What if?
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 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, more than 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 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.

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 $20.2 million in sponsored project support in FY 2005-06. Each state dollar brought in close to $6 external dollars this fiscal year.
What if? Back to the Future

Fifty years ago, Dick Schiefelbusch was given two rooms, a part-time secretary and the charge to bring life to an entity that existed in name only—the Bureau of Child Research. In 2006 we are celebrating the remarkable achievements that followed. And there really is a lot to celebrate. But then what? How can we extend this legacy into the future and beyond? What will it take to achieve our broad mission – to create research-based solutions to the problems of human and community development, disability and aging? To extend our impact, to really make a difference?

Our 2006 Annual Report is dedicated to the future. Here, summarized in a few short statements, are some of the key guideposts we are following to get there.

Collaborate – all the easy problems have been solved. Progress now will be determined by those who collaborate broadly across disciplines, agencies, communities, universities, nations and beyond.

Create – our mission is really about inventing the future. Not simply reacting to what comes along, but turning the knowledge we create into solutions that will impact the quality of life for generations to come, in Kansas and throughout the world.

Translate – knowledge locked up in academic papers alone is mere potential. The translation of that knowledge into technology, skills, practices and policies is potential realized.

Support – especially students and young researchers – they are the future.

Finally, when the road ahead gets a little rough, remember what Helen Keller said: “No pessimist ever discovered the secrets of the stars or sailed to an uncharted land or opened a new heaven to the human spirit.”

The goal of our 2006 Annual Report is to provide some concrete examples of how we are following these guideposts as we move full speed back to the future.

Steven F. Warren, Director
The Schiefelbusch Institute for Life Span Studies
What if we could prevent 30,000 children from becoming obese adults in the next five years?

Joseph Donnelly and his colleagues at the Children’s Mercy Hospital and Clinics believe they now have a chance of doing just that.

Donnelly, who directs the Life Span’s Center for Physical Activity and Weight Management, will lead a new, ambitious effort to combat the obesity epidemic that now afflicts 24.3 percent of all Kansas children and 32 percent of all Missouri children.

Located at Children’s Mercy Hospital in Kansas City, the new Center for Physical Activity, Nutrition and Weight Management, will be one of the nation’s largest public-private partnerships addressing obesity and one of the few nationwide focusing on childhood obesity.

“The new Center makes possible the critical mass of research investigators and clinicians necessary for a diverse, sustained and coordinated effort to prevent and treat obesity and associated disease,” Donnelly said.

Donnelly is well prepared to fight obesity on a public health scale. He directs several current research projects involving more than 15,000 area children in strategies to combat obesity involving physical activity and environment, diet and public policy in homes, schools and recreational settings.

The Center could have significant public health benefits in the region that will compound over time. Opening in the fall of 2007, the Center aims to serve 300 children in clinical settings in 3-6 month research programs by fall 2009 and 30,000 children in school and home-based programs in the Kansas-Missouri region by 2011.

Donnelly, nationally known for his research-based public health and clinical approaches to both prevent and treat obesity, will collaborate with a Children’s Mercy team as well as researchers and clinicians from the Kansas University Medical Center and the University of Missouri School of Medicine.

The center will occupy the second story of the new Don Chisholm Center at Children’s Mercy, currently under renovation at the northwest corner of 22nd and Holmes and scheduled to open within the next 18 months.

The 14,000-square-foot facility will have offices, exercise rooms for children and adults, a metabolic kitchen, examination rooms, a wet lab, specialized equipment for measuring body composition and metabolism, an outdoor physical activity park and meeting rooms. It will also include a whole-room calorimeter, one of the few in the United States, which measures the energy a person’s body uses in normal activities.

“Obesity is the disease of the century,” Donnelly insists. “We can’t treat every man, woman and child individually, so the public health approach is critical.”
What if we could turn around the future of thousands of children at risk for academic failure and spur economic development at the same time in the urban core?

The May 20 Kansas City Star extolled an impending $80 million “children’s campus” as the largest development project in downtown Kansas City, Kansas in decades.

And the driving force behind a potential economic engine for this chronically challenged urban core? Representatives of community non-profits committed to improving the lives and potential of the 4,000 low-income children and their families who live there.

Two Life Span Institute affiliated scientists, Charles Greenwood, director of the Juniper Gardens Children’s Project, and Martha Staker, director of Project EAGLE, both longstanding research-based community programs, have lead the private-public effort to build the Children’s Campus of Kansas City where agencies will be co-located and work collaboratively.

Along with their counterparts from the Family Conservancy, the Children’s Museum of Kansas City and several other agencies, Greenwood and Staker envision the Children’s Campus as a way to create a kind of critical mass of expertise and economy of scale in addressing the needs of the community comprehensively.

For years the Kansas City agencies were frustrated by their inability to provide coordinated support efficiently to children and their families.

Some agencies have long waiting lists while others operate below capacity and families often get sporadic and disconnected services.

“It is fiscally unwise and inefficient to continue to try to address the problems of low-income families and children in an uncoordinated way,” said Greenwood.

Located on six city blocks near the present location of Juniper Gardens at State and Minnesota Avenues and 3rd & 5th Streets, the campus will be anchored by the three-story Bounce Building (after the Bounce Learning Network). The Children’s Museum will relocate to a nearby renovated building.

The Bounce Building will house a model infant/toddler and preschool programs (Project EAGLE); dental and health-care services and family support (the Family Conservancy) and research, (the Juniper Gardens Children’s Project) serving 250 children a year.

But there’s more. The unique entrepreneurial component of the site is a proposed 10-story office tower that would be owned by the CCKC to help sustain the campus and fuel the city’s economic renaissance. The building is contingent on the group’s ability to get conventional loans and New Market tax credits.

Substantial support to date has come from many sources including the Susan A. Buffet Foundation, the Greater Kansas City Community Foundation and the Dunn Family Foundation. Individual families from the community have contributed $12,000 so far. Bank Midwest and the Unified Government of Wyandotte County have donated land. A $20 million dollar capital campaign is in progress. Construction could begin as early as the end of 2006.

“If all goes according to plan, we could be preparing children for academic success and attracting their future employers to the community at the same time,” Greenwood predicted.
What if we could discover how children learn words so language therapies could be developed and targeted precisely?

Holly Storkel wants to know how children learn words, because believe it or not, science doesn’t really know. So she reads kids stories about things like a yame.

That’s yame – a yellow candy machine with one shoot. It doesn’t exist and that’s the point. How will a child remember “yame?” Does it help that is an unusual sound sequence or not? Would a child remember yame because it has many “word neighbors,” like game, fame, and flame? Once a child hears a description of the yame and even sees a picture of it – how does that help affix it in memory?

Storkel, associate professor of speech-language-hearing, was awarded a highly competitive five-year $1.75 million grant to develop 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.

The five-year National Institutes of Health grant will allow Storkel to do the kind of basic research that is often lacking in the current practice of speech therapy and pathology.

“A lot of what we believe about how to teach kids vocabulary hasn’t been systematic or tied to proof of how they actually learn words,” she said.

Many children with language impairments have difficulty learning new words, yet the cause is poorly understood, she explains.

Storkel is conducting a series of studies of children with and without impairments as well as with adults to build a framework for practitioners based on what she discovers about how individual sounds, word sounds and word meanings contribute to verbally learning language.

Storkel describes the relationship of words to each other as sound, word and meaning neighbors. She will be exploring these neighborhoods to determine if and how words are learned more easily if words have many or few neighbors.

“Children learn which sound combinations are more or less common in their language by the time they are about nine months of age,” Storkel said. “We want to know if more common or rarer sound sequences helps you learn new words.”

Word meaning learning has been less studied but more hotly debated, according to Storkel. Do kids learn the meaning of words like dog and cat more easily because they are both furry and have four legs, or do they learn words like chair, sofa and stool because you can sit on all of them?

The project could fundamentally change the way children are assessed and treated for language impairments.

“If an assessment were based on knowledge of what factors influence word learning, you would know what types of words a child had trouble learning. You would have a clear direction from assessment to treatment.”
What if educators could instantly and securely access and analyze students’ academic and discipline records, get expert strategies for improvement, and track the results?

Schools are suspending and expelling children in record numbers. Not only are these children at risk for academic failure, but their problematic behavior ripples through the entire school system, disrupting classrooms, preventing teachers from teaching, and impeding schools from meeting federally mandated academic proficiency goals.

“Everybody loses when schools resort to discipline that excludes children from learning — including learning appropriate social behavior,” said Amy McCart, assistant research professor.

McCart and colleagues have partnered with several Kansas schools to successfully implement school-wide positive behavior support programs that have reduced disciplinary actions. And in a number of schools, student scores in math and/or reading have also climbed.

Now this expertise could be available to educators in the form of a real-time, web-based product called the eServe Initiative. Supported by a U. S. Department of Education Small Business Innovation Research Program grant, the innovative software program was developed through a partnership between the McCart group and Software Outfitters, Inc., a software development firm headed by Rob Harsh, CEO, based in Overland Park, Kansas.

Existing student data management programs used by schools are generally cumbersome and relegated to crunching data required for state and federal reporting requirements, according to McCart.

The eServe Initiative goes far beyond data management and analysis for administrative use. Designed for classroom teachers as well as administrators, the program can identify and offer fine-tuned strategies to improve the performance and behavior of individuals and groups of students.

“There’s nothing else like this,” said McCart. “Our program would allow school districts to make system-level changes without an ongoing need for expensive, external consultants.”

The eServe Initiative can take student data from any school district application, link it to analysis modules, profile and report student discipline and academic demographics, monitor ongoing behavioral and academic interventions, identify at-risk students, and provide dynamic, individualized recommendations.

The Phase One SBIR grant is evaluating the technical merit, efficacy and feasibility of the second generation web-based program based on an earlier prototype that was piloted for two years in USD 500 in Wyandotte County, Kansas.

“That’s when we learned that teachers and administrators needed more than data management and analysis—they needed immediate and specific recommendations on how to change problem behavior,” McCart explained.

If the outcomes of the Phase One SBIR grant are promising, McCart’s group and Software Outfitters will apply for a Phase Two SBIR to fully research and develop products with strong commercial viability and marketability. McCart and her partners believe that the eServe Initiative has real commercial potential in a national market.

“Educators’ need for effective and responsive ways of dealing with problem behavior has never been greater,” said McCart, “if we are to keep children in school and meet the mandates of No Child Left Behind.”
What if we could help more young people with developmental disabilities get meaningful jobs?

Only about a third of people with disabilities are employed, compared to almost 80 percent of people without disabilities.

This number has stubbornly refused to budge despite legislation aimed at leveling the playing field, including requiring schools to help students transition to jobs or further training after high school.

But researchers Michael Wehmeyer and Wendy Parent are working to turn this around.

Wehmeyer, director of the Kansas University Center on Developmental Disabilities (KUCDD), is finding out what and how existing programs help teenagers with disabilities transition to adult employment through a five-year National Institute on Disability and Rehabilitation Research grant.

“After high school, young people with disabilities are less likely have jobs, live independently or continue their education,” Wehmeyer said. “Developing self-determination — problem-solving, decision-making and goal setting — can give them control over their lives.”

Wehmeyer said that a recent government report confirmed that the quality of federally mandated transition services varies widely. “There is very little empirical knowledge about the impact of self-determination on adult success.”

Wehmeyer’s study will yield much evidence on this. Wehmeyer’s KU research group is collaborating with University of Portland researchers to evaluate high school self-determination programs in seven states involving 700 students.

“Policymakers can use this information to incorporate self-determination instruction into the high school curriculum,” said Wehmeyer.

Wendy Parent, KUCDD Lawrence assistant director, says that many more people with developmental disabilities could be competitively employed.

Parent is directing a project to help young women get good jobs in non-traditional career areas before they leave high school.

The four-year program was implemented this year in seven Kansas high schools and will add seven more high schools and seven middle schools by 2008. It is funded by the U.S. Department of Education’s Women’s Equitable Employment Act Program.

Women with disabilities earn lower wages and are even less likely to be employed, be employed full time and remain employed than men with disabilities, Parent said.

To tackle this problem, the project merges the self-determination process with supported or customized employment—a proven approach for assisting people with disabilities become competitively employed.

Parent, who has dual expertise in vocational rehabilitation and special education, and a long and successful history of helping individuals with disabilities find creative jobs, is guiding the young women to think outside the box—including considering jobs traditionally held by men.

People with disabilities want to work and can work when they have individualized supports that meet their needs, Parent maintains. “The employer gains a qualified employee and the employee becomes a contributing member of society—it’s a win-win situation.”
Financial

The Life Span Institute had another strong year with 31 new awards. We had 110 total awards (new plus continuing awards), just two short of our all-time high of 112 for the preceding fiscal year.

Despite this strong showing, the total amount of our external awards decreased $1.2 million this past year, but still topped the $20 million mark. This decrease primarily reflects the substantial decrease in federal research funding for health and education over the past year. LSI remains the largest designated research center at KU in terms of combined federal, state, and private dollars.

The National Institutes of Health (NIH) and the U.S. Department of Education (USDE) remain the leading funding sources at $8.9 million and $6.4 million respectively. Another $1.0 million in Health and Human Services Department funding means that federal awards account for more than 80 percent of the Institute’s overall external funding. We increased our number of NIH awards from 37 to 39. The number of USDE grants decreased from 33 to 28, and we had a loss in funding in this area of $1.1 million. Non-federal funds increased by more than $.4 million.

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 2006, this amount remains double the 1990 rate, where every dollar the state of Kansas invested in the Life Span Institute yielded nearly $6 in external awards.
The Centers of the Life Span Institute

Kansas Mental Retardation and Developmental Disabilities Research Center
The Kansas MRDDRR has been continuously funded by a core grant from the National Institute of Health and Human Development for the past 40 years. Over its history the MRDDRC has played a major international role in generating highly effective behavioral interventions aimed at the causes, prevention, and treatment of intellectual disabilities and related secondary conditions, and in delineating basic knowledge of the underlying biology of typical and atypical development. The Center spans the KU–Lawrence and Kansas University Medical Center campuses as well as the Juniper Gardens Children’s Project 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.

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

Kansas University Center on Developmental Disabilities
More than 35 years ago, as the Life Span Institute’s research on developmental disabilities took root, efforts began to translate this research into practice through what is now known as the Kansas University Center on Developmental Disabilities (KUCDD). Virtually all of the Life Span Institute’s direct service, technical assistance, and post-doctoral, pre- and in-service training are associated with KUCDD. These include clinics to diagnose and treat children with disabilities, a statewide project that provides assistive technology to people with disabilities and their families, and training childcare providers and social workers to support individuals with disabilities. In addition, investigators affiliated with the KUCDD conduct research that has state, national and international impact in areas like self-determination, positive behavior supports, inclusive educational practices, early childhood education, community and workplace supports, family systems and supports, and other areas critical to the lives of people with developmental disabilities and their families.

Michael L. Wehmeyer, Ph.D., FAAMR, Executive Director
Glen White, Ph.D., Associate Director
Chet Johnson, M.D., Director, KUCDD-Kansas City Site
David Lindeman, Ph.D., Director, KUCDD-Parsons Site
Michael L. Wehmeyer, Ph.D., Director, KUCDD-Lawrence Site
Wendy Parent, Ph.D., Assistant Director, KUCDD-Lawrence Site
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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 Kansans, early intervention and early childhood, and training for community organizations and agencies serving persons with developmental disabilities.

David P. Lindeman, Ph.D., Director
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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 JGCP 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
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Beach Center on Disability
Through excellence in research, training, and technical assistance and public service in Kansas, the nation, and the world, the Beach Center on Disability seeks to make a significant and sustainable difference in the quality of life of families and individuals affected by disability. Research focuses on access to the general curriculum, assistive technology, deaf-blindness, disability policy, employment, family supports and services in early childhood, family quality of life, individual control of funding, positive behavior support, and self-determination. Founded in 1988 by KU Special Education Professors Ann and Rud Turnbull, the Beach Center honors Ross and Marianna Beach for their long-standing efforts on behalf of families affected by disability.

H. Rutherford Turnbull III, LL.B./J.D., L.M., Co-Director
Ann P. Turnbull, Ed.D., Co-Director
Michael L. Wehmeyer, Ph.D., Associate Director
Wayne Sailor, Co-Associate Director
Contact: 785 664-7600, beachcenter.org

Research and Training Center on Independent Living
The Research and Training Center on Independent Living (RTC/IL) has a twenty-five year history of productive research, comprehensive training, and innovative dissemination of knowledge.
The RTC/IL was conceived as a center without walls that would do what was necessary to enhance the Independent Living field and the lives of individuals with disabilities. In this synergistic environment, persons with disabilities, researchers, trainers, and policy makers have worked to produce much more than they could have as individuals or groups.

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 cognition, 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.

David J. Ekerdt, Ph.D., Interim Director
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**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.bnch.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
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**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 web site at merrill.ku.edu has fact sheets and discussions on science and policy for the general public.

Mabel L. Rice, Ph.D., Director
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**Work Group for Community Health and Development**

Established in 1975, the KU Work Group joined the Life Span Institute as a distinct center in 1990. The Work Group has developed widely-used capabilities for: a) Community evaluation and community-based participatory research (including its Online Documentation and Support System) and b) Building capacity for community health and development (including the Community Tool Box). Recognition of these capabilities led to official designation in 2004 as a World Health Organization Collaborating Centre.

Stephen B. Fawcett, Ph.D., Director
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**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.

Joseph E. Donnelly, Ed.D., Director
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