and teaches chess.

A man who is the primary caregiver of his 40-year-old grandson who has multiple sclerosis contacted ATK to request a wheelchair. His grandson received a refurbished tilt-in-space power wheelchair. Now he can independently change positions as needed. Hospitalized due to pressure wounds, he is optimistic that the ability to change positions will help the wounds heal.

A Kansas cattle rancher with a spinal cord injury needed to get in and out of his tractor and other equipment independently. ATK staff helped him identify a boom lift with a seat that could be mounted on a trailer for increased access to equipment and work sites. A funding justification was submitted to Kansas Rehabilitation Services and the lift was funded.

A woman who is legally blind wanted a better job. ATK staff helped her identify technology that allowed her to magnify and read print as well as save text for manipulation on a computer. Funders included the iKAN Connect program, Kansas Rehabilitation Services, and the Telecommunications Access Program. She is now employed as a library assistant.

The Kansas Inservice Training System (KITS), the state’s inservice training program for early childhood special education professionals, provided training and technical assistance for all early intervention and early childhood special education programs in Kansas. This training reached 17,491 teachers, related service providers, administrators and family members.

KITS held its 21st Annual Summer Institute that focused on intentional instruction in early intervention and early childhood special education. Participants enroll for college credit from any of six participating universities in Kansas.

KU is one of four partnering universities in the National Early Childhood Personnel Center. Faculty from the LSI Lawrence and LSI Parsons are currently working together to identify standards for personnel in early childhood and linking those standards with professional organization standards. An outcome will be training and technical assistance to states establishing their own systems for professional development and aligning preservice and inservice programs.

LSI Parsons faculty are currently working with the Kansas Department of Education to develop a framework for the establishment of an early childhood data management system and training materials on the newly developed early childhood standards.

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

LSI Parsons researchers are collaborating with investigators at Texas Tech University on an NIH grant to develop an instrument to assess individuals’ transition difficulties that may trigger problem behavior in individuals with autism and other developmental disabilities. In addition, the project is collecting survey data to document the prevalence of transition difficulties in individuals with autism.

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 project from the Office of Special Education Programs is developing training procedures to prepare children for testing before they arrive at the clinic.

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

Since 2006, the Family Care Treatment Project has taught parents and caregivers of children with disruptive behaviors to support and teach their children. Through its eight years of operation, this project has provided individualized, consumer-driven and home-based behavioral service to 121 families throughout eastern and central Kansas.

The respite service program associated with LSI Parsons provided respite, supportive home care, payee and homemaker services to 283 families for a total of 26,795 hours and employed 129 part-time employees.

CW-FIT, a classroom management system developed by researchers Debra Kamps and Howard Wills, has proven to be successful in diverse urban communities in Kansas, Missouri, Utah and Tennessee.
Researchers at the Juniper Gardens Children’s Project are leading a network of researchers as part of a national effort endorsed by the White House called Bridging the Word Gap to address continuing discrepancies in children’s early language and literacy development.

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 that 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.

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Debra Kamps, Ph.D., Associate Director
Barbara Terry, Ph.D., Director of Community Relations
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FY 2013-2014 Highlights
Carta, Burke-Lefever, Bigelow, Borkowski and Warren reported results of a randomized trial involving 371 low-income mothers examining the effects of using cell phones to enhance the effectiveness of a home visiting parenting intervention. Results six months after the intervention showed that mothers who had been in a group receiving the parenting intervention enhanced with daily text and cell phone calls were more responsive to their children and showed greater reduction in depression and distress than mothers in the traditional parenting intervention group without cell phone enhancements. This was the first published randomized trial showing that using cell phones can add to the effectiveness of home-based programs with high-risk families (Pediatrics, 2013).

Lefever, Bigelow, Carta and Borkowski examined predictors of engagement and completion in a randomized trial comparing the effectiveness of two interventions for preventing child maltreatment and promoting positive parenting. They reported that early engagement and participation in the cellular phone enhanced program predicted intervention completion, and the quality of parenting prior to entrance in the program predicted engagement. The results have important implications for engagement and completion in home visitation programs aimed at promoting positive parenting among high-risk mothers (Dialog, 2013).

Guttentag, Landry, Williams, Baggett, Nora, Borkowski, Swank, Farris, Crawford, Lanz, Carta, Warren and Ramey examined the efficacy of the multi-module parenting intervention, My Baby & Me, for children beginning prenatally through 2.5 years of age. The intervention targeted specific parenting skills designed to alter trajectories of maternal and child development. Compared to mothers in the high-intensity home visitation coaching program group vs. a low intensity group, mothers showed higher levels of contingent responsiveness, higher quality verbal stimulation and more verbal scaffolding by 30 months, with higher levels of warmth and greater decreases in physical intrusiveness and negativity when their children were 24 months. Gains in maternal responsive behaviors mediated the effects of the intervention on child outcomes. A strong theoretical framework, consistent focus on maternal responsiveness, high dosage, and trusting relationships with coaches are thought to explain the positive outcomes, (Developmental Psychology, 2014).

Greenwood, Walker and Buzhardt sought to enhance the psychometrics of their online Individual Growth and Development Indicators (IGDIs). They reported that growth and change in the key skills of early communication was patterned as a continuum with early skills growing to an inflection point then declining as later skills merged and became fluent (Early Childhood Research Quarter, 2013, pp. 540-554) and that the IGDi key skills and total communication scores were shown to be equivalent across two large time-displaced samples of children served in Early Head Start (Early Childhood Research Quarterly, 2013, pp. 743-758). Both findings strengthen the validity of inferences made from IGDi data that was collected and reported by early educators and interventionists.

Greenwood, Carta, Atwater, Goldstein, Kaminski and McConnell reported applying a Response to Intervention measurement model to a large sample of Pre-K programs in four states. Key findings were that preschools with weak and very weak language and literacy skills did not catch up to children with average and above skills after a year of preschool experience. Findings argue strongly for the use of differentiated instruction that provides more intensive instruction in preschool to children with weak and very weak skills (Topics Early Childhood Special Education, 2013).

Kong and Carta reported the results of a research synthesis of studies examining the effectiveness of Responsive Interaction Intervention (RTI), an approach to promoting young children’s social-emotional, communicative, and cognitive skills. They found strong support for the effectiveness of RTI for promoting children’s gains in...
The Communications Complexity Scale, developed by Nancy Brady, is a unique measure for researchers and clinicians to assess the communication status of children and adults with disabilities as diverse as autism spectrum disorders, Down syndrome, deaf-blindness and cerebral palsy, including those who are nonverbal or have very limited speech.

these domains. The strongest support was for promoting children's social-communication outcomes. In these studies, parents were most often the interventionists. Few studies to date have reported generalization or maintenance of effects much beyond the period of intervention (Topics in Early Childhood Special Education, 2013).

Hansen, Wills, Kamps, and Greenwood sought to link self-management procedures to hypothesized behavior function in three children with emotional and behavioral disorders. They reported that self-monitoring alone could be enhanced using information derived from a function-based assessment. Consequences delivered by teachers were less effective than a self-management treatment package (Journal of Emotional and Behavioral Disorders, 2013).

Bowman-Perrott, Davis, Vannest, Williams, Greenwood and Parker in the first meta-analysis of single case design peer tutoring research across 26 experiments, including 938 students in Grades 1–12, reported that peer tutoring is an effective intervention regardless of dosage, grade level or disability status. Among students with disabilities, those with emotional and behavioral disorders benefitted most (School Psychology Review, 2013).

Peterson, Wall, Jeon, Swanson, Carta, Luze and Eshbaugh examined early indicators of disability or potential disability among preschool-aged children enrolled in the National Early Head Start Research and Evaluation Longitudinal Follow-Up. The majority of participating children (62 percent) were classified into at least one risk category (received Part B services, developmental risk and biological risk). Children living in poverty from birth through preschool and of minority status were among those most likely to be classified and also have received a variety of services. Findings highlight the importance of understanding these relations among child and family characteristics and service receipt to inform policy and practice (The Journal of Special Education, 2013).

Brady, Thiemann-Bourque, Fleming and Matthews investigated a model of language development for nonverbal preschool-age children learning to communicate with augmentative or alternative communication. A confirmatory factor analysis revealed that measures converged as a coherent construct and a structural equation model indicated that the construct predicted different words children produced. The amount of input received at home, but not at school, was a significant mediator. Children who evidenced higher initial levels of Intrinsic Symbolic Factor and more adult input at home, produced more words one year later. The findings support the need to assess multiple child variables and suggest interventions directed to the indicators of ISF and input (Journal of Speech, Language, and Hearing Research, 2013).

Barker, Akaba, Brady and Thiemann-Bourque examined how Augmentative Alternative Communication (AAC) used in preschool may impact language development for children with complex communication needs (e.g., autism, cerebral palsy, Down syndrome, and other developmental disabilities). Findings indicated that the use of AAC by peers to provide augmented input was associated with stronger language growth; the use of prompting and question asking by teachers was associated with weaker language growth. Teachers reported that they received little training regarding ways to support a child's use of AAC. Results suggest the need for further research on promoting AAC use at the preschool level, including research to promote peer interactions for AAC users (Augmentative and Alternative Communication, 2013).

Kamps, Mason, Thiemann-Bourque, Feldmiller, Turcotte and Miller examined the efficacy of peer networks that are social groups using typical peers, scripted instruction, visual text cues and reinforcement for students with autism spectrum disorders (ASD). Findings indicated improvements in total communication acts for all four participants during peer network sessions and increased initiations for three of the four. Generalization probes during classroom centers indicated increased communications following interventions for three of the four participants (Focus on Autism and Other Developmental Disabilities, 2014).

Heitzman-Powell, Buzhardt and colleagues reported findings of a formative evaluation of the Online and Applied System of Intervention Skills (OASIS) training program for parents of children with autism. The OASIS training program combines online instruction with live, remote telemedicine coaching to teach parents how to use evidence-based behavioral strategies with their children with autism. In this exploratory study, they showed that following completion of the 16-week training, parents who had little or no knowledge of behavioral interventions demonstrated mastery understanding of these complex principles and strategies, and that they could implement those strategies with their children with high levels of fidelity. The key finding was demonstrating that this training could be successfully implemented remotely, saving over 9,000 miles in travel across the four families who completed training in rural/remote areas of Kansas (Focus on Autism and Other Developmental Disabilities, 2014).

Bridging the Word Gap Research Network, HRSA/MCHB, Carta, Walker, & Greenwood), the aim of this project is to form and galvanize national efforts to bridge Hart and Risely’s (1995) disparity in words parents address to their babies by age three and four years that exists between poor and non-poor families and communities, 2014-2016. The project was publically announced at the White House Conference on Bridging the Word Gap, October 17, 2014.

Making it Happen: Stepping Up Implementation of IGDI Technology to Improve Data-based Decision Making for Infants and Toddlers with or At-risk for Disabilities, Stepping-Up Technology Project, OSEP/USDE, Buzhardt, Walker, Greenwood, & Carta. The aim of this project is to develop and test an improved model for implementation of the online IGDLs, 2014-2019.
I-CONNECT Plus, NIDRR, Wills, et al., Building on prior successful R & D developing I-CONNECT, the goal of this project is to develop online instructional modules, telecoaching and self-management strategies to improve independence for adolescents and young adults for Autism Spectrum Disorders (ASD).

Research Partnership Project with Kansas City, Kansas District, IES, USDE, Mason, et al. The aim of this translational research project is to develop a collaborative research agenda for improving the professional research and evaluation skills of paraprofessionals; teaching tasks such as developing and using surveys, direct observational measures and conducting case studies.

Greenwood, Carta and Walker, with Children’s Campus Partner, Dean Olson, at the The Family Conservancy, facilitated Kansas City, Missouri Mayor Sly James, August 25th Community Conversation on Bridging the Word Gap using Talk Read Play. Talk Read Play is a jointly developed approach to a public information campaign to Talk Read Play to your baby everyday.

Juniper Gardens Children’s Project and the Children’s Campus of Kansas City were connected to Google Fiber as part of the company’s Kansas City, Kansas Community Connections Initiative with speeds of 1GB/sec (100 times faster than average standard connection) at no cost for 10 years.

Dale Walker and Jane Atwater collaborated with Heather Schrotberger and Jessica Haremza of Project EAGLE/Educare, University of Kansas Medical Center and the Children’s Campus of Kansas City (CCKC) in an invited webinar on August 12, 2014, for the U.S. Department of Education, Institute for Education Sciences (IES) Bridge Event describing translational research. The title of the webinar was Engaging Families in the Assessment Process and Use of Data: An Early Childhood Example.

Dale Walker delivered an invited address “The Impact of Early Experience on Infant, Toddler and Pre-School Learning” at the Kansas Literacy Summit From Readers to Leaders: Improving Literacy Outcomes in Kansas on September 11, 2013, in Wichita, Kansas. This summit, sponsored by Kansas Action for Children, served as a platform for setting the agenda for efforts related to improving early literacy outcomes in Kansas.

Dale Walker conducted an invited online workshop for the teaching staff at the Ann Sullivan Center, Lima, Peru. The workshop covered the Promoting Communication Intervention strategies and results from the recently completed OSEP Kansas Model Demonstration Center for Promoting Language and Readiness (Walker, Bigelow, & Atwater) for the staff at the Ann Sullivan Center to use with children and families served in their program.

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 in St. Louis and Johns Hopkins University/ Kennedy Krieger.  
John Colombo, Ph.D., Director  
Peter Smith, Ph.D., Co-Director  
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**FY 2013-2014 Highlights**  
KIDDRC investigator Yo Jackson reported results from her NICHD-funded longitudinal study of children in foster care in an article published in the journal *Child Abuse and Neglect*. Her findings suggest that the severity of individual events of child maltreatment, rather than its frequency, predicts which children will suffer serious mental health outcomes, problems with aggression, acting-out and less adaptive behavior. The assessment of maltreatment was based on self-reports from the children to determine the frequency and severity of four types of abuse: physical, sexual, psychological and neglect.  

Eva Horn, KIDDRC investigator and professor of special education, was selected as one of two recipients for the 2014 Louise Byrd Graduate Educator Award at the May 17, 2014 doctoral hooding ceremony. Horn was nominated by her colleagues and noted for her dedication to graduate students.  

Mabel Rice reported in the *Pediatric Infectious Disease Journal* that children prenatally exposed to HIV and whose mothers received anti-HIV medications during pregnancy did not show language delays, relative to HIV-exposed children whose mothers were not treated during pregnancy. The findings ally concerns in the medical community that the typical anti-HIV drug combinations could affect the developing fetal brain in ways that cause language delays. Her team evaluated the language skills of nearly 800 children for the study that is part of a national collaboration between several NIH institutes and universities called the Pediatric HIV/AIDS Cohort Study.  

A recent review in the journal *Pediatrics* (Official Journal of the American Academy of Pediatrics) identified and analyzed the top 100 most frequently cited articles of 497,240 published in 191 journals dedicated to pediatrics between 1945 and 2010. Among the top-cited articles recognized there was a piece published on Prader-Willi syndrome by KIDDRC investigator Merlin Butler (*Pediatrics*. 1993;91(2):398–402).  

The results from the first randomized trial of the effects of cell phone technology in early parenting of at-risk children authored by KIDDRC researchers Judith Carta, Kathryn Bigelow and Steven Warren, along with a team of researchers from Notre Dame University were published in *Pediatrics*. The team found that when parenting coaches texted and called mothers, they were much more likely than the other mothers in the study to learn and use positive parenting strategies, and this effect persisted six months after the program ended. Following the parenting program, the children of such parents were more adaptable, less anxious and had better communication and social skills.  

Chancellor Bernadette Gray-Little presented Kenneth McCarson (Co-Scientific Director of the KIDDRC Biobehavioral Measurement Core) with a Distinguished Teaching Award at the KU Teaching Summit on August 21. A neurobiologist, McCarson has participated widely in medical and graduate education in addition to taking on many leadership roles. A former chair of his department's graduate training program, he is presently the course director of Essentials in Pharmacology.  

KIDDRC investigator Nancy Brady and RDA scientist Kandace Fleming, in collaboration with Connie Kasari of the UCLA Center for Autism Research and Training, secured NICHD funding to continue the development of the Communications Complexity Scale (CCS). The CCS is a unique measure for researchers and clinicians to assess the communication status of children and adults with disabilities as diverse as autism spectrum disorders, Down syndrome, deaf-blindness and cerebral palsy, including those who are nonverbal or have very limited speech. 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, to using “symbolic” communication, typically, spoken words.  

William Brooks, professor of neurology, director of the Huglund Brain Imaging Center and KIDDRC investigator, received the University of Kansas Excellence in Mentoring Award at the School of Medicine's faculty retreat on August 20, 2014. This award acknowledges the “commitments, effort and advice given to ensure that junior faculty achieve their full academic potential.”  

KIDDRC investigator Kathleen Baggett will again collaborate with the Oregon Research Institute to adapt a successful parent and childcare provider training program to 60 low-income mothers of infants of very low birth weight infants. Baggett has been a PI on previous InfantNet projects that adapt PALS (Play and Learn Strategies) to support typically hard-to-reach parents through web technology. Ultimately, the project targets the socio-emotional development of infants. The three-year project is funded by the HHS Maternal and Child Health Bureau/Health Resources and Service Administration.  

Nancy Brady, Kathy Bourque, R. Michael Barker and Sanae Akaba, KIDDRC investigators, authored a paper published in Augmentative and Alternative Communication that was selected as the 2013 AAC Editors' Best Research Paper  

**Kansas University Center on Developmental Disabilities 1973**  
More than 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 the 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  
Karrie A. Shogren, Ph.D., Associate Director  
Glen White, Ph.D., Associate Director  
G. Denise Lance, Ph.D., Consumer Activities Coordinator  
R. Matthew Reese, Director, KUCDD-Kansas City Site and KUMC Center for Child Health and Development  
David Lindeman, Ph.D., Director, KUCDD-Parsons Site  
Sara Sack, Ph.D., Director, Assistive Technology for Kansans Project  
Rachel Freeman, Ph.D., Research Coordinator Kansas Institute for Positive Behavior Supports  
Anjali Forber-Pratt, Ph.D., Cultural Diversity Coordinator and
Consumer Affairs Council Representative  
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**FY 2013–2014 Highlights**

- Faculty at the Center for Child Health and Development (CCHD) at the University of Kansas Medical Center, affiliated with the KU Center for Disability and Research, provided early identification and intervention development through health care screening and evaluation of autism diagnosis and screening to 144 families and children throughout Kansas via the Autism Referral Evaluation telemedicine clinics. The mean distance from the KUMC that families lived and were served over telemedicine was 180 miles. Through the Rural Outreach Clinics operated by the CCHD and the Kansas Children with Special Health Care Needs project, KU Center Kansas City-site faculty provided rural outreach clinics in four communities, serving almost 40 families who would not otherwise have had access to such services. Further, special arrangements were made to serve families in the military at the Kansas bases, including Ft. Riley and Ft. Leavenworth.

- The Assistive Technology for Kansans project, operated by the KU Center Parsons-site, provided training on the availability and use of assistive devices and services to 731 people in Kansas and across the United States and provided direct technical assistance on the use of AT devices to 526 Kansans at multiple sites across the state. Further, ATK loaned devices to 585 people with disabilities for them to try out in their homes, schools, work places or communities.

- The Gateway to Self-Determination Project, operated by KU Center Lawrence-site faculty, engaged in training and technical assistance on promoting and enhancing the self-determination of adults with intellectual and developmental disabilities and 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 19 technical assistance (TA) plans for early intervention providers or preschool special educators in Kansas. These TA plans are highly intensive with written plans identifying outcomes, needed resources, persons responsible, a plan for evaluation and goal attainment scales. This current year, TA plans had an impact on 61 administrators, 435 professionals and 6,185 children. Further, KITS staff conducted 15 training activities associated with technical assistance plans for 221 participants (60 total hours).

- KU Center faculty at the Kansas Institute for Positive Behavior Supports trained 1,234 professionals on positive behavior supports and responded to almost 11,000 requests for technical assistance through the KIPBS website.

- Faculty at KU Center engaged in activities to train Certified Employment Support Professionals to meet the need to support people with disabilities to get and retain meaningful jobs, resulting in 100 people certified. Further, KU Center faculty disseminated information about Employment First policies and practices to more than 500 people nationwide.

**The Research and Training Center on Independent Living 1980**

The Research and Training Center on Independent Living (RTC/IL) has a more than 30-year history of conducting disability research, providing training and transferring knowledge to practice. The Center furthers independent living for people with disabilities through the use of scientifically sound, theoretically driven sustainable interventions and measures that lead to effective community living solutions and policy change. Center researchers work closely with consumers and service providers to develop research and products that 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  
Martha J. Hodgesmith, Associate Director  
Jean Ann Summers, Research Director  
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**FY 2013-14 Highlights**

- Dot Nary received the Ann Eversole Advisor of the Year Award at the University of Kansas from the Student Involvement Leadership Center (SILC). The award recognizes her service as advisor to AbleHawks and Allies, a student group that raises awareness of disability issues at KU. AbleHawks and Allies was also named the Social Justice Program of the Year by SILC.

- Jean Ann Summers was invited to participate in an advisory group for the Patient-Centered Outcomes Research Institute, which funds research that provides information about the best available evidence to help patients and their healthcare providers make more informed decisions. The group developed recommendations on a new priority called “Patient-Empowering Care Management.”

- Glen White is the Secretary of the United States International Council on Disabilities and also serves as Chair of Delta Air Lines’ National Advisory Board on Disability.

- Martha Hodgesmith was elected to the KU Law Alumni Board of Governors. Board members represent districts that cover Kansas and the rest of the country.

- Dot Nary has been appointed to the University of Maine’s Graduate Faculty for a five-year term as part of her service on a dissertation committee. She has also been appointed to the Accessibility Executive Advisory Council at the University of Kansas.

- Dot Nary is co-author of “Exercise for Everyone: A Randomized Controlled Trial of Project Workout on Wheels in Promoting Exercise Among Wheelchair Users.” (Archives of Physical Medicine and Rehabilitation 95.1, January 2014, 20–28). Lead author is Katherine Froehlich-Grobe, with other authors Jaehoon Lee, Lauren Aaronson, Richard A. Washburn, and Todd D. Little.

- Glen White and Dot Nary contributed stories to New Mobility magazine’s April 2014 feature on air travel for wheelchair users. White wrote “Delta Reaches Out to Passengers with Disabilities” and Nary shared a personal story in “Eight Tips for Easier Air Travel.”

- Dot Nary’s research on home “visitability” for people with disabilities was featured in the Lawrence Journal-World on Dec. 17, 2013. The article “Make sure your home is ‘visitable’ during the holidays for guests with disabilities” highlights the health aspects of staying socially connected.

- The Research and Training Center on Community Living produced two infographics about housing for people with disabilities based on national data from the American Housing Survey. This information can be useful for people with disabilities, service providers, advocates and policymakers. The Center also produced a fact sheet on a housing intervention that will evaluate the efficacy of an advocacy method called “New Governance.”

- Another secondary data infographic from the Center focuses on people with disabilities who have multiple chronic health conditions.

- Glen White discussed an intervention he is leading to build the capacity of Centers for Independent Living to foster community participation by their consumers, who are people with disabilities. He presented on the project at the conference of the Association of Programs for Rural Independent Living.
White presented an online instructional tool that he and Jean Ann Summers developed at the American Public Health Association conference. The talk focused on “The ADA Accommodations Model: A New Tool for Empowering Postsecondary Students with Disabilities.”

Dot Nary made the following presentations about her work on home visitability, which explores the impact of non-visitatable homes on wheelchair users. She presented her findings at the American Public Health Association conference, the Association of Programs for Rural Independent Living conference, and for an online conversation hosted by APRIL.

Nary also spoke about disability and health on two occasions to undergraduate nursing and health studies students, staff and faculty at the University of Missouri-Kansas City School of Nursing and Health Studies.

Martha Hodgesmith presented “Building Bridges from Research to Policy and Practice: Sharing Early Results of a Research Center” in a panel on knowledge translation at the NARRTC annual conference.

She presented “Listening to Their Voices – Improving Access to Health Care Using a Community Engagement Initiative Model” at the National Home & Community-Based Services Conference.

Hodgesmith and Val Renault were panelists for a conference titled “Knowledge Translation Measurement: Concepts, Strategies and Tools” sponsored by Southwest Educational Development Laboratory.

Val Renault presented “Words of Respect: Speaking of Disability” with KU Journalism Professor Doug Ward at the American Copy Editors Society Conference.

Staff members collaborated with national and local organizations to build awareness and understanding of disability.

Martha Hodgesmith helped the National Council on Disability organize a panel on “Living with a Disability in Rural America” for the NCD’s quarterly meeting in Topeka, Kansas, in December 2013.

Dot Nary and Val Renault presented information about people with disabilities for students in a Journalism “Documentary” course at KU in Jan. 2014. They partnered with Journalism Professor Jerry Crawford to advise the students on researching disability topics.

Dot Nary conducted a disability awareness training for eight interns and staff members as well as the director of training at KU’s Counseling and Psychological Services in March 2014.

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 a longitudinal study of preschool children diagnosed as specific language impaired (SLI). The Life Span Institute, the Language Acquisition Preschool and the clinical and research facilities of the Speech-Language-Hearing Clinic provide research sites and practica.

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FY 2013-2014 Highlights

In 2013-14, the Child Language Doctoral Program hired Lesa Hoffmann, Ph.D. at the professor level. She is an outstanding quantitative scholar with multiple projects funded by NIH.

Student progress in 2013-14: Yi-Chih Chan, Megan Blossom Prentice, and Leah Kapa received their doctorate degrees and Teresa Girolamo was accepted into the program for Fall 2014.
LSI researchers Wayne Sailor and Amy McCart were awarded one of the largest grants in KU history to implement a new model for inclusive education, SWIFT (School-wide Integrated Framework for Transformation) across the U.S.

Published a series of studies documenting a causal relationship between self-determination interventions and post-school outcomes.


Completed Exceptional Family Member Benchmark Study that was then published by the Department of Defense.

Developed and delivered on multiple occasions a curriculum entitled Army Exceptional Family Member Program: Systems Navigation.

Conducted a comprehensive qualitative study of family and community partnerships in inclusive schools and submitted several articles.

Engaged Maryland, Mississippi, New Hampshire, Oregon and Vermont state educational agencies in partnerships to establish integrated state technical assistance systems with the capacity to install and scale-up the Schoolwide Integrated Framework for Transformation (SWIFT) model.

Deployed an intensive technical assistance process in 18 local educational agencies and 68 schools to explore, prepare, launch and expand SWIFT school transformation to improved academic, behavioral and social outcomes for all students, including those with the most extensive support needs.

Developed, validated and collected baseline data with a set of implementation tools, including a field guide for teachers and administrators to reference information and videos about SWIFT features, a comprehensive school fidelity of implementation tool and a brief school self-assessment for monitoring implementation progress.

Completed a knowledge development study of best practices for including and supporting students of all abilities in general education, and of educator, student, family and community perspectives of inclusive education experiences in six regionally diverse K-8 schools.

Disseminated knowledge and fostered discussions about integrated education for all students through six issue briefs, a 15-part video series, 22 community-of-practice blogs and strategic social media presence (in addition to conference presentations).

Collaborated to organize and successfully implement the SWIFT Professional Learning Institute.

Conducted training sessions (one presented in Spanish, as well as English) and follow-up technical assistance for families and professionals on competitive employment in order to provide assistance to individuals with disabilities in gaining and maintaining successful employment.

Provided co-teaching training and follow up technical assistance to implement co-teaching support to an additional 22 school districts in western Kansas, while continuing support to the first cohort of 14 districts in northeastern Kansas.

Developed four modules of an on-line tutorial for Math Essentials for use by Kansas teachers to bring mathematics instruction into alignment with Common Core standards and support instruction for students with disabilities in mathematics.

Revised and finalized a facilitator’s guide for distance mentorship of school teams serving students with deaf-blindness, using online wikis and monthly video teleconferencing.

Received a five-year doctoral training grant focusing on students at the secondary and transition levels with significant support needs in terms of access to the general curriculum, post-secondary education and careers.

Provided research consultation to international colleagues in eleven countries.

Rud Turnbull provided testimony to the Kansas Board of Education and consultation to the Kansas Department of Education on seclusion and restraint for students with disabilities.

Mike Wehmeyer received three awards: The University of Texas at Dallas Distinguished Alumni Award, School of Behavioral and Brain Sciences; Bethesda Lutheran Communities Pool of Bethesda Award for outstanding contributions of service and leadership in the field of intellectual and developmental disabilities, 2014; and The Arc of the United States Distinguished Researcher Award, presented to a career academic researcher whose work has significantly advanced the field of research in intellectual and developmental disabilities.

Karrie Shogren received the AAIDD Presidential Award for her research leadership in the norming of the Supports Intensity Scale.

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

**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.

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**FY 2013–2014 Highlights**

CTB growth, Arabic launch: In May 2014, the KU Work Group for Community Health and Development, the American University of Beirut and the Arab Resource Collective hosted an Arabic Community Tool Box dissemination workshop in Beirut, Lebanon. This conference engaged participants from the Middle East and North Africa working to build capacity in the region.

Community Tool Box translation support is being provided to extend access in world regions through Spanish, Arabic, French, Portuguese, Mandarin Chinese and Russian.

Publications: A number of articles authored and co-authored by KU Work Group staff were published, including:

A special issue of the *Journal of Prevention and Intervention in the Community, Participatory Research and Capacity Building for Community Health and Development*, featured the KU Work Group’s efforts.

Vicki Collie-Akers, Stephen Fawcett and Jerry Schultz authored a manuscript, “Measuring progress of collaborative action in a community health effort,” which was published by the Pan American Health Organization, in the *Pan American Journal of Public Health* special issue on social determinants of health. Stephen Fawcett and Jerry Schultz also co-authored another article for the issue, “Synergy for health equity: integrating health promotion and social determinants of health approaches in and beyond the Americas.”
The Global Journal of Community Psychology Practice published a manuscript, “Building community practice competencies globally through the Community Tool Box,” which was co-authored by Christina Holt, Stephen Fawcett, Jerry Schultz, Bill Berkowitz, Thomas Wolff and Vincent Francisco.


Academic Health Department: Established in 2013, the Academic Health Department is a partnership between the Lawrence-Douglas County Health Department aimed at building the capacity of health department staff, KU students, and KU Work Group staff to implement the 10 Essential Services of Public Health and to build a shared research program between the two partners. Key accomplishments in the first year have included establishment of a shared community data collection system aimed at understanding the efforts of the local public health system to promote community health, a training fellowship sponsored by the KU Work Group and LDCHD that allowed two LDCHD staff to take ABSC 310, Building Healthy Communities, and the establishment of deeper connections at KU, including partnerships with the Journalism School through Bob Basow’s Strategic Communications courses and within Applied Projects: Bristol-Myers Squibb Foundation: On February 25-26, the KU Work Group was invited to an expert meeting on social determinants of health sponsored by the World Health Organization’s African Regional Office. The meeting took place in Port Louis, Mauritius, in June 2014. Resource persons assembled to discuss challenges related to determinants of health and also share resources to overcome those challenges. Ithar Hassaballa, graduate student at the KU Work Group, delivered two presentations on resources offered by the KU Work Group. One presentation was about the Community Tool Box as a resource for capacity building, and the other was on a monitoring and evaluation system to help WHO track community health efforts in the African region.

Partnership with Colombia: On August 20-23, 2013, Jerry Schultz and Cesareo Fernandez, a WHO Collaborating Center Fellow, met with the Even Start Program team at the University of Sabana in Bogota, Colombia to prepare a framework for collaboration and design a monitoring and evaluation system for the Even Start Program. The Even Start Program will work with communities to improve the quality of life for children, ages 1-6, in Colombia.

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.

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FY 2013-2014 Highlights

The 18th annual Merrill Research Retreat was held July 16-18, 2014, at the Lied Lodge and Conference Center, on the theme, Planning for Future Research in Public Universities in Uncertain Times. There were 33 attendees at the invitation-only conference, including the keynote speaker Sally Mason, president of the University of Iowa; KU Chancellor Bernadette Gray-Little, Chancellor Harvey Perlman of the University of Nebraska and researchers and research officers from the University of Kansas, University of Kansas Medical Center; Kansas State University, Iowa State University, University of Nebraska and the University of Missouri. A white paper from the 17th annual Research Retreat, on the topic of Planning for Research Excellence in the Era of Analytics, was published and posted to the website of the Merrill Advanced Studies Center: http://www2.ku.edu/~masc/PDFfiles/2013whitepaper.pdf

Gerontology Center 1990

The Gerontology Center’s affiliation with the Bureau of Child Research in 1990 paved the way for an extended research agenda of the newly formed Life Span Institute. Center researchers are interested in all areas of aging but are distinguished by seminal research in cognition, communication and aging, longterm 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.

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FY 2013-2014 Highlights

The Gerontology Center had a lead role in hosting the I-70 Corridor Conference on Interdisciplinary Aging Research in November. The Lawrence conference attracted nearly 60 researchers from nine universities along I-70 from locations ranging from St. Louis, Missouri to Manhattan, Kansas. Supported by a Strategic Initiative II Grant, the two-day meeting explored potential regional collaborations in research and training.

Susan Kemper was a guest of the Fonobono Research Institute, Chiba University, Chiba, Japan in December, 2013. While at Chiba, she taught a master class on language and aging, demonstrating methods for the analysis of age-related changes to language. She also lectured on Language and Aging and Elderspeak at the Graduate School of Information Science and Technology, University of Tokyo, and presented a public address on Communicating across the Life Span later broadcast on NHK, Japanese television. Kemper has also led a series of webinars on Communicating across the Life Span for the International Conference on Language Resources and Evaluation which have attracted an international audience of participants.

David Ekerdt led a group that reviewed and recommended revisions to the governance structure of the Gerontological Society of America. As a result, the international membership approved bylaws to this effect in 2014.

David Ekerdt published a paper reporting the first national survey data on older Americans’ inertia toward possession management (May 2014 issue of Journal of Gerontology: Social Sciences). After age 50, people are progressively less likely to divest themselves of belongings and a majority of them admit to having more things than they need. The findings were also reported by Reuters, Newsday and in an interview on NPR Morning Edition.

David Johnson was appointed to the NIH led Consortium of Alzheimer Prevention Board in July 2014.

David Johnson presented findings from the KU clinical Trial for Exercise and Memory (TEAM) at the Alzheimer’s Association International Conference in Copenhagen Denmark, July 2014. Findings indicate that cognition in late life can improve significantly with six-months of moderate cardiovascular exercise. He found that cognition improved in dose response to exercise. The more an older adult exercised, the more benefit they received, but exercise regimens as small as 15 minutes three times a week also conveyed significant benefit.

The 2014 Excellence in Gerontology Award was given to Sharmin Kader, Ph.D. Candidate in Architecture, to support her dissertation research to develop a protocol for the evaluation of hospice facilities.

Plans for a potential intergenerational community affiliated with KU came closer to reality. This new development will combine older adults in a retirement community setting with mixed housing for families and singles of all ages. This public-private effort has considerable support from civic leaders in Lawrence. The Gerontology Center has promoted the creation of a living laboratory at this community that would be a facility for KU research and teaching. Susan Kemper and Dennis Domer generated a programming report that specified the interest of many KU schools and departments in this venture. In late spring, KU issued an invitation to developers to collaborate with the university in the creation of this resource.

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.

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FY 2013-2014 Highlights

Fifteen investigators are affiliated with the BNCD with research interests which 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.

The BNCD added a new investigator, Lesa Hoffmann. She is an outstanding quantitative scholar with multiple projects funded by NIH. Her expertise is longitudinal growth modeling, with a focus on changes related to aging in the areas of cognitive and social development and decline. She joined the BNCD as director of the Advanced Techniques and Technology (ATT) core in August 2014.

The BNCD Participant core (PARC) organized a brown bag discussion for investigators on the topic of recent updates in local IRB
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.

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FY 2013–2014 Highlights

K-CART continues to promote research and training on evidence-based practices by training professionals, practitioners and families to serve individuals with autism. K-CART sponsors:

Pilot Studies: an internal research funding source for investigators to conduct initial studies to provide pilot data for grant applications. Ten projects have been funded in bio-behavioral assessments and interventions for persons with Autism Spectrum Disorders. The work from the Discovery grants continues to support new research initiatives, many with funded projects. Examples of two new projects stemming from pilot studies: I-CONNECT Plus to develop instructional modules, telecoaching and self-management to support adolescents and young adults on the spectrum (Kamps, Wills, Mason) and an investigation by Kathy Thiemann-Bourque of the use of I-Pads to increase social-communication skills for non-verbal preschoolers with autism and their peers.

In 2014, K-CART launched the dissemination of the Autism Connections video series on the website. The three videos, Connecting Kids, Connecting Teens and Connecting Parents, is a professionally produced film series designed to give consumers general information about autism and ways to communicate and socially engage with their classmates, friends and family members with autism.

K-CART, in partnership with Johnson County Community College, hosts an annual conference: Beyond the Diagnosis: Autism Across the Life Span. More than 200 families and professionals attend this conference every year to receive information directly from KU researchers and invited community experts. The partnership also includes an on-campus ASD Support Club, bringing together same-age peer mentors to learn from each other, gain social skills and gain community experience.

The Autism Training Program is an intensive training program designed for individuals wanting to provide early autism intervention services. The Autism Training Program has conducted 81 trainings and trained more than 550 individuals since its inception.

The OASIS Parent Training Program: a research project 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 has recently transitioned into a clinical service at the Center for Child Health and Development at KU Medical Center.

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

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

The Center for Child Health and Development (CCHD) provides important clinical evaluations, diagnostics and services. Under the guidance of Matt Reese, K-CART co-director, approximately 1500 children are seen annually with more than 700 with autism seen in 11 weekly clinics. The age of diagnosis has been reduced at CCHD from 4.5 to 3.5 years of age in the last two years, dramatically increasing the likelihood of critical early intervention services.

Additionally, the CCHD has been developing its capacity to be a leader in bio-informatics for people with autism. Since 2009 the CCHD has been using the Comprehensive Research Information System (CRIS) to track all intakes into the CCHD. In 2010 a patient portal was implemented, allowing families to fill out their child's diagnostic history online. As of 2014 CCHD has a searchable database. It was a very productive session with a diverse group of investigators and doctoral students affiliated with their labs. Both the PARC and ATT cores produced newsletters for investigators, in addition to the newsletters produced by PARC for the participants in the database.
database of more than 6000 patients, including more than 300 data items regarding medical and diagnostic history.

Centro Ann Sullivan del Perú 1990

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

CASP has a formal agreement with the Life Span Institute and receives much of its staff education through university faculty from the KU departments of Special Education and Applied Behavioral Science.

Liliana Mayo, Ph.D., Director
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FY 2013–2014 Highlights

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

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

CASP was invited by the Government of Bangladesh and the World Health Organization to launch the Global Initiative for Autism during the 67th Southeast Regional Committee Meeting of the WHO that was held in Dhaka, Bangladesh, on September 9-11, 2014. This event was an opportunity for constructive dialogue among stakeholders and to assist WHO in developing an effective action plan to address the needs of individuals with autism spectrum disorders through an International Partnership for Neurodevelopmental Disorders. The presentation of the CASP Peruvian Model was very enthusiastically received.

CASP signed an agreement of cooperation with the Government of the Dominican Republic on the July 26, 2013. Liliana Mayo was invited to be the keynote speaker at an event organized by the First Lady of the Dominican Republic, Candida Montilla de Medina. Mayo received an award from the President of the Dominican Republic, Danilo Medina, of the Order Heraldica of Christopher Columbus in the order of official, for the work of CASP in the world.

The CASP online Long Distance Education Program conducted 35 conferences between 2008 and September, 2014 for more than 27,480 parents and professionals in the 24 states of Peru and 15 countries: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Germany, Guatemala, Italy, México, Nicaragua, Panama, Spain, the U.S. and Peru.

The R21, Early Prevention of Neurodevelopmental Behavior Disorders among Young At-Risk Children in Peru, project was completed May 31, 2013. Ten papers were published and two are still under review. Eight presentations were made at national and international meetings. Fifty children are still being followed by CASP, with funding from benefactors, and they are still doing well. Hopefully, they will be followed into adulthood.

Janet Marquis, Judith LeBlanc and the staff of CASP have worked three years developing a recording system showing each student’s progress in their annual individual objectives. This data will soon be computerized, providing the classroom specialists with up-to-date information on their students. Lisa Hallberg is computerizing the data for analysis. In 2014 the group began developing a complementary database of parental progress in their assigned objectives as parent-teachers in their homes working with their child on the same student objectives that have been assigned for their child. Marquis and Hallberg will travel to Peru in October to work with the CASP team to develop this part of CASP’s data. This data will show how parental advances can affect the student advances. This is the first time that CASP will have the computerized data showing the effectiveness of their work with now more than 400 students.

CASP began receiving training from Dale Walker through Skype in Building the Capacity to use Naturalistic Communication Interventions for Infants and Young Children in July 2014. This is a start of collaborations between CASP and the Juniper Gardens Children’s Project.
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