The Schiefelbusch Institute for Life Span Studies
at the University of Kansas
Research-based solutions for the challenges of human and community development, disabilities, and aging

The Life Span Institute at a Glance

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

The LSI brings together 146 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, 40,000 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 in the world on human and community development, disabilities, and aging. The Bureau was directed for 35 years by Richard L. Schiefelbusch for whom the Institute is named. Dr. Schiefelbusch’s appointment to lead the Bureau in 1956 was the beginning of its modern era.

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

Where
Administrative and Research Locations

The Institute’s central office is in the Robert Dole Human Development Center at the University of Kansas in Lawrence with components at the John T. Stewart Children’s Center and Malott Hall, in Kansas City at the Juniper Gardens Children’s Project and the University of Kansas Medical Center’s Kansas Life Sciences Innovation Center and at the Life Span Institute in Parsons, Kansas.

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

How
Funding

The Life Span Institute attracts more combined federal, state and private dollars than any other designated research center at the University of Kansas, drawing $18.1 million in sponsored project support in FY 2006-07. Each state dollar brought in $5.2 external dollars this fiscal year.
Fifty years of discovery

This past year we celebrated 50 years of making a difference—the 50 years that have transpired since Dick Schiefelbush became the director of the Bureau of Child Research. We’ve come a long way over this time. We’ve expanded our mission, size and impact. But how is this history relevant to our future? Can it help us or hurt us?

It can hurt us if we cling to it and rest on our laurels and pretend it somehow makes us immune from the winds of change. Indeed, our proud history can become a barrier that actually impedes our future.

Fortunately, our history has taught us some important lessons that can help us achieve our mission and make a real difference for the foreseeable future. Three of those lessons deserve special attention.

Persist—The Life Span Institute is largely funded by external grants that are won through national competitions. The majority of these grants come from the federal government. Many federal agencies have had their budgets cut over the past few years. Our history reveals other times when this happened. In the early 1980s, for example, the funding situation was much worse. We survived this period and soon thrived again. Why? Because we kept our heads down and stayed the course. We persisted.

Compete—the majority of our grants are awarded as the result of a highly competitive review process. The beauty of this process is that competition hones our theories and methods in ways that increase the rigor and impact of our work. Our history is largely one of competing successfully against the finest scientists in the world.

Focus on our mission—to create solutions to the problems of human and community development, disability and aging. Maintaining our focus on this will go a long way to assuring that our future is as meaningful as the past 50 years have been.

Steven F. Warren, Director
The Schiefelbusch Institute for Life Span Studies
Persistent prairie pragmatists:

LSI’s role in the history and future of human development science

We were nearly 200 strong, scientists, researchers, staff, students, friends and leaders from the state and national disability communities when we commemorated and celebrated this 50-year endeavor of doing science and doing good on September 29 and 30, 2006.

And we were only the representatives of 350 current employees and the several thousands who have studied, supported, taught and discovered here since Dick Schiefelbusch was given two rooms, a part-time secretary and the charge to bring to life an entity that existed in name only in 1956.

Through this collective effort the Bureau of Child Research and the Schiefelbusch Institute for Life Span Studies helped bring about a sea change in the status and outcome of people with disabilities and disadvantages over the last 50 years.

Declaring the LSI a “national treasure,” keynoter Dr. Yvonne Maddox, Deputy Director of the National Institute of Child Health and Human Development said that, “the Institute is truly a testimony to how the concept of scientific research was first envisioned, as a means for translating the most basic discoveries to improving the health of the nation.”

Thought-provoking questions were raised and examined by the distinguished panel of national disability research and policy leaders and our own distinguished Mabel Rice and Steve Fowler.

In a future world “flattened” by globalization that assigns supreme value to those who can compete, how will children with significant and sustained challenges in deciphering and negotiating symbolic and non-symbolic systems compete?

This challenge was posed by Edward Kame’enui, Commissioner for Special Education Research, Institute of Education Sciences, U.S. Department of Education and Director of the Institute for the Development of Educational Achievement (IDEA). Kame’enui suggested that in the next ten years there will be an “adjudication” of what passes as rigorous evidence in educational research.

George Jesien, Executive Director, Association of University Centers on Disabilities, spoke to the balancing of interests in how science is funded, conducted and disseminated. While acknowledging the energizing nature of advocacy groups who want to push the scientific agenda, for example, Jesian noted that “science has its own process.”

Maddox, touching close to that point, challenged scientific researchers to bring the community in early “as we think about studies,” to build the community’s trust in, value of and response to biomedical research. Maddox listed newborn screening and autism research as top national priorities.

Mabel Rice, Distinguished Professor of Advanced Studies and Director of three of LSI’s 12 centers, quipped that BCR/LSI was clinical and translational “…before we knew what translational was.” Today, she says, LSI scientists are...
at the "biobehavioral interface" but asserted that there is a desperate need for solid biobehavioral theory.

As a society, we must be prepared for the consequences of our research-to-practice successes, urged U.S. Assistant Surgeon General Dr. José Cordero. Cordero, who directs the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, suggested that research and public health policy should be less focused on "cross-sectional" and more on longitudinal data. People with Downs Syndrome, for example, are now living well into middle age. But with that success has come the emergence of conditions in later life not previously seen in that group.

One of those conditions is an accelerated Alzheimer-like syndrome, said Stephen Fowler, Senior Scientist, Schiefelbusch Institute for Life Span Studies and Professor of Pharmacology and Toxicology. Fowler described how scientists are testing compounds on the molecular level in genes that are associated with mental retardation common to humans and other organisms. One recent study found that, surprisingly, antibiotics had a beneficial effect on a gene that is known to be involved in the protection of neurons. This was confirmed in mouse models. Fowler speculated that this and other such discoveries could be used preventative-ly in children with Downs syndrome.

In his closing remarks, Steve Warren recalled that 50 years ago, many people - even at KU - scoffed at the ambitions of our founders, "pragmatic prairie optimists" like Dick Schiefelbusch and Joe Spradlin, and again in the dark days of 1980s, when it looked like the Bureau would collapse from radical federal budget cuts. “And yet we are here tonight as a living example of the folly of those predictions,” he said.

Today, the challenges, failures and crises are not over, Warren warned, but suggested that grounding ourselves in our history of persistence that has created solutions to the problems of human and community development, disability and aging will continue to inspire us in the future:

Quoting Helen Keller, Warren asserted, “No pessimist ever discovered the secret of the stars or sailed to an uncharted land, or opened a new heaven to the human spirit.”
David Lindeman, director of the Life Span Institute at Parsons, acknowledges that many people harbor the stereotype that universities are not grounded in reality. But Lindeman believes that the KU research center in the small town in southeastern Kansas has helped change the minds of many an average Kansan. “We are average Kansans, too!” he laughs.

Parsons and the University of Kansas go way back. Dick Schiefelbusch and his intrepid band of young researchers breathed new life into something called the KU Bureau of Research starting in 1956 at the Parsons State Hospital and Training Center, a state institution for individuals with intellectual disabilities.

That relationship, which started with a handshake, allowed Schiefelbusch to establish a foothold for the pioneering behavior-al psychology research and treatment that would eventually lead to a three-campus research center on intellectual and developmental disabilities in Parsons, Lawrence and Kansas City. In turn, this was the basis for what is now the KU Life Span Institute.

Lindeman, who came to Parsons from Vanderbilt University in 1982, said that part of his training came out of Parsons’ research, but he didn’t connect it until he had been there awhile.

“I was amazed at the impact Parsons has had on the field of disability research and the number of prominent researchers who spent part of their career in Parsons, Kansas.”

Today, the Parsons center’s vigorous research-based service and training programs are some of the best examples of how KU serves Kansas.

Among them is an assistive technology infrastructure that helps Kansans with disabilities and injuries get what they need to live as independently and productively as possible. Sara Sack, Charles Spellman and Sheila Simmons, among others, have developed model statewide programs such as an assistive technology loan cooperative, equipment loan bank, equipment consignment and reuse system, and a rehabilitation program for farmers injured in agriculture-related accidents. Many aspects of this program are being replicated in other states. The Assistive Technology for Kansans Project has access sites in Oakley, Lawrence, Salina, Parsons and Wichita.

Lindeman has helped Parsons develop strategies to get the services of special educators—scarce in many parts of Kansas—to rural Kansas preschool children. “When we began, it was the kids who were being transported long distances,” Lindeman noted, “now most early childhood service programs are taking services to the children.”

Lindeman also directs the Kansas In-service Training System, a comprehensive statewide professional development and technical assistance system for early intervention and early childhood special education professionals, paraprofessionals and parents of children with disabilities.

The Parsons group takes on some of the toughest problems of disability. Kathleen Olson, for example, developed training information and materials for helping people with a dual diagnosis of mental illness and intellectual disabilities.

Dean Williams and Kathryn Saunders are teasing out answers to what causes some people with intellectual disabilities to injure themselves. Saunders is also testing a new computer-based approach to teaching people with intellectual disabilities how to read.

Personal assistance is another high-priority issue in disability. While personal assistants are key to the quality of and participation in life for many people with mobility and motor disabilities, it is often very difficult to hire, pay and retain them. Kathleen Olson is addressing the professionalization of personal assistance and Sara Sack is studying the viability of public funding for the service in lieu of people with disabilities living in institutional settings.

Obesity in people with intellectual disabilities is even more prevalent and serious than in the general population. Richard Saunders, along with Muriel Saunders and Joe Donnelly, director of the Life Span Institute’s Center for Physical Activity and Weight Management, have begun the first weight loss study of people with intellectual disabilities. This collaboration between weight management and developmental disabilities scientists aims to develop a simple, effective and inexpensive diet plan that will eventually be promulgated throughout Kansas.

Ensuring the quality of services is the goal of any service delivery program. Chris Smith is currently working with the Kansas Early Head Start system using a continuous improvement model.

Does having a university center in a rural community benefit KU? “I would certainly hope it does,” says Lindeman. “People can identify us as being a university center out in the state. Not that there aren’t other university outreach programs or services, but we’re out here, we’re really here, and we’re here every day. And hopefully that gives people a different perspective about us.”

Breaking the silence

One of the lasting contributions of earlier Parsons researchers like Joseph Spradlin, Lyle Lloyd and Robert Fulton, was the development of precise audiometric evaluations of children with intellectual disabilities. For the first time, it was possible to evaluate the hearing of persons with severe retardation and to fit them with hearing aids so that hearing deficiencies would not compound their ability to learn and communicate. The early researchers conditioned children to respond to auditory cues by pressing a button upon receiving a signal through a headset. This, in turn, allowed children to participate in programs previously thought too difficult for them and to allow training in other forms of communication.
Juniper Gardens Children’s Project

Established 1964
Director Charles Greenwood

Debra Kamps  Charles Greenwood  Eric Kirkwood  Barbara Terry-Campbell

© The University of Kansas/ Life Span Institute
Credit: Diane Guthrie
A

n exceptionally dedicated and close-knit group of KU researchers based in northeast Kansas City, Kansas, crowded the stage to accept the prestigious Research Award of the Council for Exceptional Children in 1996.

Crowded, because this award had always been given to an individual rather than an organization. But it was altogether right and fair to recognize the collective and historical contributions of Juniper Gardens Children’s Project cited for making “an unparalleled contribution to the education of children with special learning needs.”

The current generation of researchers, who have been led since 1991 by Charles Greenwood, had a hard act to follow. The Project’s early work in the 1960s and 70s was legendary. In 1972, Psychology Today pronounced KU “probably the world leader in applied behavior analysis,” focusing largely on the Juniper Gardens Children’s Project.

The first generation of Juniper scientists, notably Todd Risley, Vance Hall, Betty Hart, Mont Wolf and Don Baer, took applied behavior analysis out of the labs and institutions and into the streets. (The Project was first located in the basement of a liquor store whose protective owner famously displayed a gun in a hip holster.) These researchers pioneered scientifically sound approaches to the problems of school failure and went on to address juvenile delinquency, teaching and parenting of children with behavior problems, and other community issues.

But they understood from the beginning that this was to be a partnership with the community and they took direction from an active community advisory board. They opened preschools with parents and worked with teachers in local schools.

“The revolution at Juniper Gardens Children’s Project was the fact that researchers realized from the beginning that parents, teachers and classroom peers were going to be the ones doing the interventions,” Greenwood noted.

This approach got results and these results were recognized as some of the first in psychology that showed that it didn’t take a psychologist to do effective interventions.

Even though knowledge generated at Juniper Gardens is now in practice far beyond community boundaries—one web-based intervention to identify communication problems in infants and toddlers is being used in all Early Head Start programs in Kansas and Missouri and is poised to go national—the sense of place and the commitment to it is a core value.

“I know that people are proud that we are still here after all these years and that we tell the world about the ability of the folks who live here to do good things in a community that is still challenged by a lot yet has huge strengths.”

Juniper Gardens’ research has focused on children at risk due to poverty and other environmental hazards (prenatal exposure to drugs and alcohol), intellectual disabilities, early childhood, learning disabilities, cultural diversity (limited English proficiency, multicultural special education), behavior disorders and autism/developmental disabilities.

The impact of this work can be seen in the scientific and professional literature of behavior analysis, special education, early education and early childhood special education, education and psychology and in the practices and policies of special education.

But the impact can also be described in terms of people. Currently, some 19,800 children and youth, 3,400 families and 760 adults are direct beneficiaries of Juniper Gardens’ projects along with 80 schools and 150 state programs. This does not, of course, reflect the lives that have indirectly benefited from children reading, succeeding in school and overcoming behavior problems, for example.

Further, the Project has been a place for KU faculty and students “to learn from the wisdom and experiences of the urban community,” Greenwood noted. These include 231 students who have completed masters and doctoral degree work at Juniper Gardens and 55 post-doctoral associates who have spent a year or more there. A quarter of post-doctoral trainees found the Juniper Gardens Children’s Project so compelling, that they stayed and became outstanding KU faculty members. Among these is Judy Carta, who is one of the top-funded KU researchers.

Federal funding agencies are increasingly stressing that research have real-world application. Some agencies are even suggesting that the national research agenda could and should be decided with community and family advocacy groups.

New ideas? Not to Juniper Gardens researchers. We plan for translating research to practice from the very start.”

“The beauty of the Internet has been that we’ve been able to scale up and disseminate all of that knowledge on good teaching and good care to the scientists, community leaders, caregivers, practitioners and parents who are looking for solutions beyond Kansas City. They want to know what we know. What we started in Northeast Kansas City, Kansas, we are doing in several states, nationally and now internationally through our websites. The world is watching!”
ne of the proudest accomplishments of the University of Kansas was on June 14, 1972, when Richard Schiefelbusch, Bureau of Child Research director, KU and state officials hop-scotched across the state to cut ribbons on the three sites of the newly completed Mental Retardation Research Center, starting in Parsons, on to Lawrence and ending at the Medical Center. This made KU one of the original 12 designated national centers for mental retardation research that President John F. Kennedy had initiated before his death.

At its fortieth anniversary on April 19, 2007, Director Steven Warren and Co-Director Peter Smith proudly reviewed the many accomplishments of the bi-campus effort now called the Kansas Intellectual and Developmental Disabilities Research Center that stands as one of the top research institutes in the country on the prevention and treatment of intellectual and developmental disabilities.

“The KIDDRC has played a major international role in generating highly effective behavioral interventions and in delineating basic knowledge of the underlying biology of typical and atypical development,” said Warren.

Several revolutionary interventions for education and behavior management were developed here. These include “time out,” perhaps the most widely used behavior management technique in the world, and the “good behavior game,” which has been described as a behavioral vaccine because of its power to prevent behavior problems.

Other techniques were developed to teach communication skills to children with moderate to severe intellectual disability, to enhance the language development of at-risk preschool children and to improve teaching children at high-risk for mild intellectual disability and school failure.

“Incidental language teaching,” one of the most effective and widely used approaches used by special educators and speech-language therapists, was first conceived and tested by affiliated researchers Betty Hart and Todd Risley. Their landmark study on the role of early parenting on the language development of children described in Meaningful Differences in the Experiences of Young American Children (1995) is still cited widely in the scientific world and by policymakers, pundits and the media.

KIDDRC investigators also did ground-breaking work on the basis of the earliest development of cells and embryos and the neuroscience of early motor development.

The Center spans the KU-Lawrence and KUMC campuses as well as the Juniper Gardens Children’s Project in urban Kansas City and the Life Span Institute at Parsons. Over the past four decades it has served as a model of interdisciplinary collaboration across campuses and disciplines.

Warren, who received all three of his degrees from KU, but spent most of his career at Vanderbilt University’s John F. Kennedy Center, took the reins of the Center in 2000 and in 2001 became the Director of the Life Span Institute as well.

His energy and optimism are palpable when he talks about the future of the KU center in the larger context of research on intellectual disabilities.

“It is an active and fertile time in the field. As just one example, the genetic basis of many intellectual and developmental disabilities is becoming better understood and this will help us understand in a more systematic way how genes and environment interact to cause disorders and diseases of all kinds.”

In his own research, Warren had an “ah-ha!” moment that demonstrated the complexities of understanding intellectual disability and gene-environment interplay.

At Vanderbilt, Warren and Paul Yoder were testing a strategy called Prelinguistic Milieu Training to improve the communication of children with intellectual disabilities.

They worked directly with the children and not their parents, but their data indicated that the children who responded best to PMT had something in common: a responsive parent. Parents who initiate communication with and respond positively to their children with specific behaviors help develop their children’s language skills. For example, when a child points to the moon, and a parent responds by saying, “Yes, that’s the moon.”

“Parental responsivity was literally the water that nourished the seeds we planted through a brief, targeted intervention,” Warren said. “It helped the intervention effect flourish and developed the child’s repertoire. I was impressed by its power then and I still am.”

This means, says Warren, that parents can learn specific behaviors to help change the course of their child’s genetically-based developmental outcomes.

What Warren wants Kansans to know about KIDDRC is that it is a national treasure that we are very fortunate to have in Kansas.

“We should be pleased to have this in Kansas, not so much because of how it affects the lives of the citizens of Kansas, but how it will impact the lives of the born and unborn for generations to come here and around the world.”

Starting with the idea of helping people

Dick Schiefelbusch, for whom the Life Span Institute is named, was a brand new Ph.D. and self-described speech clinician, when he was asked to take over a moribund Bureau of Child Research in 1956. With few funds, supporters and no academic faculty, he was determined to make the Bureau live up to its name.

By 1959 he had made a great start when he reported that his small but innovative research team could show that children with severe intellectual disabilities and little or no language could learn. This was astounding to the field and brought funding, visitors, scientific and public recognition, students, faculty and results.

“We didn’t start with acres of literature,” said Schiefelbusch, “but with the idea of helping people. We could and did improvise science.”
Kansas University Center on Developmental Disabilities

Established 1973

Director Michael Wehmeyer
In his Haworth Hall office, Michael Wehmeyer is surrounded by artifacts attesting to the treatment of people with intellectual disabilities through history that has largely ranged from benign paternalism at best to genocide in Nazi Germany.

These remind Wehmeyer, whose own research into self-determination has pushed out the boundaries of people with intellectual and developmental disabilities, that past is prologue.

Along with framed photos of Wehmeyer’s family are those of Henry Herbert Goddard, one of the fathers of American psychology, and Deborah Kallikak (a pseudonym), an inmate at the Vineland, New Jersey institution where Goddard was director of research. They were at the epicenter of the eugenics movement in the early decades of the twentieth century.

Goddard based his highly influential 1912 book on the purported lineage of Deborah Kallikak, arguing that since intelligence was strictly due to inheritance, people with intellectual disabilities should be segregated in institutions, not educated to live and work in the community.

Goddard later disavowed many of the claims he made in the *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness*, but the damage was done, says Wehmeyer, and the residual attitudes toward people with intellectual disabilities persist.

“There is still a widely-held belief in our society that people with intellectual disabilities would be better off being institutionalized,” Wehmeyer said. “I don’t think we understand that separate is not equal and segregation is not an effective social response to difference.”

Wehmeyer is concerned that we could repeat the mistakes of the early twentieth century today. Once again advances in science—in this case genetics—are raising the specter, at least to many disability advocates, of a new eugenics movement.

“We need to remember the lessons of the eugenics movement when we make decisions about genetic treatments and engineering and who gets what resources,” Wehmeyer argues. More fundamentally, he adds, “how we weight things like the notion of intelligence on the scale of human.”

Wehmeyer oversees one of the oldest centers of the Life Span Institute, the Kansas University Center on Developmental Disabilities, formed in 1967 to put into practice the research burgeoning from scientists in Lawrence, Parsons and Kansas City about disability.

Virtually all of the Life Span Institute’s direct service, technical assistance, and post-doctoral, pre- and in-service training are associated with KUCDD. These include clinics to diagnose and treat children with disabilities, a statewide project that provides assistive technology to people with disabilities and their families, and training childcare providers and social workers to support individuals with disabilities.

In addition, investigators affiliated with the KUCDD conduct research that has state, national and international impact in areas like self-determination, positive behavior supports, inclusive educational practices, early childhood education, community and workplace supports, family systems and supports and other areas critical to the lives of people with developmental disabilities and their families.

Wehmeyer sees disability as on a continuum of human existence rather than as a deficit or a disease.

“If you define disability as an interaction between peoples’ capacities and the contexts in which they function, you can design support to enable people to function effectively.”

Wehmeyer directs a project that is examining how technology design does and does not meet the needs of people with intellectual disabilities.

Ironically, the promise of technology to enhance the quality of life of people with cognitive disabilities has gone largely unfulfilled because of design features that limit their use by people with intellectual disabilities, Wehmeyer says. For example, such assistive devices as voice augmentation or motorized wheelchairs are often too complex.

However, some emerging technologies show great potential for promoting the independence of people with intellectual disabilities who often have difficulty with time management and retrieving information. For example, AbleLink Technologies has developed “Pocket Ace,” a cell phone technology built on a PDA platform, to help people make and receive phone calls.

Another KUCDD program, Assistive Technology for Kansans, directed by Sara Sack, is working with the original manufacturers of handheld electronic devices to reutilize and refurbish them for people with intellectual disabilities who can benefit from the navigational and organizational technology.

“There is a movement in the disability field, that it is a parallel to one in psychology,” Wehmeyer says. “Psychology was historically focused on impairment and pathology. Positive psychology focuses on trying to enhance and improve outcomes like well-being, happiness and hope. There’s been a similar sea-change in disability and our work has been part of that equation.”

In 1969 Sargent Shriver told Dick Schiefelbusch that the strategy behind the 1963 legislation funding facilities for mental retardation research was to draw more scientists into the field. This was the centerpiece of President John F. Kennedy’s watershed decision to focus the nation’s attention on mental retardation.

By 1972, the University of Kansas was part of that federal network of centers for research that also provided training and service. Originally called the Kansas University Affiliated Facility, the UAF operated out of four community settings and facilities in Lawrence, Parsons, Kansas City, Kansas and Topeka.

On June 14, 1972, two buildings were dedicated at Parsons, Kansas, to support professional training for approximately 300 graduate students. The clinical facilities provided diagnostic and treatment facilities for more than 1,000 children with developmental disabilities each year.
Research and Training Center on Independent Living

Established 1980

Director
Glen White

Michael Fox
Catherine “Cat” Rooney
Glen White

Image courtesy the Lawrence Journal-World
Credit: Mike Yoder
Glen White is a strong advocate of doing good and doing science in his role as director of the Research and Training Center on Independent Living.

“We want to produce good rigorous science,” White explained. “That means that our training programs, products and interventions have to work and we have to have data to back that up.”

Sometimes the doing good part of doing science is not easy to figure out. As a doctoral student, White developed a way of getting children who used wheelchairs to exercise regularly to help prevent pressure sores. An alarm would sound if a child didn’t do the prescribed three-second wheelchair push-ups every 30 minutes. The children had watches to signal them when to exercise and they could avoid the alarm if they exercised on schedule. But the data clearly showed that it took both the watch and the alarm to keep them exercising.

Later White would write an article for a rehabilitation psychology journal on the experience in which he asked himself rhetorically, “Do I want to be the researcher responsible for putting an alarm on the wheelchair of every kid in the U.S.?”

“We know we can do science that is effective,” White says, “but can we do science in a way that helps people and yet is not intrusive?”

White, a behavioral scientist, uses a wheelchair, and knows firsthand that even with the sweeping mandate of the Americans with Disabilities Act in 1990, much more needs to be known about how people with disabilities become integrated into their communities, White says.

“We need much more systematic evidence about the impact of federal and state mandates to integrate people with disabilities into their communities.”

Finding this evidence is the basis of the five-year project called the Research and Training Center on Measurement and Interdependence in Community Living funded by the National Institute on Disability Rehabilitation and Research.

Helping people with disabilities lead healthy safe lives is another interest of the center that has lead to national recognition for doing some of the first research on emergency planning and disaster response for people with disabilities. Notably, the publication of the Nobody Left Behind study in 2004 that was widely disseminated to the disability and emergency preparedness communities.

“There was virtually no empirical data on the safe and efficient evacuation of persons with disabilities in disaster planning,” White said. “We hope this study will lead to a national model that can prevent death and injury for this population in the future.”

Later, White, with colleagues Michael Fox and Catherine Rooney, investigated what happened to people with disabilities during and after Hurricane Katrina.

White and his colleagues also feel an obligation to people with disabilities in developing workshops for Peruvians with disabilities and their families in Lima, Peru, at Life Span Institute affiliate, Centro Ann Sullivan del Perú.

On a recent visit, three people approached him after a workshop. All had grade four pressure sores – deterioration of skin and muscle tissue down to the bone—and none had wheelchair cushions since they are too expensive. White will return to Peru with Wendy Parent, a Life Span Institute employment expert, to help several Peruvians with disabilities set up a business manufacturing inexpensive but effective wheelchair cushions through a grant from the Christopher Reeves Paralysis Foundation.

White believes that everyone can use research to influence private and public policy. He directed and co-authored the Get RIL! (Research Information for Independent Living) web site at http://www.getriil.org/ that has more than 2,000 reviews of disability research articles written for the layperson.

The RTC/IL has influenced the public perception of people with disabilities through its million-seller, Guidelines for Reporting and Writing about People with Disabilities, parts of which have been incorporated in a standard reference for journalists.

At the end of the day, White asks himself if the RTC/IL has made a difference in the lives of people with disabilities. “Our research is values-based. Does it offer people more dignity? More choice? Greater security or safety? If so, that to me is real success and achievement.”

Jim Budde, founding director of the Research and Training Center on Independent Living first became a convert to what is called IL, or independent living, in 1978 when a state legislator asked him to find a home and other services so that a young woman with quadriplegia could live independently. At that time, people with disabilities often had two choices: being dependent on family members or living in a nursing home. But Budde had heard of a group of people with severe disabilities who were making their own choices and demanding access to classes, employment, housing, transportation and stores at the first Independent Living Center in Berkeley, California. Budde went to Berkeley and came back to Lawrence with a mission. Budde, and others in the KU and disability communities, applied for and won a competitive grant to establish the RTC/IL in 1980, funded by what is now called the National Institute on Disability and Rehabilitation Research.
Child Language Doctoral Program

Established 1983

Director Mabel Rice
By 1980, Dick Schiefelbusch had more than 20 years of success in bringing together experts in psychology, speech-language-hearing and special education to think about the problems of children together.

So it was about time that the University of Kansas could offer graduate students an academic program that formalized that synergistic approach.

Schiefelbusch, along with KU colleagues from the Departments of Human Development, Linguistics, Psychology, and Speech-Language-Hearing, notably a young, gifted faculty member named Mabel Rice, began to build the first cross-disciplinary graduate program on the study of child language in the nation. Rice, now the Fred and Virginia Merrill Distinguished Professor of Advanced Studies, has been the program’s director for close to 25 years. Susan Kemper, another outstanding young faculty member, became and has remained the Program’s representative to the Graduate School. She is now the Roy A. Roberts Distinguished Professor of Psychology.

The study of language acquisition and impairment in children was not readily nested in one academic department, Rice explained. “So we argued that there was value in having an inter-disciplinary program for student training. We’ve stayed within the same basic framework ever since.”

By 1982, the group had convinced the University and the Board of Regents of the necessity and soundness of the Child Language Doctoral Program. It didn’t hurt that renowned child language authorities such as the late Roger Brown of Harvard University resoundingly endorsed the program and the proposed KU faculty.

The Child Language Doctoral Program prepares specialists in child language for academic scholarship and research in public and private research organizations as well as for careers in organizations that serve people with communication disorders. Sixteen students have received their doctorates from the program.

“The students have found the program very meaningful and our graduates are at universities all around the country and overseas,” said Rice.

Today, the program is sponsored by the departments of Applied Behavioral Science, Linguistics, Psychology and Speech-Language-Hearing, and includes in its 24-member faculty, some of the top KU researchers in those fields.

One of the unique resources of the Child Language Doctoral Program is the Language Acquisition Studies Lab that has been in operation for 20 years under the direction of Rice and is funded by the National Institutes of Health. For the past 15 years, the Lab has been accruing a longitudinal sample of the language development of children recruited when they were preschoolers. The team has tracked the children’s language growth through regular assessments and has also studied their family members.

The archive has yielded much knowledge, including Rice’s breakthrough identification of a grammatical marker in the speech of children with Specific Language Impairment (SLI). This, in turn, lead to the development of the Rice/Wexler Test, the first diagnostic test for SLI.

The grammatical marker, the misuse of some verb forms, seems to Rice and others to have a genetic basis and she currently directs a large study of twins in Australia to probe that possibility.

Another exceptional research and practice setting affiliated with the Program is the Language Acquisition Preschool. The LAP was the brainchild of Rice and Kim Wexler, former KU Dean of the College of Liberal Arts and Sciences and now Provost of Michigan State University, who wrote part of the curriculum. Directed by Betty Bunce, the preschool classes typically include an equal number of children with speech and language impairments, children with typical language development, and children who are learning English as a second language.

Although the Child Language Doctoral Program has remained stable, it has not been static. “As we are moving into areas of inherited weaknesses in language acquisition, that still leaves big questions,” Rice said. “How to intervene. How to find intervention programs to remediate these problems. Understanding more about the life course of individuals whose language impairments persist throughout the life span.”

Rice adds that there is a better appreciation of the role parents can play in remediation while at the same time not assuming that a child’s language impairment is a consequence of poor parenting.

Rice, Kemper, Schiefelbusch and the other visionaries of 25 years ago have been validated by the success of the Child Language Doctoral Program that was built on KU’s top-flight expertise in language acquisition, impairments and intervention, as well as the working collaboration among investigators. What’s more, says Rice, the Program is an excellent value for taxpayers because it was created out of excess elements of the University with very little money. The faculty contribute their effort—there are no salary lines. “We spun new cloth out of existing threads.”

In 2001, the first diagnostic test for Specific Language Impairment went on the market. The test was developed by Mabel Rice and MIT professor Kenneth Wexler based on their earlier identification of a grammatical marker for the often misdiagnosed and untreated language impairment. Children with SLI will frequently drop “do” and “be” from verb phrases, as in, “He like me?” The past tense of verbs also may be dropped, as in, “Yesterday she walk to my house.” Clinicians using the Rice/Wexler Test of Early Grammatical Impairment can identify SLI in children ages 3 through 8 using books and toys. Rice estimates that 7.6 percent of children have SLI. Without early diagnosis and treatment, many of them would have problems communicating all their lives. Rice is currently pursuing the genetic basis of SLI in longitudinal studies of Kansas children and their families and of twins in Australia.
Rud Turnbull, a 36-year-old attorney, was facing off against a battalion of experts from a North Carolina institution where some 600 people with intellectual disabilities were confined in 1973.

Evoking the Governor, for whom he was investigating uses of “aversive” therapy by the staff of the state’s institution, Turnbull demanded that a “learning-to-be-better box” be produced, something that the experts assured him was just a “little device we use to train patients to behave themselves.”

The box—a wooden box about 3 to 4 inches square capped with battery terminals that were connected to a switch by copper wire—was applied to the sensitive lower abdomen of an institution resident if he or she was thought to have misbehaved. Turnbull rolled up his sleeve, placed the device on his arm and tapped the switch. “It was a literally shocking experience,” he recalls, and a catalytic moment for Turnbull as a professional and as the father of Jay, his six-year-old son with significant, multiple intellectual disabilities.

“Boss, we have a problem,” Turnbull reported back to his superiors at the University of North Carolina at Chapel Hill. Thus, began a career that has taken Turnbull to the forefront of the disability civil rights movement and established him as an international expert in disability law and policy. He helped draft the regulations for the 1975 Individuals with Disabilities Education Act, testified before Congress a dozen times, most recently on the Schiavo case, and was recognized with his wife, Ann, as two of the 36 leaders who “changed the course of history” for people with intellectual disabilities. In 2007, both were named Marianna and Ross Beach Distinguished Professors.

Ann, who married Rud when Jay was seven, references the pain Rud felt that day in 1973 as the essence of Jay’s impact on them as parents and professionals. “You don’t deal with things abstractly, you feel the pain. Jay has been such a professor of ours in the 24/7 of disability.”

Ann Turnbull is passionate about making research accessible and relevant for people with disabilities and their families. Ann’s passion was forged during the traumatic years when Jay was reaching adulthood and his bi-polar disorder began to manifest itself, accompanied by challenging behavior.

Even as insiders, the Turnbulls could not find research about adults to help them respond to Jay’s problems. “What we tried did not work and we failed Jay. We had to find a different way.”

That different way is still evolving as Jay turns 40, but through what Ann Turnbull describes as developing multiple supports across all hours of the day and night, Jay has been employed regularly for 18 years and takes obvious pride in what he does, lives in his own home with housemates and has places to go and people who care in his community. He has a life.

Much more needs to be known about supporting adults with intellectual disabilities, say the Turnbulls, not the least of which relates to financial support from public and private sources. The Beach Center is researching the effects of a policy that will give families direct control over Medicaid funds to which their children with disabilities are entitled under the Social Security Act.

In practice, public agencies have had considerable discretion over how families and adults with disabilities spend Medicaid funds. “This policy has been challenged over the past decade by families and others in the disabilities community, and government policy has responded,” Ann Turnbull said.

“Other Beach Center research such as Michael Wehmeyer’s on self-determination and Wayne Sailor’s on positive behavior support are very critical for families to pull a life together,” said Ann Turnbull.

The Turnbulls are determined to bridge the gap between the academic and real worlds, most recently through the Beach Center website, www.beachcenter.org, that takes a “Community of Practice” approach.

“We want to pair experiences and insights from families and professionals with the best available research. We want to synthesize the best available research and then make it available online in multimedia ways so that people who are not researchers can understand findings and apply them,” Ann Turnbull explained.

“That would be my take-home message to families: tune in to www.beachcenter.org. We can find answers to the age-old problem of the gap between the academic world and the real world.”

“My take-home message is that we need to wear wristbands like Lance Armstrong’s that say, ‘Be strong today, because you’ll have to be stronger tomorrow,’” Rud Turnbull asserts. “Families need to be helped to be strong and science can help them be strong, but disability is a chronic condition. For us it began when Jay was born on June 24, 1967, and it will end with his death, Ann’s, his two sisters’ and mine. That one person’s life has a generational ripple effect and you’ve got to be strong to face that.”
Gerontology Center
Affiliated 1990
Director David Ekerdt
David Ekerdt says that we are profoundly ambivalent about aging: we both celebrate it and regret it. Individuals try mightily to live long, full lives, but dislike what they see in the mirror. Whole societies organize efforts to guarantee the welfare and longevity of their citizens, then resent the elders in their midst.

The 20th century view of aging was a story of worry and concern—about economic security, about the financial costs of an older population. However, Ekerdt says we now may be entering a new era with older adults, or at least the newly retired, being positively defined by their consumer clout. As the large Baby Boom cohort retires, some even see an “experience dividend” flowing to American society as they donate their time, talents and abilities to volunteer and civic activities.

Ekerdt oversees a group of scientists collectively known as the Gerontology Center. The Center administers one of the two graduate academic programs in the Life Span Institute and assists in the development and evaluation of programs and policies addressing the needs of elders.

Their research is organized around the idea of prolonging everyday competence.

Despite age-related slowing in physical and mental processes, older people are still very capable of performing complicated tasks and contributing in all sorts of roles, Ekerdt says.

“But older people do things differently,” said Ekerdt, who edited the definitive Encyclopedia of Aging published in 2002. “It is our responsibility to understand how to shape situations and contexts so older people can perform to the best of their ability on all sorts of tasks.”

Some examples. Psychologist Susan Kemper is internationally known for her work in understanding how aging effects our ability to comprehend verbal and written instructions and how our brains parse doing more than two things at once—particularly after stroke.

Mary Lee Hummert’s recent study of how negative stereotypes of aging can affect test performance netted an article in the New York Times in 2006. She and Kemper have also shown how condescending “elder-speak” by long-term care employees can have deleterious effects on older residents social communication.

Ekerdt is interested in how people can successfully transition to more appropriate housing to live independently as long as possible. Part of this process is the management of one’s possessions, typically downsizing one’s household to move to smaller quarters.

“There’s a theory of dispossession that the motive for keeping something has to outweigh the labor of keeping it. But then there’s the labor of disposing of it,” Ekerdt said. “If you have health and wealth, you will always be respected, but lose either of those and you are vulnerable – and that’s still true today.”

But what if we could live to be 200 years old? Scientists are extending the life span of animal models two, four and six-fold. That’s the equivalent of a human being living 200 or more years. But that’s not the goal—everyone a Methuselah. Rather, researchers hope to do something about reducing disease along the way, says Ekerdt, and the prospects are tantalizing.

“We are starting to unlock the process of aging at its most basic level. What a tremendous thing it would be to use this knowledge to effect just a ten percent reduction in diabetes or Alzheimer’s disease.”

“Just shut up and take it,” that’s what I want to say.”

Ekerdt’s study did not include those who were in long-term care facilities, a.k.a nursing homes, and long-term care remains one of the great challenges about aging.

According to Ekerdt, we have a 40 percent chance of needing long-term care from the age of 65 to the end of our lives. It may be a short stay for rehabilitation after surgery or an extended stay of two to four years at the end of our lives. And it is expensive—averaging $50,000 to $60,000 a year.

“When experts tell us to save for retirement, we imagine it’s for leisure activities, but the real message should be that you save for your long-term care. That’s what it’s for, not for taking Alaska cruises,” Ekerdt quipped.

“One of the big myths about aging”, Ekerdt said, “is that in the good old days, older people were treated better and were more respected.”

“It’s been hard to be old across the ages. If you have health and wealth, you will always be respected, but lose either of those and you are vulnerable – and that’s still true today.”

In 1996, Kemper, Snowden and others published the results of a study that were nothing less than astonishing. They could predict—with 85 to 90 percent accuracy—which nuns would later develop Alzheimer’s disease based on autobiographical essays written when they were 22 years old. The nuns who showed low idea density and grammatical complexity scored lower on tests of cognitive function at age 80 and later autopsies confirmed the existence of Alzheimer’s disease.

The May 14, 2001 Time cover story on the Nun Study, based on a landmark ten-year study of cloistered nuns, brought Susan Kemper into the national spotlight. Kemper, distinguished professor of psychology and Gerontology senior scientist, was drawn into the study by University of Kentucky professor David Snowden who directed the study, because of what Kemper called “idea density.” Idea density in written language is the number of distinct ideas per ten words.
When Virginia Urban Merrill and Fred Merrill endowed and created the Merrill Center for Advanced Studies in 1990, it was a tribute to the standing of the University of Kansas scientists in developmental disabilities, speech language pathology, child development, aging and special education collectively known as the Schiefelbusch Institute for Life Span Studies.

Richard Schiefelbusch was the visionary who brought together scientists with diverse expertise to rethink problems in human development and disability beginning in 1956. This tradition thrives at the Life Span Institute and is echoed in the Merrill Center’s creed that reflects the Merrill’s deeply held values:

All individuals, regardless of their opportunities and capabilities, should be encouraged and aided in attaining dignity and quality in the full course of their lives. The cumulative force of knowledge, science and technology must be employed to discover and direct all means for advancing this human purpose.

Schiefelbusch became the first director of the Merrill Center upon his retirement from the Institute that bears his name, followed by Stephen Schroeder, who was then the first director of the Life Span Institute.

But it is Mabel Rice who, since 1994, has taken the Center through a maturation process to its present status as a respected advanced studies center that brings together world-class experts to focus on pivotal issues in disability and development. These intimate scholarly conferences often bring together researchers for the first time to set the stage for interdisciplinary leadership direction.

Several definitive published volumes have come from these Scholarship on Development and Disabilities conferences on topics such as self-injurious behavior, inherited and environmental factors in language disorders and aging and communication.

The Merrill Center also started an experiment 11 years ago by providing a forum for researchers and research administrators of public research universities in Kansas, Nebraska, Iowa and Missouri to discuss the challenges of the research mission in the public university context. “To our great gratification, people returned,” said Rice.

Administrators do not often have an opportunity to be in open discussion with the people carrying out active research and struggling to get external funding, she said.

“Research is much more than the work of the individual scholar in today’s world. It is the work of the system that supports it, provides infrastructure and communicates overall direction for it. Scholars are part of it as is the commitment on the part of the public for research missions to play out. At the same time, there is a greater community of scholarship and research commitment that transcends universities. There is real value in people coming together to understand our common values.”

The Research Mission conferences help identify national priorities in research. In response to the increasingly prohibitive cost of scholarly journals to universities, the 2000 conference held in Tempe, Arizona, produced the Tempe Principles.

“As our former Provost David Shulenberger observed, it is ironic that scholars give away the product of their research and then have to pay dearly to get it back,” said Rice.

The Tempe Principles were subsequently adopted by the Association of Research Libraries and the Association of American Universities.

In 2001, the regional conference on biomedical research encouraged the development of the Kansas City Coalition for Excellence in Life Sciences (KC-CELS).

The Merrill Center internally publishes the proceedings from these conferences in a White Papers series electronically on their web site and in print. This is part of the Center’s commitment to public information.

In the Know is a public outreach project of the Merrill Center available online at www.merrill.ku.edu. Articles and fact sheets for the general reader give accurate information about disabilities, aging, and human development.

In 2003, Rice’s long history of scholarship and service was recognized by the Merrills with the Fred and Virginia Merrill distinguished professorship of advanced studies gift.

“It is a pleasure to work with the Merrills, because of their informed interest in the topics of the Advanced Studies Center and their commitment to long-term outcomes for future scientific accomplishments.”

Fred Merrill is Chairman and President of Cereal Food Processors, Incorporated, of Mission Woods, Kansas. Virginia Merrill is a native of Lucas, Kansas. She graduated from the University of Kansas with training in speech correction. The Merrills continue to be actively involved as benefactors and members of the Board of Directors.

Virginia Merrill had been a classmate of Richard Schiefelbusch at KU in 1947 where they were both studying what was then called speech correction. Forty-two years later, they had lunch where Dick, Virginia and her husband Fred imagined a unique forum for academics from many disciplines to deliberate the big questions of human development and disability. The Merrills endowed the Center for Advanced Studies in 1990 and a distinguished professorship, held by Mabel Rice, in 2003.
Work Group for Community Health and Development

Affiliated 1990

Director Stephen Fawcett
Helping the world change itself is the vision of Steve Fawcett and his colleagues at the Work Group for Community Health and Development. The name suggests its grassroots idealism, but its reputation is due to a cool determination to find scientific evidence about how communities create conditions that promote health.

“While I was a community organizer in VISTA (Volunteers in Service to America) in 1969, I saw first-hand how impoverished environments can do terrible harm to people,” Fawcett explained, “and each of my Work Group colleagues has had a comparable experience.”

Later, Fawcett the scientist embraced the kind of socially relevant behavioral psychology that KU pioneered in the 1960s. Fawcett’s work was recognized with a Kansas Health Foundation distinguished professorship in 1996.

Foundational work in “behavioral instruction” in the 1980s evolved to projects examining how community groups address substance abuse, teen pregnancy, chronic disease prevention, and other health and social issues. This began to lead the Work Group to study the change process itself.

“Before you see widespread behavior changes, many conditions in the environment have to change. We’ve got to better understand the intermediate outcomes of health development efforts—changes in programs, policies and practices.”

By 1990, the group took the earlier work they had done on advocacy training that focused more on the independent variable of training, rather than the result, and asked themselves a new question, “Under what kind of conditions can people come together and effect change in their environment that matters to them?”

This was all put to good use when the Work Group started to build the Community Toolbox in the early 1990s. The web site, today used by thousands of people around the world, is best described by its slogan, “Promoting community health and development by connecting people, ideas and resources.”

The Work Group was honored as a designated World Health Organization Collaborating Centre for Community Health and Development in 2004.

What works

Starting in 1980s, the Work Group had a tradition of research in behavioral instruction that helped them understand some important variables in developing learning modules.

By 1990, the group took the earlier work they had done on advocacy training that focused more on the independent variable of training, rather than the result, and asked themselves a new question, “Under what kind of conditions can people come together and effect change in their environment that matters to them?”

The KU Work Group was designated as a World Health Organization Collaborating Centre for Community Health and Development in 2004. The Work Group is collaborating with colleagues at the American University of Beirut to study efforts to create a safer and healthier environment for adolescents in a refugee camp in southern Beirut.

As a scholar-in-residence at the World Health Organization in Geneva in 2007, Fawcett worked with health equity staff on the social determinants of health. There is growing evidence that there are three broad determinants of health:

Income inequality. Poverty is related to people’s health, but income disparity is more important.

Social connectedness. In communities like Lawrence—where people enjoy many social connections—health outcomes are better.

Efficacy. Having control over our environment is strongly related to better health.

“The KU Work Group is having fun studying the process of community efficacy—how people come together to create conditions that promote health. It is a joy to work with colleagues from KU and around the world who are working on things that matter.”
Center for Physical Activity and Weight Management

Affiliated 2001

Director
Joseph Donnelly

© The University of Kansas/Office of University Relations
Credit: Doug Koch
Joe Donnelly is the go-to guy if you want to get the skinny on fat. In a world of glitzy self-promoters and competing diet and exercise gurus, Donnelly is a stolid and modest scientist who is successfully helping people lose and maintain weight loss and can back up it up with evidence.

“We look for strategies to prevent and treat obesity in kids and adults that are simple, cost effective and can be easily replicated in schools, day care centers, YMCAs and churches—any definable group of people.”

Donnelly does get frustrated sometimes when he hears the same old myths about weight perpetuated by the popular press. Such as that only five percent of people can lose five pounds and keep it off. Such as the “freshman 15.” Such as you can lose weight by exercising alone and that once you lose weight, you can maintain it without exercising.

On the contrary, Donnelly says that weight management success is much more prevalent than we’ve been led to believe. In a recent survey of people who went through Donnelly’s weight loss programs in the last four years, 50 percent have kept ten percent or more of their weight off for two to four years.

Losing just five to ten percent of your weight is where you get the biggest bang for the buck, said Donnelly, because that’s where you get 60 to 80 percent of the medical benefits. That would mean only ten pounds for a 200-pound person.

“So if you could get the whole country to lose 10 pounds, there would be an enormous savings in terms of medical expense.”

Obesity is like diabetes or high blood pressure, says Donnelly. If you take your medications, the disease is under control, if you don’t, it comes back because it is managed, not cured.

Donnelly uses this analogy in helping people understand that obesity is a chronic condition that must be eternally managed.

“We try to tell people who say, ‘woe is me,’ what if you had high blood pressure? Those people take their stuff and go on—that’s the way it is.”

But Donnelly hastens to add that it is a heck of a lot harder to manage obesity.

“You have a complex set of behaviors that has to change: Eating, that has massive positive reinforcement and social aspects, and physical activity, that for some people has large negative biological feedback mechanisms—sweating, high heart rate, fatigue, soreness. And they have to do that for 30 years.”

And yet, Donnelly believes that roughly the same proportion of people adhere to that tough regimen as do those with diabetes or hypertension who take their medications—about 50 percent.

Here’s what works and what doesn’t according to Donnelly:

1. Weight loss through exercise alone is extremely difficult. Energy (calorie) restriction works much better. In particular, pre-packaged state-of-the-art foods he uses in one of his weight-loss programs produced far better results than a regular calorie-restricted “free range” diet.

2. Eating high volume, low energy food seems to be a successful strategy such as the USDA’s five fruits and vegetables a day recommendation. Donnelly has found that we eat about the same weight in food in a day, so it is just a matter of what food we eat to feel full and satisfied. This approach is called volumetrics.

3. Weight management through continuing the same weight loss calorie restriction doesn’t work. It is just the opposite. The best guess is that we need to burn about 2,000 calories a week or about an hour a day, five days a week through physical activity.

4. People who try to lose weight on their own don’t do well. This doesn’t mean they have to be in a formal program for life, but they need some sort of structure and support through exercise groups, online or email programs.

Only about 20 percent of us choose to eat healthily and exercise and that hasn’t changed much since 1950. What has changed is that increasingly physical activity is a choice, not a need for most of us. When need is removed, you’ve got problems, said Donnelly.

“Now that I’m a proud owner of a 40-acre farm, I know that when it is time to fatten my cows, we confine them and feed them. And that’s exactly what we’ve done to ourselves and our environment.”

The obesity epidemic is going to get worse, warns Donnelly, peaking at 71 to 72 percent of the U.S. population by 2010 or 12.

Every chronic disease increases its incidence when associated with obesity and it is the cause of many of them, said Donnelly.

“That’s why I call it the disease of the century. I know there are more dramatic diseases like cancer, but there is no other disease that affects 65 percent of the population.”
The Biobehavioral Neurosciences in Communication Disorders Center is the Life Span Institute’s newest affiliated research center, funded in 2002 for five years by the National Institute on Deafness and Other Communication Disorders. The Center supports a group of top-flight KU researchers lead by Mabel Rice, an internationally recognized scholar in the area of child language acquisition and disorders.

Known as a core grant, the funding allows KU to provide administrative, scientific and technical infrastructure to support research projects on communication disorders at the both the Lawrence campus and the Kansas University Medical Center.

The BNCD was just refunded for its second five-year cycle through a highly competitive process that highlights the stature of its sixteen affiliated researchers.

“The process is very dynamic,” Rice explained. “We must have a certain number of funded projects within certain areas in a certain timeframe. We can’t rest on past laurels or count future work.”

“This center is a testament to the leadership of Dr. Rice and an official designation of KU as one of the strongest programs in the country on communication development and disorders throughout the life span,” said Life Span Director Steven Warren.

The BNCD assists 12 researchers and 15 projects through advanced statistical methods, human subject recruitment and digital and electrical engineering.

Their research addresses a wide range of issues relevant to the causes and treatment of communications disorders. Some examples:

Steven Barlow, professor of speech-language-hearing, invented two patented technologies—the Actifier and NTrainer—to assess and treat premature infants who are unable to take nourishment orally. Both devices are in clinical trials in Topeka.

Holly Storkel, associate professor of speech-language-hearing, is developing one of the first comprehensive models of how children learn words that will ultimately be used to improve the diagnosis and treatment of language deficits.

John Colombo, professor of psychology, is examining how an infant’s ability to recognize and remember can predict later learning and speaking problems.

Susan Kemper, distinguished professor of psychology, is showing how speech in older age reflects declines in working memory.

Rice’s research focuses on a disability called Specific Language Impairment. She is conducting a large study of twins with researchers in Australia, England and Nebraska to look for a genetic component of the disorder in tandem with a longitudinal study of non-twin children in Kansas and Missouri.

In 2002, Rice and Kenneth Wexler, MIT professor of psychology and linguistics, developed the first test to diagnose SLI since the language disability often escaped traditional testing and treatment, which is being used in school districts across the country.

Rice and other BNCD investigators are compiling extensive longitudinal databases.

“Some of us work with babies, some with children old enough to be talking, and some with adults and older adults. It turned out that we were all trying to find those same research subjects. We have a lot of pieces of this story but we were not exactly aligned because there is no single source of funding with that as a priority.”

Rice said amalgamating researchers’ individual project databases is the BNCD’s next priority. “We can tell a more continuous story of language by setting up systems of recruiting participants to allow them to stay with us as they age. This is an example of how the BNCD can make research both more efficient and more robust.”

The electronic and engineering core is essential to the researchers’ increasingly sophisticated measurement and data collection requirements such as Steven Barlow’s NTrainer and the development of a computerized pursuit rotor for Susan Kemper’s “two things at once” studies of older adults.

Kemper’s body of work with healthy older people is another example of how the BNCD will benefit future science, says Rice. “Many studies of older people are done with residents of long term facilities who are not in good health.” To be able to tell the story of healthy aging, we can build systems of keeping track of participants,” Rice explained. “Those 60 to 65 could be asked to return at 70 to 75.”

Rice says that without a funding mechanism like the BNCD, this would be very difficult and much more costly to do.

“That’s what is so great about the BNCD. It is about being able to maximize collaborative effort on part of productive people and getting better value for taxpayer investment.”

Good technology

The researchers who won the BNCD grant are the kind of scientific leaders who push rather than are pulled by technology. The unique Digital and Electrical Engineering Core, coordinated by Doug Kieweg, assists BNCD researchers with applications of electronic instrumentation essential for the study of communication disorders. Here Kieweg adjusts an oscilloscope to monitor the position of a prototype OROSTIFF, a device invented by BNCD scientist Steven Barlow, DEEC director. The OROSTIFF device measures oral stiffness in patients with advanced Parkinson’s disease and those who have sustained shrapnel wounds to the head and neck. The DEEC core is developing the OROSTIFF program to collect, display and analyze data when the device is in use.
Judith LeBlanc pretty much summed up the philosophy of Centro Ann Sullivan del Perú when she opened the International Symposium on Autism in Cancun, Mexico, in May 1997.

LeBlanc was the first University of Kansas faculty member that Liliana Mayo talked into volunteering at her school for children with autism and other developmental disabilities in Lima, Peru—the first of its kind in that country. LeBlanc agreed to take a look at the place that Mayo had started in her parents’ garage in 1979.

What LeBlanc, professor emerita of applied behavioral science, found moved and excited her. Centro Ann Sullivan del Perú, though still struggling in 1985, was, out of necessity, teaching students along with their families, what they would need to know to function in the outside world. The girls learned to cook, sew, count, shop, bank—even dress, style their hair and walk like other teenagers. Many of them left the institution and were able to successfully live and work in the community. However, such programs were thought to be too expensive and later, deinstitutionalization made such programs moot in the U.S.

But in Peru, Mayo, with LeBlanc, who decided to stay at CASP as director of research, believed in the holistic approach to treating developmental disabilities. Their comprehensive life span program is based on training parents, siblings and other caregivers in a positive educational model that is research-based. The program’s success has resulted in more than 80 individuals who are currently competitively employed, the majority of whom support their families. CASP currently enrolls more than 400 families in Lima. Eight programs in other countries are modeled on CASP and CASP regularly trains the staff of agencies in 12 Peruvian provinces.

More than 300 KU faculty members have voluntarily taught and consulted at CASP over the last 22 years. Among the most devoted are retired Life Span Director Stephen Schroeder, and his wife Carolyn Schroeder, a psychologist and adjunct KU professor. Schroeder signed an agreement in 1991 acknowledging the relationship between the Life Span Institute and CASP.

“This is a state-of-the-art program that grew up in humble circumstances, but now has a beautiful multi-purpose facility that is reaching out to many Latin American and European countries and may be a model program for the U.S. eventually,” Schroeder said.

“We have a first-class program in a third-world country with fourth-class resources,” Mayo quips, who was honored with KU’s Distinguished Service Citation in 2003.

Schroeder agrees. “Considering the limited time and treasure we have put into it, this has to be one of the greatest success stories in Life Span Institute history.”

Centro Ann Sullivan del Perú

Director

Liliana Mayo
Financial update

Life Span Institute scientists were awarded 32 new grants in FY 2007. Overall LSI investigators oversaw 98 total awards (new plus continuing awards), which matches our fifth highest total in LSI history. Despite this strong showing, the total amount of our external awards decreased $2.2 million this past year, down to $18.1M which ranks sixth in LSI history. This decrease reflects the substantial decline in federal research funding for health and education that has been going on for several years. Nevertheless, LSI remains the largest designated research center at KU in terms of combined federal, state and private dollars.

After two consecutive years in which total awards dollars have decreased, we are anticipating a nice bounce in FY 2008. Current projections indicate that external funding should once again eclipse the $20M mark, with the largest gains coming as a result of a substantial number of new NIH grants. Since the 1990 transformation from the Bureau of Child Research to the LSI, we have averaged a 9.5% increase in external dollars annually despite several years in which awards dollars declined.

The National Institutes of Health and the U.S. Department of Education remain the leading funding sources at $7.4 million and $5.5 million respectively. Another $1.4 million in Health and Human Services Department funding means that federal awards continue to account for 80 percent of the Institute’s overall external funding.

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 $3.3 in external awards. In 2007, every dollar the state of Kansas invested in the Life Span Institute yielded nearly $5.2 in external awards.
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.
Kenneth L. Audus, Ph.D.
Edward T. Auer, Jr., Ph.D.
Kathleen M. Baggett, Ph.D.
Steven M. Barlow, Ph.D.
Susan M. Bashinski, Ph.D.
Andrei B. Belousov, Ph.D.
Jane B. Atwater, Ph.D.
Kenneth L. Audus, Ph.D.
Edward T. Auer, Jr., Ph.D.
Kathleen M. Baggett, Ph.D.
Steven M. Barlow, Ph.D.
Susan M. Bashinski, Ph.D.
Andrei B. Belousov, Ph.D.
Mehmet Bilgen, Ph.D.
Nancy C. Brady, Ph.D.
William M. Brooks, Ph.D.
Jian L. Bruses, Ph.D.
James F. Budde, Ed.D.
Jay F. Buzhardt, Ph.D.
Susan E. Carlson, Ph.D.
Judith J. Carta, Ph.D.
Hugh W. Catts, Ph.D.
Paul D. Cheney, Ph.D.
Mark Chertoff, Ph.D.
Lane K. Christenson, Ph.D.
John A. Colombo, Ph.D.
Pamela J. Cress, Ed.S.
Rick T. Dobrowsky, Ph.D.
Joseph E. Donnelly, Ed.D.
Dianne Durham, Ph.D.
David J. Ekerdt, Ph.D.
Kathy A. Ellerbeck, M.D.
Stephen B. Fawcett, Ph.D.
Sarah Hargus Ferguson, Ph.D.
Barry W. Festoff, M.D.
Marc E. Fey, Ph.D.
Stephen C. Fowler, Ph.D.
Michael H. Fox, Sc.D.
Rachel L. Freeman, Ph.D.
Cheryl A. Gibson, Ph.D.
J. Leon Greene, Ph.D.
Charles R. Greenwood, Ph.D.
Peter Griggs, Ph.D.
Katherine Froehlich-Grobe, Ph.D.
Betty M. Hart, Ph.D.
Linda S. Heitzman-Powell, J.D.
Leslie L. Heckert, Ph.D.
Jessica A. Hellings, M.D.
Martha J. Hodgesmith, J.D.
Eva Horn, Ph.D.
Mary L. Hummert, Ph.D.
Joan S. Hunt, Ph.D.
Thomas J. Imig, Ph.D.
Yolanda K. Jackson, Ph.D.
Cheit D. Johnson, M.D.
Michael A. Johnson, Ph.D.
Debra M. Kamps, Ph.D.
Susan J. Kemper, Ph.D.
T. Rajendra Kumar, 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.
Erik A. Lundquist, Ph.D.
Susan M. Lunte, Ph.D.
Gregory J. Madden, Ph.D.
Janet G. Marquis, Ph.D.
Matthew S. Mayo, Ph.D.
Kenneth E. McCarson, Ph.D.
Amy McCartney, Ph.D.
Elias K. Michaelis, Ph.D.
Mary Lou Michaelis, Ph.D.
Jackob Moskovitz, D.Sc.
Brenda Smith Myles, Ph.D.
Dorothy E. Nary, M.A.
Warren B. Nortnick, Ph.D.
Randolph J. Nudo, Ph.D.
Kathleen Olson, Ph.D.
Sandra L. Padmanabhan, Ph.D.
Susan Palmer, Ph.D.
Wendy S. Parent, Ph.D.
Kenneth Peterson, Ph.D.
Brian K. Petroff, Ph.D.
Margaret G. Petroff, Ph.D.
Jonathan W. Pinkston, Ph.D.
Denise Poston, Ph.D.
Jerry A. Rea, Ph.D.
R. Matthew Reese, Ph.D.
Amanda Reichard, 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. Sailors, Ph.D.
Kathryn J. Saunders, Ph.D.
Muriel D. Saunders, Ph.D.
Richard E. Saunders, Ph.D.
Richard L. Schiefelbusch, Ph.D.
Christian Schoeneich, Ph.D.
Stephen R. Schroeder, Ph.D.
Jerry A. Schultz, Ph.D.
Jan Sheldon, Ph.D.
James A. Sherman, Ph.D.
Sheila J. Simmons, M.S.
Tom M. Skrtic, Ph.D.
Bryan K. Smith, 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. Spradlin, Ph.D.
Michael J. Werle, Ph.D.
Douglas E. Wright, Ph.D.
Edward J. Zamarripa, Ed.D.
Joseph E. Steinmetz, 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.
Lisa D. Timmons, Ph.D.
Ann P. Turnbull, Ed.D.
H. Rutherford Turnbull III, LL.M.
Cheryl A. Utley, Ph.D.
Mary B. Veerkamp, Ph.D.
Michael S. Vitevitch, Ph.D.
James L. Voogt, Ph.D.
Dale Walker, Ph.D.
Robert E. Ward, 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.