Four Decades of Discovery

By Jan Rosemergy

The story of the Vanderbilt Kennedy Center begins with the story of the Joseph and Rose Kennedy family whose nine children included a daughter, Rosemary, with intellectual disabilities, and a future president. As a brother, John F. Kennedy understood the profound effects of disability not only on the individual but on the entire family and their relationship to the community. As President, he took action.

President Kennedy’s first step, in 1962, was creating the National Institute of Child Health and Human Development (NICHD), and then the President’s Panel on Mental Retardation. Among its members were Peabody College faculty members Lloyd Dunn, Ph.D., coordinator of special education, and Nicholas Hobbs, Ph.D., professor of psychology and chair of the Division of Human Development. The Panel recommended the establishment and support of Mental Retardation Research Centers to bring together scientists from many disciplines to address the causes and treatment of intellectual disabilities. On October 31, 1963, President Kennedy signed legislation to construct a national network of 12 Mental Retardation Research Centers.

Peabody College was viewed as a world leader in this arena. It had the nation’s first doctoral training program in mental retardation research, begun in 1954. The Joseph P. Kennedy Jr. Foundation established Visiting Professorships in Mental Retardation.

As one site in the national network of Mental Retardation/Developmental Disabilities Research Centers (MRDDRCs) constructed by the federal government, Vanderbilt University’s John F. Kennedy Center is a living and visible remembrance of the President whose name it bears.

One of John Kennedy’s early acts as President was to create a President’s Panel on Mental Retardation, charged with seeking ways to improve the lives of persons with mental retardation, many of whom lived separated from social interaction and research attention in custodial institutions. Convinced largely by Robert E. Cooke, M.D., that the key to progress in mental retardation was research, and that such research needed to be conducted on university and medical school campuses rather than at isolated residential institutions, the Panel recommended that the federal government provide funds to support construction of a network of MRDDRCs in these academic locations. Legislation enacting this recommendation, the Mental Retardation Facilities and Community
Four Decades
from page one

Retardation Research at Peabody in 1962. The Institute on Mental Retardation and Intellectual Development, an NICHD program project, was founded in 1964. With this remarkable record, Peabody was successful in the national competition. The John F. Kennedy Center for Research on Education and Human Development was founded on May 19, 1965.

“The creation of the Kennedy Center resulted from a magical collaboration among the federal government, a private foundation, and a private college of education and human development,” said professor of psychology emeritus H. Carl Haywood, Ph.D., a Kennedy Foundation professor in mental retardation research at the time of the founding and the Center’s third director. “Without all three, it would not have happened.”

**Interdisciplinary research.** A fundamental principle was—and is—bringing together scientists from many disciplines to work together as a strategy for advancing knowledge more rapidly and efficiently than any single discipline can accomplish alone.

This Center was conceived initially as having an almost exclusive emphasis in education and the behavioral sciences, but with a determination that biology would not be neglected. This was accomplished through relationships with Vanderbilt University School of Medicine, Meharry Medical College, and Fisk University, as well as through the Center’s own biological research in its Psychobiology Laboratories.

When Peabody merged with Vanderbilt in 1979, the Center was able to expand its biological and biomedical research and include many more disciplines. The breadth and depth of research was enhanced further in 2001 when the Center became a university-wide research, training, diagnosis, and treatment institute, embracing faculty and resources in Medicine, Nursing, Arts and Science, and Peabody. Today the Center has 150 Vanderbilt faculty members from 19 disciplines.

**Intellectual and related disabilities and those at risk.** The Center’s initial focus was on persons with intellectual disabilities, but a new dimension was added: individuals whose learning difficulties were largely due to inadequate opportunities to learn, lack of stimulation, ill health, poor nutrition, and the effects of poverty. Concern not only for individuals with disabilities but also for those whose development is at risk is a hallmark of this Center.

Throughout its history, Center investigators have pursued research in the broad areas of intellectual disabilities and other developmental disorders, child development, and family functioning. Much of this research has been conceived and conducted with the idea that education, broadly conceived, offers promising approaches to the solutions of many of society’s problems. For example, when solutions were sought to the problem of children with emotional disorders, Project Re-ED, an educational approach, was devised, tested, evaluated, and disseminated. When it became apparent that adverse social circumstances might be depriving children from low-income families of the proper physical, social, intellectual, and emotional development, the Early Training Project, an educational solution, was devised, which influenced the establishment of Head Start. Similarly, the work of the Center has been characterized by a commitment to families and to the principle that persons are influenced in powerful ways by settings and by other persons.

**Mission-oriented research.** From the outset, the Center’s work has been organized into mission-oriented research groups. During the early years those were the Institute on Mental Retardation and Intellectual Development (IMRDiD, 1964-1996), the Demonstration and Research Center on Early Education (DARCEE, 1966-1980), the Institute on School Learning and Individual Differences (1965-1972), the Center for Community Studies (1966-1981), the Research Group on Behavior Disorders in Children (1965-1972), and the Research Group on Sensory-Motor Disorders and Adaptive Behavior (1965-1972). These institutes were led by faculty researchers including Lloyd Dunn, Ph.D., Susan Gray, Ph.D., Raymond Norris, Ph.D., Wilbert Lewis, Ph.D., and J. R. Newbrough, Ph.D. Forty years later, the Center is organized into four research groups: Communication and Learning, Developmental Neurobiology and Brain Plasticity, Mood and Emotion, and Family Research. Despite organizational changes over the decades to reflect faculty expertise and emerging knowledge, clusters of researchers from diverse disciplinary backgrounds working together on related problems have been a hallmark.

A third hallmark has been the inclusiveness of scientific efforts. Studies of learning, animal behavior, and more recently, brain development and plasticity have taken place alongside studies of the effects of early intervention and school-wide educational and mental health interventions.

Another enduring hallmark has been pursuing science and improved practices within a community context. In addition, public support for persons with disabilities and their families has been a part of the Center’s mission, along with a commitment to transfer the knowledge generated by research into practice.

**Research training.** Research training is a part of the Center’s mission. It occurs at many levels: in classrooms and laboratories, Continued on page 3

---

**Primer**

**Mental Retardation (Intellectual Disabilities)**

Core features:

• IQs below 70,

• problems in adaptive behavior (i.e., need for supports to perform daily activities required for personal and social independence),

• beginning in the childhood years.

Although debated, the standard view is that about 1% to 2% of the population has mental retardation. More males than females have mental retardation.

Mental retardation has many different causes:

• prenatal, including genetic disorders and accidents in utero,

• perinatal, including prematurity and anoxia (lack of oxygen at birth),

• postnatal, including meningitis and head trauma.

By the late 1990s, over 750 different genetic causes (or etiologies) had been identified. The most prominent genetic etiologies are Down syndrome, fragile X syndrome, and Prader-Willi syndrome. For the majority of persons with mental retardation, no cause is apparent.

Children with different etiologies of mental retardation vary in their behaviors, showing different strengths and weaknesses in cognitive, language, or adaptive skills, as well as a proneness to different maladaptive behaviors and psychiatric conditions. Such etiology-related behaviors have led to renewed excitement in research about linking specific genetic anomalies to changes in brain structure or function, to behavioral outcomes, and the issue of gene-brain-behavior relations.

Psychiatric disorders are common among children and adults with mental retardation.

In many cases, behavioral training has increased adaptive and decreased maladaptive behaviors, has been helpful to parents, and has contributed to vocational and vocational success.

Director’s Message  from page one

is that our great scientists and clinicians are well ahead of the curve in terms of bringing the most creative solutions to our most difficult challenges in understanding human development and behavior.

Nicholas Hobbs, Lloyd Dunn, Susan Gray, Carl Haywood, and a remarkable cast of faculty members knew in the 1950s what we now take as gospel: If you want to understand human nature and behavior, study it from the beginning, in children, and if you want to provide the best evidence-based interventions for those with developmental disabilities, study it with a truly interdisciplinary lens. The remarkable legacy of our Kennedy Center scientists set the gold standard for research about children with developmental disabilities, and it is astonishing to ponder the contributions that our scientists have made over the years. This special anniversary issue highlights many of these, but from my perspective, we need to judge ourselves in terms of whether we are taking the fullest advantage of this brilliant foundation of research and application in developmental disabilities.

As we have grown our research programs across the Vanderbilt campus to include 150 faculty members, the enthusiasm of my colleagues in different disciplines to participate in even greater interdisciplinary efforts to solve the mysteries of development is truly remarkable. We now link our research efforts, more than ever, to practical solutions for children and families through our Family Outreach Center and Clinics. Historically, the Kennedy Center was one of the first research units at Vanderbilt to reach out beyond the academic disciplines on which its research was founded. We are the prototype for that today on our campus, and even across the United States and abroad. My colleague and friend on the National Scientific Council for the Developing Child, Nobel economist James Heckman of the University of Chicago, has demonstrated unequivocally that investing more of our great national resources in children will have a dramatic, positive impact on the economic future for those individuals, their families, and society. It makes little sense, just from an economic standpoint, to wait. This is what the Vanderbilt Kennedy Center has been about, and what we will continue to pursue as we move beyond our 40th birthday.

Inspiration for Head Start

By Eunice Kennedy Shriver

In 1964, Carl Haywood and Nicholas Hobbs invited me to visit Peabody College to observe their research and accomplishments, especially those of Dr. Susan Gray. At that time, Dr. Gray was conducting a study on small children with mental retardation examining the impact of tutoring with their parents upon the likelihood of these children entering into normal grades in school.

As I was about to leave on my trip to Nashville from my home in Washington, D.C., I asked Sarge if he wanted to accompany me. At that time, he was organizing the War on Poverty. He seemed rather reluctant at first but he decided to accompany me. When we landed in Nashville, we were met by Dr. Gray. She invited us to view two or three different centers where the parents were working with their mentally retarded children to upgrade their skills.

Dr. Gray was excited at the thought that these children could be educated in a regular classroom. We visited the different centers and observed, for example, mothers who were tossing a ball to their children and those who were getting their children to walk in a straight line. The motor activities each child was able to perform were impressive, as was their ability to communicate.

At the conclusion of our visit, we talked for a while with Dr. Gray. Sarge and I were impressed with her results in improving the abilities of mildly retarded children. During our flight back to Washington, Sarge turned to me and said, “If you can do this with disabled children, I could do this with regular children all across America.” I said to him, “That’s wonderful, Sarge, but you must set aside a certain percentage of the funds of this program for disabled children because they are the ones that made this enormous discovery.” He said, “I certainly will.”

When we arrived back in Washington, he contacted Dr. [Robert] Cooke and Dr. Ray Adams from Massachusetts General Hospital and the process for Head Start began. The work of Dr. Gray influenced much of the efforts of the planning committee for Head Start.

I have often repeated this event and its significance to Sargent, and I told Scott Stossel, the author of Sarge’s book, that we must include this event in his book Sarge: The Life and Times of Sargent Shriver.

The credit for Head Start should be given to special children, not to Sarge and me. Neither of us would have thought of this idea if we had not traveled to Nashville, met Dr. Gray, and watched the children do their extraordinary performances.

Peabody College and Vanderbilt University benefited from Dr. Gray’s work as well as through obtaining a large grant from the Joseph P. Kennedy Jr. Foundation to establish the John F. Kennedy Center. In retrospect, Dr. Susan Gray was a pioneer who influenced the development of children worldwide.

Mrs. Eunice Kennedy Shriver is the executive vice president of the Joseph P. Kennedy Jr. Foundation. For information on the Foundation, see www.jpkf.org.

Four Decades  from page two

in the conduct of research, in consultation with experts, in lectures and presentations of research methods and findings, and in collaboration among researchers. The Center administers the Mental Retardation Research Training Program, now in its 51st year of continuous funding, first by National Institute of Mental Health and later by NICHD. Graduates hold positions of responsibility in the national Mental Retardation/Developmental Disabilities Research Centers and in the University Centers for Excellence in Developmental Disabilities, as well as positions in various levels of government.

More recent is the Center’s Developmental Psychopathology Research Training Program, which trains research scientists studying the development, life course, and prevention of abnormal behavior. It is designed for scholars in the fields of psychology, psychiatry, pediatrics, and education who will become leaders in research in developmental psychopathology and prevention.

Kennedy Center investigators also serve as faculty in other Vanderbilt research training programs including those in special education, neuroscience, vision, neurogenomics, pharmacology, and biomedical imaging.

Summary. In 1966, at the inaugural meeting of the Center’s National Advisory Committee, founding director Nicholas Hobbs challenged those present: “In the character of what has been done, you may surmise what may be done, and more quickly move to share with us the task of inventing the future.” Forty years from its founding, Vanderbilt Kennedy Center investigators are continuing to invent that future.
Two Families, Four Decades

By Stephanie Coner

The Vanderbilt Kennedy Center has been serving families for the past 40 years. The story of the Panvini and Howe families represents not only some of each family’s changes over the four decades, but also changes in the disabilities field nationwide.

When “no” is not an option

When Doria Panvini was in high school, she helped at summer camps for children with disabilities. In college, she and some friends had a Girl Scout troop for girls with mental retardation.

“We found out very quickly they could do more than we thought,” said Panvini. Little did she know that this would be only the beginning of her experience with developmental disabilities.

At the age of 1 1/2, Panvini’s son Chris was diagnosed with mental retardation. In the 1960s when Chris was born, supports available for parents were limited. Children with disabilities were not included in public schools. The Arc movement was just starting to take hold with families fighting for an education program for their children with disabilities. Panvini became an advocate for Chris’s needs as well as the welfare of others.

“The biggest difference between services then and today was the amount of childhood supports,” said Panvini. “We lived in New York at the time, and there was a program for Chris when he was 3 1/2, but he couldn’t start before then. He did start a month or two early because I kept calling them.”

When Chris was 5, the Panvini family, which included siblings Lisa and Bob, moved to Nashville when Robert Panvini joined the Vanderbilt physics faculty. “We came to the Kennedy Center and talked to Nicholas Hobbs in 1971. But at that time the Kennedy Center didn’t offer anything for Chris’s age group,” said Panvini.

Chris eventually enrolled at St. Bernard’s Preschool for the Handicapped under the direction of Sister Marietta. “She believed that all children could learn. There were about 20 children with a broad range of abilities that just didn’t fit into any other program.”

In the 1970s, Metro Public Schools did not enroll children with disabilities until they were 8. “I think that state governments were lagging behind. As parents we may not have been at the cusp of change, but we were good at looking forward.”

Panvini volunteered as a room mother when Chris was old enough to attend Metro Schools, but she began to realize that many aspects were not contributing to Chris’s growth.

“In 1979, children with disabilities ages 8 to 16 went to the same school. Nothing was tailor-made for the student’s specific needs. So a group of us parents developed the Action Committee for Special Education in Metro. We fought to get better transportation, curricula, and accountability. We met with transportation providers, discussed the issues with P.E., and talked to psychologists.”

As Chris developed and changed, so did Panvini’s involvement. She was active with The Arc of Davidson County and now The Arc of Tennessee.

“We started an agency with other families called Mid TN Supported Living, because we strongly feel you can provide supports that are relevant to each person. Chris has his own home and a companion, and many others have apartments or condos, whatever works. But he really likes it, and it is his home. It has been very successful.”

Panvini has served on a variety of committees with the Division of Mental Retardation Services (DMRS). One is the Tennessee Employment Participant in all this. Work is very important to Chris—as it is for many others.”

Chris works with an enclave from New Horizons at the Tennessee Air Guard. One of his preferred jobs is to take out the trash. He enjoys this job where he can see the start and finish and knows that he accomplished a goal—something that Panvini is quite familiar with.

“What would I be if I didn’t have Chris? I think that you begin to appreciate the successes that people have in their lives. And that the successes are different for each person. Maybe situations can be improved if people focus on the successes a little more.”

The first helping hand can make all the difference

Alex was a full-term birth. His mother Dara Howe had no idea at delivery that anything was unusual. But as time passed, Alex was not meeting developmental milestones. During Alex’s 6-month check-up, the doctor found the size of his head was smaller than it should be. He was diagnosed with microcephaly and later, cerebral palsy.

“I was working at Vanderbilt when Alex was diagnosed and knew Jan Rosemergy, director of communications at the Kennedy Center,” said Howe. “She raised my awareness about early intervention, Jan told me not only about the Susan Gray School (SGS), but she also gave me information about other early intervention programs. Jan was an example of why it is important to have many facts before you make an informed decision.”

Howe decided on the SGS because it was university-based and on the cutting edge of new technologies and best practices. Alex started in June 1985 in the Infant/Toddler Learning Project when he was 1. Howe believes that Alex’s success was related to the fact that she was taking part in his education as well.

“I was invited to participate in a parent support group that was part of this research study. I have a very clear memory of when I met a parent with a child like my child. Up until that point I felt very much alone and meeting this parent was an enlightening moment.”

Howe knew Alex was going to need help his entire life. The level of support Alex gets is what determines his success. “Taking a look back, services were very limited. We knew Alex could receive a free appropriate public education, but we stumbled outside of school services. But things are different now. There are various government programs, summer camps, and countless organizations looking to lend a hand.”

Through the years, Howe got excited about advances in technology and what it can do for children with disabilities. Continued on page 5
Leading the Vanguard of Discovery


Education
M.A., 1981, Developmental Psychology, Boston University
Ph.D., 1983, Developmental Psychology, Boston University
Postdoctoral Fellow, 1983-85, Child Study Center, Yale University

Attraction to Developmental Disabilities Research
My interest in studying developmental disabilities arose from both my work and my educational experiences. Throughout college and graduate school, I worked as a teacher of children with severe to profound disabilities. Simultaneously in my Ph.D. program, I was learning about children’s development, mother-child interactions, and families of typically developing children. As a postdoctoral fellow with Ed Zigler at Yale, I began to join these two worlds. With his help, I started exploring how theories, approaches, and findings derived from work on typically developing children might apply to children with developmental disabilities. I also began examining with Elisabeth Dykens how children with particular genetic disorders differed in their behavioral development, and how behaviors of children with particular syndromes might affect their family members.

Reasons for Kennedy Center Membership
When my wife Elizabeth Dykens and I were being recruited here three years ago, we realized the Kennedy Center combined a strongly held, multidisciplinary focus with a rock-solid commitment to children with disabilities and their families. In addition to the researchers themselves, a skilled, dedicated group of Kennedy Center staff helped everyone to get things done. More recently—with support from several private foundations and federal agencies—the Kennedy Center has expanded the services it provides to persons with disabilities and their families. Where else can one work every day with such a talented, committed group of scientists, staff, and service providers, all of whom share a mission to learn about and to serve individuals with disabilities and their families?
Each year persons from the U.S. and abroad, interested in learning about cutting-edge programs for young children with special needs, visit one or more of the major universities known for training professionals in this field. Invariably, a highlight of such experience is a visit to a demonstration school on or near the campus. Demonstration schools are highly specialized in their mission and, in many cases, have been the proving grounds for the public policies and educational experiences that have shaped today’s practices. These schools play three important roles in the field of mental retardation and developmental disabilities: teaching and learning, research, and service.

As a graduate student in the Department of Special Education when the Kennedy Center opened, I participated in several of the first programs of what was then the Experimental School and is today the Susan Gray School. As a professor I taught, supervised students, and conducted research in the Susan Gray School and later in the Experimental Education Unit of the University of Washington, and, most recently, in the Debbie School at the Mailman Center for Child Development at the University of Miami, where I served as director. A few examples of work that began in the Susan Gray School during those early years illustrate the critical roles demonstration schools have and continue to play in this field.

Teaching and Learning

Demonstration schools have provided the “hands-on” teaching and learning experiences for many of the leading professionals in the field of developmental disabilities. As students we had hands-on experience in the classrooms, learning the various techniques for meeting the needs of children. Many of us would later take what we learned to classrooms throughout the world; others would enter careers as university professors and pass on these experiences to their students, teachers in training. Students were but one beneficiary; children, their parents, and others in the field also benefited.

Research

Advances in any field are dependent on high-quality research. Education is no exception. Originally called “laboratory schools,” these sites are the scientific arenas in which professionals experiment with new ideas that advance teaching and learning. Shortly after the completion of the Kennedy Center MRL Building, Peabody researchers began several investigations that have had a significant impact on how preschool children are educated today.

First, Susan Gray, Ph.D., and her colleagues held classes of the Early Training Project in the School during the summer months. This classic longitudinal investigation was one of the first to demonstrate that intensive summer intervention, along with home visits during the other months, resulted in young children from poor environments being prepared to enter their school experiences. These findings were instrumental in opening the doors to Head Start and Early Head Start programs that are so much a part of our services to young children at risk for school difficulties.

Second, while the Early Training Project was actively working with children and training teachers on one end of the Susan Gray School, the Toddler Research and Intervention Project of William Bricker, Ph.D., and Diane Bricker, Ph.D., was ensconced on the other. Now considered a classic in the field of early intervention, this project was the first federally funded research investigation to combine the cognitive theoretical perspectives of Jean Piaget and the instructional strategies of behavioral psychologists as the curricula basis for young children with special needs. Also, the Brickers introduced the idea of including typically developing children in classrooms that had traditionally served only children with disabilities. Over time, this inclusion model became federal policy. Later, the Brickers moved their model and expanded it in demonstration schools at the University of Miami and the University of Oregon, where it is active today.

A third example is yet another illustration of how work at one demonstration school can take on a life of its own at another university. Research into curriculum development based on the cognitive mediated learning theories of Vygotsky and Feuerstein began life with associations at the Susan Gray School, under the
The Susan Gray School provides inclusive education for young children with and without disabilities and support for their families. Its fourfold mission is providing high-quality service, supporting research, contributing to the training of future teachers and researchers, and demonstrating recommended practices as a national model. It is a program of the Vanderbilt Kennedy Center and Peabody College.

In 1969, an Experimental School model classroom served children with multiple sensory and cognitive disabilities, developing curricula, training teachers, and supporting parents. auspices of H. Carl Haywood, Ph.D., Penelope Brooks, Ph.D., and then doctoral student Susan Burns. Although I was not a part of this project at the Kennedy Center, I knew about it and was instrumental in introducing the model to my colleagues and students at the Experimental Education Unit at the University of Washington. These researchers (Cole, Mills, Jenkins, and Dale) randomly assigned students to either an intervention based on the work of Haywood and his colleagues, or a direct instruction model, Distar, based on the theoretical work of Bereiter and Engelmann. Earlier this year, the Washington research group reported on their 15-year follow-up of their original study. These findings are extremely important to the field as they offer new insight into the social outcomes of preschool exposure to these two curriculum models.

Service to the Community

In addition to providing highly specialized services to children from the communities where they are located, demonstration schools play another important community role. The schools employ excellent teachers and have highly qualified graduate and undergraduate students assisting in the classrooms. The programs are developed under what is often referred to as ideal conditions. An important service the programs offer is to move the successfully developed models into the community so that more individuals can benefit from them.

In the formative years of the Susan Gray School, John Ora, Jr., Ph.D., and Ronald Wiegerink, Ph.D., initiated a program for very young children with autism. This program was quickly modified to respond to a growing community need. An increasing number of families in Middle Tennessee reported they were baffled by behavioral problems in their young children. This program moved into the community, became known as the Regional Intervention Program (RIP), and is recognized throughout the world as one of the first programs to train parents to modify their young children’s behavior.

The Kennedy Center is an important member of a national network of centers that have the capacity and expertise to respond to critical needs. For example, in the mid-1960s the country experienced the birth of 20,000 babies with Rubella syndrome. Most of these children had multiple disabilities, including being deaf and blind. The need to provide services for the children and especially to train teachers for the children was urgent. Three faculty members, Verna Hart, Ed.D., Randall Harley, Ph.D., and Samuel Ashcroft, Ph.D., responded immediately by setting up a classroom in the Susan Gray School to serve local children. They employed highly skilled graduates of their training programs as teachers and they, in turn, trained a cadre of graduate students who would take positions throughout the country where their highly specialized skills were needed.

Under the tutelage of Norman Buktenica, Ph.D., psychology students learned the art and the science of assessing the abilities of children who could neither see nor hear. In addition, children throughout the South and Midwest, their family members, and a resource person from their local communities came to Nashville to participate in this classroom and to complete extensive developmental evaluations. The adults and siblings were trained in intervention strategies to implement in their home and community settings.

Summary

The programs cited are just a few examples of the contributions from the early years of the Susan Gray School’s long and lustrous history. This story could be told over and over again as so many excellent model programs began in this demonstration school. Today’s demonstration schools, with their close proximity to university faculty and students, continue to serve as training sites for model interventions with children and families, places for experimenting with new techniques, and birth places for tomorrow’s community’s services. Demonstration schools will continue to be an integral part of universities that place a high priority on the integration of teaching, research, and service within the context of intellectual and other developmental disabilities.

Rebecca Fewell, Ph.D., retired in 2002 as professor of pediatrics and psychology, University of Miami School of Medicine; she is a Vanderbilt Kennedy Center Visiting Scholar.

Bright Start, an early education cognitive curriculum, was initially developed in a Susan Gray School classroom.
By Jan Rosemergy

The translation of knowledge into practice is a Vanderbilt Kennedy Center core value that has characterized the Center since its founding. These two pages can only suggest how much has been done over four decades to promote the development and learning of individual children with disabilities and children developmentally at risk, to serve and support families and their communities, and to help shape public policies and practices in health, human services, and education.

Inclusive education. As early as the late 1960s, Kennedy Center co-founder Lloyd Dunn, Ph.D., was using research findings to challenge the prevailing educational approaches to mental retardation. Arguing that the use of segregated schools or classes to educate students with mild mental retardation might be not only ineffective but harmful, his work helped give rise to “mainstreaming” in the 1970s and 1980s and “inclusion” today.

The Classification Project, conducted in the 1970s by Nicholas Hobbs, Ph.D., critiqued prevailing approaches to the classification of children and associated intervention strategies. This project’s findings influenced the Education of All Handicapped Children Act, or EHA today.

The Toddler Research and Intervention Project in the early 1970s demonstrated that young children with and without disabilities learning together benefited both groups of children.

The DARCEE Home Visitor Program helped parents promote their young children’s development and learning. The DARCEE Home Visitor Program helped parents promote their young children’s development and learning. The DARCEE Home Visitor Program helped parents promote their young children’s development and learning.

In the 1960s and 1970s, Hobbs led Project Re-ED, which demonstrated an ecological/educational approach to the residential treatment of children with emotional disorders and led to the successful reintegration of children into their homes, schools, and communities. Re-ED schools were started in Tennessee and other states, and Re-ED concepts influenced mental health care for children throughout the country.

In the Regional Intervention Program (RIP) during the 1960s and 1970s, parents were taught to manage the behavior of their young children with behavior disorders. After treatment, parents taught other parents. The RIP model spread and continues today in Tennessee and other states.

In recent decades, FAST Track, KidTalk, and RECAP projects have added early intervention, school-based intervention, and parent training to prevent emotional and behavior disorders. Other projects have focused on the effects of parent depression on children and the development of cognitive interventions to prevent and treat depression in children and youth.

In children and adults with disabilities, problem behaviors such as self-injury, stereotypy, and aggression are obstacles to learning and to inclusion. Kennedy Center researchers have been at the forefront of theory and research, investigating biological and environmental factors and developing behavior modification techniques. Today, the Center’s Behavior Analysis Clinic provides a research-based, comprehensive, interdisciplinary approach to functional behavior analysis and intervention.

Psychological and educational assessment.

In the remotest corners of the world, one finds the Infant Developmental Evaluation Clinic in the 1960s and 1970s. These models influenced early childhood education and home visiting programs.

Bright Start, a cognitive early education curriculum focused on helping young children develop the logical thinking, motivation, and work habits on which they can build later learning, was developed in the Susan Gray School in the 1980s, replicated in the Nashville community, then nationally. Developed originally for use with typically developing children who were at high risk of school failure, it also has been used successfully nationally and internationally with children who have mild to severe disabilities.

Developmental assessment and diagnosis. The Infant Developmental Evaluation Clinic in the late 1960s provided valuable information for studies of motor and mental development in high-risk infants, which in turn helped improve early evaluation assessments. Child development specialists consulted with local child care centers, community centers, and well baby clinics. The Clinic evolved into the Vanderbilt Center for Child Development and specialty clinics including the Treatment and Research Institute on Autism Spectrum Disorders (TRIAD) and the Down Syndrome Clinic.

Sensory and multiple disabilities. Among the earliest Experimental School programs was a program to develop curricula and to train family members and teachers to educate children with multiple disabilities, including sensory disabilities. Project Change focused on teaching strategies and curricula to help students move into less restrictive environments. Model Vision developed diagnostic, field training, and evaluation services. In the 1980s, the Infant/Toddler Learning Project developed and demonstrated intensive services for young children with multiple severe disabilities. Today, the Tennessee Deafblind Project, or TRED, provides technical assistance to individuals, birth through age 21, with combined vision and hearing losses, and to parents and educators. PAVE (Providing Access to the Visual Environment) provides comprehensive low-vision education services to children statewide.

Partnerships with school systems. Since its founding, Kennedy Center...
For many years, Discoverying in research-based instructional strategies. The Reading Clinic provides teacher training, problem behaviors that interfere with learning. The Reading Clinic offers intensive, systematic, research-based instruction and assessment for students in the early elementary grades, including students with intellectual disabilities.

**Readership and Understanding.** In the 1960s and 1970s, researchers in the Institute for School Learning and Individual Differences and later in the Institute on Teaching and Learning investigated concept development and teaching strategies in reading, math, geography, and physical education, for students with and without disabilities. In the 1980s, Instrumental Enrichment was evaluated as a cognitive education program for adolescents with learning difficulties. Dynamic Assessment was tested with children 3 to 8 years to identify cognitive deficits and assess the kind and amount of teaching needed for effective learning. In recent decades, educational research has focused on developing Peer-Assisted Learning strategies in reading and math for students with diverse learning needs, developing and evaluating Curriculum-Based Measurement, improving assessment and intervention for students with learning disabilities, implementing Positive Behavior Supports for students with disabilities, developing peer mentoring programs, and enhancing the development of gifted and talented learners.

**Reading Interventions.** For many years, the Child Study Center offered reading tutorials, benefiting both children and Peabody students preparing to teach. Today, the Vanderbilt Kennedy Reading Clinic offers intensive, systematic, research-based instruction and assessment for students in the early elementary grades, including students with intellectual disabilities.

In 1969, Kennedy Center professor H. Carl Haywood, Ph.D., addressed goals for a new decade in behavioral research in mental retardation. His challenge was: “Let us learn, to be sure. But as we learn, let us also do.” For 40 years, the Vanderbilt Kennedy Center has devoted itself to learning and doing.

**A National Mission**

Mental Health Centers Construction Act, was developed by the Kennedy administration, passed by Congress, and signed by President Kennedy as Public Law 88-164 on October 31, 1963. The construction money was distributed over several years through competitive National Institutes of Health grants, and research support was provided by another creation of the Kennedy administration’s program to help persons with mental retardation, the National Institute of Child Health and Human Development (NICHD). From 1965 when the John F. Kennedy Center at George Peabody College for Teachers was awarded its grant until 1973 when the last constructed center became operational, 12 centers were built using federal and matching construction funds. Today, that network has grown to 14 centers, receiving $18 million annually in core support alone.

Ensuing years have proved the wisdom of the Panel’s plan. With construction of the MRDDRCs on campuses, research on mental retardation flowered and, as intended, moved into the mainstream of medical and behavioral research. Scientists and clinicians were trained in the MRDDRCs and the parallel university affiliated clinical training and service facilities in all 50 states, now called University Centers for Excellence on Developmental Disabilities Education, Research, and Service. Advances in the neurosciences and genetics, in particular, opened new understanding of many disorders, including new approaches to prevention and treatment. Perhaps most important, having persons with mental retardation in these centers on university campuses and medical schools ended their status as second-class citizens shut away in remote institutions and put them and the research on their condition on a par with that of any other disorder.

Some of the major discoveries in mental retardation during the last four decades have come from the centers. Fetal alcohol syndrome, one of the most frequent causes of mental retardation, was first described by scientists from the University of Washington MRDDRC. Research on neurotoxic effects of lead at the Children’s Hospital MRDDRCs demonstrated adverse effects on IQ at levels previously considered safe, leading to marked lowering of the safe limit by the Environmental Protection Agency. The Abecedarian Project of the University of North Carolina and Boston Children’s Hospital MRDDRCs demonstrated adverse effects on IQ at levels previously considered safe, leading to marked lowering of the safe limit by the Environmental Protection Agency. The Abecedarian Project of the University of North Carolina MRDDRC and the Early Training Project at the Vanderbilt MRDDRC documented that early intervention and stimulation programs through the preschool years could markedly reduce the negative effects on cognitive functioning of being raised in a low-income family.

The Vanderbilt Kennedy Center continues its tradition of leadership in mental retardation research today. Unique among the MRDDRCs, it combines a focus on education integrated with a university and medical school environment on the same campus. The NICHD is proud of what the Vanderbilt Kennedy Center and the MRDDRC network have accomplished and anticipates a long and continued productive partnership in this research enterprise.

Duane Alexander, M.D., is director of the National Institute of Child Health and Human Development.
Fulfilling Potential

LINDA BROOKS
By Traci Fleischman

Linda Brooks is an ongoing presence at the Vanderbilt Kennedy Center. She has been involved in the Center for 35 years and has devoted her time, skills, support, and encouragement.

With her late husband Sam Brooks, she has three children, Wendy, Dan, and Ashley. Wendy was diagnosed with Down syndrome in early 1970. At that time there were not a lot of options available for her.

“Back then many people thought that children with disabilities belonged in an institution, but we knew that our family belonged together,” said Brooks. The Brooks family discovered the Kennedy Center when Wendy was a mere 6 months old and has maintained a deep belief in the Center’s research and programs.

Wendy’s early enrollment in the Experimental School (later renamed the Susan Gray School) allowed her to participate in the Toddler Research and Intervention Project, which pioneered “mainstreaming” or “inclusion,” showing that having young children with and without disabilities learn together benefited both groups of children.

“The Kennedy Center became a vital part of my family’s life. The Center helped to teach me how to reach Wendy’s potential while at home and how to remain consistent in her continued training,” said Brooks.

The options for individuals with disabilities are much greater now due to the knowledge and science that is available today. “Children with disabilities need personal attention, but they also need the opportunity to be integrated with typical and atypical children, as well as the opportunity to strive in different environments,” Brooks continued.

Linda and Sam Brooks were founding members of the Nicholas Hobbs Donor Society and co-chaired the second and third Leadership Dinners.

Since then the Brooks family has continued to help the Center by offering time and devotion. The Brooks family contributed to building the accessible Susan Gray School playground, which was dedicated in October 2002. The Brooks family was honored for their major gift at the earlier Groundbreaking in April 2002.

“We wanted to provide something that all children could enjoy. We wanted equipment that was available to many different skill levels for the children and a surface that would allow children in wheelchairs to get around,” explained Brooks.

The Brooks family endowed the Brooks Family Discovery Fund in September 2004. It supports initiatives to advance research and treatment in the areas of development and disabilities at the Vanderbilt Kennedy Center. The Fund has become a vital part of the Vanderbilt Kennedy Reading Clinic and Behavior Analysis Clinic.

“Wendy was fortunate enough to be able to learn to read at an early age and is quite vocal, but there are others that are not as fortunate,” said Brooks. This fund allows for individuals with reading disabilities to have an opportunity to excel with the help of tutors and a skilled staff.

Brooks believes the best aspects of the Kennedy Center are early intervention, research, and hope. These three aspects of the Center forever changed the lives of the Brooks family.

“The Kennedy Center taught us not to give up, to maintain hope, and to help Wendy reach her full potential, and I am grateful.”
Dan Marino Foundation Gift

By Jan Rosemergy

Reaching out to children with autism and their families is what the Dan Marino Foundation is about, and now the Foundation is touching lives through a gift to the Vanderbilt Kennedy Center. The gift will create the Dan Marino Foundation Fellowships and the Dan Marino Foundation Discovery Grants, and will support the Center’s outreach programs.

A Dan Marino Foundation Fellow is a pre- or postdoctoral fellow mentored by a Vanderbilt Kennedy Center investigator. The program encourages the best and the brightest to continue on a career path to investigate autism and related neurodevelopmental disabilities. The Dan Marino Foundation Discovery Grants provide seed funding for novel research ideas to gather the pilot data needed to be successful in competing for federal grant funds.

“The Dan Marino Foundation is proud to make this gift because of the positive impact it will have through research that directly or indirectly improves the lives of children and families in the special-needs community,” said Mary Partin, CEO of the Dan Marino Foundation. “The cutting-edge research programs and various outreach efforts taking place at the Vanderbilt Kennedy Center are some of the finest in the country.”

“By supporting young investigators and by creating a research fund to pursue new ideas, the Dan Marino Foundation is investing in the future,” said Kennedy Center director Pat Levitt, Ph.D.

The mission of the Dan Marino Foundation is to impact autism by supporting integrated treatment programs, outreach services, and disease research for children with chronic illnesses and developmental disabilities.

“Rooted in our family’s values, Claire and I founded the Dan Marino Foundation in 1992,” wrote Dan Marino. “The quest to find medical care for our son greatly impacted the mission of the Dan Marino Foundation. Claire and I are thankful for the blessings that we have received in life and believe it is important to give back to others.”

For information on the Dan Marino Foundation, see www.danmarinofoundation.org or log onto www.childnet.tv.

Share Our Story Events

Share Our Story (SOS) events are a new and fun way that the Vanderbilt Kennedy Center’s Leadership Council has created to increase community awareness of the Center. Each event features a Kennedy Center researcher and a family who has benefited from the Center’s programs.

Leadership Council members Becky Chickey, Judy Claverie, and Bethany Jackson (in photo) lead the Special Events Planning Group and welcome participation. For information on SOS events, contact Jenny Alford, (615) 322-5322, jenny.alford@vanderbilt.edu.
Hold the Date

September 28
40th Anniversary Community Celebration
Luncheon 11:30 a.m.-1 p.m.
Keynote Address 4-5 p.m.
Pat Morrissey, Commissioner of Administration on Developmental Disabilities
Luncheon by invitation; contact (615) 343-5322.
Keynote address free and open to the public; information (615) 322-8240.

October 26
Vanderbilt Kennedy Center Leadership Dinner
6:30-9 p.m.
Loews Vanderbilt Hotel
By invitation; contact (615) 343-5322.

November 30
Scientific Symposium Celebrating 40th Anniversary
“Science and Leadership in Developmental Disabilities”
1-5 p.m.
Vanderbilt Student Life Center
For speakers, see Calendar listing

Discovery is a quarterly publication of the Vanderbilt Kennedy Center for Research on Human Development designed to educate our friends and the community, from Nashville to the nation. The Vanderbilt Kennedy Center is committed to improving the quality of life of persons with disorders of thinking, learning, perception, communication, mood and emotion caused by disruption of typical development. The Center is a university-wide research, training, diagnosis, and treatment institute; and a National Institute of Child Health and Human Development designated National Mental Retardation and Developmental Disabilities Research Center.

Vanderbilt University is committed to principles of Equal Opportunity and Affirmative Action.

© 2005 Vanderbilt Kennedy Center, Vanderbilt University

Leadership Council of Vanderbilt Kennedy Center

Mrs. Barbara Gregg Phillips, Chair
Mrs. Annette Eskand, Past Chair
Mrs. Honey Alexander
Ms. Sissy Allen
Mrs. Madge Bass
Mrs. Ann Bernard
Mrs. Barbara Bovender
Mrs. Linda Brooks
Mrs. Cathy S. Brown
Mrs. Rebecca Chickley
Mrs. Judy Clavere
Mrs. Beth Dreifuss
Mrs. Ann Eaden
Mr. Glenn Funk
Mrs. Mollie Gavagan
Mrs. Bernice Gordon
Mrs. Carol Henderson
Mr. Robert W. Henderson II
Ms. Lucile Houseworth
Ms. Bethany Jackson
Mrs. Ruth Johnson
Mrs. Harla Levitt
Mrs. Lorie Lytle
Mrs. Alyne Q. Massey
Ms. Andrea Blake McDermott
Ms. Pat McNellis
Mrs. Anne Nebbitt
The Honorable Andrew Shookhoff
Ms. Laurie Lee Sok
Mr. Richard and Mrs. Rhonda Small
Dr. Karen L. Summar
Ex-Officio Members:
Dr. Pat Levitt
Ms. Sheila Jacobs
Mrs. Elise McMillan
Mr. Tim Stafford

Editor/Writer: Jan Rosemergy, Ph.D.
Assistant Editors/Writers: Stephanie Comer, Traci Fleischman
Art Director: Melanie Bridges, B.F.A.
Photography: Melanie Bridges, B.F.A.

Discovery is supported in part by Grant No. P30 HD15052 from NICHD.

Vanderbilt University is committed to principles of Equal Opportunity and Affirmative Action.
Summer 2005 Calendar of Events

Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the calendar on our Web site kc.vanderbilt.edu or call (615) 322-8240.
For disability-related training and other events statewide and nationally see www.disabilitytrainingtn.org.

Camps

JUNE 13-JULY 1
TRIAD Social Skills Summer Camp
Co-sponsored with Vanderbilt Treatment and Research Institute for Autism Spectrum Disorders
For 120 campers on the autism spectrum, 6 to 22 years, this 3-week day camp focuses on social skills enhancement. Entering its 5th year, the Camp uses peer modeling and pairs campers with and without autism to work on basic social skills using role-playing, video, and theater.
University School of Nashville
Information Sara Rich, (615) 322-8147
sara.rich@vanderbilt.edu

JUNE 20-JULY 1
My Life, My Choice, My Plan
Co-sponsored with Down Syndrome Association of Middle Tennessee
The Summer Learning Academy serves up to 12 individuals, 11 to 22 years, with Down syndrome. Meaningful educational and social experiences are provided within a literacy-rich environment. The theme My Life, My Choice, My Plan is in keeping with the need for individuals with disabilities in this age group to begin taking responsibility for their future.
ClearView Baptist Church, Franklin
Information Sara Rich, (615) 322-8147
sara.rich@vanderbilt.edu

JUNE 24-30
Williams Syndrome Music Camp
Co-sponsored with Vanderbilt Blair School of Music and National Williams Syndrome Association
This 1-week residential overnight camp provides 12 adolescents and young adults from across the country with training in keyboard, drums, guitar, vocalizing, and song writing. The program promotes the campers’ highly developed and unique skills in music to improve social skills, to reduce anxiety often seen in those with this syndrome, and to enhance their independence.
Blair School of Music and various on/off campus locations
Information Sara Rich, (615) 322-8147
sara.rich@vanderbilt.edu

JULY 5-29
Explorers Unlimited Camp
Co-sponsored with Down Syndrome Association of Middle Tennessee
Arts education programming by the Frist Center for the Visual Arts
For 12- to 22-year-olds with Down syndrome, this camp provides academic enrichment in reading, math, and social awareness.
University School of Nashville
Information Sara Rich, (615) 322-8147
sara.rich@vanderbilt.edu

Outreach

JUNE 17
Charity Golf Tournament Benefiting the Vanderbilt Kennedy Center
Great golf, door prizes, cold beverages, lunch provided! Entry fee $100 per player. Sponsored by Waddell & Reed Financial Services Variety of company sponsorship opportunities at different levels are available.
Contact Jenny Alford, (615) 343-5233, jenny.alford@vanderbilt.edu to register.
Friday 8 a.m. Shotgun start
Legends Club of Tennessee
Vanderbilt Kennedy Center for Research on Human Development

Art

Vanderbilt Kennedy Reading Clinic
Fall session begins early September, extends 12 weeks
Registration accepted now, first-come, first-served, space limited
Some scholarship assistance available
Information Caresa Young, (615) 936-5123, caresa.l.young@vanderbilt.edu

JULY 15-SEPTEMBER 30
Arts and Disabilities Exhibit
Concert of Children
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby Kennedy Center/MRL Building

Drawings of young children with Down syndrome by Nashville artist Allison Putnam

JUNE 1-5
3rd Annual Tennessee Disability Mega Conference
Sponsored by coalition of more than 50 Tennessee disability-related organizations, including the Vanderbilt Kennedy Center
Information: www.tnidsabilitymegaconference.org
Nashville Airport Marriott Hotel and Conference Center

JUNE 22
Dual Diagnosis Conference
Sponsored by the Vanderbilt Kennedy Behavior Analysis Clinic’s Community Inclusion Project
This conference is designed for those who work with individuals with a dual diagnosis of developmental disabilities and mental illness, as well as family members and advocates.
Information (615) 322-8185
Wednesday 8 a.m.-4 p.m.
First Tennessee Children’s Theater, Monroe Carell Jr. Children’s Hospital at Vanderbilt

JULY 13-16
36th Annual Autism Society of America National Conference
ASA at 40: In Tune with the Future
Keynote Speakers include Stephen Shore, Paula Kluth, & Paul Shattuck
Registration and information available http://asa.confex.com/asa/2005/
Nashville Convention Center

Community Events

JULY 21, SEPTEMBER 15, & NOVEMBER 17
Autism Society of Middle Tennessee Events
Autism Orientation
Registration required
Information ASMT (615) 385-2077
Thursday 6:30-8:30 p.m.
Room 241 Kennedy Center/MRL Building

SEPTEMBER 28
40th Anniversary Community Celebration
Luncheon 11:30 a.m.-1 p.m.
Keynote Address 4-5 p.m.
Pat Morrissey, Commissioner of Administration on Developmental Disabilities
Luncheon by invitation; contact (615) 343-5322.
Keynote address free and open to the public; information (615) 322-8240.

OCTOBER 26
Vanderbilt Kennedy Center Leadership Dinner
6:30-9 p.m.
Loews Vanderbilt Plaza Hotel
By invitation; contact (615) 343-5322.

NOVEMBER 30
Scientific Symposium Celebrating 40th Anniversary
“Science and Leadership in Developmental Disabilities”
1-5 p.m.
Vanderbilt Student Life Center
For speakers, see Calendar listing
Thomas Insel, M.D., Director, NIMH
Fred Volkmar, M.D., Irving B. Harris Professor of Child Psychiatry, Yale Child Study Center
Carla Shatz, Ph.D., Nathan Marsh Pusey Professor of Neurobiology, Harvard Medical School
Martin Seligman, Ph.D., Fox Leadership Professor of Psychology, University of Pennsylvania
Free and open to the public; information (615) 322-8240.

Taking Part in Research

The Vanderbilt Kennedy Center welcomes the participation of children and adults, with and without disabilities, in research studies.
To view a list of projects seeking participants, see kc.vanderbilt.edu/studyfinder or call (615) 936-5118.

Where to find help...

Vanderbilt Kennedy Family Outreach Center
Supported by the Lili Claire Foundation and Brooks Family Discovery Fund
(615) 936-5118
kc.vanderbilt.edu/kennedy/communityclinics.html

Tennessee Disability Pathfinder
(800) 640-INFO [4636] English and Spanish
(615) 322-8529 (Nashville)
www.familypathfinder.org

Art

THROUGH JUNE 30
Arts and Disabilities Exhibit
Esteemed Colleagues
Organized by Lain York and Untitled
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby Kennedy Center/MRL Building

Untitled is a nonprofit, grass roots, independent group of artists dedicated to supporting artistic innovation and to offering alternative visual arts experiences. This exhibit includes pieces created by the Untitled artists and artists with disabilities.