The interest across our nation in the health and welfare of children has never been greater. In Tennessee our policy makers are faced with some difficult decisions regarding program investment. We all want the best for our children, and in an ever more complicated and competitive world, we want to provide families and our communities with the guidance that will help them make the best decisions for our future.

In February, I had the honor of testifying before the Joint Education Committee of the Tennessee State Legislature. This capped off a wonderful morning of activities sponsored by the Hunger for Evidence.

New knowledge needed to improve the lives of individuals with developmental disabilities and their families comes through research. Conducting state-of-the-art research requires substantial funding. The competition for federal research funding is fierce. A key factor for success is whether an applicant has preliminary (pilot) data to demonstrate that the approach proposed is likely to be effective. The more cutting-edge and creative the approach, the more essential it is to have pilot data.

Since 1998, the Nicholas Hobbs Discovery Grant Program has provided seed funding for initiating novel research efforts (see related story, p. 11). Awards have ranged from $10,000 to $25,000 for one year of funding with the aim of collecting pilot data to lay the foundation for large, federally supported research projects. Discovery Grants have indeed given our researchers that extra competitive edge needed to secure larger grants. The following examples demonstrate the critical difference Discovery Grants have made across a broad range of research problems.

Exploring Autism Genetics

In 1998, James Sutcliffe, Ph.D. (Molecular Physiology & Biophysics), received a Discovery Grant to test whether a region of chromosome 15 already shown to be involved in Prader-Willi and Angelman syndromes was also involved in autism.

“The Discovery Grant allowed me to start examining genes in this region in families affected by autism and to begin developing specific tools to help identify children with this condition. The grant provided the opportunity to explore a new area of research and to contribute to the understanding of autism.”

The Vanderbilt Kennedy Center celebrated its 40th anniversary on November 30 with a scientific symposium and celebratory dinner. The Kennedy Center was established in 1965 as a result of legislation signed by President John F. Kennedy that aimed to improve the lives of persons with developmental disabilities through collaborative and innovative research.

“The interdisciplinary nature of the Kennedy Center is buoyed by the intimacy of the Vanderbilt campus and close-knit community of Vanderbilt researchers and clinicians,” said Kennedy Center Director Pat Levitt, Ph.D.

“The Kennedy family knew firsthand just how spare and barren was the social, medical, and psychological support available for families with developmentally disabled children,” said Harry Jacobson, M.D., vice chancellor for Health Affairs. Their support of a series of centers dedicated to the study of developmental disabilities was their most profound contribution, Jacobson said.

Directors of three National Institutes of Health branches—Duane Alexander, M.D., of the National Institute of Child Health and Human Development; Story Landis, Ph.D., of the National Institute of Neurological Disorders and Stroke; and Thomas Insel, M.D., of the National Institute of Mental Health—described their own institutes’ histories and initiatives and highlighted the unique ways in which they support research.

A Hunger for Evidence

The interest across our nation in the health and welfare of children has never been greater. In Tennessee our policy makers are faced with some difficult decisions regarding program investment. We all want the best for our children, and in an ever more complicated and competitive world, we want to provide families and our communities with the guidance that will help them make the best decisions for our future.

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Continued on page 2

Continued on page 3
Investing in Discoveries
Continued from page 1

hypothesis-driven experiments,” Sutcliffe said. This initial work made it possible to submit an application to the National Institute of Mental Health in 1999. The grant was awarded, the studies have proceeded, and the grant recently was competitively renewed. Since then, Sutcliffe has received two additional Discovery Grants, including a Dan Marino Foundation Discovery Grant.

“Both grants have funded pilot studies to explore whether the genes involved in controlling the function of the brain neurotransmitter serotonin are likely to be a factor in the genetic risk for autism,” Sutcliffe explained. “These grants allowed us to keep studies going during the lengthy process of obtaining National Institutes of Health funding and have led to important observations about particular genes.”

In the gene for the serotonin transporter, Sutcliffe’s lab has found several functional coding mutations and several noncoding DNA sequence changes of unknown function in families where there was evidence of a genetic linkage for autism. More recently, his lab has found evidence that another gene on chromosome 17 close to the serotonin transporter gene and also involved in serotonin function is associated with autism susceptibility.

Finding an ADHD Animal Model
The technology to manipulate genes has developed rapidly in recent years, with wide-ranging applications. Scientists have learned a great deal by manipulating genes in mice.

Michael McDonald, Ph.D. (Pharmacology), was working with a colleague at the National Cancer Institute who was generating mouse models of thyroid resistance. In children with genetically linked thyroid resistance, 90% of boys and 60% of girls with a particular genetic mutation have ADHD (attention deficit hyperactivity disorder). In 2000, with the help of a Discovery Grant, McDonald and graduate student Bill Siesser began doing behavioral tests on a potential mouse model of ADHD.

“Most psychiatric disorders, including ADHD, are identified by behavior alone,” McDonald explained. “ADHD is diagnosed by three behaviors: inattention, impulsivity, and hyperactivity. Most mouse models of ADHD only test hyperactivity because it is difficult to test inattention and impulsivity in mice. We have the first mouse model that shows all three symptoms of ADHD.”

With the Discovery Grant data, McDonald was successful in obtaining funding from the National Institute of Neurological Disorders and Stroke. Data from that project in turn are leading to ways to proceed. McDonald’s lab also is using their mouse model to investigate gender difference in gene expression that may play a role in ADHD, since its incidence is higher in males than females.

Helping Struggling Readers
Understanding what one reads (comprehension) is dependent not just on one’s ability to read words (decoding) but also on ease and speed of reading words and sentences (fluency). In 2001, Donald Compton, Ph.D. (Special Education), received a Discovery Grant to compare several instructional programs in decoding for very poor readers to test how well they promoted fluency. He found differences across these decoding programs, which led to a study funded by the National Institute of Child Health and Human Development (NICHD) to investigate the relationship between decoding and developing fluency.

“This pilot work, combined with the research literature, led to the idea that struggling readers have more problems in decoding and fluency,” Compton said. “They often have problems with vocabulary and being active readers—what can be thought of as metacognitive skills.”

Compton’s pilot data were instrumental in obtaining funding from the Institute of Education Sciences, U.S. Department of Education. He is testing a clinic-based multicomponent reading comprehension program designed to address the diverse needs of struggling readers in late elementary school. The components are an evidence-based decoding program, an evidence-based fluency program using repeated readings, and a program to teach students strategies to help them comprehend and remember information. For more on this reading program for students 7-11 years of age, contact (615) 343-2463, jennifer.j.bauer@vanderbilt.edu.

Improving Child Rearing Practices
A collaboration among a psychologist, a psychology graduate student, and a pediatrician led to a 2001 Discovery Grant to create and evaluate baby books to promote child health and safety. This team—Leonard Buckman, Ph.D. (Psychology & Human Development), Stephanie Reich (Psychology & Human Development), and pediatrician Kim Worley, M.D.—used the Discovery Grant to assess what mothers already know and whether embedding educational information into baby books was a feasible and effective way to educate mothers about typical child development. Since research had shown that only a small percentage of pediatricians provide “anticipatory guidance,” another avenue for providing information was needed.

“Our hypothesis,” Buckman said, “was that we needed to find something women could do repeatedly and could practice to learn content. We dreamed up a series of books that mothers could read to their babies. Each book focuses on a stage of development, with books at 2, 4, 6, and 12 months. We also thought a mother’s reading to her child would give an opportunity to form a stronger bond.”

Through the Discovery Grant, the team was able to survey over 200 women about their knowledge of child development as well as to create one of these books, with the artistic help of the Vanderbilt Kennedy Center’s graphic designer Kylie Beck. The pilot work demonstrated that women needed the information, the books taught information new to them and were attractive enough that they would read them to their children, and a sufficient number of women could be found to take part in a larger scale study.

Based on this pilot work, the team was successful in obtaining an NICHD-funded grant to create professionally illustrated and published board books and to assess their efficacy in improving mothers’ knowledge, parenting practices, and child health over children’s first 18 months of development. This study, “Using Baby Books to Promote Maternal and Child Health,” is now underway. For information on the Baby Books Project, contact (1-888) 553-2665.

Generating Discoveries
As the examples above illustrate, Discovery Grants are instrumental in generating discoveries related to the causes of developmental disabilities and in developing more effective practices to promote health, development, and learning. Since the program began in 1998, 24 Discovery Grants totaling $290,180 have been awarded. Recipients have subsequently received related NIH grants totaling $9,322,757—a 40-fold return on the investment. Vanderbilt Kennedy Center researchers are indebted to our generous, far-sighted, and caring donors who travel with us on the paths of discovery.
Symposium Marks 40th
Continued from page 1

challenges facing mental health and human development research.

While the event was a celebration of the Kennedy Center’s long history, the scientific presentations focused on the future, outlining ambitious goals and exciting new directions for research on developmental disabilities.

“Most of us come into this world intent on becoming experts on people . . . but people with autism become experts on things,” said Fred Volkmar, M.D., of Yale University. He demonstrated this apparent disinterest in other people with movie clips of social situations “seen through the eyes of a child with autism.” Using a computerized device that tracks where children focus their eyes on a movie scene, Volkmar showed how children with autism avoided looking at the actors’ eyes, focusing either on their mouths or on seemingly irrelevant background objects, like light switches. Eye-tracking, he said, could be used in very young children, possibly enabling diagnosis sooner than is currently possible. If diagnosed early enough, Volkmar predicted that early interventions could dramatically improve adult outcomes.

[For information on related Vanderbilt Kennedy Center studies involving 3- to 15-month-olds, contact (615) 322-5913 or stephanie.bradshaw@vanderbilt.edu.]

Studying the basic biological mechanisms that govern brain development also is contributing to a better understanding of developmental disorders.

“The baby’s brain is not just a miniature version of the adult brain, but is a dynamically changing structure in which circuits are not only being built but also modified by experience,” said Carla Shatz, Ph.D., of Harvard Medical School.

Using the visual system as an example, Shatz described how the ever-changing connections in the developing brain are influenced by both nature (genetic factors) and nurture (experience).

Shatz suggested that the prolonged period of development where “local” circuits within certain brain regions are being formed is a particularly sensitive period of development because of its dependence on stimulation. “This is the period where, when it goes awry, could cause many of the learning disabilities that we’re thinking about here and are being worked on at the Kennedy Center,” she said.

Martin Seligman, Ph.D., of the University of Pennsylvania, ended the symposium on a “positive” note. The author of more than 20 popular psychology books, Seligman addressed what he describes as “positive psychology” and its implications and applications for treating people with developmental disabilities.

“The psychology of developmental disabilities has not been good enough . . . . We’ve taken a remedial approach, a disease approach, where what we want to do is to ‘get rid of what’s wrong.’ That’s only half of what we want to do,” he said.

“‘The other half is to identify the strengths that people have, enable them to use those strengths and, in the same way we develop remedial interventions, develop enhancements to enhance what makes life worth living.”

Note: For a Vanderbilt News Services audio podcast of Symposium presentations, see “In the News” link at kc.vanderbilt.edu/kennedy/40th/index.html.

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Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Off to a Running Start

By Jan Rosemergy

"In our brief few months as a new University Center for Excellence, an amazing amount has been accomplished," said Elisabeth Dykens, Ph.D., director. "We had the honor of having ADD Commissioner Pat Morrissey here with us to announce our funding in September at a community celebration. We've been active in projects ranging from Tennessee assistance to Hurricane Katrina victims to statewide conferences on topics ranging from autism to family support. We've completed a demonstration project working with the Hispanic community. We were represented on the Tennessee Team in the national Alliance for Full Participation." The Center is funded by the Administration on Developmental Disabilities (ADD).

Community Advisory Council

The Community Advisory Council is a full partner in planning, implementing, and evaluating activities. The chair and a majority of the members are self-advocates or family members. Representatives of Tennessee disability organizations also serve on the Council.

"The members of the Community Advisory Council have actively participated in learning about the goals and achievements of the Center for Excellence and providing recommendations for future directions for community outreach and research," said Doria Panvini, Council chair. "The Council looks forward to continuing to participate in this valuable collaboration." Panvini invites individuals with disabilities or family members to share interests or concerns by emailing vkcac@vanderbilt.edu.

Training

Interdisciplinary training is a core function of a University Center for Excellence. It includes training university students, practicing professionals and direct care providers, individuals with disabilities and family members, and disability advocates and policymakers. Formats are varied: classes in degree programs, supervised clinical experiences, continuing education, conferences, workshops, and technical assistance. Training is led by Craig Kennedy, Ph.D., professor of special education, and Terri Urbano, Ph.D., M.P.H., R.N., clinical professor of pediatrics. Training efforts already have focused on a variety of topics. An April 8 day-long conference was held on improving supports and services for individuals with both Down syndrome and autism. A June 7 conference is planned on improving care coordination for people with dual diagnosis. Full conferences will be held, one focusing on youth empowerment, to include youth with disabilities, and another on sibling relationships. Events are developed collaboratively with Vanderbilt, community, and state partners.

Work has begun on a collaboration with staff of the Maternal Infant Health Outreach Workers (MIHOW) Project, Vanderbilt Center for Health Services, with the aim of improving identification and intervention for children with developmental delays in the high-poverty, rural regions they serve in Appalachia and the Mississippi Delta.

Service

Faculty and staff provide cutting-edge, evidence-based services and supports to address pressing needs of persons with disabilities. We focus on serving people in Tennessee and the Mid-South while creating model programs for national use. Some Center programs provide diagnosis and intervention for children and adults; others offer information and technical assistance to educators or direct service providers. Some programs are done in partnership with community and State agencies.

"In these initial months, we've been increasing the number of individuals and families served in all our programs," said Elise McMillan, J.D., associate director. "In the coming year, we plan on expanding to new locations, especially in rural areas, and continuing to work for systems change." Examples include developing Reading Clinic sites in high-poverty communities and working with Tennessee Developmental Disabilities Network partners to expand post-secondary options for students with disabilities.

One innovative, low-cost project is Access Nashville, which involves individuals from the disability, business, government, and senior citizen communities joining together to collect “accessibility friendly” information about restaurants, hotels, meeting places, and entertainment in Nashville. Tennessee Disability Pathfinder hosts and maintains the Access Nashville website (kc.vanderbilt.edu/accessnashville). The project can be replicated in other locations at minimal cost. Access Nashville can assist by providing consultation and information.

For Adult Siblings of Persons With Disabilities

We know surprisingly little about the relationship between individuals with disabilities and their adult siblings. To better understand this long-lasting relationship, the National Sibling Research Consortium has created the Adult Sibling Questionnaire.

If you are 18 or older with a sister or brother with disabilities, we invite you to complete this questionnaire online: https://kc.vanderbilt.edu/FamilyResearch

Paper copies are also available. Provide contact information (Name, Address, City, State, Zip) to Family Research (1-888) 322-5339 [free] or email FamilyResearch@vanderbilt.edu.

Thank you for your time and interest in this important area of family research.

Robert Hodapp, Ph.D.
Richard Urbano, Ph.D.
Ann Kaiser, Ph.D.

On behalf of the National Sibling Consortium and the Vanderbilt Kennedy Center, with support of The Arc of the U.S.
Making Sense of the Social World

By Stephanie Newton

Social responses in young children are often taken for granted—a wave good-bye, a happy response to an unexpected toy, or a finger pointed to a familiar friend. But these common childhood responses are not taken for granted by parents of a child with autism. The absence of these types of social responses is common among young children with autism. Their importance as early markers is increasingly being recognized.

The social world and to understand the feelings, thoughts, and perspectives of others,” said Wendy Stone, Ph.D., professor of pediatrics and psychology and director of TRIAD. “Because they don’t learn it on their own, social behavior is something that we often need to teach children with autism.”

TRIAD’s social skills groups are designed to provide social instruction in a fun, safe atmosphere,” said Stone. “We teach and practice skills that range from greeting others, to having conversations, to understanding nonverbal behaviors such as facial expressions and gestures. We want to provide children with the tools that will enable them to have successful interactions within their families, classrooms, and communities.”

LaTamara Jackson, an educational consultant with TRIAD.

“The age of participants vary. The current group is 7- to 8-years-olds, but we have a waiting list with children up to 10-years-old and some adolescents. We wait until we have enough applicants in the same age range to put a group together,” said LaTamara Jackson, an educational consultant with TRIAD.

“The social skills group includes children with an autism spectrum disorder as well as typically developing peers who meet once a week for 6 weeks.

Children enjoy sharing during a TRIAD social skills group discussion.

TRIAD’s group social skills training is activity-based and is specialized for children with autism spectrum disorders. TRIAD staff members use a variety of strategies such as role-playing, games, videotape feedback, and weekly homework assignments to help children learn and practice new skills.

“In a typical meeting of the social skills group, we introduce new social skills by sorting appropriate and inappropriate ways to perform that skill. We also role play and give the participants opportunities to practice the social skill in imaginary scenarios,” said Jackson. “We include three activities in each session that highlight the social skill of the day. Participants have homework each week, which allows them the opportunity to practice the skill in other environments like home or school. Parents have the opportunity to observe the groups through an observation window and to assist the child with completing his or her homework.”

Although Jackson has only been involved with the social skills group for a short time, she already has seen changes in the children who take part. “They have become more socially outgoing and are exhibiting more socially appropriate behavior such as understanding emotions, perspective taking, gaining attention appropriately, and cooperative play.”

The social skills group meets on the 9th floor of the Doctor’s Office Tower, Monroe Carell Jr. Children’s Hospital at Vanderbilt. Costs are $450 per 6-week session for children with an autism spectrum disorder and free for the typically developing peers.

For information, contact Sherry Conatser, (615) 936-1705, or visit the TRIAD website at www.TRIADatvanderbilt.com.
Leading the Vanguard of Discovery

LYNN WALKER, PH.D.
Professor of Pediatrics
Director of the Division of Adolescent Medicine and Behavioral Science
Professor of Psychology, Peabody College
Associate Professor of Psychology, College of Arts & Science
Vanderbilt Kennedy Center Investigator
Joined Vanderbilt Kennedy Center 1988

Research Interests
Psychosocial factors associated with the development and maintenance of chronic pain syndromes: children’s cognitive and behavioral strategies for coping with pain; adjustment in families of children with chronic illness or disability

Principal Investigator
• Illness behavior and somatization in children, National Institute of Child Health and Human Development

• Computerized assessment of pediatric patients’ symptoms: Development of a technology for pediatric clinical trials, Glaxo-Wellcome

Clinical Interests
Behavioral interventions for pediatric pain management

National Service and Awards
• Member, Behavioral Medicine Interventions and Outcomes Study Section, National Institutes of Health
• Member, Committee for Abdominal Pain Practice Guidelines, American Academy of Pediatrics
• Significant Research Contribution Award for 1998, Society of Pediatric Psychology
• Editorial Board, Journal of Pediatric Psychology

Selected Publications

Education
B.A., Latin American Studies, Oberlin College
M.S., Psychology, George Peabody College
Ph.D., Clinical Psychology, Vanderbilt University
National Research Service Award for Individual Postdoctoral Fellowship, National Institute of Child Health and Human Development

Memorial Tributes

Samuel C. Ashcroft (June 14, 2001-January 30, 2006), Ed.D., worked for over 60 years on behalf of children who were blind or visually impaired. He dedicated most of his career to education and research at Peabody College, where he was on the Special Education faculty and was a Kennedy Center investigator. In 2002, along with Helen Keller, he was inducted into the first “Hall of Fame for Leaders and Legends of the Blindness Field.”

Urie Bronfenbrenner (April 29, 1917-September 26, 2005), Ph.D., was widely regarded as one of the world’s leading scholars in developmental psychology, child-rearing, and human ecology. He was the Jacob Gould Schurman Professor of Human Development and Family Studies and Psychology, Emeritus, at Cornell University. He was a member of the Kennedy Center’s National Advisory Committee in the 1970s. Bronfenbrenner said, “In its broadest and deepest sense, education is, or should be, the process of making human beings human.”

Levitt Appointed to National Advisory Council

U.S. Department of Health and Human Services (HHS) Secretary Mike Levitt appointed Vanderbilt Kennedy Center Director Pat Levitt, Ph.D., to the National Advisory Mental Health Council. The Council advises the HHS secretary, the assistant secretary for health, the director of the National Institutes of Health, and the director of the National Institute of Mental Health (NIMH) on all policies and activities relating to the conduct and support of mental health research, research training, and other programs of NIMH. The council has 18 members and 5 non-voting ex-officio members. Appointed in January 2006, Levitt will serve a 4-year term.

Levitt also is an elected Fellow of the American Association for the Advancement of Science and the Chairman of the Scientific Advisory Board of Cure Autism Now. He is a member of the Dana Alliance for Brain Initiates, the National Scientific Council on the Developing Child, the Scientific Advisory Board of the National Center for Toxicological Research, and the MacArthur Foundation Network on Brain Development and Development of Behavior.

Pat Levitt, Ph.D.

Memorial Tributes
Accolades

Doug Fuchs, Ph.D., and Lynn Fuchs, Ph.D., Nicholas Hobbs Chair in Special Education and Human Development, were awarded Vanderbilt’s Earl Sutherland Prize for Achievement in Research. They also have been selected as among the 100 Distinguished Alumni to graduate from the University of Minnesota’s College of Education and Human Development in the last 100 years.

Craig Anne Heflinger, Ph.D., associate professor of human & organizational development, is an honoree of the Federation of Families for Children’s Mental Health’s 2005 Making a Difference Award, nominated by Tennessee Voices for Children.

Carolyn Hughes, Ph.D., professor of special education, has been named Reviewer of the Year for the journal Research and Practice for Persons with Severe Disabilities. The award honors continued scholarly and thoughtful contribution to the journal and dedication and service to both RPSD and TASH, an international association for the wide range of people with disabilities.

Jon Kaas, Ph.D., Distinguished Professor of psychology, has received sponsorship from the National Academy of Sciences to host a special research colloquium “The New Comparative Biology of Human Nature,” November 16-18, at the Beckman Center of the National Academies in Irvine, California.

René Marois, Ph.D., assistant professor of psychology, won the Chancellor’s Research Award in recognition of his recent discoveries revealing how the brain determines what we can see, what we can hold in our mind after we’ve seen something, and what we can do with these mental representations.

Elise McMillan, J.D., director of community outreach, Robin McWilliam, professor of pediatrics, and Patricia Snyder, Ph.D., professor of pediatrics, attended the Early Childhood Support Summit on January 23-24. The summit focused on how to best define and conceptualize the expansive array of family supports and services tied to policy mandates that apply to young children with developmental disabilities and their families.

Wendy Stone, Ph.D., professor of pediatrics, has two recently released books on autism that offer insights and information for both parents and practitioners. In Does My Child Have Autism? A Parent’s Guide to Early Detection in Autism Spectrum Disorders (with Theresa Foy DiGeronimo, Jossey-Bass, 2006), Stone provides a checklist of behaviors parents can discuss with their child’s pediatrician, a discussion of the various treatments available and the scientific evidence backing them up, and a discussion of behaviors that are important for early diagnosis but often missed. The second volume, Social and Communication Development in Autism Spectrum Disorders: Early Identification, Diagnosis and Intervention ( Guilford Press, 2006), is a compilation of research examining how very young children with autism develop socially and communicate, and how to use key indicators to diagnose and assist these children. Tony Charman (Behavioral Science Unit, Institute of Child Health, University College London) co-edited the book with Stone.

Anne Marie Tharpe, Ph.D., associate professor of hearing & speech sciences, received the distinction of American Speech-Language Hearing Association Fellow. This award recognizes professional or scientific achievement and is given to members who have made outstanding contributions to the professions. The award is one of the highest honors that ASHA can bestow and is retained for life.

Randolph Blake, Ph.D., Centennial Professor of psychology and chair of the department, has been elected a fellow of the Society of Experimental Psychologists, considered one of the most prestigious honors an experimental psychologist can receive. He joins fellow Vanderbilt Kennedy Center investigator Jon Kaas in this elite group. Most recently, Blake was elected a fellow of the American Academy of Arts and Sciences, one of 195 new fellows named for the 2006 Class, which included former presidents, politicians, scientists, authors, artists, and others. Current membership includes more than 170 Nobel laureates and 50 Pulitzer Prize winners.

Jo-Anne Bachorowski, Ph.D., associate professor of psychology, received the Madison Sarratt Prize for Excellence in Undergraduate Teaching at the Vanderbilt University Spring Faculty Assembly.

Thomas Catron, Ph.D., associate professor of psychiatry, has been appointed director of the Tennessee Governor’s Office of Children’s Care Coordination by Governor Phil Bredesen. The Office was established to coordinate the wide range of services and supports available to children through state departments and the private sector.

Edward Couture, Ph.D., professor of hearing & speech sciences, received the National Student Speech-Language-Hearing Association’s Honor. The highest award bestowed by NSSLHA, it recognizes those who, through work with students, have made significant contributions to both NSSLHA and the discipline. Couture also received the Frank R. Kleffner Lifetime Clinical Career Award in recognition of his lasting influence on the clinical practice of speech-language pathology, especially in the area of childhood stuttering, over more than three decades.

Anne Marie Tharpe, Ph.D., associate professor of hearing & speech sciences, received the Madison Sarratt Prize for Excellence in Undergraduate Teaching at the Vanderbilt University Spring Faculty Assembly.
Education and Research Working Hand-in-Hand

By Stephanie Newton

When the Vanderbilt Kennedy Center began in 1965, one of its key foundations was having an on-site school to serve children and families while providing cutting-edge educational research and training. Over time, the Susan Gray School (SGS) not only has been home to influential research findings and new educational tools, it also has become home to children’s first days of school and exciting learning opportunities for countless families—as the Holt family recently has discovered.

Gary and Renee Holt initially placed their son Brandon in childcare at St. Mary’s Villa. At 14 months, he was still in the “Baby Room,” unable to walk and still taking a bottle. Through Brandon’s pediatrician, the Holt family was connected with the Tennessee Early Intervention System (TEIS). TEIS staff suggested a variety of ways that the Holts could aid in Brandon’s development, and one way mentioned was the SGS Outreach Program.

Soon after completing the Outreach Program, Brandon started at the School full-time. “It was wonderful to find a school that was experienced in handling developmentally delayed children. Brandon could get the help and attention he needed so desperately as well as get exposure to his typically developing peers,” said Mrs. Holt. “All his teachers have been involved with his progress.”

Families with children in the School are invited to take part in research projects appropriate to their child’s needs. Researchers conducting projects provide information to families and answers parents’ questions. All studies are conducted according to strict federal standards for research and are approved by Vanderbilt University’s Institutional Review Board. Participation in research is voluntary. Parents give written permission to take part in research, and all individual records are confidential.

Once enrolled in the School, Brandon’s parents heard about the Milieu Teaching Project led by Ann Kaiser, Ph.D., professor of special education and director of the Family Research Program at the Vanderbilt Kennedy Center. Mrs. Holt jumped at the opportunity to participate in research.

“I have always felt that any kind of research that Brandon could take part in that might benefit him, or help benefit other children in the future, would be worthwhile. I wasn’t sure the Milieu Teaching Project would work, but I thought it was worth a try. Brandon definitely needed help, and as it turned out, I needed help, too.”

The Milieu Teaching Project is a research project studying the effects of the use of Enhanced Milieu Teaching—a natural, conversational language intervention used with children who have significant language and developmental delays. Sessions occur both at the Vanderbilt Kennedy Center and at the homes of participants. Because it is federally funded by the National Institute of Child Health and Human Development, all assessments and intervention sessions are at no charge to the participants.

Children who participate in the study are between the ages of 2 1/2 and 4 1/2, and have significant language and developmental delays. Milieu Teaching Project staff members have worked with children who have autism spectrum disorders, genetic disorders, and those who are simply diagnosed as having developmental and/or language delays.

Both participating in a research project and being in the School year-round gave Brandon the opportunity to learn new skills with the Milieu Project while using those skills in a practical manner in the classroom.

“For approximately 6 months, we see the family two times per week,” said Kelly Windsor, project coordinator. “After that, we see the family periodically for 12 months to monitor the child’s continued language progress. In total, the study usually lasts about 18 months.”

Mrs. Holt also was selected to take part in a “parent and trainer” condition of the study, which allowed her to learn the intervention by participating in every session.

“I was selected for the parent instruction group, which helped me carry the interventions into our home and daily life. I was shocked to find that I was doing so much for Brandon and not allowing him or encouraging him to speak and to do things for himself,” said Mrs. Holt.

Mrs. Holt has noticed that the combination of the research intervention and the School, as well as Brandon’s attitude, has motivated his improvement.

“He loves to see his friends and teachers every day. He really enjoys circle time. He loves for someone to read to him. Brandon wasn’t walking or talking and wasn’t very outgoing before attending the School,” Mrs. Holt said. “Now he’s running, talking non-stop, and is a social butterfly. Brandon has definitely come a long way since he started the Susan Gray School.”

For information on the Milieu Teaching Project, contact Kelly Windsor, (615) 322-8160, kelly.windsor@vanderbilt.edu. For information on the School, contact Tracy Tatum, (615) 322-8200, tracy.tatum@vanderbilt.edu.

Holidays With a Twist

In December the Susan Gray School added a fun twist to a favorite long-standing tradition. The annual cultural event Holidays Around the World now is the School’s primary fundraiser. As in years past, each of the classrooms represented a different country of the world—10 in all. Students learned about their countries throughout the year, and their learning culminated with the Holidays Around the World event. With the help of families and friends, each group of children presented information, prepared native food, and offered insight into the culture and diversity of their represented nation. Other activities included cultural entertainment, a silent auction, and a craft sale.
Celebrating 10 Years of Training Educators

By Traci Fleischman

Every year is exciting when there are new things to learn, to teach, and to implement. The Britt Henderson Training Series for Educators promotes these acts as innovatively and effectively today as it did in its inception. The Henderson Training Series is now celebrating its 10-year anniversary.

The Henderson Family Gift

The Robert Henderson family founded the Britt Henderson Training Series for Educators in 1996. It is made possible by an endowment from the Henderson family in memory of their son Britt. Its purpose is to provide training for general and special education teachers, in order to improve the quality of education for students with diverse learning needs.

“We were looking for a project to honor Britt,” explained his mother Carol Henderson. “In the 1960s, Britt had attended the Kennedy Center’s experimental school and the Bill Wilkerson Center, as well as a public school. We thought it would be beneficial to have teachers trained on how to work with his special needs. So, that is where the idea for this all began.

“Britt was a darling and funny young man. His educational needs developed into behavior problems, so educating him became quite difficult,” stated Henderson. Britt’s educational needs helped to inspire the Henderson Training Series, which are attended each year by teams from five or six schools in the Williamson County and Metro Nashville Public School systems and Currey-Ingram Academy.

School Team Approach

One of the innovative features of the training is that it is directed not just toward special education teachers but at entire teams from schools. The team approach is critical to implementing a new approach or strategy, requiring broad-based support and understanding within a school. General and special education educators are able to share knowledge and to support one another during implementation.

Kathleen Lane, Ph.D., assistant professor of special education and a Vanderbilt Kennedy Center investigator, endorses this team approach. She has been directing the Henderson Training Series for the past 4 years.

“We’ve changed the format of the training from being a series of stand-alone workshops to having ongoing training, so that when the teachers leave our workshops, they can now leave with a set of skills that they can then translate into permanent practice within their school,” explained Lane.

“The training is a great opportunity for school staff members to come together with a common area of interests. In addition to acquiring additional information, the schools are able to share their ideas and their structures with other schools going through the training.”

A student director usually works with Lane on the logistics of the Henderson Training, while Lane designs the focus and content of the training.

Focus on Positive Behavior Support

Over the past few years, the training focus has been on Positive Behavior Support (PBS). “PBS is a three-tiered model of support designed to create a climate shift in the school,” said Lane.

“It’s proactive in nature. It’s based on providing students with the level of support necessary for them to be successful in the general education setting to the maximum extent possible.”

Lane is experienced in working with school teams to develop and implement the PBS plans unique to their own schools. The three areas of prevention are primary, secondary, and tertiary. Primary prevention is for every student in the school. With input from everyone at the school, the team clarifies what behavior is expected of all children. According to Lane, primary prevention meets the needs of about 80% of students. The next level is secondary prevention. It is designed to reduce current cases of problem behavior.

The third level is tertiary prevention. It is aimed at reducing the intensity and severity of current cases of problem behavior.

An example of PBS implementation within the Williamson County School System is found in Fairview Middle School. “Fairview Middle School has done a phenomenal job,” Lane commented. “They have primary, secondary, and tertiary levels of support in place at their school.”

Fairview Middle School is now in its second year of implementation. Their team was made up of their assistant principal, a general and special education teacher, a parent, and a student.

“One of the roles of an assistant principal is to hand out punishments for bad behavior,” said Gary Shrader, assistant principal of Fairview Middle School. “That gets tiresome and as a person who likes to be positive, I saw the advantage of the school-wide PBS plan.”

“These teams from the schools are working on the PBS plans and they share ideas and collaborate,” stated Lane. “Because we have been doing this for a number of years now, we have been able to use examples from the previous years to help train. The training has really shifted since it first started.”

“PBS teaches students the social skills and behaviors they need to develop socially and do better in school,” Lane said.

Annual Poster Session

Each year the Britt Henderson Training Series hosts a poster session, which concludes the year-long workshops with a poster presentation by each participating school, to share what has been accomplished, and a reception to express appreciation for all the participants.

Many of the schools have gone on to implement the PBS models because of these workshops and the poster sessions. The Henderson family is able to see first-hand what their endowment does for schools, students, and professionals.

“Dr. Lane has taken this program to a much more beneficial level, and we are so thrilled to support her in all that she has envisioned,” stated Henderson.

“This training series allows us to collaborate with researchers and educators to put into practice strategies for students with learning differences,” said Elise McMillan, J.D., director of Community Outreach. “The vision and commitment of the Henderson family has made this possible, and we are enormously grateful.”

For more information, contact Elise McMillan, (615) 343-2540 or email elise.mcmillan@vanderbilt.edu.

By Traci Fleischman
Leading by Example

CATHY STEWART BROWN

By Traci Fleischman

Cathy Stewart Brown devotes much of her time to her community commitments. She is not only personally invested in the outreach of the Vanderbilt Kennedy Center, she is highly motivated, well-respected, and genuinely dedicated to her role as a community leader. Brown is the incoming chair of the Vanderbilt Kennedy Center Leadership Council.

Brown has a distinguished record of community involvement. She is a board member and past president of Saddle Up! Therapeutic Riding Program. She is this year’s Honorary Chair of the Regions Bank Chukkers for Charity annual polo event benefiting Saddle Up! and the Rochelle Center (which provides support for adults with developmental disabilities and seniors with memory loss). She is a board member of Monroe Carell Jr. Children’s Hospital at Vanderbilt.

Barbara Gregg Phillips, current chair of the Center’s Leadership Council, recruited Brown to join the Council. Brown had heard a Vanderbilt Medical Center symposium several years prior and had become intrigued with the research underway at the Vanderbilt Kennedy Center. After learning more about the Center’s ongoing work, Brown joined the Council in 2004. She soon found her natural place in the Council’s Outreach Committee.

“I strongly believe in connecting the practitioners and the educators with the scientists. I would like to see community and national awareness of the Vanderbilt Kennedy Center research and outreach programs increase tremendously, and I would like to see the Center continue to attract the brightest minds in the country to collaborate on this important research,” explained Brown. Brown’s attraction to the mission of the Vanderbilt Kennedy Center is second nature to her. She grew up outside of Frankfort, Kentucky, at the Stewart Home School, a residential school for children and adults with special needs founded by Brown’s great-grandfather, Dr. John Stewart, in 1893. Dr. Stewart was a pioneer in the field of rehabilitation for persons with intellectual disabilities and bought the campus from the Kentucky Military Institute to open his own school for children with special needs.

Today, the historic campus encompasses 850 acres and affords a magnificent setting for multiple educational, vocational, recreational, and spiritual pursuits to enrich the lives of each resident. The School presently is the home to individuals from 36 states and 3 foreign countries. Brown’s husband is Martin S. Brown, Jr., an attorney and partner at Adams & Reese LLP/Stoke Bartholomew. They have two children, 13-year-old Sara who is in the seventh grade, and 9-year-old Louis who is in the second grade.

“With my family’s school and my personal interest in children and adults with special needs, I have always been interested in the progress being made in human development,” stated Brown. Through this special interest, Brown found a home away from home at the Vanderbilt Kennedy Center.

“The Kennedy Center is an enlightening and inspirational place to be where there is tremendous hope and energy to improve the quality of life for children and adults with special needs.”

Kennedy Center Donors

New Nicholas Hobbs Society
Members since December 7, 2005 ($1,000 and above). A complete list is found at kc.vanderbilt.edu/giving/give2hobbs.html

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For information about joining the Nicholas Hobbs Donor Society or making honor or memorial gifts, contact (615) 343-5322.

Every effort has been made to ensure the accuracy of this report, which reflects Hobbs Society membership, and honor and memorial gifts December 7, 2005 to May 3, 2006. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contacting (615) 343-5322.
Investing in a Center Legacy for Modern Science

By Traci Fleischman

Nicholas Hobbs Society members are donors to the Vanderbilt Kennedy Center who give $1,000 or more annually to the Center. They recognize the exceptional position of the Vanderbilt Kennedy Center as a leader in bringing cutting-edge tools to bear on complex questions regarding the causes and cures of developmental disabilities. You cannot obtain an NIH or Department of Education grant without preliminary findings. In today’s climate of severe competition at the national level, we want to provide our investigators with an edge. This is why the Discovery Grants are so valuable to us, and why we have pushed so hard to expand our Hobbs Society membership. We need to award even more to Center faculty members.

Discoveries resulting from these grants have included the identification of a gene involved in autism, documentation of sleep disturbances in individuals with mental retardation, and strategies for early intervention in developmental disabilities. All have led to NIH grants. Hobbs Society donors strengthen the Center in spearheading research that is both compelling and urgent. An individual gift can spark the beginning of major, novel research initiatives and allows for the Center to be a part of research that improves the lives of families everywhere.

Applications for Discovery Grants are reviewed in a rigorous fashion by an expert scientific panel, which includes nationally renowned researchers at other universities. Funding decisions are based on overall scientific merit and the likelihood that proposed projects will lead to external funding.

The legacy of Nicholas Hobbs continues through the efforts of researchers and generous supporters. As research projects demand more interdisciplinary efforts, the Vanderbilt Kennedy Center, through the Nicholas Hobbs Society, is poised to provide the necessary support across the Vanderbilt University campus. For information about joining the Nicholas Hobbs Donor Society or making honor or memorial gifts, contact (615) 343-5322.

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Off to a Running Start

Continued from page 4

Research

Faculty and staff conduct research that aims to improve disability services and policies and to identify causes of disabilities and novel ways to intervene and provide support for persons with disabilities. We partner with our Community Advisory Council and statewide agencies to identify pressing but under-studied topics. In addition to working with families, we use existing large databases to identify research and policy issues.

“An initial planning step has been to organize a planning group to identify and prioritize efforts,” said Robert Hodapp, Ph.D., professor of special education and the Center’s research director. The group includes Community Advisory Council members and family members.

A major focus is the work of the National Research Consortium, led by Hodapp and Ann Kaiser, Ph.D., professor of special education and director of the Vanderbilt Kennedy Center Family Research Program. Working with The Arc of the U.S., the Consortium has launched a web-based survey of adult siblings of individuals with disabilities (see p. 4). A fall conference is planned on sibling research.

Dissemination

We share what we learn through research and model programs so that others can use this information. We produce easy-to-understand brochures, booklets, videos, and web-based materials. We provide information to persons with disabilities, families, trainees, professionals, direct service providers, advocates, and policy makers. Dissemination is led by Jan Rosemergy, Ph.D., director, and Traci Fleischman, associate director.

“Although we’ve accomplished a great deal in a short time, we have just begun to scratch the surface with what we can achieve as a Center for Excellence,” Dykens summarized.

“In the next few years we anticipate major growth in training, service, research, and dissemination. We look forward to working with our many partners at Vanderbilt, in Tennessee, and the national network of Centers for Excellence.”

For information, visit the Center’s website kc.vanderbilt.edu/kennedy/ucedd.
Hold the Date

Friday, June 16
Waddell & Reed
Financial Services
Charity Golf Tournament
Benefiting the Vanderbilt Kennedy Center
Entry fee; contact (615) 343-5322

Wednesday, November 15
Vanderbilt Kennedy Center Leadership Dinner
6:30-9 p.m.
Loews Vanderbilt Hotel
By invitation; contact (615) 343-5322
2006 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 website kc.vanderbilt.edu or call (615) 322-8240. For disability-related training and other events statewide and nationally see www.disabilitytrainingtn.org.

May

MAY 1-JULY 30
Arts and Disabilities Exhibits
Common Ground
Co-Sponsors Full Circle Art and Metro Arts Commission
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby
Vanderbilt Kennedy Center/MRL Building

MAY 3
Developmental Disabilities Grand Rounds
Caregiver Strain Among Families of Children and Adolescents with Emotional and Behavioral Disorders
Craig Anne Heflinger, Ph.D., Associate Professor of Human & Organizational Development, Senior Fellow of the Institute for Public Policy Studies, and Vanderbilt Kennedy Center Member
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

MAY 22
Vanderbilt Kennedy Center Special Lecture
Theoretical, Empirical, and Clinical Implications of Language Abilities and Disabilities in Autism
Cory Shulman, Ph.D., Senior Lecturer, Paul Baerwald School of Social Work, Hebrew University of Jerusalem
Monday 12 noon
Room 241
Vanderbilt Kennedy Center/MRL Building

June

JUNE 2
Vanderbilt Kennedy Center
Community Advisory Council Meeting
Friday 9 a.m.-1:15 p.m.
Peabody Library Reading Room
Open to the public; to attend call 936-5118
To send comments, email vkcac@vanderbilt.edu

JUNE 15
Psychiatry Grand Rounds
Diagnosing and Treating Tourette Syndrome
Donald Gilbert, M.D., Associate Professor of Child Neurology, Cincinnati Children’s Hospital Medical Center
Co-sponsor Vanderbilt Kennedy Center
Thursday 1:15 p.m.
Wadlington Conference Room
Monroe Carell Jr. Children’s Hospital at Vanderbilt

JUNE 16
Waddell & Reed Financial Services Charity Golf Tournament Benefiting Vanderbilt Kennedy Center
Great golf, door prizes, cold beverages, lunch provided! Entry fee $125 per player.
Variety of company sponsorship opportunities at different levels available.
Contact Jenny Alford, (615) 343-5322, jenny.alford@vanderbilt.edu to register.
Friday 8 a.m. Shotgun start
The Legends Club of Tennessee

JUNE 7
Conference on Improving Care Coordination for People with Dual Diagnosis
Keynote Address: Myths and Realities About Dual Diagnosis
Robert J. Fletcher, D.S.W., Chief Executive Officer, National Association for the Dually Diagnosed

Panels: Interdisciplinary Perspectives on
Autism Spectrum Disorders; How Special Health Care Needs Impact Behavioral Symptoms and Treatment; Transition to Adulthood: Improving Lifelong Outcomes; Accessing Tennessee Services

Sponsors Vanderbilt Kennedy Behavior Analysis Clinic’s Community Inclusion Project (CIP), Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities (MIND) Training Project
For family members, advocates, residential service providers, psychiatrists, health care providers, related service providers, and behavior analysts who work with persons with a dual diagnosis of developmental disabilities and mental illness.

CIP is funded by the Tennessee Council on Developmental Disabilities, Tennessee Division of Mental Retardation Services, and Tennessee Department of Mental Health and Developmental Disabilities.

Continental breakfast and lunch provided. No cost but pre-registration by May 31 required for free parking and food.
Contact kc.vanderbilt.edu/pre-register, (615) 322-8185, or email bac@vanderbilt.edu
Wednesday 8 a.m.-4:15 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building
**Conferences continued**

**JUNE 15-18**
4th Annual Tennessee Disability Mega Conference
Sponsored by coalition of more than 50 Tennessee disability-related organizations, including the Vanderbilt Kennedy Center
Information www.tndisabilitymegaconference.org
Cool Springs Marriott

**SEPTEMBER Dates to be announced**
Conference on Communication and Learning: Focus on Auditory Comprehension Abilities
Sponsors Vanderbilt Kennedy Center Research Program in Communication and Learning and Vanderbilt Kennedy Center for Excellence in Developmental Disabilities
Room 241
Vanderbilt Kennedy Center/MRL Building
Details available soon; call (615) 322-8240

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**Summer Camps**

For students with autism ages 6-21
- **June 5-June 23**
  TRIAD Social Skills Camp I
- **June 26-July 18**
  TRIAD Social Skills Camp II
TRIAD camps also provide a unique volunteer opportunity for teenagers ages 14-18

For students with developmental disabilities ages 16-22
- **June 12-June 30**
  Transitions Camp

For youth and young adults with Williams syndrome
- **June 17-24**
  Music Camp

For students with Down syndrome
- **July 5-28**
  Explorers Unlimited Academic Camp

Contact Jessica Pantino, Camps and Art Coordinator
(615) 322-8147
kc.vanderbilt.edu/camps

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**Family Survey**

To Tennessee families of children and youth (birth to age 22) who have disabilities, chronic illnesses, or genetic conditions: Family Voices of Tennessee invites you to participate in the comprehensive Family Survey now available online at http://webapps.nursing.vanderbilt.edu/surveys/familyvoices

Information collected will inform researchers, policymakers, and advocates about family experiences getting health care and related services for their children. Family Voices has developed the survey in coordination with researchers at Vanderbilt University School of Nursing and the State Maternal and Child Health Division. The survey is funded by the Health Resources and Services Administration.

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**ASMT Events**

Autism Society of Middle Tennessee

**MAY 25, JUNE 22 & JULY 27**

**Autism Orientation**
Registration required. Child care available upon request.
Information ASMT (615) 385-2077
Thursday 6:30-8:30 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

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**DSAMT Events**

Down Syndrome Association of Middle Tennessee

**MAY 12**

**Caleb Thompson Memorial Golf Tournament**
Casual dinner provided. Entry fee $85 per player.
Contact DSAMT (615) 386-9002
Friday 1 p.m. Shotgun start
Forest Crossing Golf Course Franklin, TN

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**Adult Sibling Survey**

To better understand the long-lasting relationship between individuals with disabilities and their adult siblings, the National Sibling Research Consortium, led by the Vanderbilt Kennedy Center, has created the Adult Sibling Questionnaire. If you are 18 or older with a sister or brother with disabilities, we invite you to complete this questionnaire online: https://kc.vanderbilt.edu/FamilyResearch

To request a paper copy, contact Family Research (1-888) 322-5339 [free] or email FamilyResearch@vanderbilt.edu.

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**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/. If you have questions about finding a study or taking part in research, contact Lynnette Henderson (615) 936-0448 or tollfree (1-866) 936-VUKC [8852].