



The University of Tennessee Health Science Center

BOLING CENTER FOR DEVELOPMENTAL DISABILITIES

Tennessee's Center of Excellence in Developmental Disabilities Education, Research, and Service

NEWSLETTER

Summer 2004

Genome Explorations, Inc. Looks to the Future

by Denice Perkins

There is a lab on the fourth floor of the Boling Center that is run by Divyen Patel, PhD, the Chief Executive Officer of Genome Explorations, Inc. Dr. Patel has degrees in Biochemistry, Molecular Biology, and Clinical Medicine from the University of Leeds in England. Dr. Patel was born in Uganda and spent his early school years in India before moving to England at age 11. He came to Memphis in 1992 to do a fellowship at the University of Tennessee Health Science Center and moved to St. Jude Children's Research Hospital in 1994. Dr. Patel was at St. Jude for eight years prior to starting up the company in November 2001 with Arno Justman, who is the Chief Operating Officer and business manager for operations. Mr. Justman's wife worked with Dr. Patel at St.



Dr. Charis Zamber, Lacy Biles, and Dr. Divyen Patel of Genome Explorations, Inc.

Jude and now has the role of quality assurance manager for the company part-time. The company was incubated by TriStar, an organization sponsored by UT to support and promote private scientific enterprises within the University system. The company conducts molecular and genetic research and development for universities and bio-

technology firms around the world.

The company uses the GeneChip technology that was made possible by the vast amounts of data acquired from the Human Genome Project. "The GeneChip allows us to get a complete picture of the genetic makeup of any tissue," Dr. Patel said. "By looking at normal and diseased tissue we can identify genetic differences that makes a

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normal tissue turn into a diseased one.” Genome Explorations provides expertise in GeneChip technology that did not previously exist at UT. This is now a global operation including Europe, Asia, and North America. There are 150 investigators worldwide. Other universities involved include Yale, Harvard, MIT, and UCLA.

The GeneChip technology will provide a basic understanding of disease, including a more definitive diagnostic and prognostic tool. Ultimately the chip will assist with tailor-made therapies. Traditional technology allowed researchers to look at one gene at a time and took seven days to assess, compared to the GeneChip technology that allows them to look at more than 47,000 genes in just three days. Traditional technology would take over 450 years to achieve what can now be done in those three days.

Genome Explorations has received awards since its inception in 2001, including Memphis Business of the Year and finalist for Health Care Heroes. There have been 12 national and international newspaper articles written about the company and its achievements.

There are two researchers in the lab with Dr. Patel: Lacy Biles, who joined the team in 2003, a graduate of Sewanee, and Charis Zamber, PhD, from California. Dr. Zamber previously worked with Dr. Patel at St. Jude. The company has recruited Dr. Robert Rooney, who is currently an Associate Professor at Duke University. Dr. Rooney will join Genome Explorations on July 1 as Chief Scientific Officer. The company has a scientific advisory board made up of scientists and professors from St. Jude, UT and the University of Alabama. The Executive board includes Dr. Patel, Mr. Justman and the former managing partner of the accounting firm Deloitte & Touche LLP.

Dr. Patel has great enthusiasm for his company and the GeneChip technology. He hopes to present further information to the staff at the Boling Center and possibly collaborate with the staff regarding concerns about developmental disabilities.

Update On UT Center of Excellence for Children in State Custody (UT COE)

by Janet Todd, PhD

During the first half of 2002, a network of pediatric referral centers was established in collaboration with the Tennessee Department of Children’s Services (DCS) and TennCare, Tennessee’s Medicaid system, to serve children in state custody and those at risk for entering state custody. The network of regional Centers of Excellence (COEs) is



Dr. Janet Todd

intended to assist DCS and community providers by improving health and behavioral health services for children in, or at risk of, state custody by providing consultative and direct services. There are three regional COEs, located at The University of Tennessee Health Science Center’s Boling Center for Developmental Disabilities in Memphis, East Tennessee State University in Johnson City, and Vanderbilt University in Nashville. The UT COE serves as a referral center for West Tennessee.

The COE draws from the clinical expertise of its home institution and comprises an interdisciplinary clinical staff. COEs assist DCS in developing individualized, coordinated care plans for children in custody or at risk of custody. Specific services range from simple case review and recommendations to extensive direct evaluations by a

child psychiatrist, psychologist, social worker, developmental pediatrician, and/or allied health professional as the case warrants. Since its inception in 2002, the UT COE has served nearly 700 children and their families. Outcome evaluation by the COE programs shows that 70-80% of recommendations have been implemented. The most common recommendations relate to placement and to behavioral health, family and educational interventions, but can also include pediatric and other medical services.

Beginning in January 2003, DCS entered a relationship with the UT COE to provide psychiatric services through telemedicine for youth detained at John C. Wilder Youth Development Center (WYDC) in rural West Tennessee. Currently, in a weekly "clinic," youth are referred for psychiatric evaluation and follow-up care by child and adolescent psychiatrists located at the medical school campus 60 miles away. More than 100 adolescents have been seen via telemedicine in over 450 sessions.

In addition to clinical consultations and evaluations, UT COE has provided focused training to DCS case managers, foster parents, and other community providers and agencies with the intent of improving the knowledge and skills of those serving children in custody and their families. These trainings have included over 45 workshops and seminars for more than 1000 individuals. Training topics include, among others, interviewing and writing skills, understanding evaluations, signs and symptoms of common behavioral health problems, basics of positive discipline, child sexual behavior, and child and adolescent development.

Recently, the COE statewide network was selected by the American Psychiatric Association's Psychiatric Services Achievement Awards Committee for a site evaluation as part of the requirements for consideration for the Gold Award. Site evaluations will occur in June. The Gold Award recognizes innovative programs that can serve as models to other programs that serve persons with mental illness or who have a disability.

Direct Support Professionals Association of Tennessee

by Don Haughton, Co-Chair/Secretary DSPAT

In 2002, three individuals met with Don Carrick of Missouri to discuss the concept of a statewide organization for direct support professionals in Tennessee. Missouri has such an organization that has led to problem-solving and uniform structure for direct support professionals in that state.

The Direct Support Professionals Association of Tennessee (DSPAT) applied to the State of Tennessee for a charter, which was approved and registered several months later. DSPAT then applied for and received funding from the Tennessee Council on Developmental Disabilities. Additional funds from the Butler Foundation and Cumberland Community Options of Nashville allowed DSPAT to purchase materials for brochures, membership cards, and mailouts. DSPAT also received support from Middle Tennessee Supported Living in the use of office supplies, equipment, and conference calls. Staff from the Middle Tennessee Regional Office attended DSPAT meetings and offered their support. At the end of the first year, DSPAT had at least 25 different companies as sponsors.

In June 2003, DSPAT was awarded another grant and also received funding from Resource Links for four workshops in Memphis, Chattanooga, Nashville, and Knoxville. The workshops focused on communication and the role of direct support professionals in the circle of support for people in their homes and in the community. The workshops, led by Heidi Joyce, were entitled "Can We Talk" and were a great success. In 2004, focus groups will be conducted throughout Tennessee as a follow-up to last year's workshops. The outcome goal for these meetings is for professionals in each region to form a plan that they can commit to and to address issues, concerns, and problems in common with other areas in the state.

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DSPAT hopes to increase support and membership in order to become a statewide association that will help in addressing the issues for direct support professionals. Some of the issues are low pay and long hours, recognition and respect as equal partners, a credentialing program for better training and job retention, better communication with direct support staff, and helping each region address and solve problems.

For more information on how to become involved in the 2004 focus groups or to learn more about DSPAT please write to Direct Support Professionals Association of Tennessee, 1161 Murfreesboro Road, Suite 215, Nashville, Tennessee 37217, or e-mail at Directsupportprofessionals@juno.com.

TNCO Provides Services to Member Community Agencies

by Robin Atwood, Executive Director

The Tennessee Community Organizations (TNCO) is a statewide trade association providing service to about 60 member agencies. TNCO members are community agencies that provide a full spectrum of services, including direct support to 10,000 people with mental retardation and developmental disabilities.

As a membership organization TNCO provides lobbying, education, e-communication, and peer networking opportunities. While the TNCO member is the community agency, there are special membership categories for the direct support professional (DSP) and other agency professionals like business/finance, health services, public relations, day services, residential, social work, and training managers.

TNCO was established in 1977 under a different name and has undergone several name changes since that time to maintain "political correctness" in changing times. TNCO has been in existence for 27 years — as long as or longer than most provider agencies.

TNCO has a sister organization that

provides education and training opportunities. It is this non-profit organization that contracts with the state of Tennessee to provide credentialing to DSPs in Tennessee. The Credentialing Program has been in existence for seven years and has credentialled more than 500 DSPs. The Credentialing Program is accomplishing its original objectives of decreasing turnover of direct support professionals and providing a professional career path for them.

The training curriculum and materials were developed to enhance the knowledge of DSPs. Candidates for the Credential in Community Support will demonstrate knowledge and utilization in the following areas:

- ◆ Community Resources
- ◆ Health and Safety
- ◆ Personal Facilitation
- ◆ Behavioral Support
- ◆ Professional Development
- ◆ Philosophy and Rights
- ◆ Introduction to Mental Retardation and Developmental Disabilities
- ◆ Rules and Regulations

Exams and case study assignments are administered to training participants in order to receive the Credential. Graduates are recognized in a formal ceremony upon successful completion.

Studies have shown that credentialed DSPs, regardless of their actual job descriptions and duties, feel better prepared to meet the challenges that arise during the course of their employment. They also reported a higher self-esteem after having completed the training.

The Credentialing Program's Mission Statement is *"To provide consistent quality support to people with developmental disabilities by fostering the career growth and development of direct support professionals."*

If you would like further information regarding TNCO programs, including credentialing, contact the TNCO office at 615-254-3077 or info@tnco.org.

Sibshops Come to a Close with Great Success

by Robin Welsh

Three Sibshops were offered in the spring of 2004 on March 27, April 24, and May 22. Children ages 8-12 years registered



Sibshops help siblings of children with disabilities

for the program. Sibshops are opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. The children have enjoyed many activities, including games, a therapeutic art project, talking with "Aunt Blabby," painting pumpkins, making edible "turkeys," and demonstrations by the Ultimate Dog Obedience Trainers. These workshops for children are the collaborative effort of the Harwood Center, the Autism Solution Center, Hope Presbyterian Church, and the Boling Center.

The Boling Center plans to add a second Sibshop group for teenagers. If you would like to be involved in Sibshops, or need additional information, please contact Robin Welsh at 901-448-3737, rwelsh@utm.edu or the Harwood Center, Inc., at 901-448-6580.

Have you bookmarked the Boling Center's web site yet? If not, please do, so you can keep up to date on continuing education opportunities and more.

Supreme Court Rules on Accessibility and State Courts

On May 17, 2004 the Supreme Court ruled by a 5-to-4 majority in the case of the *State of Tennessee v. Lane and Jones* that Congress has the constitutional authority to give private citizens with disabilities the right to seek monetary damages in Federal court when a state court facility is not accessible to them. The Court's decision was a narrow one in that it did not extend beyond guaranteeing that the Americans with Disabilities Act (ADA) applies to state court facilities. In a decision handed down in 2001, the Court ruled that state employees could not sue the state for discrimination under the ADA.

Ira Burnim, legal director at the Bazelon Center for Mental Health Law, a national legal advocacy group for the rights of people with mental disabilities, released the following statement when the Court's decision was announced.

"Today's decision is a huge win at a critical time for millions of Americans with



"Sibtree" made by participants in Sibshop

disabilities. The Supreme Court today narrowly rejected a radical interpretation of states' rights that would have robbed millions of a vital means of protecting their civil

rights.

“Unfortunately, the razor-thin margin and limited scope of the decision in *Tennessee v. Lane* underscores the fact that disability rights in this country hang by a thread.

“Court rulings in recent years have threatened to eviscerate the Americans with Disabilities Act. While the ultimate impact of the Court’s decision in *Lane* won’t be known for years, today’s ruling is an essential acknowledgement of the federal government’s important role in enforcing civil rights.”

Comparing Behavior Rating Scales for Children With ADHD or Mental Retardation

by Laura Murphy, Ed.D.
and Amy Balentine, Ph.D.

This study’s purpose was to determine the usefulness of the Behavior Rating Scales for Children (BASC) in differentiating the behaviors of 36 children with mental retardation from 36 with attention deficit-hyperactivity disorder (ADHD). We hypothesized that the acting-out behavior scales would be significantly higher for ADHD than mental retardation. We also hypothesized that the adaptive scales would be significantly lower for children with mental retardation than those with ADHD. Results indicate that hypothesized differences on externalizing behaviors were generally not supported, but the hypothesis regarding the adaptive scales was partially supported.

When professionals are considering the diagnoses of ADHD or mental retardation in children, they need reliable and valid tests. Behavior rating scales for problem behaviors are a valuable part of this process. Many such scales are available to measure behavioral symptoms, but most focus only on maladaptive behavior.

The BASC is a broad-band scale designed to gather information about many behaviors, such as short attention span and hyperactivity. The BASC also includes

scales of adaptive functioning, which must be assessed when the diagnosis of mental retardation is being considered. The BASC yields several scores that contribute to an overall score called the Behavioral Symptom Index.

Thirty-six children with ADHD and 36 with mental retardation participated. The children were 6 years to 11 years of age, with an average age of 8 years, 6.5 months. No children had both ADHD and mental retardation. There were 46 boys and 26 girls. Of those who indicated their ethnicity, 46 were African-American, 26 were Caucasian, and 2 were of mixed ethnicity. The primary caretaker completed the rating scale.

A psychologist and pediatrician, both experienced in the field of developmental disabilities, diagnosed the children. The inter-rater agreement was excellent. Consistent with the definition of mental retardation, the average IQ for that group was 60; the average IQ for the group with ADHD was 85.

We found no significant difference between the two groups on the acting-out behaviors and the Behavioral Symptoms Index. The results partially support the hypothesized differences on the adaptive scales, with scores on the Leadership and Social Skills scales significantly lower for the children with mental retardation than those with ADHD.

Therefore, the results indicate that the BASC does not differentiate children with ADHD from those with mental retardation very well. Children with ADHD did not score significantly higher on the scales measuring acting-out behaviors than did the children with mental retardation. Children with mental retardation scored significantly lower than children with ADHD on some, but not all, scales of adaptive functioning.

This study indicates that the BASC should not be used as a diagnostic tool by itself. Children with mental retardation can be mistakenly diagnosed when the BASC is used without other evidence.

Profile of a Former Trainee: Dr. Robin Wilkerson

Now a tenured associate professor at the University of Mississippi Medical Center School of Nursing, Dr. Robin Wilkerson was a trainee at the Boling Center for Developmental Disabilities from 1998 to 1999. Dr. Wilkerson teaches on the topics of developmental disabilities and genetics in the nursing curriculum. She serves as a consultant to Project Prepare, a program sponsored by the Institute for Disability Studies at the University of Southern Mississippi to enhance the quality of childcare centers by improving the capacity of programs to include children with special needs.

Among numerous honors and awards, Dr. Wilkerson is the 1994 recipient of the Theta Beta Chapter, Sigma Theta Tau Excellence in Nursing Practice award. Professional membership awards include Mississippi Nurse Association Board of Directors, Human Rights and Ethics co-chair (1997 to 2001), Society of Pediatric Nurses, American Association on Mental Retardation, Southern Nursing Research Society, and the National Association of School Nurses. Academic appointments include serving on the Committee for the Implementation of Family Centered Care, Children’s Hospital, the Pediatric Policy and Procedure (Children’s Hospital), and the School Based Clinic Project. Dr. Wilkerson serves as a gubernatorial appointee on Mississippi’s State Inter-agency Coordinating Council for Early Intervention. She has served on numerous State Board of Education Task Forces. She is also a member of the Mississippi Genetics Advisory Committee. Dr. Wilkerson is the Chair of the Committee on Communication and Membership for the Angelman Syndrome Foundation. She is an item writer for the Pediatric Certification Exam, American Nurses Credentialing Center. Dr. Wilkerson is currently developing a research proposal on the experience of being a sibling of a child with a developmental disability of genetic etiology. She also has many scholarly

presentations on topics of developmental disabilities and early intervention and belongs to many community organizations.

Interdisciplinary Leadership Training Conferences Resume in September



Students and faculty discuss research

The Boling Center’s Interdisciplinary Leadership Training series will resume in September 2004. This series of half-day conferences offers continuing education credit to nurses, speech/language pathologists, and psychologists for some or all of the programs. Save these dates; details of each conference will be announced and posted on the Boling Center’s website as soon as plans are final.

September 2	Genetics
September 16	Obesity
October 7	Mental Health/ Mental Retardation Behavioral Issues
October 21	Mental Health/ Mental Retardation Pharmacology
November 4	Leadership
November 18	Research in Developmental Disabilities

Community Calendar

June 15 — Fair Housing training conducted by Web Brewer, attorney for Memphis Legal Services. Contact Jeffrey Smith at Memphis Center for Independent Living for more information: 726-6404 or jeff.smith@mcil.org.

June 22 — Affordable Housing training conducted by a representative of the Memphis Housing Authority regarding Section 8 Voucher/subsidized living program. Contact Jeffrey Smith at Memphis Center for Independent Living for more information: 726-6404 or jeff.smith@mcil.org.

July 9-24 — Respite Provider Training at the Boling Center – Contact Elizabeth Bishop at ebishop@utmeme.edu or 901-448-3127 for more information.

The Parent Support Group meets the last Monday of every month at Hope Presbyterian Church 8500 Walnut Grove Road in Cordova. Contact Robin Welsh at rwelsh@utmeme.edu or 901-448-3737 for more information.

September 30, 2004 — “Solution Focused Brief Therapy with Self-Harming Adolescents” by Matthew Selekman, MSW, LCSW. For more information contact Professional Training Associates, Ltd., P.O Box 1282, Grafton, VA 23692, visit their web site at www.ptaltd.com , or email info@ptaltd.com



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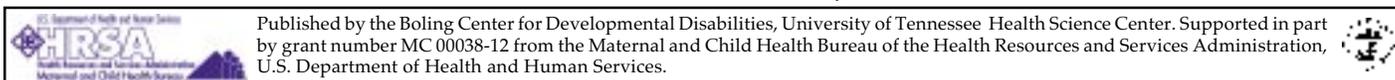
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