

DELAWARE

Information for people with disabilities, their families and the professionals who support them.



ABOUT THIS ISSUE

Center for Disabilities Studies Director Beth Mineo introduced the 2009-2010 Annual Report/2011 Calendar with a message in which she used the word *transformative* to describe the year being reviewed. She reported that, from July 1, 2009 through June 30, 2010, the Center for Disabilities Studies “realigned our organizational structure and activities in the interest of even greater strength, stability, relevance and potential.”

In introducing this issue of *delAware*, I’d like to review the ideas our director shared in the annual report. She noted that our **strength** arises from the people who contribute to the Center’s vision, aspirations and achievements: CDS staff and faculty, our partners at state agencies and nonprofit organizations, involved citizens and people with disabilities. Our **stability** depends on our success in securing long-term, consistent and adequate funding for initiatives that benefit people with disabilities and their families, professionals in the disability field, and UD students. Such funding also allows us to undertake exploratory endeavors that lead us to new knowledge, outcomes and opportunities.

As a *translational agent*, we demonstrate our **relevance**: We can interpret the latest research-based theories and evidence to benefit policy and practice; we help shape the most pressing needs in the disabilities field into “researchable” issues; and we attract the resources that enable us—in collaboration with our partners—to devise and test model approaches to important issues.

As for our **potential**—that’s the real key to the future, according to Mineo, who believes that the future depends on our ability to shift from a focus on individual projects, conditions and life domains to a focus on the integration of numerous approaches that support people throughout the course of their lives. “We intend to strengthen connections among home, work, school, family and health issues within the Center, as well as across the University, state, nation and globe, to bring the best of what we know and can do to benefit people with disabilities and their families,” she wrote.

This issue of *delAware* features efforts that are under way at CDS to **strengthen the connections** that Mineo enumerated. The four highlighted projects, all recent additions to the Center, are based on collaboration with partners, involve evaluation and research, and are committed to making changes in current systems, all for the benefit of people with disabilities and their families. We are pleased to share with you information about the Family Support Healthcare Alliance Delaware (Family SHADE) (page 1); the Career and Life Studies Certificate program (page 2); Emergency Preparedness in Individuals with Disabilities (page 3); and Accessible Instructional Materials (page 4).

My special thanks to Meredith Cooke for researching and writing the articles in this issue. Meredith, a graduate assistant with the CDS Dissemination and Advocacy unit, is a school psychology major in the School of Education.

Michele Sands

Michele Sands, Editor

The Center for Disabilities Studies at the University of Delaware supports the well-being, inclusion and empowerment of people with disabilities and their families. Our mission is to enhance the lives of individuals and families in Delaware through education, prevention, service and research related to disabilities. We promote independence and productivity so individuals and families can fully participate in the life of the community.

CDS, the Developmental Disabilities Council and the Disabilities Law Program are partners in Delaware’s developmental disabilities network. Each partner receives a portion of its funding from the Administration on Developmental Disabilities, which is the U.S. Government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. CDS also relies on public and private support from individuals, corporations, foundations and state and federal entities to operate its programs. All gifts to CDS are tax deductible to the extent provided by law. Please visit our website at www.udel.edu/cds or call 302-831-6974 for more information about supporting CDS’ mission.

delAware is published by Center for Disabilities Studies. Editor: Michele Sands. Designer: Cindy Dolan. CDS contact information: 302-831-6974 (phone), 302-831-4689 (TDD), 302-831-4690 (fax), ud-cds@udel.edu (e-mail), www.udel.edu (website), 461 Wyoming Road, Newark, DE 19716 (mailing address).

Family SHADE: Collaboration Improves Access to Information, Resources and Services

Families of children and youth with special health care needs (CYSHCN) know how important it is to have access to the type of services their children need—and how hard it can be to locate the appropriate providers of these services.

In 2009, the Delaware Division of Public Health’s Maternal and Child Health (MCH) Program conducted a needs assessment to evaluate the gaps in service provision to CYSHCN and their families. The survey found duplication of services, inefficient use of resources and gaps in services throughout the state.

To promote more cohesion and collaboration, MCH awarded a contract (#10-380) to the Center for Disabilities Studies to establish the Family Support Initiative. This initiative was recently renamed the Family Support Healthcare Alliance Delaware (Family SHADE). “It is a member-driven alliance that brings together more than 40 organizations, agencies and parent groups across the state into a single, collaborative effort, with CDS as the administrative hub. Family SHADE members are committed to sharing information, resources and expertise and achieving systemic improvements to benefit and support families of children with special health care needs.

Family SHADE will soon offer families a single point of entry for information and referral through a comprehensive database currently under development. Specifically designed with needs of families of CYSHCN in mind, this database will provide families with direct online access to services and resources. Individual Family SHADE member organizations also will have access to the database, which will enable them to offer families the same information. There will also be a toll-free number staffed by trained information and referral specialists to help families locate service providers with the expertise they need.

Families Know Best

One of the first Family SHADE activities that will directly benefit families and service providers is the “Families Know Best” program. It was created to give families a stronger voice and provide a reliable mechanism for securing input from families. Parents who volunteer as



Families like the Liews will benefit from Family SHADE’s efforts to connect families of children and youth with special health care needs with information, resources and services.

Families Know Best members will receive periodic online surveys about their needs and their satisfaction with the services they receive. The survey findings will then be available to Family SHADE member organizations to assist their program planning and development efforts.

Collaboration among providers and organizations is the cornerstone of Family SHADE. Participating organizations range from government-funded programs to support groups. In addition to CDS, two lead organizations anchor the Family SHADE effort. The Parent Information Center (PIC) serves as a resource for families that need assistance with educational issues. Delaware Family Voices Family to Family Health Information Center provides support to families that have challenges in accessing the health care system. The Coordinating Council for Children with DisAbilities serves as a conduit of information exchange between Family SHADE organizations, families and the medical community.

Participating organizations receive technical assistance from Family SHADE in areas such as grant writing, strategic planning and fundraising. Family SHADE also provides information about funding opportunities and encourages collaborative projects that pool funding among organizations to develop new services or to improve or increase the capacity of existing services.

Increased communication among agencies is already showing a positive effect. When families expressed interest in a sexual education course for young adults with disabilities, Family SHADE contacted its partnering organizations and discovered that PIC already had such a program planned. By coordinating with a variety of agencies, Family SHADE helps increase the efficiency of systems serving CYSHCN. Such collaboration will further reduce fragmentation and duplication of services, allowing resources to be allocated more effectively to produce unique and valuable programs.

With funding in place for the next year and a renewal option of three additional years, families in the Delaware community will continue to benefit from Family SHADE’s support of individuals with disabilities and special health care needs throughout their lifetime.

For more information, contact Phyllis Guinivan at pguiniva@udel.edu or 302-831-7464.

Career and Life Studies Certificate: A New Postsecondary Option for Students with Intellectual Disabilities

A stimulating curriculum, supportive relationships, social activities and internship opportunities: These factors are what most students consider when deciding where to pursue their postsecondary education. They are also defining characteristics of the University of Delaware's new certificate program for students with intellectual disabilities.

In March 2011, the Center for Disabilities Studies began accepting applications for the Career and Life Studies Certificate (CLSC) program offered through UD's Professional and Continuing Studies. CLSC serves individuals who do not qualify for traditional postsecondary education programs but desire more than a high school certificate or diploma.

CDS received a \$2.3 million Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) grant from the U.S. Department of Education for the creation of this certificate program.

The principles on which CLSC was based ensure that each student will receive a comprehensive, inclusive and customized learning experience. The program recognizes that an individual needs more than job skills to be successful; therefore, it concentrates on skills in various domains that will help students achieve success in the workplace. The curriculum includes teaching social skills that students need to adapt to diverse environments, navigation skills to help them make their way through the community, and communication skills that enable them to network successfully with faculty and peers. CLSC integrates person-centered planning into the development of each student's course of study and includes peer mentoring and staff coaching as needed.

CLSC students will take classes in two modules. The Life Studies module focuses on life skills, self-determination, social networking and increasing independence. The Career Studies module includes classes on career exploration, work readiness, networking skills, business communication and stress management. Students will be able to participate in internships that have the potential to lead to employment options with university, community and network partners. In accordance with their individual

plans, students will engage in university courses, pursue additional certificates in specific academic or career areas, and have access to a variety of integrated academic, work and social activities on campus.

The students' academic year will begin in the summer with an orientation and other sessions that help them acclimate to campus life. CLSC's focus on inclusion will also benefit full-time UD students. The Transition, Education and Employment Model (TEEM) unit at CDS is offering a mentoring class to University students to train them as peer mentors and coaches for CLSC students who need additional support. Further, the program aligns with UD's commitment to a diverse and strong education environment where all are welcomed, including non-traditional students.

Collaboration between the University as a whole and CDS—with support from several university departments—makes CLSC possible. The Office of Disability Support Services will ensure that any CLSC student who needs additional accommodations will have these supports. Staff from UD's Delaware Education Research and Development Center will evaluate the changes that take place in the student, the program and the system during the course of the grant (see related article on this page).

The Delaware Department of Education, the Division of Development Disabilities Services and the Division of Vocational Rehabilitation are important partners in the referral process and in systems-change activities. Changes will focus on establishing mechanisms for monitoring statewide needs, identifying funding options, and planning for sustainability after the grant period ends.

CDS expects that CLSC participants will be among the first students with intellectual disabilities eligible to receive federal financial aid. An example of such aid is the Pell Grant, a grant awarded through



Lazyra Cornish and Matthew Kuliszewski, two of the students who were accepted into the first CLSC class, attend the orientation session.

participating institutions to students with financial need who have not earned a bachelor's or professional degree.

The TPSID project also includes outreach to Delaware's other institutions of higher education to increase the availability of postsecondary education to students with intellectual disabilities on their campuses.

When students complete the CLSC program, they will be in a position to pursue employment or further their education and training, with options including an additional certificate in a more specialized program or a degree program at UD or other institutions of higher learning. Whatever path students choose to pursue, one thing is certain: The integrated experiences and collaborative learning environment that CLSC provides will be invaluable in preparing students for future employment, scholastic opportunities and life.

For more information, contact Mary Thomas at maryt@udel.edu or 302-831-2940.

Evaluating the CLSC Program and its Impact on Students and Systems

The Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) grant requires the collection of information to show what works—and what does not—in the context of overall program goals. Linda Grusenmeyer, research and evaluation coordinator for the Career and Life Studies Certificate (CLSC) program, is evaluating each component of the program. She has created an evaluation design that focuses on both developmental and systems assessment. An advisory council will review the information to make ongoing decisions to the program and recommend needed changes in the system.

For the developmental evaluation, data that are instrumental to enhancing the program as it grows will be collected and interpreted. To gather data, the evaluator typically talks to the provider of the services and to users to see if their goals are met and they are satisfied with the program. This type of assessment alone would not serve the goals of CLSC. Because one of the goals is to impact the systems of the state, evaluation must look beyond the UD program to the relationships between CLSC and the state, funders and the national coordinating center.

A systems evaluation examines the conditions, dynamics and points of influence at work within the collaborative partnerships that are contributing to CLSC's success. The evaluation seeks to learn what will change or has changed across time, locations and contexts due to an innovation such as CLSC. Impacts on students, the program and state systems will be assessed.

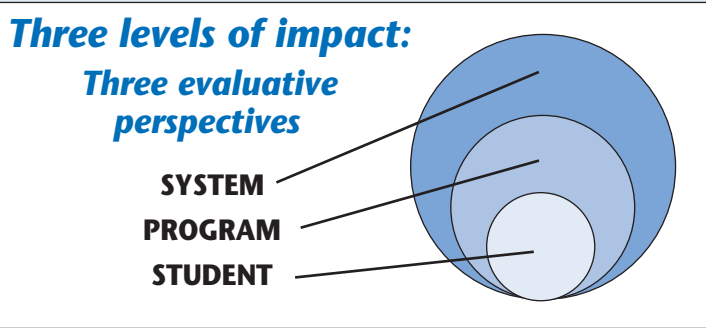
Student participants will be surveyed during the two-year program and in succeeding years to learn how the program affected them. Are they satisfied with their experiences in the program? Does CLSC impact long-term employment and independent living? What do students recommend to improve the CLSC program or to improve its outreach, enrollment and retention?

The second level focuses on how the program impacts the changing system. Are CLSC's certification programs meeting the needs of both students and employers? Is the program model being achieved as intended? Are ongoing adaptations effective at addressing evolving needs? Is CLSC accomplishing its larger impact goal: creating efficient, sustainable access to higher education experiences for students with intellectual disabilities?

The third level examines what happens to the system itself as it changes. Is the advisory council operating as intended? Does the council effectively identify future needs for postsecondary transition services? Are there sufficient funding

options, sites and openings available to meet those needs? Does the council work to improve outreach, enrollment, student retention and long-term outcomes?

The ultimate question is: Where will systems changes lead? Will CLSC achieve its long-term goal of sustainability, with sufficient funding options, sites and available openings for people with intellectual disabilities to have access to higher education?



Partnerships, Communication Vital to Emergency Preparedness

With the recent series of natural disasters—including tornados and flooding in the U.S., earthquakes and a tsunami in Japan—and the resulting destruction, power outages and other devastating consequences, people around the world are realizing, now more than ever, how critical it is to be prepared for an emergency. If a disaster strikes, it is important for individuals to know what to do, where to go (or how to stay in place), and the supplies to have ready. With the additional challenges that individuals with disabilities face, advanced preparation for an emergency is even more critical.

In 2009, the Administration on Developmental Disabilities awarded the Center for Disabilities Studies a one-year planning grant (#90DN0247) to expand family-centered and inclusive emergency planning and preparedness in Delaware. The resulting Emergency Preparedness for Individuals with Disabilities (EPID) project at CDS focused its efforts on family involvement and preparedness of individuals with disabilities. Staff members also researched the need for training for emergency planners and responders. The planning grant was carried out in partnership with the Inclusive Preparedness Center (IPC) in Washington, D.C.

One of the most valuable lessons that emerged from the planning year, noted EPID Project Coordinator Phyllis Guinivan, was the importance of developing relationships and fostering collaboration. The August 2010 emergency preparedness forums were an excellent case in point. Each forum featured presentations from organizations and agencies that are partnering with CDS in its emergency preparedness efforts. These include IPC, Delaware Citizens Corps, Delaware Developmental Disabilities Council, Delaware Emergency Management Agency and local and county emergency management agencies. Homeland Security Secretary Lewis Schilero and Homeland Security Advisor Kurt Reuther spoke at two of the forums.

The forums, which were open to individuals with disabilities, family members and professionals, presented information that is valuable for everyone during a disaster. However, the primary focus was on the people who are most vulnerable—those with conditions that put them at greater risk if they are not well-prepared for a disaster. Delaware Citizen Corps provided a “Go-Bag” for all attendees to encourage them to think about items they need for an evacuation.

Advisory council to address emergency planning concerns

At the conclusion of the planning year, Delaware was one of 12 states eligible to apply for a three-year implementation grant (\$150,000 a year) to continue EPID’s important work. In October 2010, CDS received one of the five grants awarded. Staff members are now addressing issues that were identified during the planning year as well as carrying out objectives of the new grant.



EPID Research Associate Gary Mears demonstrates a wind-up flashlight/radio to Paula Talarowski. This item should be included in a “Go-Bag.”

One of the objectives is to form an advisory council that includes representation from families, government agencies and other organizations. In addition to the partners that collaborated on the emergency preparedness forums, the advisory council includes many organizations that work with vulnerable populations. Council members will review existing emergency plans, laws and policies, identify gaps, and recommend strategies to integrate and improve emergency planning where necessary.

For example, at one of the emergency preparedness forums, an attendee raised an important question related to prescription drugs: If Medicaid limits prescription refills to once every 30 days, how can someone get access to a supply of medicine that will last through a disaster at home or if they go to an evacuation site. The advisory council will research concerns such as this and generate solutions or recommendations for policy and practice changes.

Individualized emergency preparation planning

Being prepared for an emergency is the key to successfully “weathering the storm” for people with disabilities. The way to start the process, EPID Research Associate Gary Mears points out, is to develop an individualized emergency preparation plan. The plan should include possible responses to various emergency situations and the materials needed to carry out each response. Individuals are encouraged to work on their plan with family members or friends and to discuss the risks they may face because of their disabilities and the ways to meet these challenges. Supplies identified as necessary in an emergency should be acquired and placed in a Go-Bag the individual can take along during an evacuation or in a sturdy container if sheltering at home.

EPID and Delaware Citizen Corps will conduct workshops for people with disabilities about emergency preparedness. For families that need assistance making a plan and determining the items needed to carry out the plan, EPID will prepare “navigators” from the Delaware Family Voices Family to Family Health Information Center to provide such support. EPID will also hold “train the trainer” workshops for groups such as pastors who want to help parishioners

with disabilities prepare their own emergency plan.

Emergency preparedness also involves planning beyond the individual level, emphasized Guinivan, who stated, “First responders play a critical role in ensuring that individuals with disabilities receive proper care as soon as possible.”

To that end, EPID will offer a conference and materials to first responders who wish to better understand the specific challenges that people with disabilities face and the needs that might occur during an emergency. In addition, to help emergency management personnel allocate resources and increase the preparedness of first responders to meet an individual’s needs, Delaware has developed a statewide voluntary 911/emergency preparedness registry for vulnerable populations with non-typical functional needs (see box).

EPID recently developed a partnership with another center at the University of Delaware. The Disaster Resource Center (DRC) is a multi-disciplinary unit devoted to research, education and outreach. A UD graduate student at DRC will serve as a research fellow with EPID to augment his/her disaster research training with additional training about the specific challenges people with disabilities face during an evacuation or when sheltering in place. This partnership will give both CDS and DRC the opportunity to consider emergency preparedness and disabilities from a broader perspective and to utilize their combined expertise to address these issues, said EPID’s Guinivan.

In addition to addressing Medicaid challenges, EPID plans to work with the Inclusive Preparedness Center and other states to assess other areas for interstate agreements. Possibilities include borrowing assistive technology and durable medical equipment from other states when Delaware residents are evacuated to these states. EPID staff also are exploring ways to offer training in emergency preparedness and/or fire safety for people with disabilities through online webinars.

With plans now in place to carry out these and other objectives, Delawareans with disabilities can expect the next three years to bring further advancement in emergency preparedness resources and services throughout the state.

For more information, contact Phyllis Guinivan at pguiniva@udel.edu or 302-831-7464.

Emergencies and Disasters Sometimes Happen Without Warning. You Need to be Ready.

Emergency Preparedness Voluntary Registry

Delaware now has a secure online Voluntary Registry at www.de911assist.delaware.gov for individuals with non-typical functional needs to help prepare for an emergency event before it happens. Among those who qualify for the registry are individuals with disabilities and/or special health care needs, those who do not speak English and the Amish.



Local and state emergency planners and first responders will use the information gathered from this site to plan for local and state emergencies. Should you ever need to dial ‘911,’ emergency personnel and first responders, including fire fighters, police officers and emergency medical technicians, will have access to this information and will use it to better serve you.

Resources to develop a self-preparedness plan

- www.delawarecitizencorps.org/videos – View a five-part video series on disaster preparedness that Delaware Citizen Corps produced for the State of Delaware. Videos are available in three formats: English (no captions); English with English captions; and English with Spanish captions.
- www.delawarecitizencorps.org/resources – Find links to other emergency preparedness videos, brochures and training.
- www.prepared.org – Learn how to make a plan, build a kit and stay informed, the basics in becoming prepared for a disaster. Call Delaware Citizen Corps at 302-659-2243 for information if you do not have internet access.
- www.acf.hhs.gov/programs/add/resources/dispub.html – Find emergency preparedness links and checklists for people with disabilities.

Accessible Instructional Materials Aid Students with Print Disabilities

For students with a print disability, accessible instructional materials are a requirement, not a luxury, according to federal law. When a student is unable to gain a sufficient amount of information from printed materials, schools must provide content in specialized formats such as audio, Braille, digital text and large print. Students who qualify include those with blindness, visual impairments, reading difficulties that have an organic basis, or other physical conditions.

It is the 2004 reauthorization of the Individuals with Disabilities Education Act (IDEA) that includes the provision for accessible instructional materials (AIM). This act states that all students with qualifying print disabilities in elementary and secondary schools must have access to print instructional materials—including textbooks—in appropriate accessible formats, free of charge.

Following the passage of the IDEA reauthorization, Beth Mineo addressed audiences throughout the country and testified at federal hearings about the need for AIM for students with print disabilities. She also raised awareness among Delaware’s educators and parents about this need, but the challenge was how to make it happen. How would 19 school districts and a like number of charter schools carry out the labor-intensive process of transforming print materials into alternate formats?

The answer began to unfold in October 2007 when Delaware was selected to join the AIM Consortium, a 15-state two-year collaborative led by the Center for Applied Special Technology (CAST) in Massachusetts. The Delaware Assistive Technology Initiative (DATI), now at the Center for Disabilities Studies, and the Delaware Department of Education (DOE) partnered on Delaware’s application for inclusion in the consortium. The state’s selection was due in large part to the long history the two organizations have

had in working together to assure curricular access for students with disabilities and to create professional development opportunities for educators. The start-up project was funded by the Office of Special Education Programs, U.S. Department of Education.

Delaware and other members of the AIM Consortium worked together to interpret and respond to IDEA’s mandate for AIM. Delaware’s original approach was two-fold: (1) to raise awareness of the mandate among students, families, educators and administrators; and (2) to help districts implement their transformation plans for materials through training and technical assistance—these materials needed to be available quickly and easily for students with print disabilities.

It soon became apparent that the development of AIM mechanisms in each district or school represented an astonishing duplication of services in dozens of settings statewide. In the interest of a more efficient and cost-effective approach, DOE and DATI/CDS are creating a completely new centralized service that will relieve local educational teams of the materials production burden.

In this new centralized model, the local educational team has responsibility for identifying students’ print disabilities and figuring out which formats will best meet their needs. Once the education team places an order with the AIM Center for the

needed materials, it is the center’s responsibility to determine how to provide the materials—by contacting vendors, communicating with other providers or building the materials from scratch. With the AIM Center then taking the lead in delivering materials in suitable formats, school teams can more appropriately spend their time educating students rather than producing materials.

CDS is partnering with AgoraNet, a local technology company, to create and maintain the service, including

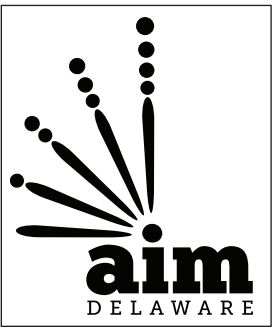
a website on which school districts place orders for accessible instructional materials. The company will also maintain a database of AIM materials that have been developed. Examples include: converting print content into audio files that can be played on devices such as MP3 players or iPods; altering the appearance of print by making it larger or changing the font; and delivering content with the support of a text reader that provides highlighting of words as they are read aloud.

The AIM Center website will be the “go-to” place for teachers, parents and other parties interested in supporting students who need their learning materials in specialized formats. It will include tutorials, frequently asked questions and general information supporting students with diverse instructional needs. The centralization of services will make it easier and more efficient for schools to find and provide curricular materials in alternate forms in the future.

Delaware’s schools are excited about the potential of alternate learning formats to make the general education curriculum more accessible to students with print disabilities. Drawing on the strength of its relationship with the schools, CDS can begin working on the next phase of the project: increasing student access to accessible instructional materials. This can be accomplished by informing students and families about their rights under the federal law and the various ways that AIM can improve their educational experience. CDS will also conduct professional development for teachers and administrators.

CDS has played a critical role in bringing partners together to assure a student’s rights to accessible instructional materials. In addition to working with DOE, CDS will coordinate with the Division for the Visually Impaired to make certain that services are inclusive. With the AIM project, the Center for Disabilities Studies has been a catalyst for systems change, ensuring that Delaware’s schools are responsive to the federal IDEA mandate.

For more information, contact Beth Mineo at mineo@udel.edu or 302-831-1589.



Audio support helps this student complete his reading assignment.

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