SETTING PRIORITIES FOR BEHAVIORAL RESEARCH AT THE SCHIEFELBUSCH INSTITUTE FOR LIFE SPAN STUDIES

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Dick Schiefelbusch took over what was then called the Bureau of Child Research in the 1950's with a part-time secretary and one office with three rooms. Dick retired in the late 1980's and the Bureau was renamed the Schiefelbusch Institute for Life Span Studies in his honor. Before I discuss how we establish research priorities at the Life Span Institute (LSI), I'd like to provide you with an overview of our program. I think it's essential to understand what we are in order to understand how we set priorities. Achieving our mission – to discover or invent solutions to the problems of human and community development, disabilities and aging – depends entirely on the creativity of our investigators. It has always been that way. In this respect, we live by our wits. No one guarantees our future. Instead, our future depends entirely on the extent to which we can achieve our ambitious mission. We have a broad mission, which is an advantage, and it is manifested through the work of investigators affiliated with 12 different centers.

The Kansas Mental Retardation and Developmental Disabilities Research Center is our largest and oldest center (it is almost 40 years old). We share it with the KU Medical Center. It is one of the best examples KU has of a "one-university endeavor." At any given point in time it has roughly 60 NIH R01 research grants and two or three large program projects clustered around a million dollar a year core grant from the NIH that is competitively renewed every five years. We could easily lose a core grant if we fail to keep our science on the cutting edge of basic and applied research relevant to mental retardation and developmental disabilities. Other universities with these core grants include Johns Hopkins, Harvard, the University of Wisconsin, Vanderbilt, UCLA and other elite research universities. Our center has been a long time source of strength for the Life Span Institute as a whole. Much of what has gone forward over the past four decades has either been a spin off of this center or done as part of it.

The Kansas University Center on Developmental Disabilities is nearly as old as our mental retardation research center and it is also large. The intent is to translate research relevant to disabilities into practice through training and technical assistance. This center spans the entire institute and operates at KU-Lawrence, at the Life Span Institute at Parsons, at the Juniper Gardens Children's Center, and at the KU Medical Center.

The Life Span Institute at Parsons is a research and development center focused primarily on the needs of citizens of the state with disabilities and their families. Research and development efforts done at the Parsons State Hospital over 40 years ago was the genesis of the founding of our Mental Retardation Research Center and our Center on Developmental Disabilities. The LSI at Parsons has evolved a great deal over the years. For example, because of efforts of LSI investigators at Parsons, the state of Kansas has one of the leading programs in the world in assistive technology. If you need a wheelchair because you came back from the war in Iraq seriously disabled, or if you have cerebral palsy – this program helps you to live independently. An estimated 54 million people in the US have disabilities, and for most of these persons, assistive technology allows a degree of independence while enhancing their quality of life. By the way, Senator Pat Roberts has taken a leadership role in helping establish these programs across the country probably in part because they are very cost effective. We just received a $10 million dollar grant for one year – this is not research money. What we are doing in partnership with the state government and thousands of citizens is establishing co-ops/credit unions in Kansas so people can get money to buy the assistive technology they need. This one-time investment will create a permanent foundation for these low cost programs.

The Juniper Gardens Children's Project will celebrate its 40th anniversary this fall. It is located in Wyandotte County – traditionally the poorest county in the state and a place with many challenges. Juniper Gardens is unlike any other research center in the country. It focuses on education, parenting and community issues central to the healthy development of children in partnership with this challenged community. Ground breaking research has come out of this program over the years and has led to the formation of many highly effective intervention and education programs and a much deeper understanding of the impact of poverty and related issues on children's development.

The Beach Center on Disability was established in 1988 with a substantial gift from Ross and Marianna Beach. The Center also had a core grant from the National Institute for Disability Research and Rehabilitation. The Beach Center focuses on quality-of-life outcomes, human and social services; health policies and practices and a number of other issues of central importance to the lives of individuals with intellectual and developmental disabilities and their families.

The Research and Training Center on Independent Living, founded in 1980, focuses on the needs of adults with physical disabilities. This center also has a core grant from the National Institute for Disability Research and Rehabilitation as well as support from the Centers on Disease Control. One of the center's current grants is a result of the 9/11 disaster. When the World Trade Centers collapsed a number of people were killed because they were wheelchair users and could not be evacuated from the buildings in time.

The Gerontology Center was founded in 1976 and became part of the Life Span Institute in 1990. Its focus is on aging Americans – a fast growing segment of the population. This has enormous consequences. The Medical Center also does research on this topic, and increasingly there are links between the two campuses – one approach is behavioral and the other biomedical. The Gerontology Center also is home to an interdisciplinary doctoral program.

The Biobehavioral Neurosciences in Communication Disorders Center is our second NIH-funded center and is only 2 years old. It's the new kid on the block. Communication disorders are one of the leading impairments in the world. Speech, language, and hearing disabilities are almost always at the forefront of disabilities. This Center, like several others at LSI, grew out of the vision of one of our most successful senior investigators. Mabel Rice stepped up and said she thought we could get this center. So we successfully competed for it. This program is funded by the National Institute on Deafness and Communication Disorders. The growing number of NIH grants associated with it focus on issues relevant to the causes and treatment of communication disorders from infancy to old age.

The Child Language Doctoral Program was established in 1983. The Life Span Institute serves as its home because as an interdisciplinary program, it does not fit within a single academic department. This program focuses on interdisciplinary doctoral and post-doctoral training.

The Work Group on Health Promotion and Community Development was founded in 1976. This program truly has a world-wide reach. It will soon be designated a World Health Organization Collaborating Center. Over the years the Work-Group's research has resulted in the establishment of an online "community toolbox" that is used by individuals all over the world to learn how to create all kinds of "community tools" – from electing a city council to public health awareness campaigns. This is an important piece of intellectual property that is touching the lives of people world-wide on a daily basis.

The Center for Physical Activity and Weight Management is one of our newer centers. The Center is focused on obesity in children and adults – a problem that has grown to the level of a public heath crisis. This center conducts clinical research and also provides treatment programs throughout the state of Kansas.

And last but certainly not least, you are all familiar with the Merrill Advanced Studies Center, our hosts of this conference. The Merrill Center was established by a generous gift from Virginia and Fred Merrill in 1990. This program serves as a major catalyst for scholarship on disabilities as well as policies that shape university research.

These 12 programs have quite a history. We currently have 87 Principal Investigators associated with the Institute. Our external awards have increased to nearly 20 million per year – and this doesn't include our partnership with the Medical Center. The combined footprint of the Institute, together with our shared programs at the Medical Center represents approximately 36 million dollars in research, development, training, and clinical activity in a given year. Dick Schiefelbusch working with many other creative scientists built the foundation for this program in the 1960's and 70's. So this is by no means a new program, which is an important point. We've been doing this for over 4 decades. And we leverage about 6 external dollars for every dollar we receive from the state of Kansas – a figure that is well above the national average for programs like ours. NIH is the largest source of our funding – 42% right now. Other major sources of support are Health and Human Services, the Department of Education, the state of Kansas, and foundations.

In a "mature center" like ours, what are the signs of vitality? What signs are there that we are still being truly successful and not losing our edge? Well, for one thing we have two new centers – BNCD and the Weight Management Center – and 40 new grants. Grants end all the time – the question is do new ones come online? This year we had 40. But the "competitive renewal" of ongoing programs is extremely important too. We have to go through competitive renewal next year with the Kansas Mental Retardation Center. These centers get knocked off all the time. The fact that you are an "old, established center" just makes you a bigger target. If we lost that center, it would have a massive impact on the Life Span Institute. The 60 R01's would continue at least for a while but the million dollars a year in infrastructure to the organization would disappear. We have cores in imaging and in research design and analysis that are critical. You can never take a renewal for granted. In the last three years, we have increased the proportion of our portfolio fund by NIH from 33 to 42% -- another sign of vitality. It's important to have a diversity of funding, but it is equally important to emphasize the "quality" of funding. In the "go-go 90's" we added some projects that may not have been funded from the most stable and reliable sources. Over time we have had some problems with some of these funding sources. As just one example, several small foundations supporting LSI grants went bankrupt, leaving us with our own financial challenges. As a result we are more conservative now about those with whom we will work and we ask more front end questions. With regard to recruitment and retention of top talent – this can be another sign of vitality. We've retained extraordinary scientific talent that is world class. It is not true that you can't compete when you are in the Midwest. We are competitive. We don't need special help or assistance to do this.

What are some of the important characteristics of our Institute? Stable leadership and a long history. I've been the director for the past four years, Steve Schroeder served as director for 11 years and Dick Schiefelbusch for 30 years before that. Our university leadership will often support some of our more

daring initiatives probably because we are a mature program rather than an upstart. Another characteristic is that we have investigators with all kinds of appointments – regular tenure-track, as well as many people who are appointed 100% by the Institute and not on tenure lines. But we also have many people on joint appointments – tenure line academic and research programs where the salary is split. Our history with this is important in terms of the university's willingness to support this degree of flexibility. We want to be in partnership with deans and the rest of the university – not competitors. Also because of our history we have many seasoned investigators that have seen research support fall, but because of their experiences they know that dips in funding are normal and don't mean the sky is falling. The confidence and ability of the group to survive down times is central to its success. We also have a stable but evolving infrastructure. We have good state support. This may not have been necessary at the start, but it has been important in the long run. I don't believe you can endure 40 years without some stable state support. This support isn't large compared to our overall budget, yet it is crucial to assuring a stable core to our program.

A paradox perhaps is that to be "stable" we have to evolve and change. We must keep up with technology. We must be administratively flexible. For this reason we essentially function as a federation of interests – not a top down hierarchy. Every director is autonomous to some extent. They report to me as well as jointly to a dean in some cases – but in any case they are given a reasonable amount of administrative flexibility. The LSI central office does not micro-manage. This allows us to change when the world changes. All of our directors are active scientists as well. None of us are just "administrators". Consequently, even though I direct the Life Span Institute and our largest single center (the Mental Retardation Research Center), I maintain a lively program of research just like all other LSI investigators. This is important for my credibility both locally and nationally. So I'm impacted by the same things the PI's face. Thus, when I say to our center directors and investigators that "we" are all in this together, that's exactly what I mean. In this respect, we do not see the KU Center for Research, the umbrella organization that we are part of, in terms of "us and them." We understand that our success is important to their success and vice versa.

What are the challenges we continually face? Evolve or die is the most basic one. Research centers often go away. They should die when they are no longer meeting their mission. Research centers should be seen as an intellectual tool – a way of organizing talent and resources to solve important problems. Right now the rapidly changing nature of science is a huge challenge for us. It has had a huge impact on behavioral science and this is central to us. We can't keep doing what we've been doing. There are changing federal research priorities – as there should be. We are stretching the infrastructure and our talent to meet these. In practice this is a little bit akin to the idea of rebuilding an airplane while you fly it. This is what we must do in a large mature program to

keep it moving forward. There is no time to simply stop and retool – you have to make changes on the fly.

What are our strategies? Create synergies is a basic one. The 12 centers are not silos. We experience collaboration among our centers and with many others at KU, throughout the state, nation, and world. Kim Wilcox, the Dean of Arts and Sciences, is one of our most important collaborators, for example. We want to collaborate where our mission overlaps with his. We are collaborating right now on recruiting a senior investigator with experience doing clinical trials in behavioral research – this will fit well with our neuroscience initiative. We are also collaborating on hiring a director for our Gerontology Center. Look at who our people work with now – they may be working with faculty at North Carolina, UCLA, or MIT. You'd be amazed at how much collaboration goes on if you looked at the grants and who is on them. About half are from the KU Medical Center, for example. Mabel Rice has a large NIH grant where much of the data is being collected in Perth, Australia. I could give dozens of other examples of collaborations our investigators engage in.

These are the key elements:

- Recruit, retain, mentor – our future is the young investigators.
- Evolve with the science.
- Diversify the portfolio while enhancing its quality. Don't depend on a single source of anything.
- Build from your strengths and don't go into an area where you have no strength.
- Measure and evaluate the effects of your policies and initiatives.
- Reinforce innovation, creation, and making a difference at all levels.

Most of our investigators are not interested in the size of grants they have. They got into this line of work because they want to make a difference at all levels – to have a meaningful impact on the problems of aging, disabilities, human development and communities. If they keep focused on the mission and they are typically successful – their work does have an impact, particularly if they keep it focused.

How do we set priorities? In the short-term, investigators and centers set the priorities – I don't. The process is often "opportunity driven." In the long term, strategic reinvestment is important. The behavioral sciences are changing rapidly. Rapid developments in biology are beginning to cause an increase in the value of some types of behavioral research. Much of what happens with aging and disability comes about because of interactions between biology, environment and behavior. Consequently, we increasingly have people studying gene-behavior interactions. Mabel Rice is doing research on specific language impairment. I am involved with colleagues studying Fragile X syndrome – a single gene disorder for which the gene was cloned in 1990. Fragile X is a fascinating disorder and it is attracting the attention of both basic and applied

researchers. The development of children with Fragile X is affected by the interaction between the environment and the genes. This world of "bio-behavioral science" is a rapidly shifting landscape. Today, the emphasis is on how the brain changes as development occurs. With transgenic mice, the genes are knocked out and we look at the environmental interactions. This research can actually lead directly to behavioral interventions. One of our investigators, Steve Fowler, has looked at how various mental health and mental retardation disorders are related in a number of genes. He uses measurement strategies with mice and rat models that are similar to the disorders being studied in humans.

What strategic investments should be made to reflect changes in science? We have some research positions and a reasonable state budget. Sometimes someone retires or leaves and then this opens up new opportunities. Kim Wilcox and I are recruiting a cognitive scientist to study interventions in terms of clinical trials. The government will clearly be supporting more of this research. We need talented scientists here at KU to help us participate in this important work. So the effort by Kim and I reflects a strategic reinvestment in our program. You saw the list of our centers – are they past their prime? Sometimes you see change and the need to move money from one group to another. If we don't do it, we won't have a future. When we go to recruit someone, we hire because we want to create synergies with new talent. It is important to build for the future and to support the next generation. Junior investigators must be well supported too. The challenge is to keep your focus. There are some things we do better than anyone in the U.S. or the world. That must remain our focus.