

# 2021-2022 Annual Report

### Greetings, from CDS

After the pandemic forced us apart, we've experienced a slow return of children to school, employees to the workplace, and family and friends to in-person gatherings. The return was a process, not an event, although there was one moment that was so striking that it brought me to tears. In September, students and faculty at UD first were permitted to remove masks in the classroom. I didn't realize how emotional it would be to see "whole" faces again. What were your "moments"? What did they tell you about yourself?

I don't think we'll appreciate the full impact of the pandemic for decades, although we have all come to understand the life-altering consequences of social isolation, loss, grief, missed opportunities and powerlessness against circumstances imposed on us by forces beyond our control. Our shared experience can transform the way we process and respond to the world around us – if we let it.

Although it can be hard to muster energy when we see so many challenges around us, I can assure you that CDS is moving ahead with remarkable energy. We finished work on a new five-year strategic plan this year – informed and endorsed by individuals with disabilities, family members, and our many other community partners – that is ambitious, grounded in lessons learned, and aspires to catalyze greater access, inclusion, opportunity, and authentic belonging as well as more personcentered services and supports. This annual report gives you a glimpse of where we are and where we are going.

Wishing you memorable moments in the days and months ahead,

beth



<u>Beth Mineo</u> served her 14th year as director of CDS in 2022.

### Every student deserves to thrive

At 2:45 p.m., Monday through Thursday, 15 middle school students from the <u>Seaford School District</u> begin arriving at the <u>Western Sussex Boys & Girls</u> <u>Club</u>. By 4:15, another 150 students spanning grades K through 5 join them.

Unlike many of their Delaware student peers who break from their studies with the sounding of their school's dismissal bell, they receive tutoring from District teachers hired by the Club to enrich their math and reading skills. They also on those days and on Fridays learn gardening, the culinary arts, mindfulness, and more.

A federally funded <u>21st Century Community Learning</u> <u>Center</u> – one of 20 in Delaware in receipt of that five-year designation – the Club, like all 21st CCLCs, primarily supports students attending high-poverty and low-performing schools. CDS, in partnership with the <u>Delaware Department of Education</u>, provides technical assistance to the Centers to help them track and report attendance, activities and other data to ensure they're operating as intended.

About 80 percent of the students the Western Sussex Club serves read below their grade level, says Kelsey Stave, the Club's Family School & Community Engagement Specialist. Approximately one-third are homeless, more than 20 have <u>Individualized</u> <u>Education Programs</u>, and many are English language learners. "The supports we provide them as a 21st CCLC help them be successful," she says.

"Enrichment activities, both academic and social, enhance outcomes for the kids," says <u>Teresita</u> <u>Cuevas</u>, CDS's 21st CCLC technical coordinator. "Every child, every student, no matter their background, deserves every chance to thrive."



With Kelsey Stave (standing, left) and Teresita Cuevas (standing, right), two students enjoy their computer time at the Western Sussex Boys & Girls Club.

# Getting the knowledge out there

When James Murphy started kindergarten, he found the transition to school challenging. Then he started working with Molly Perdue, a K-5 Family and Student Interventionist.

"He did a 180," says James' mother, Kimberly Dearth.

Perdue at the time was taking an intensive series of trainings offered through the CDS-led <u>Delaware</u> <u>Network for Excellence in Autism (DNEA)</u>. The information provided "helped me understand how to guide my students," she says.

Hundreds more clinicians, educators, family members and autistic individuals have undergone trainings launched last year by the DNEA. The trainings – some advanced, others introductory – offer everything from lessons on the history and core characteristics of autism to best practices on how to better support and care for people with autism, says <u>Alisha Fletcher</u>, director of the DNEA.

Many professionals like Perdue also found themselves passing along what they learned in the trainings to others in the community. "Now there are people like us that are getting the knowledge out there," she says.

The knowledge she used to support James' family made a difference in his ability to self-regulate. In turn, he is doing much better in school.

"He would never read, and now he's reading independently," Dearth says.

Reasons to smile: Molly Perdue is better able to guide her students. James Murphy is reading independently.

# Better able to succeed

In 2011, for the first time, individuals with intellectual disabilities got the opportunity to attend a college program in Delaware designed especially for them. Students in UD's twoyear <u>Career & Life Studies Certificate (CLSC)</u> program, administered by CDS, attended classes, established career goals, connected with peers, and grew their independent living skills.

They still do. But in 2021, several CLSC (pronounced "classic") students got the chance to "step it up a notch," says program developer <u>Rebecca Jewell</u>. "We launched CLSC Advanced, a third and fourth year of CLSC that enables participating students to expand their education, further develop their leadership skills, do community service, and engage in paid internships."

Kirk "KJ" Vollmecke leapt at CLSC Advanced and, in Year 3 of his program, began living independently off campus. "I knew I could do this," he says, while crediting his CLSC coach for making him feel more confident. "My schoolwork's improving. My positive attitude helps me interact with people." Next up for KJ: possibly a second internship at Delaware Stadium and, he hopes, a job helping manage sporting events.

A career in fashion could be next up for Ciana Peters. "I feel supported and better able to succeed," she says. In classes and internships, she's learning about garment making and entrepreneurship, skills and knowledge that complement her demonstrated talent at designing clothing. Midway through her third year, she says she's happier in her schoolwork, appreciating how women of color can excel in the workforce, and building relationships. "I'm so blessed," she says.

Ś Stepping it up a notch: CDS's Rebecca Jewell is flanked by Kirk "KJ" Vollmecke and Ciana Peters, students enrolled in an advanced twoyear extension of UD's Career & Life Studies Certificate program.

# Self-advocates like Laura

After she graduates from UD in May with her master's degree in speech-language pathology (SLP), Hannah Mennella plans to apply the training she received toward supporting children with complex communication needs, including those with autism.

But Mennella says insights she gained through the CDS-led <u>Leadership Education in</u> <u>Neurodevelopmental and Related Disabilities</u> (<u>LEND</u>) program will influence how she practices every bit as profoundly. One in particular, she says, came from a self-advocate in the community – "an open and absolutely wonderful single mother who uses a wheelchair, Laura Greene."

"I want the kids I'll be working with," Mennella says, "to be strong self-advocates like Laura."

Greene says she wasn't sure at first why the LEND, as part of its new self-advocate mentoring component, teamed her with Mennella and two other trainees on track to becoming a nutritionist and epidemiologist. But she and Mennella said it readily became apparent. No matter a service provider's specialty, the aim when supporting individuals with disabilities is the same: making it possible for them to succeed. "And as independently as possible," Greene says.

"Barriers can be social as much as physical," she says. "I don't want anyone to assume that I can't be successful alone or with my son."

That's an assumption Mennella won't make in her own clinical practice. "It's our role as service providers," she says, "to understand and support the needs and desires of our clients and patients."

The ties that bind: Laura Greene (left) and Hannah Mennella bonded on the importance of empowering self-advocates to be independent.

# Discovering what is possible

In June 2022, CDS opened the doors of its <u>new</u> <u>Assistive Technology Resource Center (ATRC)</u> in Milford. Thanks to a federal appropriation secured by Sens. <u>Tom Carper</u> and <u>Chris Coons</u> – with an assist from Rep. <u>Lisa Blunt Rochester</u> – its inventory and the inventory of its sister ATRC in Newark will soon include the latest technology for most any user.

Communication devices with eye-tracking technology. Toothbrushing aids for amputees. Voice-activated glasses that read text. But the Centers also house longstanding popular items, such as large-face digital clocks, accessible eating utensils, and tactile toys.

"Assistive technology unleashes the human spirit," said Coons at a celebratory event at the downstate ATRC. "It makes it possible for our friends, our family, our neighbors, to live with the dignity God gave them and a life full of potential."

"We can do extraordinary things on behalf of children today with disabilities and those in the years to come," said Carper.

At the <u>Milford and Newark Centers</u>, users meet with staff who help identify options for their individual needs. Most devices can be borrowed, free, for up to two weeks. "Each item in our inventory is there to help individuals discover what is possible," says AT Specialist <u>Karen Latimer</u>.

A desktop magnifier found through the ATRC allows 84-year-old Barbara Blades of Lewes to stay in her home.

"I am comfortable in my home," she says. "I'd stay here forever if I could manage it."



Federal funding secured by Sens. Carper (left) and Coons, seen speaking at CDS's new Assistive Technology Resource Center in Milford, will support people with disabilities throughout Delaware.

# Stakeholder- and data-driven

To advocates and researchers who collaborated with CDS last year on its new strategic plan, it comes as no surprise that the plan guiding the Center's programmatic work over the next five years will address several systemic shortcomings the community indicated are most in need of improvement.

Mental health; check. Healthcare accessibility; check. Community integration; check.

"I know from working previously with CDS that when it asks stakeholders for input, it's going to use that input," says Sue Giancola, senior associate director with UD's <u>Center for Research in Education</u> <u>& Social Policy</u>, which administered and analyzed responses to CDS's <u>Community Needs Assessment</u>.

Feedback CDS got on the plan from its <u>Community</u> <u>Advisory Council (CAC)</u> also informed its decisions, says CAC member Meedra Surratte, director of the <u>Parent Information Center of Delaware</u>. "We represent different areas of disability, and CDS meaningfully engages us."

"It's best to begin with the community," says CAC member Kristin Harvey, director of the <u>Delaware</u> <u>Developmental Disabilities Council (DDC)</u>. "Data from the community can drive decisions." Still, she says, CDS, like the DDC, can't address all gaps. "We all have our parameters."

"We're very stakeholder driven," says CDS director Beth Mineo, "and the feedback we got galvanized our resolve." She says it validated the increasing emphasis CDS has been placing on accessible community settings; on mental health supports in schools; on inclusive care offered by health care providers; and on its work to integrate and empower underserved individuals, such as those with complex communication needs.



The feedback given CDS by (from left to right) Meedra Surratte, Sue Giancola and Kristin Harvey informed and validated its new five-year strategic plan.

### Trust can make the difference

As Covid-19 vaccines and boosters became available to the public, the <u>Delaware Division</u> of <u>Services for Aging and Adults with Physical</u> <u>Disabilities (DSAAPD)</u> wanted to ensure they reached all Delawareans, including those with disabilities. In surveys and interviews conducted by CDS, Delawareans with disabilities and their caregivers were asked what influenced their decisions about getting vaccinated. A common theme emerged from the responses: relationships matter.

If individuals trusted the person sharing information about the vaccine, they were more likely to follow their advice.

It is important that people with disabilities have access to a trusted healthcare provider because that would "make the difference for those who felt hesitant," says Melissa Smith, director of DSAAPD.

To help providers become more informed about making their practices inclusive of people with disabilities, CDS and DSAAPD launched an interactive website, <u>cds.udel.edu/</u> <u>healthcareaccess</u>. It offers providers practical information on how they can make their parking facilities, professional staff, office equipment and space accessible to patients with disabilities.

"Accessibility isn't just about legal compliance," says <u>Sarah Mallory</u>, director of CDS's Health and Wellness unit. "It's about understanding what individuals with disabilities need to access preventive and primary care, then educating providers so they can effectively meet the needs of all their patients."



Melissa Smith partnered with CDS amid the pandemic to develop a website that aims to make it easier for people with disabilities to visit the offices of health care providers.

# The most functional skill of all

Andrea Creed's campaign to get Delaware schools to provide equitable literacy instruction for its students began years ago on behalf of her son. "He has complex communication needs," she says. "This is what we'd face: I told staff, 'He needs to learn to read.' They said, 'He's receiving an accommodation. He's being read to.""

That's not acceptable, says Creed. Nor, she says, are the systemic obstacles that her literacyadvocacy workgroup has come across. "Many educators think teaching literacy to students with complex communication needs is too time consuming. Schools don't require it or complain they don't have the resources to provide it. And some question the intelligence of nonspeaking people and think they can't be taught literacy."

All students need literacy instruction and can benefit from it, says CDS School-Age Unit Director <u>Debby Boyer</u>. To that end, her <u>Systematic</u> <u>Processes for Enhancing and Assessing</u> <u>Communication Supports (SPEACS)</u> team is sharing tools and offering coaching that promote literacy instruction to district educators. "The myth that students with complex needs should access a curriculum focusing primarily on 'functional skills' is misguided," Boyer says. "Literacy is actually the most functional skill of all. It increases opportunities in school and in life."

Delaware schools are moving toward a common goal, says the <u>Department of Education</u>'s Lauren Irwin. "A presumption of competence among all its students.... We're striving to empower our teachers and the system to support all students."

> Adrian and Andrea Creed converse on their front porch. Andrea says Adrian uses his <u>NovaChat 8 Active</u> device "for everything. To tell stories, to talk about songs, to say where he wants to drive or fly to."

### Equal access to mental health care

CDS last year expanded its efforts to enhance mental health supports in the community with two programs focused on individuals with autism.

Its <u>Spectrum Scholars</u> college-to-career program piloted a project to address anxiety in autistic college students, while the CDS-led <u>Delaware Network</u> for <u>Excellence in Autism (DNEA)</u> introduced training sessions to educate mental health professionals about the needs of autistic people.

For the Spectrum Scholars undergraduate cohort at UD, whose members had reported they frequently feel anxious navigating campus life, Research Manager <u>Jessica Monahan</u>'s team worked collaboratively with autistic students on campus to adapt an anxiety-reduction program originally developed for children and adolescents.

After participating in the program, students reported understanding their anxiety better and having more coping strategies. "The students told us the group dynamic was so important in helping them feel they weren't alone," says Monahan. The next step, she says, is to modify the program to make it practical for colleges to adopt.

"Autistic people are traditionally underserved despite an increased prevalence of mental health challenges," says DNEA Director <u>Alisha Fletcher</u>, who led trainings that addressed risk factors unique to autistic people and practical strategies for diagnosis and treatment.

The DNEA plans to continue to offer monthly trainings for the public about autism and mental health, online training videos, and digital resource guides.

"People with autism deserve equal access to mental health care," says Fletcher. And better understanding among providers and the community, adds Monahan. That can happen, she says, the more they learn about autism.



# Able to serve the whole child

Before she finished her enrollment in Delaware's new <u>Special Education Administrative Leadership</u> (SEAL) program, Vienna Walker began implementing what she was learning. As the <u>Polytech School District</u>'s director of Personnel and Student Supports, Walker worked to ensure <u>Individualized Education Programs</u> reflected each student's unique situation and that the district's curriculum and supports built students' confidence in their future success.

Upon completing her enrollment in the twoyear SEAL program, Courtney Casperson was determined that students with disabilities participating in the <u>Smyrna School District</u>'s summer education program feel safe and welcome. The district's supervisor of Support Services, Casperson saw that efforts designed to foster development of the students' IEP goals were complemented with recreational activities that emphasized accessibility.

A five-year partnership launched in 2020 between CDS and the <u>Department of Education</u>, SEAL prepares trainees to become certified as special education administrators. "The program reflects a person-centered perspective" says <u>Debby Boyer</u>, CDS's School-Age unit director. "A way of thinking and a set of values that are more inclusive."

"I walked away from SEAL with the tools to provide students the individualized resources they need to help them flourish," says Casperson.

Walker says SEAL's passion around inclusion enhanced her efforts to provide all children with access to an equitable education. "I practice inclusivity," she says. "I'm able to serve the whole child."

Vienna Walker now works to provide students with access to an equitable education as an administrator in the Kent County, Md., Public Schools.

### Lesson 1: Everyone is capable

Disability Studies "drew me to UD," says Caroline SanAngelo, a Cognitive Science and Psychology major who's pursuing a career as a school psychologist. "I knew from an early age that I wanted to work with people with disabilities."

Ed Holden didn't know the Disability Studies minor existed when he enrolled at UD. Now, the History major expects it will one day give him "a leg up" as a labor rights lawyer. "It widened my perspective. People with disabilities often get hired last; their workplaces can be inaccessible; some earn a subminimum wage."

Administered by CDS, Disability Studies last year attracted students from 37 majors and for the eighth year running was UD's largest minor. "Many select it because they'll apply lessons learned in the classroom and community to their future professions," says faculty coordinator Laura Eisenman. Others come to it because they're passionate about social justice or because of their personal connection to disability, she says.

"My sister has autism and I've worked with people with disabilities," says Early Childhood Education major Katie Joynt. "The advocacy skills I'm learning in the minor will support what I do inside schools and out. Disability intersects with all aspects of life."

"I have a disability but never hung out with others with disabilities," says Criminal Justice major Isabella Haigney. "The minor teaches me what others with disabilities experience and teaches my classmates how you can't judge someone by their disability. Everyone is capable."



Thirty-seven majors and counting: The Disability Studies minor draws students with varying interests. Caroline SanAngelo studies cognitive science and psychology; Ed Holden's degree will be in history.

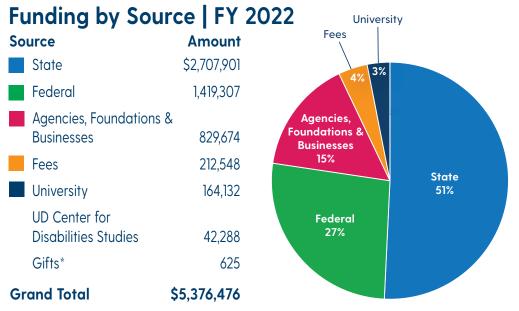
# THE YEAR IN REVIEW

# FUNDING AND FINANCIALS

#### The <u>Center for Disabilities Studies</u> had an operating budget of \$5,376,476 from July 1, 2021 through June 30, 2022.

### Sources of funding

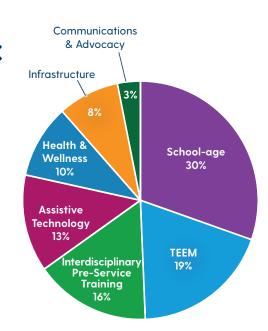
More than 96 percent of CDS funding is realized through grants and contracts from federal and state agencies, non-profit organizations, foundations, businesses, and fees. Included in the federal portion is \$577,449 from the <u>Administration for Community Living</u>, <u>Administration on Disabilities</u> for our core funding as a <u>University Center for Excellence in Developmental Disabilities</u>. This U.S. government organization is responsible for implementation of the <u>Developmental</u> <u>Disabilities Assistance and Bill of Rights Act of 2000</u>. CDS also benefits from gifts made by individuals and organizations.



\*This amount indicates what was spent from gift funds. New gifts to CDS in the 2021-2022 reporting year totaled \$7,394.

### 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.



Domain	Amount
School-age	\$1,632,114
TEEM	1,020,269
Interdisciplinary Pre-Service Training	853,466
Assistive Technology	710,835
Health & Wellness	538,035
Infrastructure	453,065
Communications & Advocacy	168,692
Grand Total	\$5,376,476

#### Funding by Domain | FY 2022

# FUNDERS

#### FEDERAL GOVERNMENT AGENCIES

Federal Communications CommissionU.S. Department of Health and Human ServicesAdministration for Community LivingCenters for Disease Control and PreventionHealth Resources and Services Administration

#### **STATE GOVERNMENT AGENCIES**

Delaware Department of EducationDelaware Department of Health and Social ServicesDivision of Developmental Disabilities ServicesDivision of Medicaid and Medical AssistanceDivision of Public HealthDivision of Services for Aging and Adults with PhysicalDisabilitiesDelaware Department of LaborDivision of Vocational RehabilitationDelaware Department of Safety and Homeland SecurityDelaware Department of Safety and Homeland SecurityDelaware Department of Safety and Homeland SecurityDelaware Department of Services for Children, Youthand Their FamiliesDivision 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. University of Delaware University of Massachusetts University of New Hampshire

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We would like to give special THANKS to those listed here for their generous support through gifts received in the year beginning July 1, 2021 and extending through June 30, 2022.

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#### To donate to CDS, please visit <u>cds.udel.edu/support</u>

# 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 <u>University Centers</u> <u>for Excellence in Developmental</u> <u>Disabilities Education, Research</u> <u>and Service</u> nationwide, with core funding from the <u>U.S. Department</u> <u>of Health and Human Services,</u> <u>Administration on Disabilities</u>.

• The administrative home to the interdisciplinary <u>Disability</u> <u>Studies minor</u>, the largest minor on campus with enrollment this past year reaching 437 students from 37 majors across six colleges at the University of Delaware.

### In 2021–2022, CDS staff and faculty cultivated student learning by...

- Teaching or co-teaching 55 courses/course sections and independent studies, reaching a total of 145 graduate and 998 undergraduate students.
  Delivering 12 guest lectures to 57 UD graduate students, 160
- UD undergraduate students and 95 students at three other institutions of higher education. • Providing assistantships/traineeships to 19 graduate students from the <u>School of Education</u> and the Departments of <u>Physical Therapy</u>, <u>Communication Sciences and</u> <u>Disorders</u>, <u>Epidemiology</u>, and <u>Behavioral Health and Nutrition</u> at the University of Delaware as well as the <u>Social Work Department at</u> <u>Delaware State University</u>. • Engaging 45 undergraduate students in the work of the Center.

#### In 2021-2022, CDS staff and faculty fostered the development of new knowledge–and the translation of existing knowledge–by...

- •Developing 29 project proposals internally and with external partners.
- •Offering 15 conference presentations and publishing five journal articles,

book chapters and other reports.
Providing editorial support for seven journals and serving as proposal reviewers for one conference and one funding agency.

#### In 2021-2022, CDS staff and faculty engaged with national, state and local communities by...

- Serving on 46 boards, committees and task forces external to the University (33 percent of these at the national level).
- Collaborating with 18 state agencies, 18 national and international agencies and organizations, 48 other units at UD, 43 community-based organizations and 21 other institutions of higher education.
- Contributing to media coverage about disability issues and the work of the Center in six online/print articles.





Top: (From left to right) Loretta MacLaren and Sandy Walls, administrative assistants with the CDS-led Delaware Assistive Technology Initiative Middle: (From left to right) Danielle Blachard, Adam Driscoll and Gabby Petro, students in the CDS-administered Access:Ability Scholars program, checking accessibility of polling places on Election Day

Bottom: CDS graduate assistant Thyra Broadnax





At top: <u>Ashley Steinbrecher</u>, limited term researcher, with CDS's COVID-19 Project

At bottom: (From left to right) Milford Mayor <u>Archie</u> <u>Campbell</u> and <u>Ron Sibert</u>, limited term researcher, with CDS's <u>Delaware Assistive</u> <u>Technology Initiative</u>

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# THE YEAR IN REVIEW

# **OUR COMMUNITY ADVISORY COUNCIL**

Members of the <u>Community Advisory Council</u> partner with the <u>Center for Disabilities Studies</u> 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.



# H SUSANNAH EATON-RYAI

#### **CAC Executive Committee**

Ira Shepherd II, chairperson, selfadvocate Cory Nourie, advocate Alyssa Cowin, self-advocate Terri Hancharick, <u>Endless Possibilities</u> in the Community, parent Susannah Eaton-Ryan, <u>The Arc of</u> <u>Delaware</u>

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John McNeal, <u>State Council for</u> <u>Persons with Disabilities</u>, selfadvocate Melissa Smith, <u>Division of Services</u> for Aging and Adults with Physical <u>Disabilities</u> Meedra Surratte, Parent Information

Center of Delaware

Debbie Talley Beane, Division for the Visually Impaired 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:

**Carmella Giddins-Jones,** Division of Prevention and Behavioral Health Services, parent

Stephen Groff, Division of Medicaid and Medical AssistanceDaniel Madrid, Office of the State TreasurerMaryAnn Mieczkowski, Department of Education



#### UNIVERSITY OF DELAWARE CENTER FOR DISABILITIES STUDIES

**FRONT COVER:** Abel Benjamin and Phoebe Jeddy, moments before they and their fellow <u>Career & Life</u> <u>Studies Certificate program</u> classmates take the stage at the <u>College of Education and Human Development</u>'s May 2022 convocation ceremonies. **BACK COVER**: Composite photos accompanying stories featured in the 2021-2022 annual report.



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