Greetings, from CDS

One of the realities reinforced by our experiences in a global pandemic is that mental health is a critical component of overall health and well-being. Once a taboo topic, we now have a greater awareness that many people we encounter experience mental health challenges. We also have a keener sense of how mental wellness can be influenced by isolation, cultural divisiveness, economic hardship and lack of understanding and empathy.

Considered “invisible” disabilities, mental health challenges are often misunderstood and minimized. The Center for Disabilities Studies has been influential in changing the narrative about mental wellness and in innovating effective services and supports for school-age children as well as young adults with autism and/or intellectual disabilities. One really exciting theme uniting our work—and the work of so many others—is that services supporting mental wellness should be as available, accessible and individualized as services supporting other aspects of health. We need to eliminate any remaining stigma so that people who need supports are no longer reluctant to seek them out, instead feeling empowered to secure the assistance they need.

I am genuinely hopeful that one of the “silver linings” of our collective pandemic experience has been an awakening about how we can better support the holistic health and well-being of our fellow humans . . . and why we must make mental health a priority.

Beth Mineo served her 13th year as director of CDS in 2021.
Training to make an impact

To be an effective advocate for her son who has Down Syndrome, Tauheedah Muhammad learned how to access resources and how not to take “No” for an answer. “If one organization tells you ‘No’ when you want to help your child, ask someone else,” she says.

To ensure that students receive all the services they need, school psychologist-in-training Cassidy Edmondson learned how to effectively collaborate with other education professionals. “I have a more rounded picture of how I can help students and feel assured that I am in the right field,” she says.

Both are now graduates of the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, which trains people with disabilities, family members and those pursuing careers in psychology, physical therapy and other service professions to become champions for interdisciplinary, culturally-competent and family-centered care. Funded by the Federal Health Resources and Services Administration (HRSA) and run by CDS, LEND’s Delaware program has trained 54 individuals in the past five years.

And now it will train 65 more. A second five-year HRSA grant awarded to the Delaware LEND in May 2021 enabled the program to add Delaware State University as a training partner, include other fields of study, such as social work and public health, and place more emphasis on self-advocacy. “As more advocates and professionals complete LEND training,” says program coordinator Stephanie Kaznica, “their impact will strengthen and grow.”
Building a world for every body

The first cohort of 20 Access:Ability Scholars will graduate this spring. Some have disabilities, some do not. All are committed to developing real-world solutions for people with disabilities.

“Our scholars have 40 different majors, from art history to mechanical engineering,” says Laura Eisenman, coordinator of the CDS-run Disability Studies minor and Scholars programs. “They embrace disability and possibility and share a desire to learn more.”

Scholars integrate academics and life experiences in “building a world for everybody.” That includes peer mentoring, community activities and customized independent study.

Mandy Zicherman, a Scholar with a double major in entrepreneurship and management, was a winner in UD’s Hen Hatch startup funding competition for her “Navigating Access” social venture creating accessibility maps that can be updated to identify improvements. “The map identifies accessibility features that can help people get around more easily,” she says.

Sarah Bailey, a Scholar majoring in biomedical engineering, was inspired to design a walker that can handle stairs and rugged terrain during her independent study at Nemours Children’s Hospital. “Becoming an Access:Ability Scholar opened my mind to being a better advocate and ally,” she says. “I've applied that to my daily life, including taking training so my dog Gus can be a therapy dog.”
At CDS, commitment to equity, diversity and inclusion is REAL, as staff build their knowledge and explore the intersection of race, disability and culture. REAL stands for Racial Equity and Access Liaisons, launched in 2020 and led by Jessica Bass and James Sellers to promote a culturally aware workplace. “REAL is not a flash in the pan. We are keeping that fire burning,” Bass says.

This year, a dozen members of the CDS team trained with UD’s Office of Institutional Equity, Diversity, and Inclusion (EDI) to earn LEAD Ally certification. LEAD (Leveraging Equity And Diversity) is designed to nurture understanding of multiculturalism so trainees can become campus diversity allies, applying their insights to their work and lives.

“Talking about issues that increase our awareness, like white privilege and how to recognize it, was a valuable experience that gave me a clearer view of what an equitable world looks like,” says Megan Conway, Adapting Curriculum & Classroom Environments for Student Success (ACCESS) manager.

Adam Foley, director of Diversity Education, Assessment, & Outreach at EDI, says CDS participants are contributing to positive change. “Their willingness to engage in challenging and often uncomfortable dialogue,” he says, “is a testament to their commitment to further equity and inclusion, not only with those they serve, but as members of the UD community.”
Driving their own decisions

Meet author Michaelino Keleta, whose book about his paternal ancestry in the northeast African country of Eritrea says as much about Keleta’s promising future as his family’s rich history. Organized during his enrollment in the CDS-led Career and Life Studies Certificate (CLSC) program for students with intellectual disabilities, the book, together with the coaching he received in CLSC, changed Keleta. Before CLSC, “doing things on time was difficult for me,” he says.

“We involve the students in driving their own decisions, in developing their own person-centered goals,” says CLSC Program Manager James Sellers. “From that we see incredible individual growth.”

Keleta says encouragement from CLSC staff gave him confidence to write the book upon completing CLSC. Keleta also works at a payment processing firm. Many of his fellow CLSC alums – there are 60 since CLSC enrolled its first cohort in 2011 – similarly flourish upon finishing CLSC, some by furthering their education and others by entering the workforce.

A fellow 2020 CLSC graduate of Keleta’s is pursuing mechanic-based certifications to enhance his skills as an assistant auto technician. Another is pursuing an associate’s degree at an area community college. At UD, another coordinates CLSC’s alumni program.

Keleta’s mother, Amy Ghebre, says her son may return to UD to study anthropology. “CLSC showed him what he’s capable of doing,” she says. What he’s doing now is writing another book. “This one’s about my mother’s ancestors,” he says.
Appreciating the person first

Jessica Davenport loves (and can’t help but be a little surprised) that three years after they collaborated at UD, Colleen Yerger continues to reach out to her on Facebook and pops by for a face-to-face visit.

“It’s like wow, they really care,” Davenport says of students, like Yerger, who Davenport has mentored annually as a focus person in Senior Seminar, the Disability Studies minor capstone course led by CDS.

Yerger cares a great deal. “Jessica’s a very cool person,” Yerger says. “Genuine. Hilarious. A good person to have in your life.”

Davenport also shares an important message with people in and out of the classroom, says Yerger: Birth control can carry health risks for women with certain blood disorders. For Davenport, it caused a brain stem stroke.

But Yerger says Davenport’s disability doesn’t define her. “Jessica’s pursuing an internship. She’s in a relationship. She mentors students. It’s important … to understand people beyond their disability.”

The Seminar teaches that “you serve people most effectively when you genuinely know them and take the time to learn what’s important to them” says CDS Director Beth Mineo. To accept that they come in “different packages and appearances,” says Davenport.

The more that professionals “learn what’s meaningful to people with disabilities,” says Yerger, who now works as a speech language pathologist with the Red Clay School District, “the better they can support them.”
Emphasize equity, not punishment

Concerns over disproportionate discipline meted out to African American students and students with disabilities in schools nationally led CDS and the Delaware Department of Education (DDOE) in 2021 to further encourage more constructive and equitable practices in Delaware public schools.

“We saw a groundswell of advocacy for things we are promoting,” says CDS instructional coach Megan Pell, “including addressing implicit bias and supporting all students equitably.”

Through the DDOE-CDS Positive Behavior Support project, and its emphasis on creating safe and caring learning environments, school and district educators focus more on establishing trust and less on exercising punitive measures.

At Claymont Elementary School, students are learning to reach out rather than act out when they feel upset. “We knew suspensions weren’t solving the problem,” says Tamara Grimes-Stewart, the school’s principal. “We are building relationships with kids who are struggling emotionally so they know there is someone they can talk to.”

In the Brandywine School District, a multi-tiered system of support now includes social workers, psychologists and two recently hired equity specialists. With an emphasis on building relationships rather than issuing punishment, students can focus on learning, says Marqueia Davis, supervisor of Equity and Culture. “We want school to be a place,” she says, “where students can feel good about themselves and flourish.”

Principal Tamara Grimes-Stewart of Claymont Elementary School, where students are learning to reach out rather than act out.
The bottom line is communication

The My Emergency Care Plan (MECP) developed last year by CDS “can potentially save lives,” says Wade Shrader, a Nemours Children’s Hospital orthopedic surgeon, because it fills a critical communications gap.

It can instantly provide a medical team with a clear and concise medical and personal care profile, created by a person with disabilities before an emergency happens, that can tell them what the providers might not know to ask or what the patient may not be in a position to reveal.

Shrader, a father to two sons with cerebral palsy, says medical personnel overall “don’t have great experience caring for patients with disabilities” and can be intimidated, making it hard for them to capably assess a person’s chronic disability and treat the acute issue that brought the patient to them. Add to that the situation where the patient in a crisis is unconscious or could communicate but not in the manner providers expect – or where some medical teams can’t readily access fragmented patient records – and it’s apparent, Shrader says, why the MECP’s “incredibly valuable.”

With a grant from the Delaware Developmental Disabilities Council, CDS’s Sarah Mallory and Pat Heineman helped create it after the disability community reported deficiencies in responsive emergency care and concerns about their ability to effectively self-advocate in emergency situations. CDS sent its MECP template to several thousand Delawareans in June 2021.

“The bottom line is communication,” says Shrader. With the MECP, “it will be so much better.”

Dr. Wade Shrader, with his son, Benjamin, says CDS’s emergency care plan will help first responders assess a person’s disability and treat acute issues.
Flourishing at home: Working virtually isn’t a perk, says Emmanuel Jenkins. “It’s accessibility.”

As real as it gets: becoming faculty

Before the pandemic, Emmanuel Jenkins often gauged an entity’s accessibility based on whether he could get to it on paratransit. To an extent. A roundtrip with connections from his home in Greenwood to Newark could take eight hours and come with no chance to use a restroom. Drivers, he says, sometimes wouldn’t stop because they’d worry it might make them late. How accessible is that?

Now, Jenkins says he determines whether something’s accessible based on whether he can get to it virtually, thanks in large part to his experience with CDS. In the first year of the pandemic, Jenkins put in the required 400 hours as a trainee in the CDS-run Leadership Education in Neurodevelopmental Disabilities (LEND) program, but remotely, as happened with all his fellow trainees. In the pandemic’s second year, Jenkins continued remotely with LEND, as faculty.

“I could not have trained, let alone become faculty, if CDS hadn’t first turned an in-person program into a remote one and then the following year made it hybrid,” he says.

“We’re always exploring ways to make what we provide more accessible,” says Center Director Beth Mineo.

Providing services virtually throughout Delaware should be the new reality, says Jenkins. “People used to look at working from home as a perk,” he says “It’s not a perk. It’s accessibility.”
Valuing autism on and off campus

Samantha Fowle and her fellow academic advisors in UD’s College of Engineering improved their ability last year to guide students on the autism spectrum. Alison Wessel and her staff at UD’s Morris Library worked on making the library’s spaces more “sensory-friendly.” Jennifer Follett’s tutors at UD’s Writing Center learned how to better support autistic students whose methods of communicating sometimes differ from those of other students.

They did so after accepting an invitation from CDS’s Spectrum Scholars, led by Wes Garton, to participate in trainings designed to increase their ability to empower autistic students.

A college-to-career program funded by JPMorgan Chase for select UD students with autism, Spectrum Scholars coaches its cohorts on how to develop study skills, campus connections and self-determination. Equally important, Garton says, is how “the program also aims to nurture a greater appreciation of neurodiversity” among UD faculty, staff and the surrounding community.

The writing tutors would “learn not to judge if a student doesn’t interact as expected,” said Follett. At the library we “learned how to be more inclusive,” said Wessel. Neurodiverse students may have needs that are less typical, suggested Fowle, but at the end of the day, “they’re just students getting an education.”
Debra Scott and son, Wilson Sharp. Sharp was the first recipient of an assistive technology device from CDS’s CSI Delaware program.

Building skills, staying connected

To help people with intellectual and developmental disabilities stay connected to family, friends and community resources amid the pandemic, CDS last year introduced CSI Delaware (Combating Social Isolation and Promoting Community Engagement through Assistive Technology). The program matches applicants who meet financial guidelines with devices that support their particular needs. “We knew technology could enable many individuals to maintain connections to people and favorite activities,” says CDS Director Beth Mineo.

Wilson Sharp, who has Down syndrome, received an iPad that allows him to continue to communicate with relatives, his medical team and friends from church. Each device is personalized for the individual who uses it, says CSI coordinator Allison Berdoulay, and is provided to the individual at no cost.

Sharp communicates by selecting pictures on the Proloquo2Go app, which is fitted with amplified speakers to help him hear the words he’s chosen. Hearing the word that corresponds with the picture helps build his verbal skills, says Sharp’s mother, Debra Scott.

Sharp’s iPad was delivered to his home on Feb. 25, 2021, his 24th birthday. He was the first recipient of a device through CSI, which is funded in part by the Delaware Developmental Disabilities Council. “CDS made the application process easy, completely seamless,” Scott says.

CSI builds on other programs in which CDS provides technology to people with disabilities that helps keep them connected. “For people with disabilities,” says Mineo, “technology is not a luxury. It’s a necessity.”
Early screening, positive outcomes

By July 2023, all childcare providers in Delaware must use an evidence-based tool to monitor children’s development. That tool, the Ages & Stages Questionnaire, can help identify potential areas of delay in order to improve the identification of children who may benefit from intervention or additional services. To aid parents and childcare providers in understanding the importance of developmental monitoring and screening, CDS is partnering with the Delaware Department of Education (DDOE) Office of Early Learning to roll out a statewide training initiative.

“There is a significant body of research that links early identification and intervention with positive outcomes for children and their families,” says Sarah Mallory, director of CDS’s Health and Wellness Unit and Delaware’s Act Early Ambassador. Ambassadors are part of the “Learn the Signs, Act Early” campaign spearheaded by the Association of University Centers on Disability and Centers for Disease Control and Prevention. The campaign aims to support states’ work toward improving early identification of developmental delays and disabilities.

Mallory has collaborated with Cindy Brown and Jamie Walko of DDOE to develop a model in which parents and providers who complete training will be empowered to help train others. “CDS is teaching us how to implement that model,” says Jenny Grady, Developmental Screening Technical Assistant at DDOE. “Their partnership is helping us to build our support for families and providers.”
The Center for Disabilities Studies had an operating budget of $5,305,078 from July 1, 2020 through June 30, 2021.

**Sources of funding**

More than 95% of CDS funding is realized through grants and contracts from federal and state agencies, non-profit organizations, foundations, businesses, and fees. Included in the federal portion is $571,732 from the Administration for Community Living, Administration on Disabilities 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. CDS also benefits from gifts made by individuals and organizations.

**Funding by Source—FY 2021**

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<th>Source</th>
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*This amount indicates what was spent from gift funds. New gifts to CDS in the 2020-2021 reporting year totaled $5,465.

**Project-specific funding by domain**

This chart shows the proportion of the budget expended in support of each of the Center’s programmatic domains. The infrastructure domain includes those funds that support overall Center operations rather than domain-specific activities.

**Funding by Domain—FY 2021**

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<td>Communications &amp; Advocacy</td>
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<tr>
<td><strong>Grand Total</strong></td>
<td><strong>$5,305,078</strong></td>
</tr>
</tbody>
</table>
We would like to give special THANKS to those listed here for their generous support through gifts received in the year beginning July 1, 2020 and extending through June 30, 2021.

**CDS GENERAL FUND**
Heidi L. Beck '99M
Sharon A. Feucht '75 and Gary E. Miller
Gary H. Heckert '72 '76 and Beth A. Mineo
Katherine Hughes
Richard E. Lytton
Yolanda McKinney '07M
Megan M. Pell '16PhD
Donald L. and Lynn A. Peters
Pamela Frank Reinholz '84
Michele F. Sands

**THE W.E. TOBIN FUND FOR VISUAL ASSISTIVE TECHNOLOGY**
Gary H. Heckert '72 '76 and Beth A. Mineo
Allen E. Smith
Sandra L. Walls

**CLSC SCHOLARSHIP FUND**
Gary H. Heckert '72 '76 and Beth A. Mineo

**SPECTRUM SCHOLARS**
Gary H. Heckert '72 '76 and Beth A. Mineo
Sheela P. Dattani '91 and Suken A. Shah

**UNDERGRADUATE PROGRAM ENRICHMENT**
Tracy L. Beird
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**I HEART UD DAY DONORS**
Tracy L. Beird
Allison Obsatrz Berdoulay '89
Amy Johnston Brown '96 and Joseph Brown
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Megan E. Conway '03 '13M
Sarah and Caleb D. Curtiss
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Brian H. Freedman
Gail Hamblin
Gary H. Heckert '72 '76 and Beth A. Mineo

**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
  - Centers for Disease Control and Prevention
  - Health Resources and Services Administration

**STATE GOVERNMENT AGENCIES**
- Delaware Department of Education
- Delaware Department of Health and Social Services
  - Division of Medicaid and Medical Assistance
  - Division of Public Health
    - Bureau of Maternal and Child Health
  - Division for the Visually Impaired
- Delaware Department of Labor
  - Division of Vocational Rehabilitation
- Delaware Department of Safety and Homeland Security
  - Delaware Emergency Management Agency
- Delaware Developmental Disabilities Council
- Delaware Department of Services for Children, Youth and Their Families
  - Division of Prevention and Behavioral Health Services

**NONPROFIT ORGANIZATIONS, SCHOOLS, FOUNDATIONS AND BUSINESSES**
- Association of University Centers on Disabilities
- JPMorgan Chase & Co.
- Organization for Autism Research
- TransCen, Inc.
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- University of Massachusetts
- University of New Hampshire
- University of South Carolina

To donate to CDS, please visit [cds.udel.edu/support](http://cds.udel.edu/support)
The Year in Review

Who We Are and What We Do

The Center for Disabilities Studies works to enhance the lives of individuals with disabilities and their families through education, advocacy, service and research. It promotes empowerment and opportunity, accessibility and inclusiveness, so all may fully participate in—and enrich—their communities.

The Center for Disabilities Studies is...

- One of 67 University Centers for Excellence in Developmental Disabilities Education, Research and Service nationwide, with core funding from the U.S. Department of Health and Human Services, Administration on Disabilities.

- The administrative home to the interdisciplinary Disability Studies minor, the largest minor on campus with enrollment this past year reaching 490 students from 35 majors across six colleges at the University of Delaware.

In 2020–2021, CDS staff and faculty...

- Teaching or co-teaching 40 courses/course sections and independent studies, reaching a total of 127 graduate and 614 undergraduate students.

- Delivering eight guest lectures to 30 UD graduate students, 191 UD undergraduate students and 44 students at four other institutions of higher education.

In 2020–2021, CDS staff and faculty fostered the development of new knowledge—and the translation of existing knowledge—by...

- Developing 32 project proposals internally and with external partners.

- Offering 17 conference presentations and publishing 10 journal articles and four book chapters.

- Providing editorial support for nine journals and serving as proposal reviewers for three conferences and four funding agencies.

In 2020–2021, CDS staff and faculty engaged with national, state and local communities by...

- Serving on 28 boards, committees and task forces external to the university (29 percent of these at the national level).

- Collaborating with 18 state agencies, 20 national and international agencies and organizations, 47 other units at UD, 51 community based organizations and 27 other institutions of higher education.

(From left to right) Katie LaChance, Lindsey Hawtof, Hannah Mennella, Jessica Decker, Chelsea Busch and Rebecca Lloyd, trainees in the CDS-run Leadership Education in Neurodevelopmental Disabilities (LEND) program.

CDS administrative assistant Blake Bossert.
At top: Laura Eisenman coordinates the CDS-led Access:Ability Scholars program and the CDS-administered Disability Studies minor.

At bottom: Megan Conway manages and coordinates curriculum and communication initiatives within CDS’s school-age unit.

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Allison Berdoulay
Blake Bossert
Deborah Boyer
Amy Brown
Valerie Brown
Megan Conway
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Rosalie Corbett
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Vicr Schaffner
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James Sellers
Mackenzie Shane
Melanie Sipko
Angela Soltys
Shirlinda Tucker
Sandra Walls

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Brelynn Garrison
Brenna Gause
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Mark Miller
Deja Rodriguez-Santiago
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Taylor Barto
Michelle Bertram
Emily Brown
Adam Bungarden
Angela Bussone
Amita Chatterjee
Gavin Ferrandino
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Elaine Kaplan
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Kristina Longo
Emily Marsh
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Kaitlyn Myers
Sara Paone
Bethany Pasmor
Jessica Price
Jorge Ramirez Marin
Janna Rus
Caroline SanAngelo
Blair Schnitzer
Matthew Seafass
Aimee Skwers
Natalie Testa
Jaelyn Turner
Hiren Walia
Amanda Zacherman

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Kelsey Baldwin
Chelsea Busch
Asia Coleman
Julianna Danese
Jessica Deck
Shannon Dowling
Cassidy Edmonson
LeeAnn Harden
Lindsay Hawtow
Emmanuel Jenkins
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Katie LaChance
Erica Lehman
Rebecca Lloyd
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Tauheedah Mohammed
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Laura Dewey
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Olga Goncharova-Zapata
Amy Habeger
Jennifer Horney
Emmanuel Jenkins
Persephone Jones
Stephanie Kaznica
Sarah Mallory
Anthony Middlebrooks
Beth Mineo
Jillian Trabulsi

SEAL Faculty and Mentors
Sarah Celestin
Joyce Denman
Sharon DiGiralamo
Susan Dutton
Mary Herrera
Lauren Irwin
Dorothy Linn
Janella Newman
Mary Norris

Individuals whose service concluded during the past year

At top: Laura Eisenman coordinates the CDS-led Access:Ability Scholars program and the CDS-administered Disability Studies minor.

At bottom: Megan Conway manages and coordinates curriculum and communication initiatives within CDS’s school-age unit.
Members of the **Community Advisory Council** partner with the **Center for Disabilities Studies** to advance its 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, Division of Developmental Disabilities Services  
**Alyssa Cowin**, self-advocate  
**Deborah Dunlap**, parent  
**Terri Hancharick**, Endless Possibilities in the Community, parent  
**Ira Shepherd II**, self-advocate

**CAC Members**

**Karl Booksh**, University of Delaware, self-advocate  
**Charles Bryant**, Division of Developmental Disabilities Services, parent  
**Anthony Carter**, JEVS Support for Independence  
**Karen Doneker**, parent  
**Susannah Eaton-Ryan**, The Arc of Delaware  
**Carmella Giddins-Jones**, Division of Prevention and Behavioral Health Services, parent  
**Stephen Groff**, Division of Medicaid and Medical Assistance  
**Brigette Hancharick**, self-advocate  
**Kristin Harvey**, Developmental Disabilities Council  
**Kathy Hughes**, family member  
**Nancy Lemus**, parent  
**Jane Luke**, parent  
**Daniel Madrid**, Office of the State Treasurer  
**Daniene McMullin-Powell**, self-advocate  
**John McNeal**, State Council for Persons with Disabilities, self-advocate  
**MaryAnn Mieczkowski**, Department of Education  
**Melissa Smith**, Division of Services for Aging and Adults with Physical Disabilities  
**Meedra Surratte**, Parent Information Center of Delaware  
**Laura Waterland**, Disabilities Law Program  
**Pam Weir**, Governor’s Advisory Council for Exceptional Citizens  
**Despina Wilson**, Independent Resources, Inc.

**Members whose service concluded during the past year:**  
**Sandi Miller**, Division for the Visually Impaired  
**Dava Newnam**, Division of Services for Aging and Adults with Physical Disabilities  
**Wendy Strauss**, Governor’s Advisory Council for Exceptional Citizens
FRONT COVER: CDS’s Sarah Hearn (left, gesturing) and UD undergraduates Jessica Bellini (right) and Brianna Costa discuss the students’ final multimedia project for Senior Seminar, the capstone course within the CDS-led Disabilities Studies minor, alongside other student groups.

BACK COVER: With support from CDS’s Karen Latimer, Alvin Emory samples speech-to-text software and a magnification lens at one of CDS’s assistive technology centers.

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