

Fall 2013

EDUCATE. CONNECT. EMPOWER.

## DELAWARE

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

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## The Center for Disabilities Studies Turns 20!

## A letter from CDS Director Beth Mineo

This year marks the 20th anniversary of the founding of the Center for Disabilities Studies (CDS), which originally was known as the University Affiliated Program for Families and Developmental Disabilities (UAP). In its relatively short history, CDS has made an enduring impression on Delaware, not only with *what* has been accomplished but also with *how* we go about impacting the state, the region and the nation. But more on that after a brief review of the Center's founding and its growth under the guidance of its first two visionary leaders.

In the late 1980s, Delaware was one of only two states without a UAP, a federally funded entity charged with improving supports and services across the lifespan for people with disabilities. With encouragement from Tom Pledge, then-director of the Delaware Division of Mental Retardation (now known as the Division of Developmental Disabilities Services), and support from the University of Delaware, a feasibility study was conducted and funding was received to establish UD's UAP in 1993.

Donald Peters, who worked on the design of the UAP with then-UD President David Roselle, was named the program's first director. Don had been a professor and chair of the Department of Individual and Family Studies (IFST), now the Department of Human Development and Family Studies. As the UAP's director, he recognized its potential as a catalyst for bringing people together—from University faculty for their input about disabilities studies to state agency staff providing services and supports—to work on behalf of people with disabilities.

Advisory councils were formed to get the work started. In its early years, the →



*Donald Peters,  
CDS founding director*

UAP was part of UD’s research arm, advised by a council that consisted of the University’s vice presidents. Another council, now known as the Community Advisory Council (CAC), was composed of community partners, people with disabilities and their family members. Marie-Anne Aghazadian, who has been the director of the Parent Information Center since 1989, served as the first chair of this council and continued as a member until earlier this year (see page 13).

The first five years of the UAP saw the development of an extensive community education program, a transition program that brought high school students with significant disabilities to campus, and involvement in an early childhood program evaluation. The disabilities studies minor began in 1997 and continues to influence the attitude and future careers of hundreds of UD students each year (see page 11).

In 1998, the UAP joined the College of Urban Affairs and Public Policy, became a center within the University and adopted its current name. With the passage of the Developmental Disabilities Act in 2000, UAPs became University Centers for Excellence in Developmental Disabilities (UCEDDs). Their fundamental purpose remained the same, yet their charge expanded to include advocacy, capacity building and systemic change.

CDS leadership also changed around that time, with Michael Gamel-McCormick succeeding Don Peters in January 2001. Michael was an IFST faculty member with research and teaching interests focused on children with disabilities, and the benefit of early intervention and

**Our mission is to enhance the lives of individuals and families 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 their communities in Delaware and beyond.**

education for those children. He launched an agenda for the expansion of services in areas of adult education, early intervention, school inclusion, program evaluation, and community education and training, and over the next seven years he broadened the Center’s reach and visibility.



*Michael Gamel-McCormick,  
former CDS director*

I succeeded Michael as the Center’s director in 2008, but I was far from a newcomer to CDS. I had collaborated with many Center staff—Michael, Ilka Riddle, Debby Boyer, Jamie Wolfe, Theda Ellis and Bev Stapleford—for years, and knew that my work in assistive technology, communication disorders and systems evaluation and improvement would be enriched by virtue of the Center’s orientation and context. My transition to the Center happened to coincide with the dramatic downturn of the economy, so one of my enduring priorities has been the diversification of the

Center’s portfolio of funded projects to ensure that we not only survive, but *thrive*—even in the face of economic uncertainty.

The characteristics that drew me to the Center are the same ones that enable CDS to fulfill its mission with such distinction. The staff is an amazing bunch—

engaged, knowledgeable, collaborative and passionate—and they attract others who are equally committed to the vision endorsed by the CAC in our 2012–2017 strategic plan. The *what* in that plan focuses on inclusion, equity and opportunity across the domains of education, employment, health and community living. But I think it is in the *how* that CDS really shines. Nothing we do is conceived of or executed in a vacuum. We have been



*Beth Mineo,  
current CDS director*

successful in impacting systems—and thus impacting individuals with disabilities and their families—because we **dream, plan** and **act** hand-in-hand with those very systems and people.

While our ultimate goal is to impact those with disabilities and their families, we know that challenging and mentoring the next generation of service providers and policymakers is

essential if we are to achieve that goal. Our affiliation with the University of Delaware—and specifically with the College of Education and Human Development—affords us the opportunity to influence students in the classroom, as well as through volunteer opportunities, undergraduate internships and graduate assistantships. Countless students touched by CDS have gone on to make their own mark on disability advocacy, services and policy in Delaware and throughout the nation.

The *delAware* newsletter has been sharing information with the community since 1993. This issue is dedicated

to our founders and those who have supported our mission over these two decades. You'll find articles about the Center's role in trendsetting research and services, educating students, forming partnerships that have strengthened services and supports for Delawareans, and responding to federal and state mandates for increased equity and inclusion.

This issue of *delAware* unveils a new, more accessible format. Articles were researched and written by staff of the Center's Dissemination and Advocacy Unit: Michele Sands, its former director; Victoria Clark, communications specialist; and Katie Hoffman, graduate assistant. Our heartfelt thanks are extended to Michele, who served as the editor of *delAware* for close to five years and retired from her position at the end of June.

As we look back on the last 20 years, there is much to celebrate. By seeking to enhance the lives of individuals and their families, we have also transformed communities. Educate. Connect. Empower. These words reflect our past and guide our future.

Sincerely,

A handwritten signature in black ink that reads "Beth". The script is cursive and fluid.

*Beth Mineo, Ph.D., CCC-SLP*

*The University of Delaware's Center for Disabilities Studies (CDS) supports the well-being, inclusion and empowerment of people with disabilities and their families. CDS, the Delaware Developmental Disabilities Council and the Disabilities Law Program of Community Legal Aid Society are partners in Delaware's developmental disabilities network. Each partner receives a portion of its funding from the Administration on Intellectual and Developmental Disabilities, which is the federal agency 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. The easiest way to make a gift is to visit the web page [www.udel.edu/makeagift](http://www.udel.edu/makeagift). The online form allows you to give via check or credit card. Please note "Center for Disabilities Studies" in the "other" designation box. To mail in a check, please indicate "Center for Disabilities Studies" in the check's memo section and mail it to: University of Delaware, Gifts Receiving and Processing Office, 001 Hullihen Hall, Newark, DE 19716. For additional information on how to make a gift, please contact the Development Office at 866-535-4504 or email [annualgiving@udel.edu](mailto:annualgiving@udel.edu).*

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## 20th Anniversary Celebration

October 2, 2013 was a big day for the Center as we marked our 20th anniversary with a celebration at Clayton Hall. Featuring interactive displays, a timeline marking important milestones for CDS and its state and national partners, and a memorable hour with featured speaker Keith Jones, the event reunited friends and colleagues, and symbolized the Center’s transition into its “adult years.” The pictures tell the story...



*Andrew Dinsmore from Senator Coons’ office discusses advocacy with CDS staff member Jamie Wolfe.*



*Secretary Rita Landgraf, Honorary Chair of the event, with author Rachel Simon, CDS Director Beth Mineo and longtime advocate Gary Heckert.*



*Featured speaker Keith Jones advocates changing policies and attitudes.*



*CDS staff member Max Kursh and CLSC program graduate Geoffrey Steggell at the Empowered Transitions display.*



## Twenty Impactful Years for the Disability Community

The Center for Disabilities Studies (CDS) was founded at a critical time in disability history. The Americans with Disabilities Act—often considered the most important civil rights law for cross-disability support—had passed just three years earlier in 1990. The signing of this act into law by President George H.W. Bush came at the end of a decade in which other significant legislation requiring accessibility and inclusion in employment, housing and transportation had also been mandated by law. Such federal laws and national trends have consistently guided the Center’s strategic planning and project development, especially when proposals for competitive federal grants were awarded funding.

CDS projects have reflected both state and national priorities. Consequently, Delaware government agencies repeatedly choose the Center to partner on projects because of our expertise in disabilities, technical assistance, professional training and project evaluation. As Don Peters, the Center’s founding director, explained, “We had no choice but to respond to national trends and mandates. Throughout our work, we wanted to keep in mind how trends were emerging, how laws were changing and how the state was responding to laws being made at a national level.”

This article explores how CDS has responded to trends and mandates in the past 20 years and how people with disabilities in Delaware and beyond have contributed to and benefited from our efforts.

### Education as a core component

Education is at the center of many projects at CDS because it helps build a solid foundation for systems change, capacity building and information dissemination of best practices. For nearly 20 years, the Center has offered pre-service training for undergraduate and graduate students—largely through the disabilities studies minor (see page 11). In addition to university education, CDS also has a long tradition of community education for professionals, families and other community members. Through community and university education, we act as a conduit for cutting-edge information in Delaware and beyond.

Professional development for educators was one of the first initiatives at CDS, focusing on inclusive practices and improved access to K-12 education for students with disabilities. The Comprehensive System of Personnel Development (CSPD) started at CDS in 1994 to analyze and address the professional development needs of

Delaware school personnel. Although the project initially focused on students with disabilities, the program eventually expanded to include broader professional development needs throughout Delaware, which continues in many of our current school-related projects.

In 1997, the Center narrowed its focus in response to the Individuals with Disabilities in Education Act Amendments (IDEA 1997). Not only did IDEA 1997 redefine what students with disabilities should know and be able to do, but it included the first federal requirement for alternate assessments of students with disabilities. CDS responded immediately by developing the Delaware Alternate Portfolio Assessment (DAPA)—a collaboration with the Delaware Department of Education (DDOE)—that pioneered new methods for evaluating the progress of Delaware’s most challenged learners. After the 2001 passage of the Elementary and Secondary Education Act (commonly known as the No Child Left Behind Act), DAPA evolved to align with the state’s revised testing requirements.

Although DAPA was absorbed into the new Delaware Comprehensive Assessment System (DCAS), the Center continues to support equal access to educational opportunities through its ACCESS (Adapting Curriculum and Classroom Environments for Student Success) project, which began in 2011. The project provides educators, families and community members with the necessary tools to improve educational outcomes for students with significant intellectual disabilities. In addition to professional development, ACCESS also adapts books so students with disabilities can access Delaware’s common core curriculum.



IDEA 1997 also mandated that school personnel consider positive behavioral interventions and supports within students’ individualized education programs (IEPs). In 2000, CDS launched the Delaware Positive Behavior Support (DE-PBS) project to address professional development needs across the state. DE-PBS took that a step further, however, and advocated for Delaware schools to adopt a school-wide approach to positive behavior support.

Michael Gamel-McCormick, the Center’s former director, remarked, “Disability issues are often issues that touch every person. DE-PBS really enhanced school climate and the learning environment for everyone in schools—not just for students with disabilities.”

**Disabilities across the lifespan**

The Center’s original goal was to “respond to the needs, wishes and hopes of people of all ages and with all types of disabilities.” For the past two years, the autism planning initiative did just that as it explored the ongoing needs of Delawareans with autism spectrum disorder



*Special educators from all three Delaware counties would gather every year to score the Delaware Alternate Portfolio Assessment materials.*



*The Full-Day Kindergarten Pilot Evaluation project compared the outcomes of full-day and part-day kindergarten models during the 2004-2005 academic year. The evaluation included nine school districts and one charter school. One of the participating kindergarten programs is shown above.*

(ASD). By collaborating with other organizations and community members, CDS conducted a comprehensive needs assessment and developed a strategic plan to improve services for individuals with ASD and their families. Reflecting on this collaboration, Mary Ann Mieczkowski, director of Exceptional Children Resources for DDOE, commented, “This is not just a strategic plan—it has come alive.”

Additionally, CDS addresses specific age groups through efforts targeting early intervention and youth-to-adult transition. In the Center’s first few years, we evaluated several early intervention programs throughout the state to identify needs. In 1997, the Center responded by creating the Northern Delaware (now New Directions) Early Head Start program (NDEHS). NDEHS’s efforts focused on building capacity for early childhood care, disability support, training and service coordination.

Although NDEHS has migrated to the Department of Human Development and Family Studies at UD, the

Center continues to support early intervention through its developmental screening program and assistive technology in early childhood project. The latter is one of only three programs in the country supported by a model demonstration grant from the federal Office of Special Education Programs.

Just as early intervention helps set children on the right developmental path, youth-to-adult transition ensures that young adults with disabilities are prepared to lead more independent and interdependent lives.

Michael Gamel-McCormick observed, “From its first school-to-community transition project, the Center was innovative in exploring how to ensure employment and community living was a possibility for all, focusing on empowering young adults with disabilities to take control of their lives.” In addition to several education-based transition programs (see page 10), CDS also works on projects that facilitate health care transition, increase self-determination and promote self-advocacy.

**Equal access to health and wellness**

In 2005, the U.S. Surgeon General released the *Call to Action to Improve the Health and Wellness of Persons with Disabilities*. The message was clear: Good health is necessary for people with disabilities to have the freedom to work, learn and engage actively with their families and in their communities.

In many cases, medical, fitness and other health-related facilities are inaccessible to people with disabilities. Through research, training, technical assistance and advocacy, CDS has served as a catalyst for systems change and capacity building in the public health arena throughout Delaware.

In 2007, the Center received a grant from the Centers for Disease Control and Prevention (CDC) for Healthy Delawareans with Disabilities (HDWD) with the goal of reducing health disparities for people with disabilities. The project’s mission is to ensure that individuals with disabilities will live active and healthy lives and will have the resources, supports, programs and services necessary to do so.

With the recent passage of the Affordable Care Act, HDWD has become an invaluable resource for its partner, Delaware Health and Social Services. According to Secretary Rita Landgraf, “people with disabilities play a critical role in the legislation, and that perspective needs to be a key piece in health care delivery and transformation throughout the state. CDS has been tremendous in integrating access and inclusion in health care throughout Delaware. We gain in our public health level because CDS staff has that level of expertise as well as knowledge of population health.”

**“CDS has been tremendous in integrating access and inclusion in health care throughout Delaware.”**

**-Secretary Rita Landgraf**

**Empowering through assistive technology**

Advances in technology—and an alarming disparity in access to technology for people with disabilities—led

Congress to pass the Assistive Technology Act in 1988. The Delaware Assistive Technology Initiative (DATI) was established in 1991 with funding from this legislation to improve access to assistive technology for Delawareans with disabilities.



*People of all ages, types of disabilities and technological experience can find the tools they need at our Assistive Technology Resource Centers.*

The Center had a strong partnership with the Delaware Assistive Technology Initiative (DATI) before it became a part of CDS in 2008. For nearly a decade before that, CDS and DATI collaborated on a variety of projects, including increased availability of AT for consumers, and training and technical assistance for educators on Universal Design for Learning (UDL) applications.

When DATI joined the Center, it brought a wealth of resources and expert staff who have been indispensable to many of our initiatives—particularly education, employment and transition. Brian Hartman, project director at the Disabilities Law Program and Community Advisory Council member, knew DATI before it joined CDS and shared, “DATI is critical in connecting individuals with disabilities with the assistive technology they need to succeed in life.” He added, “It is just one of many projects at the Center that impact a large population of Delawareans with disabilities.”

In retrospect, the last two decades have offered many opportunities for the Center for Disabilities Studies to respond to trends and mandates, as well as to identify and seek to improve issues in the disability community. Our actions and our reactions across the past 20 years have translated these opportunities into the chance to educate, connect, empower and—above all—transform the lives of those with disabilities in Delaware and beyond.



## Becoming the Person You Wish To Be

When Michael Denny entered the Career and Life Studies Certificate (CLSC) program at the University of Delaware in 2011, he wasn't sure what his goals would be. He was passionate about George Lucas and Star Wars, and enjoyed playing video games and writing stories. As he progressed through CLSC, which is the Center for Disabilities Studies' (CDS) two-year postsecondary transition program for young adults with intellectual disabilities, the staff helped Michael focus on his long-term goal of becoming a writer.

Some of Michael's internships provided guidance and opportunities to develop his writing skills, and as a member of the Classic Composers he was one of the authors of the 2013 issue of the *CLSC Gazette*. His article, "World of Work-craft," describes the type of work experiences CLSC students had over the first two years of the program.

Michael's own work experiences provided him with what he calls "endurance," the ability to work at a job for increasingly longer periods of time. He notes that his internships and worksite experiences at UD were exhaust-

ing for him at times, but that "doing those types of jobs built up my endurance and I learned a job ethic." Michael views endurance as the most important change in him while in the CLSC program.

"I might not  
have got this far  
without coaching."

-Michael Denny

At the same time, through CLSC classes taught by CDS staff members, experiences on campus, and the support of coaches in all activities, Michael learned to communicate more effectively and conduct himself appropriately in the community and workplaces. The resulting changes in his behavior have been observed

by those who have known Michael since he was a student in the Center's Community-based Education Alliance (CBEA) program; they note that he is now more comfortable with himself and others, is more receptive to suggestions about his actions and engages more easily in conversation.

### Coaching makes a difference

Coaching is a key factor in facilitating such change in Michael and the other participants in CDS's transition programs. Coaches work with CLSC students in all phases and settings of the program. Although there were times when Michael resisted this support, he learned the importance of cooperating with his coach and discovered that he was benefiting from this guidance, whether learning to organize his thoughts or to focus on a particular task.

"I might not have got this far without coaching," Michael commented when sharing his experiences as a CBEA and CLSC student.

After completing CLSC and receiving his certificate at the College of Education and Human Development's May 2013 convocation, Michael accepted a part-time job at the animal lab in UD's Department of Animal and Food Sciences. There, he



*Michael Denny practices sharing his work portfolio along with other CLSC students as part of the career services component of the CLSC program.*

receives coaching from Deanna Pedicone through Swank Employment Services, a CDS program that contracts with Delaware's Division of Vocational Rehabilitation and Division of Developmental Disabilities Services to provide supported employment services to individuals with disabilities. According to Deanna, on-the-job coaching gives Michael the feedback he needs to be productive and relate well to other employees.

Michael hasn't forgotten his long-term goal of becoming a writer. While continuing his part-time job in the fall, he plans to enroll in Delaware Technical Community College and register for an English course. He is among the 10 students in CLSC's first graduating class who received their certificates and are now better prepared to take their next steps in life. As Michael's classmate, Andrew Netta, observed, "CLSC helped get our futures started."

## Person-Centered Transition Programs at the Center

Michael Denny is just one of the many young adults who have benefited from our person-centered transition programs. Throughout the past 20 years, these transition, education and employment programs have supported young adults with disabilities in an inclusive environment, as well as provided connections to the University and employment opportunities.

These transition programs use person-centered planning to chart a course for the future—using each young adult's own strengths, hopes and dreams as a starting point. The person-centered model allows all students to increase their self-determination and improve their community-based competence.

### Transition Partnership Project

The Transition Partnership Project (TPP) began in 1994 as an agreement between CDS and the Red Clay Consolidated School District's Meadowood Program. The goal was to provide a consumer-driven, person-centered educational model program for students with moderate to severe disabilities. For the first time in Delaware, high school students with significant disabilities came to UD's campus as part of the transition process. The program used an apartment near campus to provide a daytime base for students where they learned independent living skills.

### Community-based Education Alliance

When the TPP program concluded in 2006, CDS offered a similar program—the Community-based Education Alliance (CBEA) program—to three other

Delaware school districts for their 18- to 21-year old students with disabilities. Through CBEA, students learned skills necessary to prepare for a more independent life before exploring potential career paths and developing job skills. They then transitioned to a work site on or near campus for an unpaid internship.

### Career and Life Studies Certificate

In 2011, the CBEA program ended with the launch of the Career and Life Studies Certificate (CLSC) program, a two-year certificate program for individuals with intellectual disabilities. The program provides academic, career and independent-living instruction in preparation for gainful employment or further education. CLSC students attend classes, participate in internships and work experiences, and engage in campus activities.

### Swank Employment Services

Swank Employment Services began at CDS in 2008 to offer the full range of employment-related services for people with disabilities. The project's staff provides job skills assessments, career exploration, pre-vocational and on-site job skills training, internship and paid employment opportunities, job site accommodations, and follow-along services for supported employment, as well as academic coaching.

*Swank and CLSC are both programs of the Transition, Education and Employment Model (TEEM) unit at CDS. For more information about the TEEM unit, visit our website at [www.udel.edu/cds](http://www.udel.edu/cds).*

## Building Toward the Future Through University Education

The 20th anniversary of the Center for Disabilities Studies (CDS) also marks close to 20 years of our involvement in the education of University of Delaware students. Since our establishment in 1993, one of the core functions of the Center has been to provide training to those who are interested in disabilities. CDS has contributed to both undergraduate and graduate education at the University.

Families and Developmental Disabilities was developed and taught as an experimental course during the 1994 spring semester by Penny Deiner, a professor in the Department of Individual and Family Studies and associate director of CDS. This interdisciplinary course had a target enrollment of 50 students, but attracted more than 140 students in its first year. Interest in the course continued to grow over the next few years, inspiring CDS-affiliated faculty from across the University to gather in 1996 to design the disabilities studies minor. The minor was approved by the University in 1997, at which time a capstone senior seminar also was created.

A minor in disabilities studies provides students with the opportunity to learn about the policies, services and systems that support the full participation of people with disabilities in community life. The six-course structure of the program has not changed since its initial approval. Students in the minor must complete three core courses—Introduction to Exceptional Children, Families with Developmental Disabilities and Senior Seminar in Disabilities Studies—that are taught by CDS staff and other College of Education and Human Development faculty. In the seminar, students discuss current disability policies, different types of disability advocacy and the person-centered approach evident in all Center programs.

The core courses provide a foundation that students can apply to both their professional and personal lives. Katie Eaken, a 2010 graduate with a minor in disabilities studies, went on to receive a master of arts (2011) and educational specialist degree (2013) in school psychology from the University. She reflects, “The Families and



*Disabilities Studies minors Danielle Pack, Anne Yuskevich, Elizabeth Watson, Anna DePace and Amy Smith meet with Community Advisory Council member Linda Heller (second from the left) as part of their senior seminar.*

Developmental Disabilities course made the biggest impact on me because I learned about the struggles and the successes of having a family member with a significant disability.”

Associate Professor Laura Eisenman, coordinator of the minor, explains that regardless of their major, students “graduate with a broader perspective and deeper understanding of the experiences of people with disabilities.” In addition, she said, “Students gain an appreciation for engaging and working with people who have disabilities.”

With a fairly flexible curriculum, including a choice of electives in human development, social systems and service delivery, students are able to tailor their studies within the minor to their interests. Former UD student Rachel McCulley, who currently is the resident program director for the Spectrum College Transition Program in Scottsdale, Ariz., elaborates, “The broad range of experiences I had in the disabilities studies minor—from scholarships, to work experience, to study abroad—have all contributed to my professional career.”

The disabilities studies minor has grown exponentially over the past 15 years. In total, the program has graduated more than 440 students, with another 400 students from six of the seven UD colleges enrolled during the 2012-2013 academic year. At UD’s May 2013 commencement, 90 students graduated with a minor in disabilities studies.

**“I learned about the struggles and the successes of having a family member with a significant disability.”**

**-Katie Eaken**

In addition to the experiences and education that CDS offers as part of the disabilities studies minor, the Center has long provided work experiences and internships to UD undergraduates and assistantships to graduate students. In fact, a graduate assistant was on staff when the Center was established in 1993. Graduate assistants receive funding for their work, which often influences the direction of their future careers.

Looking forward, UD students will continue to benefit from the Center for Disabilities Studies, whether through enrollment in a single course, completion of the disabilities studies minor or work experiences at the Center. Regardless of how students cross paths with CDS, they will carry the lessons and experiences learned about disabilities far beyond their time at UD.



*Disabilities Studies minors were able to take their skills and studies global with a study abroad trip to Ghana, the United Arab Emirates, Nepal and Thailand, where they met with a variety of people and organizations to learn about the cultural dimensions of disability experiences.*

## Connecting with the Community

The Center is uniquely positioned to connect the expertise and resources at the University of Delaware with the state's disability community. Our affiliation with the University provides a platform for research and evaluation, which helps influence current trends and best practices for disability-related issues. On the other side, our partnerships with community organizations give us a first-hand perspective on needs and opportunities within the disability community.

Former UD President David Roselle was pleased when Don Peters approached him in the early 1990s about establishing the Center. Roselle commented, "It was important for the University to support a program designed to enable people with developmental disabilities to achieve their personal goals."

At that time, the population of Delawareans with developmental disabilities was growing annually. By involving UD faculty from a range of disciplines, CDS was able to work in conjunction with several Delaware agencies and organizations to accomplish the Center's goals.

Throughout its history, CDS has been a strong proponent of inclusion, equity and opportunity. According to Bob Valihura, chair of the Center's Community Advisory Council (CAC), "CDS is a jewel in the University's crown, whose influence is felt throughout the state as it transforms communities for people with disabilities."

### CDS embraces its community partnerships

The Center's work has benefited from long-standing partnerships with state agencies like the Delaware Department of Education and Delaware Health and Social Services; Delaware's developmental disabilities network partners, including the Developmental Disabilities (DD) Council and Disabilities Law Program at Community Legal Aid Society; and countless others.

"CDS is a jewel in the University's crown, whose influence is felt throughout the state as it transforms communities for people with disabilities."

-Bob Valihura

Owing to the richness of these partnerships, CDS has managed to address the full breadth of disability issues in Delaware and beyond. Cory Nourie, a former CDS staff member who currently serves on the executive committee of the CAC, comments, "CDS staff often have their finger on the pulse of disability issues in Delaware, or know who does."

In her role as executive director of Delaware's Parent Information Center and a longtime CAC member, Marie-Anne Aghazadian has seen the Center grow and take on new challenges over the past 20 years. She remarked, "The Center has been invaluable for me, both professionally and personally. The Delaware Positive Behavior Support project has been a very useful resource for the parents we serve and for our staff, who attend the social skills and other training sessions."

These connections to community organizations have been crucial in supporting our vision and spreading the word about what CDS has to offer. Theda Ellis, an associate director of CDS for several years,

stressed the importance of connecting with community: "It was important for the Center to develop a network of people throughout the state. We would always work with advisory councils to make sure that we were delivering what the disability community needed."

### Community Advisory Council

Although many of the Center's projects have their own advisory councils, CDS relies first and foremost on its central council—the Community Advisory Council—to focus our work on key disability issues in Delaware. By lending their voices and individual experiences, members advise the Center on critical disability-related issues within the state and guide our energy to address the most pressing issues impacting people with disabilities in Delaware and throughout the nation.



*Community Advisory Council members David Lynch (foreground) and Larry Henderson (background) engage with state leaders about the roll-out of the health insurance marketplace in Delaware.*

The CAC is made up of about 50 engaged stakeholders in the disability community, including people with disabilities, their families and caregivers, and professionals and policymakers in disability-related fields. In order to ensure that the CAC reflects Delaware’s demographics both geographically and culturally, members come from all three counties and a majority of the members are people with disabilities and their families.

The Center for Disabilities Studies has always counted on its solid connections to the University of Delaware and community organizations to help advocate, educate and provide services for people with disabilities and their families. Pat Maichle, a CAC member and executive director of the DD Council, commented, “I’ve been around long enough to remember when there was no Center. The camaraderie and collaborations have made it significantly better for people with disabilities in the state and services will only continue to get better.”

**“The camaraderie and collaborations have made it significantly better for people with disabilities in the state.”**

**-Pat Maichle**

## On the Path to Prominence

As part of the University of Delaware, we contribute to the realization of the University’s vision. Our work aligns perfectly with UD’s Path to Prominence, the strategic plan guiding its progress over the past five years. The Path’s guiding principles are Delaware First, Diversity, Partnership, Engagement and Impact—all of which are ideals that characterize our projects.

In keeping with the “Delaware First” principle, most of our work directly impacts the Delaware community. However, many of our efforts receive national attention as well. Dean Lynn Okagaki of the College of Education and Human and Development adds, “By building on the latest research, the Center has been able to create programs that are models for organizations across the country.”

In particular, the Center advances UD’s goal of becoming an “engaged university” through its involvement of faculty, staff and students in finding solutions to real-world challenges. Most of the Center’s activities are designed to answer important questions that directly impact the lives of people with disabilities, their families and the professionals who serve them.

UD President Patrick Harker comments, “CDS research isn’t conducted in a lab; it’s out in the real world, determining more effective ways to help people with disabilities learn; get and keep jobs; and maintain healthier lives. Their research also explores how schools, health care facilities and communities can be more inclusive and accessible. CDS translates these research findings into new policies and guidance for new practices, bringing the research full circle—back to having a direct impact on the lives of people with disabilities.”

## Advocacy Comes Full Circle

Like most recent community college and university graduates, 24-year old Lizzy MacDonald is looking for a job in her chosen field. With an associate degree in human services from Delaware Technical and Community College (Delaware Tech), she hopes to work as an advocate for people with disabilities.

Lizzy was born with spondyloepiphyseal dysplasia congenita, a form of dwarfism that resulted in serious medical issues. She was inspired to aim for a career in human services by many of the people she got to know over the years because of the role her mom, Beth MacDonald, plays in the disability community.

As the parent of a child with disabilities, Beth learned the importance of connecting with other parents of children with special health care needs and disabilities, and becoming involved in and collaborating with organizations that advocate and provide resources for these children. Beth first made her voice heard in 1992 as a member of Delaware's Interagency Coordinating Council (ICC), a governor-appointed advisory council that assists and advises Delaware Health and Social Services to develop, implement and improve Delaware's early intervention (birth to three) system.

“Finally, somebody was listening to other issues besides the medical ones,” she said, recalling how the ICC gave her the opportunity to share her concerns about how to handle other issues at home related to her daughter's health. It was then that Beth realized that volunteering information and opinions while connecting with community organizations and resources “can change the course of what happens in your life and what happens for your child.”

With continued involvement in disability-related organizations, including Delaware Family Voices, the Coordinating Council for Children with Disabilities and the Special Needs Alert Program, Beth found herself sitting across the table and interacting on a regular basis with staff from the Center for Disabilities Studies (CDS). And Lizzy was often right next to her, observing human services in action by people with and without disabilities.



*Lizzy MacDonald waits with fellow students before Delaware Tech's graduation ceremony.*

According to Beth, Lizzy was motivated to consider human services because of the positive work that was being done by CDS staff members such as Michael Gamel-McCormick and Ilka Riddle. She also learned that other people with disabilities, including CDS Disabilities Specialist Jamie Wolfe and the late John Jefferson, had jobs that helped move the system forward.

“Jamie is a role model for my daughter,” Beth noted. “She has seen Jamie working at CDS since she was younger.” Beth pointed out that “having folks that are in tune with what is going on in the disability community is really important. It's not just lip service—CDS follows through.”

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Before graduating from Delaware Tech, Lizzy interned at the Governor's Advisory Council for Exceptional Citizens with Executive Director Wendy Strauss. One of Lizzy's projects involved interviewing her former teachers, school administrators and parents of former classmates about having a student with disabilities at their school. Lizzy said she was able to talk with them about their experiences and gain a broader understanding of working with people.

While she looks for a job, Lizzy has been volunteering at events that raise awareness and funding for disability-related initiatives because, her mother says, "It is important to give back to those that have given her so much."

At Autism Delaware's Drive for Autism event, a celebrity golf tournament that raises money for families affected by autism, Lizzy posted pictures and updates on social media outlets. Reflecting on this experience, she said, "It's a whole different situation when you're helping others. It's a great experience and a great cause."

*Lizzy and Beth MacDonald have been featured in previous issues of delAware (Spring 1998 and Summer 2001) and in the second edition of Connecting the Dots, A Guide to Finding Services for Children and Adults with Disabilities and Special Health Care Needs in Delaware. These publications can be found on the CDS website, [www.udel.edu/cds](http://www.udel.edu/cds).*