



The Insider

Life Span Institute at Parsons

January 2010

Patty Black Moore, Editor

Family Care Treatment: There's a Replication Afoot!

By Katie Hine, Ph.D.

Originally we were Southeast Kansas Foster Care Treatment, however, because we have become more focused on the family and our services are not restricted to children and youth in foster care, we've chosen to change our name to Southeast Kansas **Family** Care Treatment (FCT) – same acronym, different referent.

Our team remains the same. Peggy Gentry is our Program Assistant. Peggy telephones each family every day (M-F), keeps all of our demographic information up to date, maintains all of our consents, and coordinates the semi-annual consumer and teacher satisfaction survey process. Sara Major and Roger Stanley serve the families as Behavior Therapists. Sara and Roger serve about 5 families each. Their core responsibilities include weekly observations in the home and school, ongoing data analysis, and weekly in-home meetings with each family. Mambu Sherman works directly with the youth as a Skills Trainer and spends his time promoting activities in the community. As the Program Coordinator, Katie Hine provides technical and clinical support to the team and in *continued on page 9...*



Clockwise from top left: Katie Hine, Mambu Sherman, Peggy Gentry; not pictured, Sara Major and Roger Stanley.

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Did you know?

The Insider back issues, since 1998, are archived on the Life Span Institute at Parsons website, thanks to Webmaster Cynthia Huebner. The newsletter is available as a .doc file as well as a .pdf for the reader's convenience. And while you're perusing, take a look around the site and check out your colleagues, their projects, a handy map of the campus, as well as other interesting information. Check it out at <http://parsons.lsi.ku.edu/ParsonsLSI/html/Newsletters/Archive.shtml>

PROJECT HIGHLIGHT



Inclusive Community Gardens: Food, Exercise, Friends, and Maybe Money

This new three-year grant received by Sara Sack, Ph.D., project director, is funded by the U.S. Department of Education. The grant start date: October 1, 2009.

Project staff: Patty Black Moore and Sheila Simmons.



Providing persons with disabilities and their family members with opportunities to become involved in the community gardening movement may result in new knowledge, new friends, more exercise, access to fresh food, and possibly a new hobby or small business related to agriculture. Community gardening is not new, but with the current economic "recession in full swing, many Americans are returning to their roots—literally—cultivating vegetables to squeeze every penny out of their food budget" (Associated Press: Dollars from Dirt, Long Beach, CA, March 16, 2009).

Project Summary

Community gardening is not a new concept but is designed to include persons with disabilities, inclusive community gardening can provide recreational activities and related experiences that aid in employment, mobility, socialization, independence, and community integration. Through this

effort, persons with disabilities across the state will have access to community garden programs that provide innovative gardening education and supports to help all people garden regardless of the disability or health limitation.

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Project Highlight continued from page 2...

In addition to access to many examples of inclusive gardening strategies, a range of adaptive gardening tools will be available through the statewide Assistive Technology Program for gardeners to “Try Before They Buy.” Program staff will work with local garden coordinators, master gardeners, 4-H Programs, USDA County Extension Agents, and others to collect strategies and offer educational programs through the winter months so that maximum use is made of the growing season and expert horticultural advice is obtained. Staff will work with local community garden programs to ensure that policies and practices support participation by persons with disabilities. At present there is little evidence available of persons with disabilities participating in community gardening efforts occurring across the country.

Project staff will work with 150 persons of all disabilities and all ages in five communities per year across the state. Over the three-year period of time it is anticipated that 450 persons with disabilities and approximately 1,350 family members and friends will be impacted from these recreational and employment activities. The project is specifically designed to include youth with disabilities and persons with disabilities from traditionally underrepresented groups.

The benefits of participation in community gardening go beyond access to nutritional food, exercise, and new knowledge. The informational exchange and social interactions lead to improved mental health, feelings of being connected to the local community, leadership skills, and possibly new employment contacts and opportunities. However, project staff also recognize that

the recreational benefits of gardening should not be denied if the person with disabilities is not physically able to participate in the community gardening effort. Inclusive gardening materials, access to adapted gardening equipment, and access to informational exchanges through the gardening blog will be available to these individuals as well as to participants in the community gardening program.

Communities with established community garden efforts as well as with communities/entities that are establishing new community garden programs will be recruited to participate in this innovative project. Local community garden coordinators will be recruited in the selected communities and will help to set up garden education opportunities, share innovative strategies, help answer garden questions and share knowledge by encouraging participation in the gardening blog, and help the project coordinator disseminate press releases and public awareness information. To further increase the likelihood of maximum participation by persons with disabilities, a gardening seed/plant stipend will be available to individuals completing the educational sessions.

Ed Bell, a person with disabilities who has established a profitable strawberry business will consult with the program and with vocational rehabilitation counselors. Through this effort model community gardens with inclusive policies and practices will be in place across the state. Grant writing and sustainability initiatives will begin at the start of the program to further ensure continued access to inclusive community gardens after the federal funding has ended. Adapted tools will continue to be available for loan as long as the equipment is useful.



NEWS FROM THE BUSINESS OFFICE

The 2010 insurance benefits went into effect Jan 1st and will run through December 31, 2010. If you signed up with a different company for 2010, you should have received your new insurance card in December of 2009, otherwise you will keep your same card from the previous year. If you have not received your new card, please contact your insurance carrier.

Please mark your calendar for the official 2010 state holidays.

Holiday	Date
New Year's Day	Friday, January 1, 2010
Martin Luther King Jr. Day	Monday, January 18, 2010
Memorial Day	Monday, May 31, 2010
Independence Day	Monday, July 5, 2010
Labor Day	Monday, September 6, 2010
Veterans Day	Thursday, November 11, 2010
Thanksgiving Day	Thursday, November 25, 2010
	Friday, November 26, 2010
Christmas	Friday, December 24, 2010
Discretionary Day	May be used starting 12/27/2009 - 12/25/2010

The Business office has been entrusted in the use of credit cards for both state and KUCR funds, therefore if you have purchases that may be paid with by credit card, please stop what you are doing and give all information to the business office so they may proceed in obtaining the merchandise, registration, airfare and etc. Please note, it is necessary for you to continue to provide the leg work in obtaining the information of what is needed, what vendor it is coming from, why it is needed, who it is for, what project is going to pay for it, and when and where this is going to take place. Yes, there will be some things that we can not pay with our cards such as business with international vendors, individuals, pay pal accounts and some of the same things we can not purchase through Purchase Orders and invoices such as alcoholic beverages, personal items, entertainment and etc. If you have concerns, just contact us and we will work with you in proceeding in the most efficient route.

by Laura Hanigan and Tammy Schoenhofer

PRESENTATIONS

Buck, D., Golden, D., Sack, S., Powers, K., & Root-Elledge, S. (2010, January). *Reviewing the data from 56 Statewide Assistive Technology Programs and considering the possible legislative impact, meeting with the Assistant Secretary of Education, Washington, D.C.*

Goosen, M. (2009, November). *Kansas Inservice Training System overview*. Presentation at State Interagency Coordinating Council & Special Education Advisory Council joint meeting, Topeka, KS.

Rinkel, P., Affholder, C., Hayes, S., & Steffens, P. (2009, November). *Effective practices for transitioning preschoolers with autism spectrum disorders to kindergarten*. Presentation at the Autism Across the Life Span conference, Wichita, KS.

PRESENTATIONS

- Rinkel, P., Hoffmeier, S., & Chambers, L. B. (2009, November). *Talking with parents of young children about autism spectrum disorders*. Presentation at the Ohio Center for Autism and Low Incidence (OCALI) conference, Columbus, Ohio.
- Rinkel, P., Hoffmeier, S., Chambers, L. B., & Zortman, J. (2009, November). *Talking with parents of young children about autism spectrum disorders*. Presentation at the Autism Across the Life Span, A Conference for Professionals and Families, Wichita, KS.
- Sack, S. (2009, November). *Assistive Technology for Kansans: Helping people find technology solutions to enhance learning, participation and safety*. Presentation at the Autism Across the Life Span, A Conference for Professionals and Families, Wichita, KS.
- Sack, S., & Brodey, J. (2009, December). *Strategies to increase coverage of durable medical equipment for Kansas beneficiaries*, Kansas Association of Health Policies, Topeka, KS.
- Sack, S. (January, 2010). *Federal and state data collection requirements: Selecting a tool to meet your needs*, Temple University, Philadelphia, PA.
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STAFF NEWS

Chancellor's visit to Parsons highlighted in The Oread "Snapshots"

Kim Page, KITS Early Childhood Resource Center Coordinator, stepped in as staff photographer during Chancellor Bernadette Gray-Little's recent visit to the Life Span Institute at Parsons. The picture she took was featured on the front page of the November issue of The Insider and was also chosen to be a feature photograph in The Oread, the KU employee newsletter, available online at <http://www.oread.ku.edu/>. Find the December 7, 2009 issue, scroll down to "Snapshots" and look for the picture that Kim snapped.

Kate Saunders invited to present at 2010 ABAI Autism Conference

Kate Saunders joins eight colleagues as an invited presenter at the 2010 Association of Behavior Analysis International (ABAI) Autism Conference in January in Chicago. The conference title is Translational Science and Effective Practice and Dr. Saunders will speak about The Science and Practice of Discrete-Trial Training: Why Some Teaching Procedures are More Effective Than Others.

Dean Williams invited presenter, EK Shriver Center Colloquium Series

Dean Williams is the invited presenter on January 15 to the 2009-2010 Colloquium Series at the Eunice Kennedy Shriver Center, Department of Psychiatry, University of Massachusetts Medical School, Waltham, MA. Dr. Williams' topic is Understanding Problem Behaviors and Transitions Between Activities: Bench and Bedside Translational Research.

<http://www.umassmed.edu/shriver/research/psychological/colloquium/index.aspx?linkidentifier=id&itemid=12610>

WELCOME!

Kat Stremel Thomas **Research Associate**

Kathleen “Kat” Stremel Thomas, Research Fellow at The Teaching Research Institute, Western Oregon University, now calls Parsons home, both personally and professionally. Educated at Kansas State University with degrees in Speech Pathology and Audiology, Kat has more than 35 years of experience in the area of communication and language assessment, intervention and evaluation for infants, children, and youth with severe disabilities and deaf-blindness.

Kat recently stepped down as the Project Director for the National Consortium on Deaf-Blindness in order to devote her time to conducting research and intervention activities with children who are deaf-blind with cochlear implants. Twenty-seven states are collaborating with Kat and her colleagues on the cochlear implant research. They are also using the *Language ENvironment Analysis* (LENA) system to collect outcome data.

Based on her extensive experience working with families and children as a speech and language pathologist, Kat has written numerous articles and conducts workshops nationally and internationally.

Current projects include Steppingstones of Technology Innovation for Children with Disabilities, Influencing Outcomes for Children

Who Are Deaf-Blind with Cochlear Implants, and Outcomes for Children Who Are Deaf-Blind After Cochlear Implantation.

About her current research, Kat says: “ At heart, I am an interventionist! I love working directly with the children, their families, and the service providers in their natural environments and seeing the positive outcomes. For many children with deafness and severe vision impairments, the cochlear implants are an amazing technology. Ten years ago many of these children would have been using inappropriate behaviors to communicate and now many are using speech both receptively and expressively. My colleagues and I are especially excited about the new LENA technology that allows us to capture the auditory environment, the parent’s speech to the child and the frequency of the child’s vocalizations in their natural environments.”

Kat is also enjoying collaborations with agencies and Part C professionals in Kansas. With her new office at the Life Span Institute at Parsons, a new courtesy position with the University of Kansas, and house hunting with husband, Paul, Kat’s settling into life in Southeast Kansas.



PROJECT NEWS

Sharon Morton, Assistive Technology for Kansans (ATK) KEE reuse coordinator, recently received an inquiry from Valerie Warner, Rifton Equipment. Valerie wanted to know if a KEE customer could use a Small Pacer Gait Trainer in very good condition... for free. Sharon searched the real time KEE database, located a young boy who had been waiting for just this equipment, made the deal and Rifton Equipment, a valued KEE partner, shipped the expensive mobility empowering equipment to a child in southeast Kansas.

Additionally, following up on Sharon’s story about her accident while traveling in Kenya, a wheelchair is on its way to the Kenyan hospital where Sharon and her husband received medical treatment, compliments of Charles Lifer’s organization, Humanitarians, Ft. Scott, KS.

NEW RESEARCH ASSISTANTS

Mia Caccavale Research Assistant



My name is Mia Caccavale. I was born in Maryland, and moved to Weirton, West Virginia when I was ten. I received my Bachelor's degree in Psychology with a minor in Child Development from West Virginia University in December 2009. There, I worked with Dr. Claire St. Peter Pipkin in her lab and with the Behavior Analysis Services Program for Public Schools (BASP). I worked with mainly elementary school children while I was with BASP. In addition, I worked at a before and an after school program for the children in Morgantown. I haven't had too much time to focus on my hobbies with school and work, but I like to cross stitch and take spinning classes at the gym whenever possible.

I am a Research Assistant, working under Kate Saunders and Dean Williams. I am working on one project right now, *Recombinative Generalization of Within-Syllable Units in MR* with Dr. Saunders, and I hope to start another project soon, *Laboratory Models of Maladaptive Escape Behaviors* with Dr. Williams.

I heard about this job through my lab supervisor, Dr. Claire St. Peter Pipkin, and I felt that it would give me more research experience, as well as experience working with a different population than I have previously worked with.

Currently, I am more interested in applied work with children from preschool to second grade because of my experiences working in the public school system. I am applying for Master's programs in the field of Applied Behavior Analysis, hoping to become BCBA certified and work for a school district as

a Behavior Analyst, but who knows what will happen after my experiences here in Parsons.

Ibari Ezekwe Research Assistant



My job here at Life Span Institute at Parsons is a Research Assistant position to two projects- Dr. Kate Saunders' *Recombinative Generalization of Within-syllable Units in MR* and Dr. Dean Williams' *Laboratory Models of Maladaptive Escape Behaviors*. I am a recent University of Kansas graduate and McNair scholar; I earned my bachelor's degree in Psychology in May 2009. I am originally from Nigeria, but also grew up in Kansas City, KS. For my undergraduate career, I moved to Lawrence to attend KU.

The research contents, applied behavioral principles, and the subject pool of persons with developmental disabilities are the sole reasons I came to Parsons, KS. So far, my colleagues and others I have encountered have been quite amiable. I appreciate engaging in the unique working environment that I am in, as well as discussing profound and pertinent articles to both basic and applied behavioral analysis. Although my specific path of study in graduate education is not yet finalized, I intend to further my education in a graduate institution.

My leisure times are often spent with family & friends, in creative writing, experimenting with unique food recipes, and dining at various restaurants. So far in Parsons, I have been to Shredders and Kitchen Pass and it has been somewhat of a mini adventure. I have yet to explore the few remaining restaurants in town.

DECONSTRUCTING DESTRUCTIVE BEHAVIOR

Researchers focus on transitions to pinpoint triggers of aggression and self-injury in people with intellectual disabilities.

Despite increasing community integration of people with intellectual disabilities in the last 20 years, rates of serious behavior disorders in this population remain high and psychoactive medication remains the treatment of choice.



From left: Mambu Sherman, Dean Williams, Ph.D., and Yusuke Hayashi, Ph.D., photograph by Kim Page.

But a multi-university research team headed by Dean Williams, Parsons senior scientist, is unscrambling the triggers of Chronic Aberrant Behavior (CAB), marked by aggression, head banging, biting and other forms of self-injury. With Parsons colleague Kathryn Saunders and researchers at Johns Hopkins University and West Virginia University, Williams is pinpointing the interplay of environmental and individual differences that cause CAB.

While clinicians know that transitioning between activities generates agitation and the characteristic behaviors in people with CAB, understanding which transitions, and why, remains a challenge.

Williams' team has observed that some activities cause problems only when they follow more favored activities. "A person might have problems in math class when it follows recess, but not when it follows spelling class."

The take-home point? "It may not be transitions, per se, or the particular activities that generate problem behavior," Williams asserts. "A solution may be looking closely at the context of activities and ways of making activities equivalent to individuals."

CAB strains families, communities and the health care system and causes immeasurable suffering for those with the disorder. Williams hopes to translate this research to therapeutic approaches across settings, people and circumstances, a priority of the funding agency, the National Institutes of Health.

The Schiefelbusch Institute Life Span Studies. (2009). Annual Report 2008-2009. The University of Kansas: Lawrence, p. 12, reprinted with permission. Available online at <http://www2.ku.edu/~lsi/aboutus/annualreports.shtml>.

PROJECT NEWS

ATK partner honored with national reuse award

Sara Sack, director of Assistive Technology for Kansans (ATK) traveled to Topeka on December 15 to participate in the presentation of a national Pass It On Center Visionary Award to long-time ATK program partner, Kim Brink, Program Manager for Kansas Health Policy Authority. This Visionary Award recognizes Kim and KHPA for their role in the development of a cost-effective model reutilization program that has been implemented in several other states, and subsequently, more Kansans have access to needed assistive technology. ATK's reuse program, KEE, was recognized nationally as a model program in 2009.

Family Care Treatment, continued from page 1...

conjunction with Jerry Rea (Primary Investigator) engineers and directs research efforts.

Although Family Care Treatment started providing services only three and a half years ago the outcomes have been overwhelmingly positive. We have evaluated four features of the program (a) participant demographics, (b) stability and restrictiveness of placements, (c) service type and duration, and (d) behavioral outcomes.

FCT has served 73 youth in 23 southeast Kansas communities, and has worked in cooperation with 26 different schools. Youth have ranged in age from 2 to 19 years, are primarily boys (71%), and often have a developmental disability (47%), a mental health diagnosis (79%) or both (40%). A number of the families we serve are low-income, many have a history of familial mental health and substance abuse issues, and are often single-parent households with multiple children. FCT has served youth in 28 biological family homes, 38 foster homes, and 1 adoptive home. We have also served youth in supported living and in the homes of relatives.

FCT promotes the family's ability to support their children. Family members identify the behavioral goals; FCT consults with them to identify strategies that are realistic and target the function of youth challenging behavior. During FCT 79% of youth have demonstrated increased pro-social behavior with an average increase of 16%. While receiving FCT, 64% of youth did not move. Of those youth who did move 37% moved from one foster home to another, 37% moved into a less restrictive setting (i.e., back into the family home or the home of a relative), and only 7 youth moved to a more restrictive setting (i.e., from a grandparent's home into a residential treatment facility). Of the youth who moved, those who moved to a less restrictive setting received FCT for an average of a little more than 8 months; youth who moved to a more restrictive setting received FCT an average of slightly more than 2 months.

A replication of FCT is underway now in Wichita, Kansas. In 2009 Youthville, a private agency providing child placement services in Sedgwick County, received a 1-year grant from the Kansas Department of Social and Rehabilitation Services to fund the personnel needed to replicate FCT. The Youthville team has named their new program Behavior Emphasis for Successful Treatment or BEST. The BEST team consists of Carmel Poor, Therapist; Aaron Walker, Program Assistant, and two Skills Trainers. Lori Gonzales, an existing Youthville employee, will provide on-site program coordination. FCT and BEST personnel have travelled back and forth between Parsons and Wichita in an effort to promote a technically accurate replication of services that both builds on the strengths of the BEST team and meets the needs of the families and youth in Sedgwick County. BEST began serving their first family on January 5, 2010.