



The Insider

Life Span Institute at Parsons

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Patty Black Moore, Editor

LSI Parsons Colleagues Try Out a Segway

Assistive Technology for Kansans (ATK) at the University of Kansas Life Span Institute (LSI) at Parsons invited their staff as well as colleagues and friends to Parsons, Kansas on Thursday, January 8, 2009 to try out a Segway, the innovative, two-wheeled, battery powered personal transporter.

Assistive Technology for Kansans (ATK) provides the opportunity for Kansans with disabilities and chronic health conditions to try out assistive technology before they buy. Recognizing that the Segway has great potential for increasing options for people with a variety of mobility issues including fatigue, two Segways are now available to ATK customers statewide. Jim Peterson, Segway of Kansas, Hutchinson, provided a 2 ½ hour workshop beginning with a review of safety issues and concluding with an extended demonstration as all in attendance took their turn riding a Segway.

ATK coordinator, Sheila Simmons and Peterson supervised as participants from age

19 to 70+ strapped on their helmet, experienced “people shake” and were quickly zooming around on the lawn outside the LSI Research Building. Anxiety quickly turned to enthusiasm as each person discovered the thrill of riding a Segway in a

matter of minutes and amid much laughter, the cry “I want one” brought nods and smiles. Peterson said that people who need some mobility assistance but aren’t ready for a scooter often find that the Segway is a confidence booster as well as providing an independent way to travel. The Segway has a top speed of 12 ½ mph and a plethora of built-in safety features.



In the picture: Sheila Simmons (left) explains the Segway’s safety features to Rita Nance (right), Southeast AT Access Site as Sharon Morton (center), Kansas Equipment Exchange (KEE) coordinator, waits her turn. Photo by Bob Christensen, Media Lab.

Sara Sack, ATK director said, “It’s great that people will be able to go to their regional Assistive Technology Access Site to try out one of these mobility devices. Being at eye-level with other people and the easy maneuverability of these devices makes them very appealing. We’re seeing them

used in a number of employment settings in Kansas and across the country.”

For more information about assistive technology including the Segway, call your local ATK Access Site toll free at 1-800-KAN DO IT (1-800-526-3648).



Project Highlight

Prevalence of Developmental Disabilities Among Children with Epilepsy in Rural Populations

Collaborating Grant Partners

University of Kansas

University of Kansas School of Medicine – Wichita

Columbia University

This 3-year grant received by Dave Lindeman from the Association of University Centers on Disabilities under a contract from the Center for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities began on October 1, 2008.



Project Summary

Epilepsy is one of the most common disabling neurological disorders, but there are significant gaps in our knowledge about childhood epilepsy and associated comorbid conditions, including developmental disabilities. The extent to which these disorders exist in rural populations, especially among children, has not been fully assessed.

The proposed study will assess the prevalence of epilepsy and secondary disabilities among children in a low-income rural setting. This information is important for policy makers and health care, education, and mental health providers that serve these children in identifying risk factors and planning and providing appropriate services.

Long-Term Goal: To broaden knowledge of the epidemiology of epilepsy and determine the frequency of associated secondary disabilities among children of midwestern rural, impoverished, predominantly white, low-income populations.

Specific Objectives: (1) to ascertain all cases of epilepsy among children 0-17 years of age in nine rural Kansas counties. This will be accomplished through case identification, followed by a primary consensus review conducted by two epileptologists and an epidemiologist to determine classification, followed by a family interview to gain additional information on secondary conditions, medical treatment, access to care and quality of life, and then followed by a final consensus review to assimilate all information. (2) to determine how epilepsy is associated with secondary developmental disabilities. This will be accomplished by data analysis establishing an epidemiologic assessment of epilepsy and then associated secondary conditions. Both analyses will include epilepsy types, syndromes, etiologies, assessment of stress and quality of life, and access to and quality of care.

Study Procedures: The investigators will use three approaches in identifying cases: (1) Medical records from hospitals, neurological clinics, and other medical facilities will be reviewed for those children identified with epilepsy; (2) Assistance will be sought from special education agencies, mental health facilities, social service agencies, schools, and key community informants in identifying children who are potentially epileptic and who have developmental disabilities; (3) Interviews will be completed with the parents of identified children in order to obtain additional information and/or to seek release of medical record information. Appropriate statistical procedures will be utilized to assure confidence in sample group and data analysis.

Potential Benefits: (1) Information collected may further understanding of the needs for specific interventions and services in the poor rural population with epilepsy and comorbid disabilities; (2) For participants not in the medical system, referral to appropriate sources of care will be provided if desired; and (3) Study personnel will develop expert-reviewed and community-specific “toolkits” of educational materials on epilepsy and developmental disabilities in children for community partners.

Staff News

Kathryn Saunders has been nominated to run as a member-at-large of the Executive Council of the Association for Behavior Analysis International (ABAI). Established in 1974, ABAI is the primary professional organization for members interested in philosophy, science, application and teaching of behavior analysis.



Currently, Dr. Saunders is an Associate Editor for *The Behavior Analyst* and a member of the Board of Editors of the *Journal of Applied Behavior Analysis*. She has served as an Associate Editor, and for several terms on the Board of Editors, for the *Journal of the Experimental Analysis of Behavior*. She is a Fellow of Division 25 of the American Psychological Association, and has just completed a term as its president.

Project News and Updates

College of Direct Support: Kansans Complete over 40,000 Lessons



Training for the Direct Support Professionals supporting persons with disabilities is moving from the classroom to the Internet. Kathy Olson oversees the statewide implementation of

the College of Direct Support (CDC) and reports that over 40,000 lessons have been completed by more than 3,000 Kansas learners. Forty-three foster parents and eight self-advocates now use the College of Direct Support along with staff from 105 service providers, five case management providers and others. (data as of January 1, 2009)

The College of Direct Support includes 23 online courses covering essential topics in providing support ranging from Safety and Maltreatment to Functional Assessment and Employment. The e-learning curriculum is available to qualifying Kansans without cost and can be accessed from most any computer, anywhere, at any time, making quality training available throughout the state.

The College of Direct Support has been developed by national experts and is managed by the University of Minnesota. Dr. Olson, of the KUCDD, serves on the CDC national board of directors and has coordinated statewide implementation through a grant from the Kansas Department of Social and Rehabilitation Services since 2007.

Southeast Kansas Foster Care Treatment Project (SEK FCT) Update

Katie Hine, Southeast Kansas Foster Care Treatment (FCT) project coordinator, reports that FCT just received word that the project will continue to receive grant funding from the Kansas Department of Social & Rehabilitation Services for the 2010 fiscal year. Dr. Hine continues, "We are all excited to know that we may continue providing services and supports to families in the 12 counties of southeast Kansas with children who exhibit challenging behavior. Since we opened our first cases in July, 2006 we've been able to work with the families, schools and communities for 58 children and youth between 2 and 21 years of age. We have served 33 youth in foster homes, 17 youth in biological family homes, 7 youth in relatives' homes, 1 youth in an

independent living arrangement, and 2 youth in adoptive homes.

Dr. Jerry Rea is the Primary Investigator for the FCT project.

Dr. Katie Hine (right) is the Project Coordinator. Sara Major and Roger Stanley are the FCT behavior therapists. Both Roger and Sara are Licensed Masters Level Psychologists, and Sara recently became a Board Certified Behavior Analyst. Roger and his wife, Brandy, are foster parents and will be welcoming their second biological son (Levi) into the world January 15, 2009. Peggy Gentry is Project Assistant and is



responsible for calling each family every day Monday through Friday. On average, Peggy makes just over 145 calls per month to check in on the families and find out what has happened over the last 24 hours. Additionally, FCT employs several hourly Skills Trainers – people who work with the kids according to the written support plan and offer 1-on-1 supervision and training on skills related to recreation, community access, social interaction and adult living.

Our outcome measures have been positive. While receiving FCT services 53% of the youth have remained in the same residential setting. Of the youth who moved, 75% moved to a setting equal to or less restrictive than foster care. Pro-social behavior has increased or maintained for 82% of the 39 youth served for whom sufficient data were available. We've served 43 boys and 17 girls. Eighty-five percent of the youth have a mental health diagnosis, and 50% of the youth have a developmental disability.”

Staff News

Pat White Retires from LSI Parsons

Pat White celebrated 40+ years of service with the University of Kansas, Life Span Institute at Parsons surrounded by family, friends, and colleagues at her retirement luncheon on Friday, December 12, 2008 in Parsons, Kansas. Accompanied by her husband, Fred, their sons, daughters-in-law and grandchildren, Pat led the way for an estimated 50 guests through a bountiful pot luck buffet.

Dr. Dave Lindeman, LSI at Parsons Director, thanked Pat for her dedication to the work of the LSI on behalf of the many grant projects and colleagues who have benefited from her long history with the program and her many skills. Dr. Joe Spradlin, added his congratulations and applauded Pat's contribution to the success of the LSI research community. Paul Diedrich, Grant's Manager, LSI, Lawrence, offered his best wishes and noted that he, among many, will miss Pat during the next round of grant applications. Dr. Dean Williams presented Pat with a monetary gift on behalf of the Southeastern Association for Behavior Analysis for her work on the national front. Dr. Kathryn Saunders stated that while many may not realize it, Pat is well known for her service to professional organizations nationally. While her editing and proofing skills are legendary, she also shared her expertise in ways too numerous to list and



has earned the respect of researchers across the country.

Pat's many retirement gifts included a stone KU plaque, 2 dozen red roses, and a congratulatory message on cookware. The Pat White Retirement Celebration was planned and coordinated by Laura Hanigan and concluded with the cutting of the "KU" cake.

Pat said, "I have really enjoyed working with everyone at the LSI for all these years – people who have been here, as well as the people who are still here. It has been a wonderful career and it has been a pleasure to work with everyone. Thanks for a wonderful retirement party and all the gifts that I received – I couldn't have asked for anything better. It was great to see everyone that attended."

In her newly found "free" time, Pat is working with Pam Cress and Dr. Chuck Spellman on a Kansas Humanities Council oral history grant focusing on the impact of the New Deal programs of the 1930s on Southeast Kansas farm life, and in 2009 is busy traveling with Fred in their RV to all parts of the USA. "Happy trails," Pat!

The LSI at Parsons Archives

One legacy that Pat White leaves the Parsons Life Span Institute is the Archives, the collection of past grant work including articles, books, and products located in the northwest corner of the LSI Research Building. Visit the Archives and be amazed at the scope of work accomplished and the ease with which you can locate project products, publications and other items of interest.

Presentations

- ◆ Major, S. & Stanley, R. A. (2008, October). Southeast Kansas Foster Care Treatment: Service and success. In R. A. Stanley (Chair), *Supporting Caregivers and Families with Children and Youth with Challenging Behavior*. Symposium conducted at the Heartland Association for Behavior Analysis 3rd Annual Conference, Omaha, NE.
- ◆ Stanley, R. A. & Major, S. (2008, October). Using positive behavior supports with caregivers. In R. A. Stanley (Chair), *Supporting Caregivers and Families with Children and Youth with Challenging Behavior*. Symposium conducted at the Heartland Association for Behavior Analysis 3rd Annual Conference, Omaha, NE.
- ◆ Major, S. & Stanley, R. A. (2008, October). Training caregivers to implement behavior support plans through modeling. In R. A. Stanley (Chair), *Supporting Caregivers and Families with Children and Youth with Challenging Behavior*. Symposium conducted at the Heartland Association for Behavior Analysis 3rd Annual Conference, Omaha, NE.
- ◆ Hine, K., Major, S. & Stanley, R. A. (2008, November). *Supporting Caregivers and Families With Children and Youth With Challenging Behavior*. Paper presented at the meeting of the International Child and Adolescent Conference XIV, Minneapolis, MN.