Center for Disabilities Studies

2016-2017 Annual Report

Artfest

Center for Disabilities Studies

EIAWARE

Greetings, from CDS

DISAB

The University of Delaware received prestigious national recognition in 2015 as an "engaged university" from the Carnegie Foundation for the Advancement of Teaching. That means we connect to and with communities, not only bringing knowledge to them but authentically partnering with them in joint discovery and in the preparation of students for the lives they will lead when their formal studies have concluded. As you will see throughout this annual report, CDS engages meaningfully with scores of community organizations and agencies. What the data don't reflect, however, are the defining roles that individuals with disabilities and families play in the work of the Center. They are collaborators in designing and executing research and demonstration projects, partners in advocacy for more responsive laws and policies, and also some of the most effective teachers our undergraduate and graduate students encounter.

They invite students into their world, engaging student teams in the <u>Senior Seminar in Disability Studies</u> for an entire semester, and they serve as mentors for trainees in our new <u>LEND program</u>. In these roles, they teach students about the impact of society's misconceptions and biases about disability on their personal lives; about the life-altering power of faith, love and resilience; and about the role that our students can and will have in enacting more responsive policies and practices in their personal and professional lives. Just look at the annual report story, <u>How could I do any less?</u>, recounting LEND trainee Dave Cavagnino's time spent with the Cole family.

From the bottom of my heart, and on behalf of all touched by their generosity of time, energy and wisdom, I thank these individuals and families for engaging *us* as learners, collaborators and partners in making our work more inclusive, accessible, welcoming and affirming for all people.

beth

Beth Mineo marked her ninth year as director of CDS in 2017.

Doing things I've never done

All smiles outside her dorm room, Catherine Lin admitted later to her pal Hannah Craighton that she felt nervous about her new situation: living on campus. Not to worry, Craighton told Lin, predicting her nerves would vanish like Craighton's did the year before when *she* was new to dorm life.

Lin and Craighton are among the students pioneering the <u>Career and Life Studies Certificate's (CLSC)</u> new residential program, an option for individuals with intellectual disabilities enrolled in UD's two-year program that offers academic, life skills and career development opportunities. "I can have a hard time making decisions," Lin said. "So did I," said Craighton, when she lived in a UD dorm the year before. "But on campus, you have the freedom and flexibility to make decisions."

The residential program's goal, says <u>CLSC Director Brian</u> <u>Freedman</u>, is to "create opportunities for CLSC students to take the next steps in living independently and interdependently." It offers the typical college experience – from the joys and challenges of greater autonomy to living with roommates. By immersing themselves in everyday life at UD, CLSC residential students, supported by staff and mentors, encounter opportunities to balance responsibility and recreation on top of studying and developing their skills alongside non-residential CLSC students.

Craighton and her boyfriend Spencer Haber, another CLSC residential student, seized every opportunity to venture into the community. Elected president of <u>Going</u> <u>Social</u>, a club open to the entire student body, Haber expanded the club's events calendar and was, with Craighton, an avid participant.

Lin prefers the low-key approach, spending the time between classes and her internship watching TV and exploring campus with friends. But she noted she's already benefiting from the greater freedom and flexibility that Craighton spoke of. "I'm more confident now. I'm doing things I've never done," she said. "It's the new Catherine."

<u>CLSC applications</u> are open year-round. To apply, or learn whether dorm life is right for you, <u>contact Candy Greenleaf</u>.

The "new" Catherine Lin (right) and pal Hannah Craighton, pioneers in the Career and Life Studies Certificate's residential program.

It really changed my life

From ramps to roll-in bathrooms to automatic door-openers, home accessibility modifications enable people with paralysis to live with dignity, independence and comfort. But as Frank and Donna Santoro found out, they can come with a hefty price tag.

Frank Santoro had a stroke five years ago, just after he and his wife Donna moved into their new house in Wilmington. Left unable to climb the stairs, Santoro couldn't reach his secondfloor bedroom or bathrooms. The couple couldn't afford to install a chair lift that would enable him to go upstairs, and they couldn't secure any financial assistance.

That changed once they connected with CDS's Delaware Assistive Technology Initiative. As part of its new program, Nowhere Else to Turn, DATI paid for the purchase and installation of a chair lift for the Santoros.

"It really changed my life," Frank Santoro says. "It's phenomenal to sleep in my own bed, to take a shower and get really clean." "Taking care of him wore me down," Donna Santoro adds. "Getting that chair lift – it was like Christmas."

Nowhere Else to Turn offers funding to selected applicants who cannot afford home modifications and have not been able to obtain help from other sources, including state agencies such as the Delaware Division of Medicaid and Medical Assistance, Division of Services for Aging and Adults with Physical Disabilities and Division of Vocational Rehabilitation, and nonprofits such as Paralyzed Veterans of America.

Unfortunately, the "overwhelming" need for home modifications in Delaware far exceeds the budgets of agencies and organizations helping people with paralysis defray their costs, says CDS Director Beth Mineo. Nowhere Else to Turn is helping fill that gap through a High Impact Innovative Assistive Technology grant received from the <u>Christopher and</u> <u>Dana Reeve Foundation</u>, a leading nonprofit in the research and treatment of paralysis.

"We are committed to helping people with paralysis live in their communities of choice," Mineo says.

For more information and an application for Nowhere Else to Turn, <u>contact Beth Mineo</u>.

To view a video of the Santoro's experience, click here.

'It was like Christmas': A chair lift from the Nowhere Else to Turn program became the gift that keeps on giving for Frank and Donna Santoro.

Building better outcomes

Application, denial. Appeal, denial.

Red Clay School District speech-language pathologist Mary Anne Terzaghi was used to having her students' applications for augmentative and alternative communication (AAC) devices denied. AAC devices, operated by hand, eye or other body part, enable people with complex communication needs to be understood. However, Medicaid managed care organizations (MCOs), which serve as agents of Delaware Medicaid, often don't approve requests.

Elizabeth Bortz, a speech-language pathologist who works for an AAC vendor and helps prepare applications for Medicaid funding, says, "It's almost [the MCOs' policy] to deny the first application. And in many cases the denials don't make sense." Sehaj Kaur's six-year old eyegaze device was unreliable; for example, when she attempted to tell her mom she had to go to the bathroom, the device wrongly said she wanted to go for a walk. Her application was turned down.

Convinced her students qualified for support under Delaware's Medicaid policy, Terzaghi turned to CDS **Director Beth Mineo**. Mineo pointed out the conflicts between Medicaid's AAC policy and the MCOs' practices, and suggested engaging the state's Protection and Advocacy organization, the Disabilities Law Program (DLP). With help from Mineo and CDS AAC Specialist Dick Lytton, DLP lawyers Brian Eng and Bill Molchen crafted a strategy to represent two students, including Kaur, at a new appeal held in front of a state officer from the Department of Health and Social Services. The officer approved Kaur's appeal. The other case didn't even get that far - the managed care organization's representatives stopped the proceedings halfway and reversed their position. Manjeet Kaur, Sehaj's mother, says the decision thrilled her daughter. "She's all excited," Kaur says. "With the new device, she's learning more, communicating better."

Mineo hopes to build on these outcomes by raising awareness of the policy – and how it impacts access and use of AAC devices – among clinicians and MCO decision-makers. She is also hoping to expand Medicaid coverage to less expensive alternatives, such as iPads and tablets.

Bortz has already seen the cases bear fruit. Two other eyegaze applications she facilitated were approved on the first try – no appeal necessary.

Mary Anne Terzaghi (left) watches Sehaj Kaur access her new eyegaze device, acquired through the intervention of <u>CDS</u>, Terzaghi and the Disabilities Law Program.

Focus on the individual

"Person-first language" provided the spark, say Sarah Hearn, Rebecca Jewell and Audrey Rossi. After learning more about it as students in <u>UD's Disability Studies minor</u> – how the word arrangement in the phrase "person with a disability" puts the focus on the individual, a complex being with wants, needs and values, rather than the person's disability – each decided she wanted to advance the practice and the philosophy behind it.

After graduating, they got the opportunity to do so at UD's Center for Disabilities Studies, which administers the Disability Studies minor and promotes person-centered approaches in all its work.

For several years at CDS, <u>Hearn</u> has championed respect of students as individuals, regardless of need. As a coach for the <u>Positive Behavior Support Project</u>, Hearn says she urges educators who support students with academic or behavioral needs not to "lead with labels." Instead of "special ed student," for example, she might recommend "student receiving special education services."

Jewell puts her students first by stepping back and letting them grow. Starting in a Disability Studies class on mentoring, Jewell supported students with intellectual disabilities who are pursuing the <u>Career and Life Studies</u> <u>Certificate (CLSC)</u>, CDS's two-year postsecondary program. Now CLSC program assistant, she says she has learned not to look at people with disabilities as people who need help.

"My job as an advocate isn't to protect students," she says, "it's teaching students to advocate for themselves."

Rossi's job is to provide opportunities for people with disabilities to speak for themselves. In the minor, she says she was drawn to community inclusion and personcentered supports. At CDS, she coordinates the National Core Indicators surveys, asking people with disabilities and their family members about their quality of life and satisfaction with services they receive. She says the goals are to amplify their voices and identify needed improvements in services.

But that's not the only motivator. "My favorite part is training student surveyors to be person-centered," she says. "I love being able to spread that perspective." R-E-S-P-E-C-T: Audrey Rossi (left), Rebecca Jewell (center) and Sarah Hearn work to ensure that individuals with disabilities get the regard and support they deserve through the programs they help steer at CDS.

How could I do any less?

Over tea and pie with his mentors, the Coles, Dave Cavagnino was learning. Hazel and Robert Cole and their daughter Grace, who has autism and Down syndrome, made sure of that, giving Cavagnino a sense of what everyday life is like for families of children with developmental disabilities.

Earlier, he'd gotten a taste while accompanying the Coles to a therapeutic horseback riding session. He'd also joined them for Grace's dance therapy, a swimming outing and a workshop on ABLE savings accounts.

His experiences with the Coles changed him. A trainee in UD's Leadership Education in Neurodevelopmental Disabilities (LEND) program, a yearlong course of study for future professionals and family members of children with disabilities that emphasizes family-centered holistic care, Cavagnino says he's "a better physical therapist now. I realized I'm part of this interconnected web of people supporting children like Grace."

With funding from the <u>U.S. Department of Health and Human</u> <u>Services, Health Resources and Services Administration</u>, CDS launched the <u>Delaware LEND</u> in 2016. Program Coordinator Christine Grott says the LEND fills a void in service delivery systems that too often fail to properly support those with neurodevelopmental disabilities and their families by nurturing a new generation of professionals and advocates who embrace collaboration with clients, families and specialists in other disciplines. "We need providers who know how to engage with families," she says, "who know what resources are out there and how to get them."

To that end, the LEND curriculum exposes trainees to the disability community through lectures, panel discussions, interactions with specialists, group reflections and faculty mentoring.

Spending 15 hours with families like the Coles is a core LEND component. Their time together, says Grott, is a powerful reminder that clients live full, complex lives beyond the walls of classrooms and therapy settings.

"Families are the experts," Cavagnino says. "They're always looking to learn more." As a future professional in the field, "how could I do any less?"

Graduate students, postdoctoral fellows and family members interested in participating in LEND should contact <u>CDS Director</u> <u>Beth Mineo</u>.



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Advocates shine the light

"It's important we all speak up, get out and advocate," says Bill Monaghan. "And give support to others who need it so *they* can speak up for themselves," adds Barb Monaghan.

When the Monaghans and other people with disabilities who sit on the <u>Community Advisory Council (CAC)</u> of the Center for Disabilities Studies speak up, CDS administrators and staff listen – and act.

"Without them, we'd be lost concerning best practices," says CAC Chairwoman Cory Nourie. "It may be professionals who make policy, but self-advocates and family members shine the light. Their experiences provide guidance – about how services or the lack of services may affect them and other people with disabilities."

A majority of CDS's advisory council includes people with disabilities and family members of individuals with disabilities. One says his infant son's death "ignited a flame" in his heart to serve people with developmental disabilities. Another, an advocate with a traumatic brain injury, champions accessible paratransit and inclusive communities. Another self-advocate leads and takes part in protests in Delaware and Washington when the civil rights of people with disabilities are under seige. Another graduated from UD's <u>Career and Life Studies Certificate</u> <u>program</u> for students with intellectual disabilities and sits on the executive committee of the CAC.

"Their voices and the voices of other self-advocates on the Council impact the work the Center does," says Nourie.

Last year, when the CAC helped CDS craft the Center's fiveyear strategic plan, Barb Monaghan encouraged staff to connect young students to their communities. Bill Monaghan asked whether UD students with disabilities access public transportation. The plan incorporates the issues they raised.

"Some think people with disabilities can't make it in the community," says Barb Monaghan. "Bill and I have, together, for 38 years."

"Barb and I feel included," says Bill Monaghan. "But for a lot of people there's still a long way to go."

Read about the Monaghans' receipt of the <u>David Lynch</u> award here.

First in Delaware: More often seen in Legislative Hall in Dover, in classrooms at UD or at conferences statewide speaking about community inclusion, the Monaghans stroll the hallways at CDS.

Improved coordination

Delaware schools struggle to coordinate the many programs occurring in their buildings while simultaneously working to identify gaps in services and interventions needed to address the unmet needs of students. School districts, too, find it challenging to coordinate initiatives across departments, at times leading to fragmentation, inefficiency and confusion in the schools.

That's beginning to change. <u>The Delaware Department</u> of Education, through a five-year federal School Climate Transformation Grant, tapped CDS to help the <u>Brandywine</u>, <u>Capital</u> and <u>Red Clay</u> school districts and their schools meet their programmatic goals while supporting the needs of all students, no matter their abilities.

Red Clay Consolidated, with the support of Sarah Celestin, its director of special education, and Sarah Schmittinger-Kashner, its Positive Behavior Support coach, formed a district leadership team to coordinate the district's social, emotional and behavior-related activities. The district also hired four behavior-support coaches to assist schools and provide a consistent message.

One beneficiary, <u>Austin D. Baltz Elementary School</u>, worked with district coach Adriane Simpson over the summer to plan interventions for students with behavior challenges. It was "time-consuming trying to determine services to support students on a case-by-case basis," says Baltz Principal Amy O'Neill.

Now, the school has effective interventions students can access within three days. In its <u>Check-In Check-Out</u> <u>intervention program</u>, students meet each morning with a trusted adult who helps them set goals for the day and brainstorm strategies to be successful – and who later checks back in with them to discuss whether they met their goals. Baltz student Tanyea likes what she sees. "I've been working on ways to handle my feelings and listen to my teacher when I get frustrated," she says.

Referrals that detail challenging behaviors among students at Baltz dropped by almost two-thirds in the past year, says O'Neill. "All this planning with district professionals," says Counselor Stacey Papa, "is quickly getting students the services they need."

Check-In Check-Out: Baltz Principal Amy O'Neill (left) supports Tanyea as she sets her goals for the school day.

Spanning gaps in service

Only 17 percent of Delaware children with autism receive early intervention services before age three, and no wonder: <u>A 2013 CDS-led survey</u> revealed that diagnoses of autism come an average of two-and-a-half years after parents express concerns to their family doctor, and waiting lists for evaluation and therapy can exceed 12 months.

Parents and clinicians hope that will change with the help of <u>Building Bridges</u>, a new collaboration between CDS, state agencies, healthcare providers and community stakeholders that aims to improve the quality and accessibility of early intervention services for young children with autism and their families.

It helped Jennifer Schmidt, who'd previously felt frustrated and disoriented when her son, Paul, was diagnosed with autism at age three. "I did my due diligence, but there weren't enough resources," she says. Schmidt joined a six-week pilot program offered through Building Bridges and administered by <u>Nemours/A. I. duPont Hospital for</u> <u>Children</u>. Through behavioral coaching sessions with psychologist Emily Bernabe, she soon was able to make better sense of, and calm, some of her son's behaviors. The therapy sessions with Bernabe, held via teleconferencing, happened after she waited four months to schedule an appointment with a specialist in her hometown of Milford.

Connecting Sussex families and Nemours psychologists, but without wait times and the need to travel, is just one benefit of Building Bridges, which is backed by a three-year grant from the <u>Health Resources and Services</u> <u>Administration</u>. <u>Brittany Powers</u>, the program coordinator, says it also seeks to create an accessible pathway for families with autism so they can more easily attain screening, diagnosis and therapy.

That's why, for example, Powers is training clinicians to use autism screening tools. It's also why Building Bridges partner <u>Autism Delaware</u> has doubled its number of family navigators, who help parents and other caregivers find the services and resources they need. The new navigators are bilingual, to address the needs of Delaware's growing Hispanic population.

Through this communal approach, say Bernabe and fellow Nemours psychologist Colleen Sherman, they'll be expanding their ability to provide support. It's been a "powerful experience," says Schmidt. Reason to smile: Teleconferencing lets Nemours psychologist Emily Bernabe (right) connect with Jennifer Schmidt (on screen) about Schmidt's son, whose downstate residence makes it difficult to access services in person.

Empowered and heard

A PODD may look like a picture book, but in reality it's a powerful tool for children with communication challenges, their families and their support teams.

Pragmatic Organization Dynamic Display (PODD)

devices, which come in book or software form, enable users to communicate by pointing at pictures that represent words or phrases – a pair of hands for "I want to do something," an arrow for "Let's go," a book inside a building for "library."

And the users aren't just children. The PODD philosophy, developed 15 years ago at the <u>Cerebral Palsy Education</u> <u>Centre</u> in Australia, is that children learn language skills most effectively when everyone around them models the use of the system they are learning.

In March 2017, responding to concerns from educators and clinicians that common interventions were not helping some children improve their language skills, CDS's Delaware Early Childhood Assistive Technology Demonstration sponsored PODD training for parents and support teams. "We needed a fresh approach," says CDS Director Beth Mineo, "and PODD caught on like wildfire." Participants reported later that children using PODD were learning new words and interacting with more confidence, results that inspired subsequent training held by CDS's School Age unit.

<u>UD's Laboratory Preschool</u> sent a team of teachers and clinicians who support students like Natalie Rohe, a sixyear-old with Down syndrome. Natalie's mother Shawn, who also attended, says that adopting PODD "opened up her world." Soon, Natalie was using her PODD to express four- to six-word sentences and to interact with her siblings and classmates.

That was a welcome, if surprising, development to Laboratory Preschool instructor Monica Shire. She says her students – those with and without disabilities – took to PODD, offering them a shared system and vocabulary.

"All my kids use it," she says. "It helps them grow socially and emotionally. They feel empowered and heard."



Preschool instructor Monica Shire (right) says all her students use PODD communication devices, regardless of whether they have a disability. Here she works with English Language Learners Luiz (center) and Umut.

Transparency about disability

UD Professor Karl Booksh encourages students with disabilities in his <u>Chemical Sciences Leadership Initiative</u> to disclose their disabilities "early" (when writing applications) and "often" (to counselors, professors and classmates). Doing so, advises Booksh, who uses a wheelchair, can secure them the individual or technical supports they need to succeed, particularly at progressive campuses that foster diversity, accessibility and inclusion.

Disclosing can also lead to mixed outcomes, says Daniel Lanier. It landed him tutoring services at his previous school, but disclosing his autism made some doubt his abilities. "I didn't get guidance from others in pursuing my desire to write professionally," he says. That changed when he enrolled and disclosed at UD. Now a student in the <u>Career and Life Studies Certificate program</u> for people with intellectual disabilities, Lanier says his transparency about his disability ushered in accommodations, acceptance and opportunities.

The challenges faculty and students like Booksh and Lanier face on college campuses when deciding whether to disclose their disabilities fill the pages of <u>Negotiating</u> <u>Disability: Disclosure and Higher Education</u> (2017), a collection of faculty and student essays, reports and research studies assembled and edited by UD professors <u>Stephanie Kerschbaum</u>, <u>Laura Eisenman</u> and <u>James</u> <u>Jones</u>. The book is intended to promote conversations about disability as an aspect of diversity and the needs of people with disabilities in higher education, say Kerschbaum and Eisenman.

Readers learn what it means for some African-American students to contend with racial issues while wrestling with disclosing disability; how undergraduates tap different strategies to negotiate classroom disclosures; what it means for faculty members wary of stigma to disclose mental disability; and how colleges can help students with intellectual disabilities make choices about disclosure. "Understanding these complex issues is important to enable all members of the campus community to succeed," says Eisenman.

"I'm more encouraged and empowered" since disclosing, says Lanier. "I'm getting closer to my dreams and goals in life."

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Daniel Lanier felt encouraged and empowered after disclosing his disability and getting supports through UD's Career and Life Studies Certificate program.

Overcoming barriers to care

After 41 percent of Delawareans with disabilities in a 2015 CDS report indicated they had never seen a dentist or had last visited one more than a year earlier, CDS drilled down further to learn why.

In two 2016 CDS surveys, <u>Delawareans with disabilities</u> <u>expressed their concerns with the cost of care, dentists'</u> <u>competency and appropriate office accommodations</u>, while less than half of dentists reported having had formal training in the care of people with <u>disabilities</u>.

Encouragingly, "dentists kept saying, 'I want to learn how to do this better," says Jane Donovan, coordinator of CDS's oral health project, funded by the <u>Delaware Bureau</u> of Oral Health and Dental Services (BOHDS) through a grant from the federal <u>Health Resources and Services</u> <u>Administration</u>. In fact, *four-fifths* of dentists surveyed said they wanted formal training. "It was a ripe climate" to do something about that, Donovan says.

To that end, CDS, incorporating input from BOHDS, dentists, hygienists, people with disabilities and families, designed continuing education courses for dental professionals that focus on disability awareness and effective treatment. One session features video testimony from several people with disabilities about negative and positive oral care experiences they've had. Aaron Deede, a man with a traumatic brain injury who uses a wheelchair, discusses how his dentist accommodates his need for occasional weight shifts by setting aside extra time for his visits. Lynisha Fountaine, a woman who is deaf, mentions a dentist who wanted to pull her tooth but refused to provide her with an ASL interpreter.

In another session, Evan Spivack, DDS, offers dentists strategies for taking a thorough medical, behavioral and social history, developing a care plan and modifying office routines to accommodate patients' needs.

Nicholas Conte, the state dental director, envisions further collaboration with CDS to create trainings that delve into the needs of specific populations, such as patients with autism or mobility needs.

"I want to show dental professionals that the barriers they see to care aren't nearly as high as they think," he says.



Aaron Deede and his mother, Ann Phillips, recall his personcentered oral health care during the filming of a video used to train dental professionals.

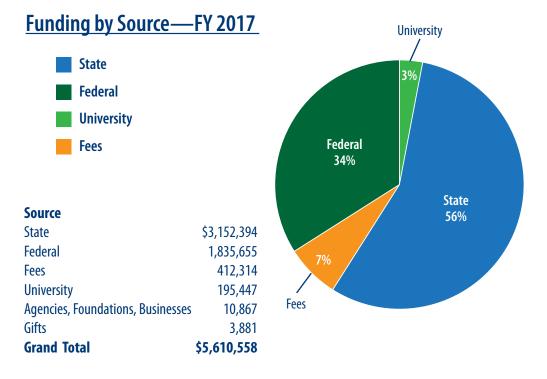
The Year in Review

Funding and Financials

The Center for Disabilities Studies had an operating budget of \$5,610,558 from July 1, 2016 through June 30, 2017.

Sources of funding

The vast majority of CDS funding is realized through grants and contracts from federal and state agencies, fees and the University of Delaware. Included in the federal portion is \$517,294 from the Administration on Intellectual and Developmental Disabilities (AIDD) for our core funding as a University Center for Excellence in Developmental Disabilities. This U.S. government organization is responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Other sources of funding are grants and contracts from nonprofit organizations, foundations and businesses, and gifts from individuals and organizations.

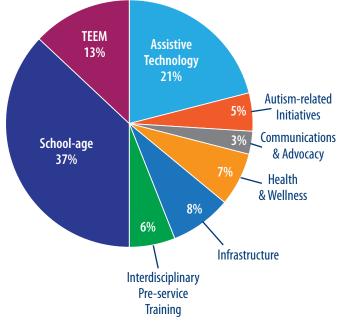


Project-specific funding by domain

This chart shows the proportion of external funding supporting each of the Center's programmatic domains. The infrastructure domain includes those funds that support overall Center operation rather than domain-specific activities.

<u>Funding by Domain</u> <u>FY 2017</u>

- Assistive Technology
- Autism-related Initiatives
- Communications and Advocacy
- Health and Wellness
- Infrastructure
- Interdisciplinary Pre-service Training
- School-age
- TEEM (Transition, Education and Employment Model)



Domain

Assistive Technology	\$1,179,231
Autism-related Initiatives	296,135
Communications and Advocacy	173,916
Health and Wellness	372,146
Infrastructure	431,409
Interdisciplinary Pre-service Training	g 338,683
School-age	2,078,187
TEEM	740,851
Grand Total	\$5,610,558

Funders

Federal government agencies

Federal Communications Commission

U.S. Department of Education

Office of Special Education Programs

U.S. Department of Health and Human Services

- Administration for Community Living
- <u>Centers for Disease Control and Prevention</u>
- Health Resources and Services Administration

State government agencies

Delaware Department of Education

Delaware Department of Health and Social Services

- Division for the Visually Impaired
- Division of Developmental Disabilities Services
- Division of Public Health (DPH)
- Bureau of Oral Health and Dental Services
- Maternal and Child Health Bureau

Delaware Department of Labor

• Division of Vocational Rehabilitation

Department of Safety and Homeland Security

• Division of Emergency Management

Nonprofit organizations, schools, foundations and businesses

Association of University Centers on Disabilities Christopher and Dana Reeve Foundation TransCen, Inc.

University of Delaware

We would like to give special THANKS to those listed in this section for their generous support of the Center for Disabilities Studies. This acknowledges gifts received in the year beginning July 1, 2016 and extending through June 30, 2017.

Donors

Gifts to the CDS General Fund

Nona Barnett Heidi Beck Lynn & David Clinger Anne Harris Gregory High Katherine Hughes Kevin Linton Lauren Luber James Lynch Melissa MacCord Beth Mineo & Gary Heckert Cory Nourie Megan Pell Krista Piarulli Eunice & Richard Pryor Michele and Howard Sands Marie & Anthony Sheridan Sandra Walls Kevin Westreich

Gifts to the Tobin Fund for Visual Assistive Technology Virginia Appleby Center for Disabilities Studies Beth Mineo & Gary Heckert Shirley & Allen Smith

The Year in Review

Who we are and what we do

Our mission is to enhance the lives of individuals and families through education, advocacy, service and research related to disabilities. We promote independence and productivity so individuals and families can participate fully in the life of their communities in Delaware and beyond.

The Center for Disabilities Studies is...

- One of 67 <u>University Centers for Excellence in Developmental Disabilities Education,</u> <u>Research and Service</u> nationwide, with core funding from the <u>U.S. Department of Health</u> and Human Services, Administration on Intellectual and Developmental Disabilities.
- The administrative home to the interdisciplinary <u>Disability Studies minor</u>, the largest minor on campus with enrollment this past year reaching 510 students from 40 majors across all seven colleges.

In 2016–2017, CDS staff and faculty cultivated student learning by...

- Teaching or co-teaching 27 courses, reaching a total of 166 graduate and 277 undergraduate students.
- Delivering 14 guest lectures to 46 UD graduate students, 157 UD undergraduate students and 72 students at three other institutions of higher education.



Sonja Rathel (left), Karen Latimer (center) and Lillian McCuen of <u>CDS's</u> <u>Assistive Technology</u> (<u>AT) unit</u> share a moment of camaraderie at an AT open house in Newark.

- Providing full assistantships/traineeships to nine graduate students from the <u>School of</u> <u>Education</u> and the Departments of <u>Physical Therapy</u>, <u>Communication Sciences and</u> <u>Disorders</u> and <u>Behavioral Health and Nutrition</u>.
- Engaging 86 undergraduate students and eight additional graduate students in the work of the Center.

In 2016–2017, CDS staff and faculty fostered the development of new knowledge—and the translation of existing knowledge—by...

- Developing 31 project proposals internally and with external partners.
- Offering 51 conference presentations and publishing 13 journal articles and 18 other documents.
- Providing editorial support for 16 journals.

In 2016–2017, CDS staff and faculty engaged meaningfully with national, state and local communities by...

- Serving on 47 boards, committees and task forces external to the university (30 percent of these at the national level).
- Collaborating with 14 state agencies, 65 other units at CDS, 70 community-based organizations and 15 other institutions of higher education.

Visit <u>www.cds.udel.edu</u> for more information about the Center for Disabilities Studies.

Staff and Faculty

Beth Mineo, director Debbie Bain **George Bear Tracy Beird Blake Bossert Debby Bover Rochelle Brittingham Amy Brown** Megan Conway Teresita Cuevas **Diane Davis Zachary Davis Jane Donovan** Melissa Ebling Laura Eisenman Dan Fendler **Roseann Ferri Brian Freedman** Wes Garton **Candy Greenleaf** Linda Gregory **Christine Grott Phyllis Guinivan** Sarah Hearn **Rebecca** Jewell Karen Jones Erin Konrad **Karen Latimer** Ann Lofting **Dick Lytton** Judi MacBride

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Undergraduate Students

Nicole Anacay **Amanda Bagnell** Lori Barcello **Rachel Braitman** Natalie Brown Stephanie Caggiano Anthony Drzal **Catherine Gehringer** Marissa Giardina Maxwell Grozovsky Katherine Johnson **Taylor Matthews** Tara O'Brien Miranda Partie Alexa Pepe Madison Pruitt Phoebe Walls Lauren Young

LEND Trainees

Chelsea Alling David Cavagnino Samantha Costa **Allyson Davis Catherine Flaherty** Jennifer Godlewski **Oshav Johnson Elizabeth Knocke** Shelby McMenamin **Angela Mitchell** Jessica Mueller Jolyn Pinamonti Ted Sato **Becca Smith Jennifer Sparks** Christina Ushler **Erin Williams**

Left: CDS Associate Director <u>Brian Freedman</u> (left) confers with U.S. Sen. Chris Coons.



Top left: Smiles all around as CDS graduate assistant Jasmina Chatani bonds with Ian Snitch, a student in UD's <u>Career and Life</u> <u>Studies Certificate (CLSC) program</u>, on Disability Mentoring Day.

Top right: Esley Newton, program manager for CDS's <u>Adapting Curriculum and Classroom</u> <u>Environments for Student Success (ACCESS)</u> Project.

Right: Carol Henderson, UD's vice provost for diversity, and <u>CDS's Laura Eisenman</u>, coordinator of UD's Disability Studies minor, following <u>Eisenman's receipt of the Mary</u> <u>Custis Straughn Disability Advocacy in Higher</u> Education Award.



Individuals whose service concluded during the past year

Staff and Faculty Jane Adewole

Eileen Baker Skye Beckley Sandi Bradford Susan Brewster Jamie Caruso Jae Chul Lee Chelsea Claiser Wendy Claiser Sophie DeMesse Annalisa Ekbladh Carly Herring Sarah Mester Tiana Peele Vanessa Relvas Steve Smith Eileen Sparling Ben Szmidt Ryan Taylor Susan Veenema Sharon Wiegner

n **Graduate** Assistants/Interns Kristen Black Amanda Czik Laura Davidson Madeline Halkowski Haley Olsen Courtney Wilson Jordana Woodford

Undergraduate Students Colleen Hagan Kiera Schaindlin

The Year in Review

Our Community Advisory Council

Nancy Lemus

Members of the Community Advisory Council partner with the Center for Disabilities Studies to advance our mission. The council includes individuals with developmental and related disabilities who serve as self-advocates; parents and other family members of individuals with developmental disabilities; representatives from disability-related training, service and advocacy organizations; state agency representatives; and others who advocate on behalf of people with disabilities.



CAC Executive Committee

Cory Nourie, chairperson Nemours/Alfred I. duPont Hospital for Children Bob Valihura, Esq., advocate Ira Shepherd II, self-advocate Deborah Dunlap, parent Linda Heller, self-advocate

CAC Members

Lisa Bond, Division of Management Services Karl Booksh, self-advocate Deborah Bradl, Division for the Visually Impaired, parent Charles Bryant, Division of Developmental Disabilities Services Anthony Carter, JEVS Support for Independence Alyssa Cowin, Delaware Health and Social Services, self-advocate

Jessica Davenport, self-advocate **Anne Dunlap**, self-advocate Susannah Eaton-Ryan, The Arc of Delaware Monica Edgar, United Cerebral Palsy of Delaware, Inc., self-advocate Carmella Giddins-Jones, Division of Prevention and **Behavioral Health Services, parent** Stephen Groff, Division of Medicaid and Medical Assistance Brigitte Hancharick, self-advocate Terri Hancharick, Endless Possibilities in the Community, parent Kathy Hughes, family member Elisha Jenkins, Division for the Visually Impaired Nancy Lemus, parent Jane Luke, parent Daniel Madrid, Delaware Health and Social Services Pat Maichle, Developmental Disabilities Council, parent Karen Mancini, parent Daniese McMullin-Powell, self-advocate

ra Shepherd II

John McNeal, State Council for Persons with Disabilities, State ADA Coordinator, self-advocate Mary Ann Mieczkowski, Department of Education Sandra Miller, Division of Vocational Rehabilitation Jill Rogers, Division of Developmental Disabilities Services Wendy Strauss, Governor's Advisory Council for Exceptional Citizens Meedra Surratte, Parent Information Center of Delaware Laura Waterland, Disabilities Law Program Kim Williams, State Representative, parent

Members whose service concluded during the past year

Brian Hartman, Disabilities Law Program Bill Monaghan, self-advocate Barbara Monaghan, self-advocate

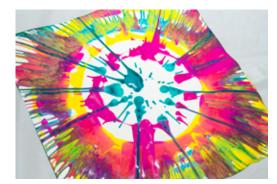
Despina Wilson, Independent Resources, Inc.









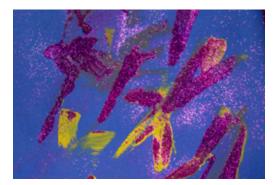












About the covers:

Front: Rory DiLouie applies his finishing touches to a collaborative circle painting project at Artfest, the creative community celebration and workshop hosted by CDS and <u>Art Therapy Express</u>, while UD student volunteer Tess Hanley enjoys the moment. **Back:** More Artfest participants, volunteers and exhibits.

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