The Life Span Institute at a Glance

Who
Investigators, research and administrative staff, graduate and post-doctoral students

The LSI brings together 140 scientists who are affiliated with 20 academic departments to study human development from its genetic origins through the final stages of life. These investigators are supported by 360 research and administrative staff members, including 60 graduate research assistants.

The Institute has two affiliated multidisciplinary graduate doctoral programs, the Child Language Doctoral Program and the Gerontology Graduate and Doctoral programs, as well as several post-doctoral training programs.

What
Research, training, technical assistance, direct services, and leadership

The Life Span Institute’s 12 centers currently have 110 active programs and projects that constitute basic and applied research, training, direct services, consultation, and technical assistance.

Research informs everything that the Institute does and ranges from groundbreaking studies in cellular and molecular biology of the early stages of development to designing school-wide models to improve classroom behavior and learning.

Last year, 49,000 Kansans benefited from the Institute’s direct services, training and technical assistance.

When
History

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

The Institute has had two directors, Stephen R. Schroeder, who retired in 2001, and presently, Steven F. Warren.

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, in Kansas City at the Juniper Gardens Children’s Project and the University of Kansas Medical Center’s Ralph L. Smith Research Center, and at the Life Span Institute in Parsons.

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.

Where
Administrative and Research Locations

The Robert J. Dole Human Development Center
The University of Kansas
1000 Sunnyside Avenue, Room 1052
Lawrence, Kansas 66045-7555
785 864-4295 TTY 785 864-5051
fax 785 864-5323
lsi.ku.edu

Editor: Karen Henry  Design: Chris Lorenzen
Editorial assistance: Jessica Black and Marit Genero

How
Funding

The Life Span Institute attracts more combined federal, state, and private dollars than any other designated research center at the University of Kansas, drawing $21.4 million in sponsored project support in FY 2004-05. Each state dollar brought in $6.5 external dollars this fiscal year.
Impact on Kansas

When the forerunner of the Life Span Institute, the Bureau of Child Research, was established in state statute in 1921, it was “for the purpose of studying the problems of the child life in the state, including studies as to the diagnosis, treatment, and prevention of delinquency, defectiveness, and dependency: studies in normal inheritance, development, and training; studies of family and community life in their relation to the child.” (L. 1921, ch. 282, S1; May 25). Given the historic focus of our original charter on the needs of the state, we chose to devote this annual report to exploring our impact on our fellow Kansans.

The contemporary mission of the Institute—to find research-based solutions for the challenges of human and community development, disabilities, and aging—reflects both a continuation of our original focus and a much needed expansion to adults and communities. We pursue this mission on a national, and indeed, global scale. The Institute has a worldwide reputation and many of our investigators similarly are internationally renowned for their efforts. This is all well and good. But what about our own backyard? What are we doing in 2005 to impact the lives of our neighbors and fellow citizens? A careful reading of this report will confirm that LSI scientists and staff continue to engage in a wide range of research, training, technical assistance, and service that directly impacts the quality of life of Kansans across the state.

Steven F. Warren, Director
The Schiefelbusch Institute for Life Span Studies
Babies who are born prematurely are often in grave danger. They may not be able to suck, swallow, or breathe on their own. Some “premies” suffer strokes or hemorrhage during or shortly after birth. Many more have subtle brain injuries that affect the development of intelligence and speech. All of them may benefit from a unique device developed at the University of Kansas, called the Actifier, invented by University of Kansas Speech-Language-Hearing Professor Steven Barlow with University of Colorado Assistant Professor Donald Finan.

The Actifier is a pacifier that becomes an active diagnostic and treatment device once it is plugged into a rolling cribside laboratory. KU has a patent pending on the device. Barlow and his colleagues are testing the device on infants at neonatal intensive care units at Stormont-Vail Regional Health Center in Topeka and the KU Medical Center in Kansas City, Kansas. A total of 390 infants will participate in the study over the next two years.

From the front page of the September 15 Kansas City Star, the story spread across the U.S. and on to Canada, Great Britain, Europe and South America over the following several months.

A study that showed that infants whose mothers have higher levels of an essential omega-3 fatty acid show more advanced cognitive development directed by John Colombo, Susan Carlson and Kathleen Kannass attracted wide attention in 2004.

The researchers found that docosahexaenoic acid (DHA), which affects brain and eye development, is derived by fetuses from their mothers and accumulates in the brain primarily in the third trimester. They measured the DHA levels of 70 mothers’ blood when their infants were born and then followed the infants for the first two years of their lives, evaluating them on different tests of attention during the first and second years.

Colombo is the Life Span’s associate director for cognitive neuroscience and professor of psychology; Carlson, professor of nutrition at the KU Medical Center, and Kathleen Kannass, research associate at the Life Span Institute, now an assistant professor of psychology at Loyola University.
Juniper Gardens Children’s Project celebrates 40 years

The Juniper Gardens Children’s Project (JGCP), founded in an urban Kansas City, Kansas neighborhood 40 years ago by visionaries from that community and the University of Kansas, celebrated its impact on thousands of children, teachers, researchers, and on the fields of special education and child development on October 23.

The daylong event brought together the legendary founders, alumni who propagated what they learned at JGCP as leaders in their fields, admiring national special education experts, as well as the vibrant current faculty, staff, and students.

During the conference their individual perspectives took shape as one moving testament to, as renowned alumni Todd Risely, put it, “doing good and doing science.”

The event culminated with a gala dinner and awards ceremony featuring addresses from JGCP Director Charles Greenwood; former community board member Judge Cordell D. Meeks, Jr., District Court Judge for the 29th Judicial District of Kansas; LSI Director Steven Warren, and former LSI Director Stephen Schroeder.

Today, in programs of intervention research and training, JGCP is working toward solutions to a range of challenging problems and issue areas including child neglect, teen parenting, children learning to talk, measurement of early intervention results, accelerating literacy and achievement, effective school-wide discipline, and improving the home and schooling experiences of children.

JGCP continues to develop researchers at the pre- and post-doctoral levels and increasingly plays a role in national research efforts and policy.

Friends of the Life Span Institute gather for first event

The spirit was warm, comfortable, and quietly confident at the inaugural Friends of the Life Span event on April 9 at the Adams Alumni Center in Lawrence. The event began with a reception where longtime Life Span friends such as Virginia and Fred Merrill and John and Linda Stewart gathered with current LSI faculty Friends as well as alumni from near (Vance and Marilyn Hall, Steve and Carolyn Schroeder, Joe and Rita Spradlin) and far (Jim and Lee McLean from North Carolina, Sunny Foster and Gary Waldron from California).

All together 37 Friends attended the first Annual Dinner that was preceded by a business meeting. The dinner program featured remarks from Chancellor Robert Hemenway, Director Steve Warren and Distinguished Professor Emeritus Dick Schiefelbusch. The evening wound up with a presenta-

tion by Professor Steve Barlow on his groundbreaking invention, the Actifier, that trains at-risk premature infants to suck and evaluates their neuromotor functioning.

The Friends of the Life Span Institute, launched in 2004, is a group of supporters with a compelling interest in furthering the Institute’s research, development and teaching opportunities. The Friends annual membership for an individual or couple is $1000. The Friends serve as a sounding board for shaping the long-term goals of the Institute and help the Institute communicate Life Span’s mission to increase its circle of Friends.
David Ekerdt named director of Gerontology Center

David J. Ekerdt became the new director of the Gerontology Center in January. Ekerdt, the interim director of the Gerontology Center and professor of sociology, was appointed after a national search.

“David Ekerdt is a recognized research leader with the vision to define and expand KU’s scholarly and academic initiatives in aging,” said Steven Warren, Life Span Institute director.

Ekerdt will oversee the Gerontology Center’s research agenda that includes seminal research in aging and communication, the social and psychological aspects of retirement, long-term care, housing alternatives, and age discrimination.

Ekerdt’s charge includes the Gerontology Center’s multidisciplinary graduate program that offers both master’s and doctoral degrees in gerontology.

He will direct the Center’s work with public and private agencies in developing programs for older persons and their families and assisting agencies and organizations with evaluations of programs and public policies.

He will also be responsible for the Center’s activities as part of a wider, multidisciplinary group of affiliated faculty, including scientists and clinicians at the Center on Aging of the University of Kansas Medical Center.

Previously, Ekerdt was the associate director of the Center on Aging and associate professor of family medicine at the University of Kansas Medical Center.

A graduate of Boston University, Ekerdt has also been a member of the faculties of the Harvard School of Dental Medicine and the Boston University School of Public Health.

Ekerdt is presently conducting research on American workers’ changing plans and decisions for retirement, and on the ways that people manage and dispose of their possessions in later life funded by grants from the National Institute on Aging.

He also is editor-in-chief of the Macmillan Encyclopedia of Aging, a four-volume, one-million-word work published in 2002 that is the first standard reference on aging for both the general public and academic researchers.

Ekerdt teaches the sociology of aging and quantitative research methods, and has supervised graduate students on both campuses. His funded studies of work and retirement have examined the retirement process and its effects on health, well-being, and the marital relationship, as well as behavioral expectations on later life.

Rud Turnbull testifies at Senate “Terry Schiavo” Hearing

Rud Turnbull, co-director of the Beach Center on Disability, testified on April 6 before the U.S. Senate Health, Education, Labor and Pensions (HELP) Committee on issues related to the Terry Schiavo case.

Turnbull testified as the father of J.T., who has developmental disabilities, and as an attorney and special education expert who has played a significant role in developing legislation and policy to protect the rights of people with developmental disabilities.

Turnbull reviewed the cruel history of the world’s treatment of people with disabilities and pointed out to the committee that most of us will have disabilities if we live long enough.

Turnbull suggested that federal intervention in some cases is warranted. But at the same time, he reminded Congress that,

“Congress should recognize that there already are principles guiding health-care decision making and that these principles have garnered widespread consensus from health-care providers and organizations representing people with disabilities and their professional care-givers.”

He also took the opportunity to warn against turning back the hard-won system of entitlement programs for people with disabilities and cautioned that:

“Congress should acknowledge that any government that compels a life to be lived is ethically obliged to provide the person with a right to individually chosen and appropriate supports necessary to implement the ADA “natural experience” declaration and the ADA national policy aspirations. Civil rights are the necessary precursors to rights and entitlements within service-delivery systems.”
As a young speech-language pathologist, Sara Sack knew that technology could give people with no speech the ability to communicate. Problem was, such technology—augmentative communication devices—was usually expensive and there was often no way to pay for it.

To Sack, a communication device was the same as any other prosthesis, and ought to be covered by insurance companies and state Medicaid programs. She started looking for new ways to fund communication devices, and while she was at it, she looked for funding for powered wheelchairs, ramps and telecommunications systems—the full range of assistive technology that her clients needed to be independent and productive.

It became clear to Sack that the problem was too big to tackle on a case-by-case basis. It was the system and she wanted to be part of changing it.

By 1992, Sack was a Ph.D. at the Life Span Institute at Parsons, working with an old hand at changing systems, Senior Scientist Chuck Spellman, and the stage had been set for one of the most monumental system changes in American history with the passage of the Americans with Disabilities Act in 1990.

When the U.S. Department of Education offered grants to develop statewide systems to give people with disabilities access to life-changing assistive technology, Sack and Spellman jumped on it. “We talked to more than 600 people with disabilities and about 70 people from state agencies to discover what services existed and what they wanted,” Sack recalls.

This meant things like finding qualified professionals in sparsely populated western Kansas to evaluate and train people to use assistive technology—including adapted farm equipment.

They were awarded the grant, and the result is Assistive Technology for Kansans, a model program for getting assistive technology to Kansans with disabilities with centers in Oakley, Salina, Wichita, Lawrence, and Parsons. This was just the first demonstration of Sack’s leadership that has been critical in establishing an assistive technology loan cooperative, equipment loan bank, equipment consignment and reuse system, and a rehabilitation program for farmers injured in agriculture-related accidents in Kansas.

Her testimony to the U.S. Senate Health, Education, Labor and Pensions Committee on stable funding for assistive technology programs “blew them away,” according to Spellman, who said that one committee member commented that it was the most compelling she had ever heard.

She later served on the U.S. Senate working committee that helped draft the successfully re-funded Assistive Technology Act of 2004 that Senator Pat Roberts co-sponsored.

But Sack doesn’t like to talk about herself. She would rather talk about people like Adam, one of the first people to benefit from the system change she worked to bring about.

“He was injured in an accident, got very few services and was returned home to live in bed. There was no thought of augmented communication, adaptive switches or powered mobility. Now Adam is out in the community, has the resources he needs, and is doing great. If the same accident were to occur today, I feel much more confident that someone like Adam would get the answers and resources he needs.”
Shannon, a poised White Church Elementary Wildcat in the fourth grade, used to spend a lot of time in trouble in the third grade. That was time that he wasn’t learning. That was before he learned to follow the Wildcat Way.

The Wildcat Way is the slogan of White Church Elementary School in Kansas City that epitomizes what’s behind something called school-wide positive behavior support: less time dealing with behavior problems means more time learning.

For White Church Elementary, more time learning in an innovative academic program has resulted in soaring achievement scores over the last five years, earning the school national attention.

Office discipline referrals went from 432 in 2000 to 32 in 2003. Reading proficiency went from 41.6 percent in 2000 to 87.5 percent in 2003, math from 29.4 percent to 90 percent during the same time period.

Positive behavior support (PBS) is a package of strategies that focuses on teaching new skills, changing school environments and preventing problem behavior from occurring, according to Amy McCart, assistant research professor, who directs several PBS-based projects in Kansas City, Kansas USD 500 with other Beach Center on Disability researchers.

PBS is based on the belief that appropriate behavior can be taught by educators. School-wide PBS is a strategy that addresses school-wide discipline.

“Traditional discipline systems in schools have focused on student behavior control through practices like suspension and expulsion,” she said, “but research shows that these practices don’t work well and don’t teach appropriate behaviors.”

Put simply, in school-wide PBS, schools develop and systematically teach three to five school-wide behavioral expectations like the “be respectful, be a learner and be in control” of the Wildcat Way.

“When all staff and students have a clear understanding of these behaviors, students know how to respect each other and teachers can focus on teaching rather than dealing with problem behavior,” McCart said. “Office referrals go down and academic achievement goes up.”

How do kids know what being respectful or being in control means?

“You have to very carefully describe each behavior and what each behavior looks like in each setting,” McCart explained. “In a classroom setting you would describe what the Wildcat Way looks like in that environment.”

“Being respectful in the classroom means that you sit nicely in your chair without getting up. You talk in a 5-inch voice. You follow directions. Those sorts of things, that may look very different when you’re in the hall or the cafeteria,” said Susan Keetle, USD 500 instructional coach and KU special education.
It may seem obvious that kids should know how to behave at school. But discipline is one the biggest challenges educators face in diverse, urban school districts like Wyandotte County.

“In the past, we thought that kids knew what to do at school, but they really don’t know,” said Keetle. “How do five-year-olds coming into school know that they are supposed to go down the hall in a straight line behind their peers, not talking, and keeping their hands to themselves?”

Even if they do have an inkling of what to do, Keetle said, most of them have a hard time transitioning between classrooms and more social and unstructured school environments. “That’s where you’re really doing that intensive teaching to get kids back on track.”

And everyone at White Church Elementary does this intensive teaching, including the front office, library, and cafeteria staff.

Goodness may be its own reward, but at White Church they also use Wildcat Wealth to reward good behavior. Teachers and staff can issue the school currency on the spot to reward kids whose behavior is exemplary that students can exchange for things like snacks, computer time, playing with a friend, drawing, or not having homework.

Some kids like Isaiah learn to monitor their own behavior. He sets his own goals every day on a form and gives himself pluses and minuses depending on if he reaches those goals. If he meets 80 percent of his goals, he chooses a reward.

White Church Elementary has implemented school-wide PBS since 2001. The school has met Adequate Yearly Progress (AYP) in reading and math for three years. AYP, mandated by the 2001 No Child Left Behind Act, is each state’s definition of academic proficiency. All students are expected to be at 100 percent proficiency by 2013-14. At White Church the preliminary 2005 AYP was 87 percent in reading and 100 percent in math.

“Although we cannot and would not say that the school’s academic success is due to School-Wide PBS, it has certainly contributed,” said McCart. “When you increase the amount of time students are in classrooms and you pair that with a really good instructional program, that’s where you begin to see the acceleration in academic outcomes.”
B
ehaviors like hitting, biting, or destroying property that disrupt classrooms and families and sometimes destine children to tragic adult
domains.
That’s why she was attracted to, graduated from, and eventually joined the staff of a joint KU-state program called the Kansas Institute for Positive Behavior Support (KIPBS) staffed by KU academic and clinical faculty.

The joint KU-state effort is building consistency and additional expertise in how professionals across the state work with families, schools, and community members to address behavior problems of the most vulnerable kids in Kansas—those whose behavior threatens their future happiness and independence.

The effort is also building a strong network of highly trained behavioral experts across the state who support each other and have KU’s renowned expertise in behavioral psychology only a phone call or a mouse click away.

“There’s a full complement of people at KU and across the state who are interested in making you successful where you are,” Slothower said.

Slothower, director of behavioral service at Creative Community Living in Winfield, is typical of the practicing professionals who commit to the rigorous year-long program while holding down demanding jobs.

“The KIPBS program sets itself apart from most other educational opportunities—even master’s pro-
grams,” said Slothower, “it is a program that builds on itself.”

Rachel Freeman, associate research professor at the Life Span Institute, directs the four-year-old program that trains professionals in an approach called positive behavior support (PBS).

“PBS is a set of research-based strategies that are designed to reduce problem behavior and improve the quality of the lives of children both with and without developmental disabilities,” Freeman explained.

Behavior facilitators teach teams of parents, staff, school professionals, and other community members to look for what triggers a child’s problem behavior and to figure out why those problems happen at certain times, places, or during certain activities.

They teach these “team members” to collect and analyze data about a child’s behavior at home, in school or other community settings.

From this process, the facilitator and the team develop a positive behavior support plan—a sort of guide to the child—for families, teachers, and others to use in helping the child decrease problem behavior.

“Sometimes problem behavior is a way of communicating either something a child wants or wants to escape or avoid,” Freeman pointed out. “It becomes the way a child lets others know what he needs.”

For example, facilitators help identify how to in-
crease ways for a child to get attention before prob-

A seasoned professional like Susan Slothower, who works with children who have developmental disabilities in Cowley County, knows how daunting behavior problems can be for families, teachers, and communities.
Problem behavior occurs, help adults learn how to prompt a child to ask for what she needs and how and when to pay attention to appropriate behavior rather than problem behavior.

The Kansas Department of Social and Rehabilitation Services (SRS) believes that PBS training is important for Kansas developmental disabilities professionals, according to Freeman. That’s why they partnered with KU to establish the program in 2001.

KIPBS graduates can bill Medicaid for their services to eligible Kansas children with developmental disabilities who have problem behaviors that are likely to become more serious as they become older.

KIPBS graduates are committed to the program for the rest of their professional lives. They spend 12 hours a year on professional development, mentoring new professionals, and helping state agencies implement policy changes.

Slothower likens KIPBS to KU’s version of Kansas State University’s county-based Research and Extension Service.

“Bringing KU’s wealth of resources right here to Winfield, Kansas, is amazing for parents and such a relief for me,” she said. “Everything they need for their child is literally brought to their kitchen table—because that’s where we meet. I think it makes sense for everybody.”

Susan Slothower analyzes what triggers Lissa Misasi’s problem behaviors at school and home and guides teachers and family in addressing those behaviors in specific, positive, supportive ways. Slothower is the director of behavioral services at Creative Community Living in Winfield.
Sand, like her counterparts at the 13 Early Head Start sites in Kansas and Missouri uses a unique tool developed by Juniper Gardens Children’s Project scientists that can measure language and communication development in infants and young children quickly, inexpensively, and often. This means that at-risk children can get help early—when it matters the most.

The Early Communication Indicator or ECI allows program coordinators like Sand and those on the front lines of child care—home visitors and childcare center workers—to record a child’s communication in six minutes, input the results on a web site and immediately see, for example, if an intervention like speech therapy is working.

Childcare practitioners are trained to observe a child and record his/her expressive communication, ranging from gestures to multi-word occurrences, on a coding sheet while a family member or familiar caregiver plays with the child. In some cases, the observer videotapes the session and scores it later. Finally, the results of the test are input into forms on a web site that graph the child’s progress in several ways, such as by key skill elements and total communication, and in comparison to developmental norms based on research of similar populations of children.

The ECI passes on measurement tools from researchers to practitioners, according to de-
developer Charles Greenwood, director of the Juniper Gardens Children’s project.

“When a practitioner asks, “Given the data I have so far and given this child’s growth in early communication, should I keep on doing what I’m doing or try something different?” — she becomes a kind of researcher,” said Greenwood.

“When you start answering those questions, you begin to identify things that work and things that don’t work.”

The ECI is only one of the Individual Growth and Development Indicators for Infants and Toddlers or IGDIs developed at KU as part of a multi-university effort.

Investigators at the Universities of Kansas, Minnesota and Oregon launched the Early Childhood Research Institute on Measuring Growth and Development in October 1996 to produce a comprehensive system for measuring the skills and needs of individual children with disabilities from birth to eight years of age.

The IGDIs are KU’s contribution to the U.S. Department of Education project. Arguably, the Juniper Gardens team took on the most challenging task of devising a way of measuring the development of infants and toddlers from birth to 42 months because it hadn’t been done quite this way before.

The project was partly in response to increasing demands for greater accountability for those childcare programs that are supported by initiatives such as the Federal Early Head Start program and the IDEA Part C program for infants and toddlers with disabilities.

Unlike standardized tests that are administered infrequently, IGDIs are designed to be used repeatedly by practitioners in order to estimate each child’s short-term rate of development to directly guide the design, implementation, and modification of interventions at reasonable levels of training, time, and cost.

IGDIs, like pediatricians’ height and weight charts, display an individual’s growth trend compared to normative growth over time. Similarly, the IGDIs are used to measure progress within early communication, movement, social competency, and other general outcomes such as problem solving.

The IGD project is ramping up for potentially national use and Greenwood says that the implications could be groundbreaking.

“This is going to give practitioners more tools to improve what they are doing and help scientists study many of the programs serving children because it will allow collection of population-level samples on how well interventions and programs are working.

One of the intriguing notions of science is that every time a new measure is invented that didn’t exist before, what often follows is a flurry of new research on that phenomena,” Greenwood pointed out. “The knowledge about it grows because it now can now be measured—whether it is a telescope, a microscope or an IGD— it leads to better knowledge and better outcomes.”

Darcie Sand, the early childhood education coordinator for Wyandotte County Early Head Start at Project Eagle, can quickly graph the communication development of individual children and gauge her program’s success in that area. “This really helps parents understand when their child needs extra help,” she says.

©The University of Kansas/Office of University Relations Credit: Elissa Monroe/KU Photo Services
Of this “dream team” of seven developmental disabilities experts, the only ones still awake in the van six hours after leaving the Kansas University Medical Center at the end of their usual busy day were the driver, Vicki Miller, a social worker who coordinates these on-the-road special child clinics, and psychologist Matt Reese, who was anxiously searching the sky for funnel clouds.

Various clinical faculty and staff associated with the KUMC Developmental Disabilities Clinic become the DDC Outreach Team at least twice a year. They drive long hours to serve an increasingly urgent and growing need to assess and diagnose children whose behavior, speech, or general development suggests autism in the parts of Kansas where specialists in developmental disabilities are rare or non-existent.

In the Dodge City area, families who want their child to be assessed by a developmental disabilities specialist must either drive three hours to Wichita or six to Denver—and this after being on a waiting list of up to 14 months, according to Jeanie Zortman, mother of a 10-year-old daughter with autism and local ARC president.

Zortman is determined to spare other area parents what she went through to get Mikela diagnosed. She began to suspect something wasn’t right from the time her daughter was an infant. But she was told that children develop at different rates and not to worry. When Mikela was three, a special education teacher finally told Zortman that she thought her daughter had autism. Then Zortman and her husband Tony had to wait six more months to have the diagnosis confirmed by a specialist.

She remembered the long drive back home that day. “You’ve been waiting for a diagnosis for years and to see a specialist for months. The doctor spends about a half an hour with your child and then you hear the “A” word. After that you don’t hear much of anything else and you’re driving back home for hours wondering, now what do I do?”

Fortunately, parents who hear a diagnosis of autism or other developmental disability from the DDC team will know what to do next. “Families leave with a complete written diagnostic and assessment report with recommendations to the family and local care providers for treatment and support,” said Miller.

The DDC teams, composed of specialists including pediatricians, psychologists and speech pathologists spend up to two hours with each child assessing how he or she interacts, hears, speaks, and moves, among other behavioral indicators of developmental delays and disabilities. The staff are funded through a joint grant from the DDC’s Children with Special Health Care Needs Program and the Kansas Department of Education. The local community picks up the cost for lodging and some meals.

The DDC faculty and staff members who went to Dodge City on April 21 and 22 included three Life Span Institute-affiliated researchers: R. Matt Reese, Ph.D., child psychologist, clinical associate professor of pediatrics and DDC training director; Kathy Ellerbeck, M.D., M.P.H., a developmental
psychiatrist; and Georgina Peacock, M.D., a developmental pediatrician. They were joined by Vicki Miller, M.S.W., L.S.C.S.W.; Debora Daniels, Ph.D., clinical assistant professor, a speech pathologist; Louann Rinner, M.S. Ed., an occupational therapist; and Gabriel Bargen, speech-language-hearing audiology doctoral student.

In Dodge City the group split into two teams that together assessed 13 children from the Dodge City area at Arrowhead West Child Service Center. These children and families were the lucky ones—there were many other children on a waiting list who would not be seen.

While the waiting lists are growing all over rural Kansas, family physicians, speech therapists, psychologists and special education teachers are stretched to the breaking point trying to deal with what some experts believe is an epidemic of autism.

Reese explained that many physicians have no training in treating developmental disabilities, are unfamiliar with behavioral treatment options and often can’t get mental health services for their patients.

Reese and other KUMC faculty affiliated with the DDC are doing something about this through training KUMC medical, nursing, and allied health students about diagnosing and treating developmental disabilities in association with the Life Span Institute’s Kansas University Center on Developmental Disabilities.

Reese also suggested that they could offer local physicians medication and behavioral consultations through the KU Center for TeleMedicine and TeleHealth as they do to help physicians treat patients in Girard, Parsons, and Pittsburg. The first consultation in Dodge City took place in July.

Jeanie Zortman had worked hard to bring the DDC Team to Dodge City, garnering local sponsors Arrowhead West, C & S Medical Clinic, and the Southwest Kansas Area Cooperative District 613 to make the visit possible. She was at Arrowhead West the entire time the DDC team was in town, concerned for the parents whose faces reflected what she had felt many years ago, but gratified that they would find resolution, help and hope. “To have this magnitude of professionals in this building is simply overwhelming.”
When Dava Walker started her career in early childhood education 25 years ago, teachers who taught children with disabilities did not have to have any special certification. Congress had only just passed the Individuals with Disabilities Education Act or IDEA and the No Child Left Behind Act was far in the future.

Now Walker, an Early Childhood Disabilities instructor, is part of the highly trained group of professionals at the South Central Kansas Special Education Cooperative in Pratt that serves 1,400 students in Barber, Comanche, Harper, Kingman, Kiowa, Pratt, and Stafford counties. Her professional credentials require that she take four graduate hours in her field as well as inservice training every year.

She teaches in the new era of accountability demanded by state and Federal requirements that means, for example, that she is responsible for making sure that the more than half of the children in her class who have disabilities meet the goals specified in each of their Individualized Education Programs as mandated by the IDEA.

This is where the Kansas Inservice Training System or KITS comes in. Directed by David Lindeman, as part of the Life Span Institute’s Kansas University Center on Developmental Disabilities, the program was developed through an initial grant from the US Department of Education over 10 years ago.

KITS was developed to meet the need for comprehensive statewide inservice training and technical assistance for early childhood special education professionals, paraprofessionals, related services professionals, and parents of young children with disabilities in Kansas.

“KITS is how information from research on early childhood education and development generated at KU and other universities reaches the people on the front lines,” Lindeman said.

At this year’s annual Summer Institute, nationally recognized experts like KU Professor of Special Education Eva Horn, and Tufts University Associate Professor of Child Development Rebecca New, focused on how the 73 participants could link early childhood curriculum to building better Individualized Education Programs.

The Summer Institute, sponsored by KITS, which is now supported by the Kansas State Department of Education and Kansas Department of Health and Environment, is open to those who work with young children in Kansas, but priority is given to professionals working with children birth to eight who have disabilities. The intensive four-day course earns participants college credit at any of the Kansas Regents universities and several other colleges.

KITS also holds workshops around the state throughout the year, provides on-site technical assistance to individuals and groups, and offers an online Early Childhood Resource Center—a library of continuously updated tools, plans, and research on children with special needs for Kansas early childhood practitioners.

Not every state has a KITS. Walker thinks that’s part of why Kansas is so far ahead of neighboring states in serving children with disabilities. “Early childhood education is one of the very best things a state can do for its future.”
External awards increased by $2 million this past year, now totaling $21.4 million for FY 2005, a new milestone for the LSI. The Institute had 33 new awards this past year. Those, combined with ongoing projects, totaled 112 awards during FY 2005. The 33 new awards continue to demonstrate LSI’s versatility and vitality while maintaining its status as the largest designated research center at the University of Kansas in terms of combined federal, state, and private dollars.

The National Institutes of Health (NIH) and the U.S. Department of Education (DE) remain the leading funding sources at $9 million and $7.5 million respectively. With the addition of $1.3 million in Health and Human Services Department funding, federal awards account for 83 percent of the Institute’s overall external funding.

In 2004 we had 30 NIH awards totaling $8.1 million. Continued funding and 10 new awards increased these numbers to 37 awards totaling $9 million. Likewise, in 2004 we had 28 DE awards totaling $6.3 million. Continued funding and 12 new awards increased these numbers to 33 awards totaling $7.5 million. These two critical funding sources accounted for the $2 million increase in external funding.

Finally, the LSI continues to leverage external funding at an impressive rate. In 1990, every dollar the state of Kansas invested in the Institute yielded approximately $3 in external awards. In 2005, every dollar the state of Kansas invested in the Life Span Institute yielded over $6.5 in external awards.
The Centers

Kansas Mental Retardation and Developmental Disabilities Research Center

The Kansas Mental Retardation and Developmental Disabilities Research Center (MRDDRC), is one of 14 national centers dedicated to the scientific investigation of the causes, prevention, and treatment of intellectual and developmental disabilities supported by the National Institute of Child Health and Human Development (NICHD). Research is conducted in labs, clinics, and the community by 60 investigators from the biological and behavioral sciences who seek solutions to the challenges of intellectual and developmental disabilities. Research projects are organized around four themes: language, communication disorders and cognition in mental retardation; risk, intervention, and prevention in mental retardation; the neurobiology of mental retardation, and the cellular and molecular biology of early development. The need for fundamental, systematic research on disabilities is as critical now as when the NICHD research centers were established more than 40 years ago. The MRDDRC remains at the forefront of this national effort.

Steven F. Warren, Ph.D., Director
Peter Smith, Ph.D., Co-Director
Contact: 785 864-4295, mrddrc.ku.edu

Kansas University Center on Developmental Disabilities

More than 30 years ago, as the 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 Institute’s direct service, technical assistance, and post-doctoral, pre- and in-service training are associated with KUCDD. These include clinics to diagnose and treat children with disabilities, a statewide project that provides assistive technology to clinics to diagnose and treat children with disabilities, early childhood education, community and workplace supports, and family systems and supports.

Michael L. Wehmeier, Ph.D., Director
Glen W. White, Ph.D., Associate Director
Wendy Parent, Ph.D., Lawrence Assistant Director
David P. Lindeman, Ph.D., Parsons Director
Chet D. Johnson, M.D., Kansas City Director
R. Matthew Reese, Ph.D., Kansas City Assistant Director
Contact: 785 864-4295

The Life Span Institute at Parsons

For more than 40 years, the University of Kansas has maintained research, service, and training programs housed on the campus of the Parsons State Hospital, including a major component of the Kansas University Center on Developmental Disabilities. This Institute, located in rural southeast Kansas, currently has research addressing early literacy and reading, maladaptive/challenging behavior, and program evaluation strategies. Additionally, this program has provided significant service and training across the State of Kansas addressing the assistive technology needs of Kansas, early intervention and early childhood, and training for community organizations and agencies serving persons with developmental disabilities.

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

Juniper Gardens Children’s Project

The Juniper Gardens Children’s Project began in 1964 when citizens from the northeast Kansas City, Kansas neighborhood 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 Project 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 multiple community sites, projects, and investigators. The Project 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 JGCIM was given the Research Award of the International Council for Exceptional Children in recognition of its outstanding research contributions.

Charles R. Greenwood, Ph.D., Director
Contact: 913 321-3143, www.jgcp.ku.edu

Beach Center on Disability

The Beach Center on Disability has a steadfast commitment to making a difference in the quality of life for persons with disabilities and their families. It is committed to listening to the priorities of families, service providers, policy makers, and researchers, incorporating those priorities into the Center’s research agenda, related training, technical assistance, dissemination and utilization activities. Primary areas of Beach Center research include the effects of public policy on the quality of life and community integration of families; the ethical, legal, and social implications of the Human Genome Project; disability policy generally; family professional partnerships; access to the general curriculum; self-determination; assistive technology for individuals with cognitive disabilities, and positive behavioral supports in schools, homes and communities. The Beach Center was named for Ross and Marianna Beach in 1988 in honor of their significant roles in advocating for families affected by disabilities.

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

Research and Training Center on Independent Living

Since 1980, the Research and Training Center on Independent Living (RTC/IL) has worked to improve the lives of people with disabilities using systematic research and training initiatives to help them increase their health and independence to take control of their lives. The RTC/IL uses a participatory action research approach to address research questions and outcomes, actively recruiting the involvement of consumers who are affected by the problems being
The Independent Living core activities address advocacy, services, and interventions; the Health Promotion Core promotes health practices that reduce the risk of health problems; and the Disability Policy Core is concerned with policy issues that impede or facilitate independent living. The RTC/IL continues to strengthen international connections with colleagues in Vietnam, Korea, and Peru.

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

Gerontology Center

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 communication and aging, long-term health care and housing alternatives, and decision making in later life. The Center coordinates an interdisciplinary graduate certificate program in gerontology for students enrolled in any master’s or doctoral program at the University as well as a multidisciplinary graduate program that offers both masters and doctoral degrees in gerontology. Center staff members also work with a wide variety of public and private agencies in developing programs for older persons and their families and assisting agencies and organizations with evaluations of programs and public policies.

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

The Center for Biobehavioral Neurosciences in Communication Disorders

The Center for Biobehavioral Neurosciences in Communication Disorders (BNCD) became the Life Span Institute's newest affiliated research center in 2002 when the National Institute on Deafness and Other Communication Disorders awarded a core grant to establish the center. The BNCD is a natural outgrowth of the Life Span Institute’s long standing focus on communication and language development and intervention. The BNCD’s research spans a wide range of issues relevant to the causes and treatment of communication disorders from infancy to old age including studies on infant attention, the genetics of language impairments, language intervention, the decline of working memory in old age as reflected in speech, and more precise measures of hearing loss to aid cochlear implant design.

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

Child Language Doctoral Program

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 bring diverse approaches to the study of how children communicate and speak. The program offers students a wide choice of research tools, facilities, and field sites including the Child Language Acquisition Studies Lab that has the largest known archive of transcribed spontaneous samples from preschool children diagnosed as receptive/expressive specific language impaired. Research sites and practica are provided by the Life Span Institute, the Language Acquisition Preschool, and the clinical and research facilities of the Speech-Language-Hearing Clinic.

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

Merrill Advanced Studies Center

The Merrill Advanced Studies Center, founded 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 website at merrill.ku.edu has fact sheets and discussions on science and policy for the general public.

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

Work Group for Community Health and Development

The mission of the Work Group for Community Health and Development is to promote community health and development through collaborative research, teaching, and public service. Formed in 1976, the Work Group has focused on measurement and analysis of the process of community/system change; and on building capacity for efforts to create conditions that improve community-level outcomes. Its current work is in three domains: community/public health (e.g., substance abuse, adolescent pregnancy), child/youth health and development, and community development. Many years of the Group's work has been distilled into an Internet site, the Community Tool Box at ctb.ku.edu. This site provides comprehensive technical assistance, consultation, and distance learning to connect people, ideas, and resources for promoting community health and development. In 2004, the Work Group was designated as a World Health Organization Collaborating Centre for Community Health and Development at KU.

Joseph E. Donnelly, Ed.D., Director
Contact: 785 864-0797, ctb.ku.edu/wg

Center for Physical Activity and Weight Management

The Center for Physical Activity and Weight Management joined the Institute in 2001 and supports research, training, and clinics for weight loss and weight maintenance. The Center is interested in the metabolic syndrome, abnormal values for blood lipids, glucose, insulin, and blood pressure that accompany overweight and obesity. The Center also has a major effort aimed at preventing overweight and obesity in children by increasing physical activity and reducing high fat, energy dense foods in elementary schools. The Center's Energy Balance Laboratory features a whole-room indirect calorimeter that measures energy expenditure precisely under a variety of experimental conditions.

Stephen B. Fawcett, Ph.D., Director
Contact: 785 864-0533, ctb.ku.edu/wg
Life Span Institute Affiliated Investigators

Mary I. Abbott, Ph.D.
David F. Albertini, Ph.D.
Carmen Arreaga-Mayer, Ed.D.
Jane B. Atwater, Ph.D.
Edward T. Auer, Jr., Ph.D.
Kathleen M. Baggett, Ph.D.
Steven M. Barlow, Ph.D.
Susan M. Bashinski, Ph.D.
Nancy E. Berman, Ph.D.
Mehmet Bilgen, Ph.D.
Lisa J. Bowman, Ph.D.
Nancy C. Brady, Ph.D.
William M. Brooks, Ph.D.
James F. Budde, Ed.D.
Jay F. Buzhardt, Ph.D.
Judith J. Carta, Ph.D.
Hugh W. Catts, Ph.D.
Paul D. Cheney, Ph.D.
Mark Chertoff, Ph.D.
John A. Colombo, Ph.D.
Pamela J. Cress, Ed.S.
Rick T. Dobrowsky, Ph.D.
Eosph E. Donnelly, Ed.D.
Dianne Durham, Ph.D.
David J. Ekerdt, Ph.D.
Kathy A. Ellerbeck, M.D.
Stephen B. Fawcett, Ph.D.
Barry W. Festoff, M.D.
Marc E. Fey, Ph.D.
Jacqueline L. Fisher, M.P.H.
Stephen C. Fowler, Ph.D.
Michael H. Fox, Sc.D.

Vincent T. Francisco, Ph.D.
Rachel L. Freeman, Ph.D.
Katherine Froehlich-Grobe, Ph.D.
Cheryl A. Gibson, Ph.D.
Alan R. Godwin, Ph.D.
Jacob U. Gordon, Ph.D.
J. Leon Greene, Ph.D.
Charles R. Greenwood, Ph.D.
Irene Grote, Ph.D.
Jacquelyn Hampton, LSCSW
Betty M. Hart, Ph.D.
Jessica A. Hellings, M.D.
Jennifer Hill–Karrer, Ph.D.
Martha J. Hodgesmith, Ph.D.
Eva Horn, Ph.D.
Kere Hughes, Ph.D.
Mary L. Hummert, Ph.D.
Joan S. Hunt, Ph.D.
Susan L. Jack, M.Ed.
Chet D. Johnson, M.D.
Debra M. Kamps, Ph.D.
Rathe Karrer, Ph.D.
Susan J. Kemper, Ph.D.
G. Denise Lance, Ph.D.
Jennifer Lattimore, Ph.D.
Judith M. LeBlanc, Ph.D.
Beth Levant, Ph.D.
Steven M. LeVine, Ph.D.
David P. Lindeman, Ph.D.
Todd D. Little, Ph.D.
Diane Frome Loeb, Ph.D.
Susan M. Lunte, Ph.D.

Janet G. Marquis, Ph.D.
R. Mark Mathews, Ph.D.
Matthew S. Mayo, Ph.D.
Kenneth E. McCarson, Ph.D.
Amy McCart, Ph.D.
Elias K. Michaelis, Ph.D.
Mary Lou Michaelis, Ph.D.
Steven C. Mills, Ph.D.
Kim M. Mitchell, Ph.D.
Brenda Smith Myles, Ph.D.
Warren B. Nothnick, Ph.D.
Randolph J. Nudo, Ph.D.
Kathleen Olson, Ph.D.
Susan Palmer, Ph.D.
Wendy S. Parent, Ph.D.
Georgina Peacock, M.D.
Kenneth Peterson, Ph.D.
Denise Poston, Ph.D.
R. Matthew Reese, Ph.D.
Mabel L. Rice, Ph.D.
Katherine F. Roby, Ph.D.
Carolyn A.M. Roy, Ph.D.
Sara H. Sack, Ph.D.
Wayne S. Sailor, Ph.D.
Kathryn J. Saunders, Ph.D.
Muriel D. Saunders, Ph.D.
Richard R. Saunders, Ph.D.
Richard L. Schiefelbusch, Ph.D.
Stephen R. Schroeder, Ph.D.
Jerry A. Schultz, Ph.D.
James A. Sherman, Ph.D.
Tom M. Skrtic, Ph.D.
Christopher L. Smith, Ph.D.

Peter G. Smith, Ph.D.
Sean J. Smith, Ph.D.
Michael J. Soares, Ph.D.
Charles R. Spellman, Ed.D.
Joseph E. Spaldin, Ph.D.
Martha D. Staker, R.N.
John A. Stanford, Ph.D.
Holly L. Storkel, Ph.D.
Matthew J. Stowe, J.D.
Debra K. Sullivan, Ph.D.
Jean Ann Summers, Ph.D.
Paul F. Terranova, Ph.D.
Barbara J. Terry, Ph.D.
Kathy S. Thiemann, Ph.D.
Ann P. Turnbull, Ed.D.
H. Rutherford Turnbull III, LL.M.
Cheryl A. Utley, Ph.D.
Michael S. Vitevitch, Ph.D.
James L. Voogt, Ph.D.
Dale Walker, Ph.D.
Steven F. Warren, Ph.D.
Richard A. Washburn, Ph.D.
Jane R. Wegner, Ph.D.
Michael L. Wehmeyer, Ph.D.
Michael J. Werle, Ph.D.
Glen W. White, Ph.D.
Dean C. Williams, Ph.D.
Howard Wills, Ph.D.
George S. Wilson, Ph.D.
Douglas E. Wright, Ph.D.
Edward J. Zamarripa, Ed.D.
Jennifer R. Zarcone, Ph.D.
Troy J. Zarcone, Ph.D.