



PROJECT BRIDGE

THE MONTHLY NEWSLETTER OF THE CENTER FOR DISABILITIES STUDIES

NOVEMBER-DECEMBER 2011

The November-December 2011 issue of Project Bridge includes project updates from recent months and events that will take place in the next few months. The next issue will be in January. Please send news and events for this issue to mercooke@udel.edu by **December 6**.

PROJECT UPDATES

- Delaware's **text4baby** program, with CDS as the lead organization, took first place in the State Enrollment Contest sponsored by the National Healthy Mothers, Healthy Babies Coalition. Congratulations to **Karen Zalewski** and **Annalisa Ekblad**, who accepted the award at a reception in Washington on November 1. Earlier in the day, they met with Sen. Tom Carper (see photo below) and his health policy adviser. With a 97% increase, Delaware led all state partners in increasing the number of pregnant women and moms who signed up to receive messages that connect them with critical health information.



Karen (left) and Annalisa with Senator Carper

- CDS hosted the “**Understanding Self-Determination**” workshop on October 24. Approximately 140 people attended the event, which featured keynote speakers Sue Swenson and Liz Weintraub. Sue and Liz presented self-determination from specific perspectives, those of a parent and a self-advocate, respectively. The workshop also included a panel discussion moderated by Community Advisory Council Chairman **Bob Valihura** that included local community members **Berni Edwards, Ikea Glover, Kevin Huckshorn, Drew Netta** and **Barbara Robleto**. They offered their views on scenarios and questions about self-determination posed by the audience.
- Congratulations to **Terri Hancharick** for receiving the “**Custie**” **Award** from the State Council for Persons with Disabilities (SCPD) on October 17. Formally named the Mary Custis “Custie” Straughn Memorial Award, the “Custie” is given annually to a person who makes outstanding contributions to the disability community. Terri has been involved in this community on many different levels—first as a parent and currently as chairperson of Delaware’s Governor’s Advisory Council for Exceptional Citizens. Terri is also a member of the Developmental Disabilities Council, the Board of Directors of Art Therapy Express, Inc., the Legislative Priorities Committee, and the Alliance on Oral Health Care for Individuals with Disabilities. Terri was also instrumental in the development, launch and expansion of C.E.R.T.S., Inc. (Collaborative Effort to Reinforce Transition Success)—an adult action center that provides meaningful activities for adults with severe disabilities who are not integrated into the workforce. In part due to Terri’s efforts, C.E.R.T.S. became the first MOVE for Adults Model site in Delaware (the third in the world) in 2009. Terri was honored with the award at the annual SCPD luncheon in Dover.
- **Chris Barthold** co-authored the book, ***School Success for Kids with Autism***, which will be published in December. Chris wrote the book with Andrew Egel and Katherine C. Holman. The book describes how parents and teachers can work together to create nurturing, supportive, and effective classroom environments from preschool to high school. Topics include a general overview of autism spectrum disorders (ASD); how schools assess and define ASD; general instructional strategies for students with ASD; targeted interventions for early childhood, elementary and secondary students with ASD; and fostering family and school partnerships. Visit the publisher’s [website](#) for more information.
- The Association for Behavior Analysis International recently approved the **Delaware Association for Behavior Analysis** as an affiliate chapter. The Association’s board, which includes **Chris Barthold** as President and **Gary Allison** as Vice President, worked for about a year and a half to achieve this honor. Chris also serves as chair of ABAI’s Teaching Behavior analysis special interest group. ABAI is a nonprofit membership organization that contributes to the well-being of society by developing, enhancing and supporting the growth and vitality of the science of behavior analysis through research, education and practice. According to ABAI, behavior analysis is the scientific study of behavior. Behavior analysts ask "Why does behavior change over time?" They seek answers by looking at the biological and environmental factors, although they are primarily interested in the role of environment in behavior change.

- **Chris Barthold** presented at conference, “**Best Practice in Asperger Syndrome Assessment and Intervention**” in October. She led a break-out session about Functional Behavioral Assessment. The conference was attended by both educational and mental health professionals and was co-sponsored by CDS, Delaware’s Department of Education, Autism Delaware, Delaware Health and Social Services -Division of Public Health and Division of Developmental Disabilities Services and PAR, Inc.
- In October, **Linda Grusenmeyer** and **Laura Eisenman** presented at the Council for Exceptional Children's Division on Career Development and Transition (DCDT) conference in Kansas City, Mo. The presentation, "Mentoring Young Adults with Intellectual Disabilities: Responding to Pre-Service Professionals’ Concerns," described a new undergraduate mentoring course and an application of the Concerns-Based Adoption Model to support student and course development within the context of program evaluation. Along with **Wendy Clauser** and **Debbie Bain**, they made a similar presentation, "Preparing Undergraduates to Mentor Peers with Intellectual Disabilities," at the November State of the Art Conference on Postsecondary Education for Students with Intellectual Disabilities in Fairfax, Va.
- In September, CDS staff members **Beth Mineo**, **Dan Fendler**, **Phyllis Guinivan**, **Gary Mears** and **Sonja Rathel** and graduate assistant **Rochelle Brittingham** attended the FEMA Region III Summit on Assistive Technology Reuse and Emergency Management, an invitation-only meeting held at the Pass It On Center in Philadelphia. Pass It On is the national technical assistance center for the reutilization of assistive technology. The purpose of the Federal Emergency Management Agency meeting was to address the role of reused assistive technology in emergency management. Speakers included key national and regional leaders in Emergency Management and services for people with functional needs. **Marcia Nickle**, emergency preparedness manager in the Office of Campus and Public Safety at UD, and representatives from state agencies and Goodwill of Delaware and Delaware County also represented Delaware at this meeting.
- **Eileen Sparling** attended the **139th Annual Meeting and Exposition of the Disability Section of the American Public Health Association (APHA)** in collaboration with the Association of University Centers on Disabilities (AUCD) in Washington, D.C. This year's APHA Annual Meeting theme, "Healthy Communities Promote Healthy Minds and Bodies," explored successful community models and practices that can be adopted to reduce health disparities and improve health outcomes for all. Of particular interest were the presentations of the disability section, in which disability and health researchers, planners, interventionists and advocates met to share research findings and innovative programs.
- **Eileen Sparling** also attended the inaugural meeting of the federal **Interagency Committee on Disability Research (ICDR)**, Interagency Subcommittee on Health Disparities (ISHD) in Washington. The ISHD is charged with determining future directions and establishing goals and activities for the coming year with respect to federal health disparities and disability research and policy.

- **Eileen Sparling** presented at the **Delaware Cancer Education Alliance Conference** at Delaware State University in Dover. She participated in a panel discussion about “Best Practices for Prevention: Disability and Health,” which included speakers on strategies for prevention in primary care, schools and the built environment.
- **Brian Freedman, Wendy Claiser** and **Max Kursh** presented an overview of their Transition, Education and Employment Model unit projects and programs at two community events in October: the Governor’s Committee on Employment of People with Disabilities Awards Luncheon and Ceremony and the Second Annual Transition to Adult Life Fair in Christina School District. **Debbie Bain** and members of the Community Connectors also presented at the Transition to Adult Life Fair.
- **Phyllis Guinivan and Gary Mears** attended the FEMA Getting Real II Conference in Crystal City, Va. in September, along with **Larry Henderson** of IRI, Inc., and **Marcia Nickle**, representing Voluntary Organizations Active in Disasters (VOAD) as well as UD. The conference identified practices that strengthen the whole community’s capacity to prepare for, respond to, recover from and mitigate the impact of disasters. These practices must also emphasize inclusion, integration, dignity, independence, accessibility and self-determination for individuals with disabilities before, during and after an emergency.
- **Several CDS staff members presented at the 2011 AUCD Annual Meeting and Conference in November.** The theme was “The Journey Continues: 40 Years Advancing Equity and Excellence through Research, Education and Service.” It celebrated the fortieth anniversary of the founding of the Association of University Centers on Disabilities network and provided a special opportunity for network members and partners to share their interests, talents and perspectives.
 - **Beth Mineo:** “Future Directions for Communication Intervention Research and Severe Disabilities”
 - **Karen Zalewski:** “Increasing Early Developmental Screening Through a Critical Two-pronged Approach: Reaching parents and reaching the medical community”
 - **Phyllis Guinivan and Gary Mears:** “The impact of disaster on individuals with disabilities and collaborative approaches to inclusive emergency preparedness”
 - **Eileen Sparling and Annalisa Ekbladh, with Linda Gottfredson and Kathy Stroh** (poster session): “Redesigning a diabetes self-management curriculum to address accessibility for individuals with intellectual disabilities”
 - Graduate assistant **Katie Borrás** was the recipient of a student travel scholarship to attend the 2011 AUCD conference. As part of her scholarship responsibilities, Katie will document her experience at the AUCD Conference and share it with the larger trainee community.
- Three students from the CLSC (Career and Life Studies Certificate) program participated in **Kids Inspiring Kids**, an interactive workshop to train students as leaders for transition planning. It was sponsored by Brandywine Special Needs PTA (BSNPTA) on October 20. This was an opportunity for youth to empower other youth by demonstrating how they prepare for their future as they leave

high school. Middle and high school students, with the assistance of college student facilitators, including **Devon Dant**, **Oliver Dynes** and **Aaron Pretlow** from CLSC, developed goals around employment, further education and living independently. The CLSC students also helped to greet parents, teachers and students who attended. Teachers and parents were included in activities where youth showed their advocacy and leadership skills. CDS staff member **Judi MacBride** and graduate assistant **Megan Pell** were involved in the workshop. UD student **Clement Coulston** was a presenter. For information about future BSNPTA programs, contact **Ellen Coulston** at 302-798-4642 or ellencoulston@comcast.net.

- The Delaware Positive Behavior Support (DE-PBS) project is hosting two workshops in November and December. Contact Debby Boyer at dboyer@udel.edu or 302-831-3503 with any questions.
 - **November 29.** Prevent-Teach-Reinforce (PTR) for Tier 3 Professional Development is a course designed for educators that gives participants information about the PTR behavior intervention process for completing Functional Behavior Assessments and developing Behavior Intervention Plans. Participants will learn the five steps of PTR and how to facilitate the process with teams in their school. This workshop is presented by **Rose Iovannone**, Ph.D., current director of the Prevent-Teach-Reinforce (PTR) Project and co-principal investigator in the Professional Development in Autism (PDA) project.
 - **December 8.** Thinking Social at Home is a program for parents, caregivers and educators designed to teach participants the Social Thinking© approach for teaching social skills to children. The workshop will show participants how to use the Vocabulary/Experience sample lessons included in the program, as well as address the following questions: What does it mean to have good Social Skills? Why do we call it Social Thinking©? What's anxiety got to do with it?
- CDS in the News:
 - On October 19, CDS hosted the third annual **Disability Mentoring Day**. CDS partnered with the city of Newark and local businesses to host 15 young adults with disabilities for on-site job shadowing and career exploration. Disability Mentoring Day is a national program that involves about 20,000 students and job seekers with disabilities. Newark Mayor Vance Funk, III welcomed Delaware's participants at a breakfast hosted by the Marriott Courtyard Newark at the University of Delaware. The day concluded with a celebratory lunch and award ceremony at California Tortilla on Main Street. The featured speaker was Sara Wolff, a young woman who advocates for individuals with Down Syndrome and other developmental disabilities. Read about Disability Mentoring Day in the [UDaily article](#) published about the event.
 - The Transition, Education and Employment Model (TEEM) project's **Career and Life Studies Certificate (CLSC) program** was profiled in [Think College's fall newsletter](#). CLSC is a federally-funded model demonstration postsecondary program for students with intellectual disabilities. It is part of a \$ 2.3 million grant received from the U.S. Department of Education to develop such programs at UD and around the state. Thirteen students with disabilities are enrolled in the CLSC program, which is in its inaugural year at UD.

- Goodwill Industries of Delaware and Delaware County was chosen as a recipient of the 2011 City of Wilmington ACCESS Wilmington Award for its **Durable Medical Equipment (DME)** program. This program developed through a partnership with CDS' Delaware Assistive Technology Initiative (DATI) with funding from the U.S. Department of Education, Rehabilitation Services Administration. In a letter to Ted Van Name, Goodwill's president, ACCESS Wilmington Chairperson (and former CDS staff member) Bev Stapleford wrote that Goodwill is "being honored as an example of success in the community as well as among your peers." A plaque was presented by Mayor James Baker at an awards ceremony as "a symbol of your status as a champion for the cause of accessibility for the people of Wilmington." ACCESS Wilmington is the Mayor's Committee on People with Disabilities.
- The deadline to apply for the **2012 Partners in Policymaking** program is December 16. This innovative leadership training program, which teaches people to be community leaders, is designed for parents raising young or school-aged children with a developmental disability or young adults with developmental disabilities. All sessions take place in Dover. Eight two-day sessions are held once a month from February through September. There is no fee to participate. Please download the [application form](#) or visit the [Developmental Disabilities Council website](#) for more information.
- [Online registration](#) is open for the **LIFE Conference**, which will be held January 19, 2012. This annual conference for people with disabilities and those who support them features national speakers and a wide variety of topics. The keynote speaker is **Constance Garner**, Ph.D., executive director of Advance CLASS—a national advocacy organization dedicated to the implementation of a strong and vital long-term services and supports program for both the aging and disability communities. Featured topics at the conference include emergency preparedness, state legislation, assistive technology and increasing accessibility in the home. CDS is a sponsor of this event and many staff members are presenters. Additional information will be included in the next issue of Project Bridge.

HIGHLIGHTED PROJECT OF THE MONTH

Lunchtime Learning Offers Information and Strategies about Autism Spectrum Disorders

- On October 10, TEEM Unit Director Brian Freedman, Ph.D., and author and psychologist Robert Naseef, Ph.D., confronted misconceptions about the impact of autism spectrum disorders (ASD) on marriages and families and offered strategies for coping with the difficulties that the diagnosis can bring to a family's interactions. Approximately 40 people attended the Lunchtime Learning session, "Autism: The Impact on Families and Strategies for Coping."

Participants were given information about previous and current research on separation and divorce in families of children with ASD, and how these results can be interpreted to avoid misinterpretations. The speakers also identified strategies for coping with the stressors of raising a

child with ASD and enhancing relationships between parents of children with ASD. They also highlighted common differences between men and women while raising a child with ASD.

Despite claims that the divorce rate for couples who have a child with autism is 80%, there is no evidence to support this rate, according to Brian. Many families of children with autism, in fact, display factors of resilience, or report having become stronger as a result of disability in the family, he added. What research *does* show is that children with autism live in a married household approximately 75% of the time. In addition, there is no evidence of an association between a child having an ASD diagnosis and not living in a family with both biological and adoptive parents.

The speakers were clear to maintain that although “a diagnosis of autism is not a diagnosis of divorce,” families often still feel heightened levels of stress, hopelessness, conflict and drops in marital satisfaction. The way to avoid allowing these challenges to lead to divorce, Dr. Naseef explained, is to work on understanding your spouse’s needs, spend time alone together, take care of your individual selves and be open and honest about your own needs.

For more information or additional resources, please contact Brian Freedman at brianf@udel.edu or Robert Naseef at rnaseef@alternativechoices.com. Information can also be found on Dr. Naseef’s website, www.alternativechoices.com.

RESOURCES

- The Center for Disabilities Studies now has print copies available of the second edition of ***Connecting the Dots—A Guide to Finding Services for Children and Adults with Special Health Care Needs in Delaware***. This guide is designed to help individuals with a newly-diagnosed disability or special health care need and their families find available supports and services. If you would like to receive copies of *Connecting the Dots* for personal or professional use, please contact Mary Thomas at maryt@udel.edu. The guide is also currently available for download on the [CDS website](#).
- The National Institute of Dental and Craniofacial Research released a dental resource guide for caregivers. ***Dental Care Every Day: A Caregiver's Guide*** includes information about visits to the dentist, brushing, flossing and body positioning for these exercises for people with developmental disabilities and their caregivers. The introduction of the booklet states: “Taking care of someone with a developmental disability requires patience and skill. It takes planning, time and the ability to manage physical, mental and behavioral problems. Dental care isn't always easy, but you can make it work for you and the person you help. This booklet will show you how to help someone brush, floss and have a healthy mouth.” It is available [online](#) and in a [pdf format](#).

- The Arc of the United States launched [a new website](#) in October offering a one-stop overview of the services available to people with developmental disabilities in each state. The site, dubbed the **Medicaid Reference Desk**, offers a breakdown of the various Medicaid benefits—including medical and social services—offered to those with disabilities based on where they live. The reference desk is designed to help families wade through the bureaucracy, provide basic information about each state’s programs and resources, and features a glossary of common terms and a selection of frequently asked questions about Medicaid benefits. The Arc created the new website with funding from the U.S. Department of Health and Human Services.
- The ***Navigating College Handbook***, written by adults with autism and released in October, offers a step-by-step look at college life for those with this developmental disorder. It is produced by the Autistic Self Advocacy Network and is geared toward individuals with autism rather than parents or professionals. Its first-person accounts give young people with autism a look at the changes they can expect, both socially and academically, when transitioning to college. It includes tips on everything from classroom accommodations to dealing with roommates. The guide also touches on topics like self-advocacy, independent living and basics like maintaining good eating and sleeping habits. The guide is available as a [free download](#).
- The **Infant Motor Behavior Laboratory** with the Department of Physical Therapy at the University of Delaware is studying the effects of a ride-on toy car on children’s mobility, socialization and development. Children between 12 months and 3 years old who are not able to crawl or walk independently are invited to participate. Please contact Hsiang-Han (Sara) Huang at hsiangha@udel.edu or 302-831-3214 or Christina Ragonesi at clbr@udel.edu or 626-380-7957 for more information or to participate in the study.

EVENTS

Visit the CDS website calendar at http://www.udel.edu/cds/index_calendar.html for more events.

- **Healthy Eating Workshops in November.** Yes U Can Corporation is offering three free workshops for individuals with eating challenges, weight loss or weight gain due to mobility issues. These problem-solving workshops include consultation with registered dietitians. The first workshop was held on November 4. Two additional sessions are being offered in November at Easter Seals, 61 Corporate Circle, New Castle, from 1–2 p.m. To register, call (302) 286-1399 or email info@yesucanusa.com.

- **November 11. Got Portion Distortion?** What is a proper serving size today? It can be confusing, especially when faced with additional challenges. What portion is good for you may be different for another person.
- **November 18. Quick and Healthy Food Choices.** Explore simple ways to increase your overall health through food. Learn easily prepared recipes and how you can benefit from reading food labels.
- **November 14. CDS Lunchtime Learning,** Center for Disabilities Studies, 12 noon–1 p.m. “Learning from Catastrophe: The 2011 Tohoku earthquake and tsunami and the challenges facing people with disabilities.” Three months after the March 2011 earthquake, tsunami and related disasters struck Japan, UD Disaster Research Center (DRC) Associate Director Tricia Wachtendorf and graduate research assistant Rochelle Brittingham traveled to Japan. They were part of a reconnaissance team that visited Iwata and Miyagi prefecture to learn about the social impacts of the disasters. They will discuss some of the factors that led to disparate evacuation and sheltering strategies for those with a range of functional and intellectual disabilities, the challenges these survivors faced months after the event, and the potential implications for disaster planning in the United States. To reserve a place, contact Michele Sands at msands@udel.edu or 302-831-3038.
- **November 29. Prevent-Teach-Reinforce (PTR) for Tier 3 Professional Development.** See description under “Project Updates” for more information.
- **December 7. Transition of Care: Monthly Seminar Series,** A.I. duPont Hospital for Children, 6:30–8:30 p.m. Young adults with disabilities and their family members are invited to attend this free seminar, which is one in a series of events focused on giving participants the opportunity to learn about changes in services and supports that occur as teens move into adulthood. The topic this month is “Estate Planning/Legal Options: Planning for the future and what happens after you turn 18.” Contact Cory Nourie at (302) 651-4812 or cnourie@nemours.org to register.
- **December 8. Thinking Social at Home,** Center for Disabilities Studies, 6-8 p.m. See description under “Project Updates” for more information. Register by **November 30** at <http://www.surveymonkey.com/s/Dec8>.
- **January 4, 2012. Transition of Care: Monthly Seminar Series,** A.I. duPont Hospital for Children, 6:30–8:30 p.m. The topic for this seminar is “2012 Education/Vocational Options: Where will you spend time after school is finished?” See December 7 listing for registration information.
- **January 19, 2012. LIFE Conference XIV,** Sheraton Dover Hotel, 8 a.m.–3:45 p.m. CDS is a sponsor of this event. See description under “Project Updates” for more information.
- **Additional 2012 Annual Conferences,** Sheraton Dover Hotel, Dover.
 - **March 15.** Inclusion Conference
 - **April 3.** Transition Conference

ADVOCACY CORNER

This section is dedicated to informing you about new or pending policies that relate to individuals with disabilities. If you would like to suggest information to share in upcoming editions of Project Bridge, contact mercooke@udel.edu.

- The White House offers a [disability-related blog](#) where people can read about what the Obama administration is doing for Americans with disabilities and other disability-related issues. Some recent posts were submitted by Kathleen Martinez, assistant secretary of Disability Employment Policy at the Department of Labor; John Berry, director for the Office of Personnel Management; Henry Claypool, director of the Office on Disability at the U.S. Department of Health and Human Services; and Kareem Dale, special assistant to the President for Disability Policy. To read or follow the blog, please visit www.WhiteHouse.gov/blog/issues/disabilities. You can also email disability@who.eop.gov to be added to the White House disability distribution list.

ADMINISTRATIVE UPDATES

The next issue of Project Bridge will appear in early January. If you want to share information about your project or professional activities or announce events that will occur in January or February, please contact Meredith Cooke at mercooke@udel.edu by **December 6**.

CONTACT US

The University of Delaware's Center for Disabilities Studies is located at 461 Wyoming Road, Newark, Delaware, 19716. Please call us at 302-831-6974 or 302-831-4689 (TDD) or visit our website at www.udel.edu/cds.

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Support Services, 240 Academy Street, Alison Hall Suite 119, University of Delaware, Newark, DE 19716, 302-831-4643. The following person has been designated to handle inquiries regarding the non-discrimination policies and to serve as the overall campus coordinator for purposes of Title IX compliance: Bindu Kolli, Chief Policy Advisor, Office of Equity and Inclusion, 305 Hullihen Hall, University of Delaware, Newark, DE 19716, 302-831-8063. The following individuals have been designated as deputy Title IX coordinators: for Athletics, Jennifer W. Davis, Vice President for Finance and Administration, 220 Hullihen Hall, University of Delaware, Newark, DE 19716, 302-831-2769; and for Student Life, Dawn Thompson, Dean of Students/AVP for Student Life, 101 Hullihen Hall, University of Delaware, Newark, DE 19716, 302-831-8939. Inquiries concerning the application of anti-discrimination laws may be referred to the Title IX coordinator or to the Office for Civil Rights, United States Department of Education. For further information on notice of nondiscrimination, visit <http://wdcrobcopl01.ed.gov/CFAPPS/OCR/contactus.cfm> for the address and phone number of the U.S. Department of Education office that serves your area, or call 1-800-421-3481.



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