2022-2023 Annual Report
Center for Disabilities Studies
Greetings, from CDS

The 2024 elections are shaping up to be a referendum on identity: which ones “matter,” which are devalued, and which are outright denied.

Our identities—how we define ourselves—influence how we process and interact with the world around us. Here at CDS, we promote the perspective that a single person likely has many identities shaped by relationships, cultures, experiences, values, and aspirations. As you see in this annual report, we also celebrate and honor disability identity and amplify the voices of those with lived experience in our teaching, our research, and our work in communities across the state.

It troubles me when people are encouraged to constrain their identities in deference to a cause. When the cause comes to define our entire identity, we lose what makes us—in the words of speech-language pathologist and author Barry Prizant—uniquely human.

We all have a part to play in upholding the rights and dignity of our fellow humans. It starts with the recognition that our identities arise from our stories: the circumstances that make us who we are.

Everyone has a story, and those stories aren’t evident from outward appearance alone. Our stories are complex and full of plot twists; they reveal what propels us and what repels us. We can’t begin to know another person’s story unless we give them the space to tell it and then genuinely listen. At this critical juncture, we can’t afford not to listen.

Beth Mineo served her 15th year as director of CDS in 2023.
The experience of others

“We’re so westernized,” says Kate Capossela, “accustomed to viewing things a particular way.” Only not so much for Capossela since her Study Abroad trip last year to Thailand. “The excursion made me a better world citizen,” she says. It was, says the Disability Studies Minor senior, “the most humbling experience of my life.”

Study Abroad lets students see where their way isn’t necessarily the way, says CDS’s Laura Eisenman, co-coordinator with UD’s Stephanie Raible of the Thailand trip. “It gives students the chance to immerse themselves in the experience of others, expand their perspectives, and become more effective advocates and allies,” says Eisenman. “They leave their comfort zone, explore intersections, and build empathy,” adds Raible, whose cohort of business- and social-entrepreneurship-oriented students joined Eisenman’s.

A Thai facility for autistic students that the Study Abroad students visited didn’t showcase the technology or credentialed staff that are commonplace in Delaware, says Capossela. But she says the palpable sense of community and love between administrators and students was “beautiful.”

Other locations she and her fellow Study Abroad students came across often weren’t fully accessible—“too many stairs, too few elevators”—but Capossela says most everyone she met felt safe, trusted, valued, and empowered. “People there were thriving,” she says.

“After graduation I’ll be working in healthcare,” Capossela says, and “looking to foster what I saw in Thailand—positive attitudes and teamwork.”
More support for mental health

“People with intellectual and developmental disabilities (IDD) have mental health needs like anyone else,” says Sarah Mallory, director of CDS’s Health and Wellness unit. CDS has embarked on a multi-year mission, in partnership with Delaware’s Division of Developmental Disabilities Services (DDDS), to better understand and address why those needs often go unmet.

DDDS’s collaboration with CDS and organizations like the National Center for START Services (NCSS) have focused on engaging the community through stakeholder meetings, a statewide survey, and an analysis of Medicaid claims data.

“These data have shown us that there are not enough IDD providers who understand mental health, and not enough mental health providers who understand individuals with IDD,” says Mallory. “As a consequence, we often rely on our first responder and crisis systems to serve the needs of this population.”

People with IDD over-rely on emergency services and police departments, says DDDS Director Jody Roberts. That wouldn’t be the case, he notes, if there were enough outpatient mental health services for people with IDD and adequate expertise among mental health and IDD providers.

“There’s also a historical bias to overcome that a person with IDD doesn’t have the ability to benefit from mental health services,” he says.

This year, DDDS, CDS and a network of community partners will work to increase the capacity of Delaware to support the mental health needs of people with IDD. “There’s an opportunity to build on the momentum of our first year,” says Roberts, “to train more professionals and enhance the availability of resources.”

“It’s a matter of health equity,” says Mallory, “so we can take steps to improve mental health supports available to people with IDD.”

This work was funded, in part, by Contract #DDDS 23-0317-00 from Delaware Health & Social Services/Division of Developmental Disabilities Services.
Improved response, better outcomes

In 2013, police confronted Ethan Saylor for not purchasing a movie ticket in Frederick, Maryland. Saylor had Down syndrome and demonstrated difficulty understanding and following the theater’s rules. Law enforcement based its response on how to handle criminal behavior rather than how to respond to a person with a disability, and it led to Saylor’s arrest and death.

Trainings by the CDS-run Delaware Network for Excellence in Autism (DNEA) are providing first responders with the information and approaches they can use to ensure safe outcomes when encountering individuals with disabilities.

Chuck Sawchenko, a retired police lieutenant and parent of a child with autism, leads these trainings. He explains, “First responders often have contact with people when they are in crisis or stressful situations. Without proper awareness and understanding, these types of situations can easily turn into traumatic experiences for an autistic person.”

For example, an officer encountering a person with autism who’s engaging in repetitive behaviors might wrongly infer they are intoxicated, Sawchenko said. Rather, the person may simply be calming themselves.

The DNEA trainings are helping first responders develop the skills they need to have “more patience, common sense, and understanding,” one trainee explained.

“Thanks to Retired Lieutenant Sawchenko,” a police officer said, “we have been able to successfully recognize autism and use the strategies discussed in his training to compassionately respond to situations involving autistic people.”

The broader community stands to benefit, said DNEA Director Alisha Fletcher. “Training first responders to support autistic individuals,” she said, “creates a sense of belonging and inclusion.”

This work was supported by Delaware Health & Social Services/Division of Developmental Disabilities Services with funding from the Health Fund Advisory Committee.
At home with world languages

Last summer, Elizabeth Capone and other world language teachers from Brandywine School District attended a training session from CDS’s ACCESS Project to learn how to make their lessons more approachable and understandable to their students.

The training was part of a three-year project between the school district and the Delaware Department of Education (DOE) to make languages beyond English more accessible to all students. DOE tapped CDS to lead the Brandywine training.

“We conducted the training with two objectives in mind,” says Mackenzie Shane, ACCESS instructional coach. “We wanted instructors to embrace the Universal Design for Learning [UDL] approach, to anticipate and remove barriers to learning in ways that make lessons engaging for all students. Then we asked them to align UDL to strategies familiar to them that also aim to make lessons universally inviting.”

Capone, a Spanish instructor at Mount Pleasant High School, began implementing new approaches in her classroom such as breaking lessons into small steps and using role-play to try out new vocabulary. She says she’s seen improvement in retention and willingness to engage with the material. “Panic levels of the students are way lower,” she says.

“Students need to feel comfortable to take a risk in front of their teachers, in front of their peers,” says Kristi Fry, ACCESS program manager.

Since the training, the Brandywine curriculum has been expanded to include other world languages. ACCESS Project staff also have trained more world language teachers statewide.

When you make lessons accessible, says Capone, “everyone benefits.”

Gathered with all world language teachers in the Brandywine School District, Mackenzie Shane models how UDL principles can make learning more accessible to all students.

This work was supported by Contract #S23-57 from the Delaware Department of Education.
Assistive technology equals access

During a recent visit to the Assistive Technology Resource Center (ATRC) at CDS, assistive technology (AT) coordinators Liz Merrick, Elizabeth Gamble and Amy Micklos of the Colonial School District answered what to them seemed the world’s easiest question: “Why is your district committed to providing assistive technology to its students with disabilities?”

“It’s the law,” said Merrick, referring to the federal requirement that AT be considered for every student for whom an Individualized Education Program (IEP) is developed.

“Providing AT equals access,” said Gamble.

“It’s about access and opportunity; the Power of WE,” said Micklos, reciting the district’s mantra. “Students who use it can succeed like anyone else.”

Then why do so few districts in Delaware take full advantage of the benefits AT offers students? A study, conducted last year by CDS in collaboration with UD’s Center for Research in Education & Social Policy, uncovered several reasons.

Educators pointed to access barriers arising from little training in AT, inconsistent policy on AT, and the expense of AT. Family members explained how these—and other—challenges impact their children. A New Castle County parent reported that it falls to her to prove that her child needs AT. “It’s very frustrating.”

And avoidable, said Beth Mineo, CDS director and leader of its AT initiatives. There are abundant training opportunities in Delaware, she said, yet educators may not know about them or aren’t given release time to access them. And there’s no shortage of AT devices to borrow from the ATRC. When students have an opportunity to try AT, everyone gets to see first-hand how the equipment impacts motivation and success. “Failure to provide AT is often blamed on lack of funding,” said Mineo. “Yet our students can’t afford to be without it.”

This work was supported by Grant #2301DEATSG-00 from the Administration for Community Living, U.S. Department of Health and Human Services and Grant #P116Z220070 from the U.S. Department of Education, Office of Special Education Programs.
“I’m just a mother of two sons, one of whom has autism,” says Kendra Haynes. “I’m not a medical professional and I’m certainly not a video producer.”

But Haynes is an influencer. The video she created as a trainee in the CDS-run Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program continues to impact professionals several years after she made it.

“That’s what happens with our trainees’ leadership projects over the course of their year with LEND,” says Stephanie Kaznica, the program’s coordinator. “The trainees—some are budding or practicing professionals, others are self-advocates or family members—identify challenges in the community that need to be overcome.”

“Then, through their research, recommendations and often personal connections to the subject matter, their projects make a difference,” Kaznica says.

Haynes’ Mama’s Baby, Autism Maybe video features three mothers who, like herself, struggled to get timely and accurate diagnoses of autism for their child. The medical residents, disability advocates and community organizations who view it learn how practitioners discounted or explained away what the mothers, who represent historically underserved populations, reported about their child’s developmental delays.

Other trainee projects seek to make similar impacts. LEND faculty member Jillian Trabulsi expects 2022-2023 trainee Melanie Rojas’ nutritional resource guide will enhance dieticians’ ability to serve clients with autism.

“Her guide fills knowledge gaps,” Trabulsi says.

Kaznica says LEND leadership projects like Haynes’ and Rojas’ heighten awareness about the need for timely diagnoses, added supports for medically complex children, improved access to assistive technology, and more.

“I’m happy,” Haynes says, “that people still are finding value in my video.”

This work was supported by Grant #T32MC30116 from the Health Resources and Services Administration, U.S. Department of Health and Human Services.
Discovering what’s out there

Like many of their high school classmates, Lindsay Massaro and Sheldon Brannon hadn’t spent extended time away from their homes and families.

That changed with their immersion in CDS’s UDiscover program, which gives high school students with disabilities the chance to explore their educational and career interests, advocate for themselves, and develop ways to become more independent.

For two summer weeks, Massaro, Brannon and 12 other students got to live in University of Delaware residence halls and receive hands-on experience that “prepared them for life beyond high school,” says CDS’s Rebecca Jewell. Students participated in job shadows, attended workshops on independent living and spent time exploring the campus and Newark’s Main Street.

Before his participation in UDiscover, Brannon, a Newark Charter School junior, dreamt of working in sports management. Now, he says he plans to pursue that dream after graduating. “I’m more confident in my ability to be away from home,” he says. “I learned how to advocate for myself.”

As a high school student from Highstown, New Jersey, Massaro visited UD and fell in love with the campus. UDiscover cemented her attraction to UD, where she is now enrolled in its multi-year Career and Life Studies Certificate program. Massaro also helps other first-year students in her residence hall find their way around campus.

“I enjoy meeting new people, getting out there to discover,” says Massaro. “You can’t rely on your parents or guardians forever.”

This work was funded, in part, by Contract #LAB-22100 from the Delaware Department of Labor on behalf of the Delaware Statewide Independent Living Council and agreements with the Freedom Center for Independent Living, Independent Resources, Inc., and the Delaware Developmental Disabilities Council.
Ambassadors for access and inclusion

Talk about paying it forward. Paige Johnson and Kaitlyn Myers, like so many of their fellow Access:Ability Scholars graduates, are passing on what they learned in the CDS-run program to others. Every day.

“Wholeheartedly!” says Johnson. Now a care coordinator at Sloan Kettering Cancer Center in New Jersey, Johnson says she routinely practices what the program encourages: make the world more accessible and inclusive.

Whether interacting with patients at check-in or in clinical settings, Johnson says she “treat(s) anyone with a disability as an individual. No one’s the same. No two cancers are the same.

“A couple can enter our Center, one in a wheelchair, another on foot, and I know not to assume anything,” Johnson says. “I’ll ask which one of them is the patient. Other providers might assume the patient’s the person in the wheelchair. If they do, I’ll give them a nudge and suggest the right approach.”

Myers is pursuing her PhD in Intellectual and Developmental Disabilities and Psychology at Ohio State University. When she speaks up among her peers, Myers says she knows she’s doing so in the most progressive and appropriate way because she puts the person with a disability first. “When I research people with disabilities, they’re also on my research team,” she says. “They’re the experts, more than any scholar.

“People in an academic setting often approach others through a medical lens” Myers says. “I let them know they need to approach others as people first. I got that from Access:Ability Scholars.”

Paige Johnson (above) and Kaitlyn Myers during their undergraduate career at the University of Delaware.
Leveling the playing field

“People should be making their own health care decisions,” says Debbie Bain, recently retired executive director of the Statewide Independent Living Council (SILC). “And this,” she says, “this will make that happen. It will help level the playing field.”

Bain is referencing a teaching guide being developed by CDS with funding from SILC’s first-ever Community Innovative Venture Grant Project. It’s designed to give people with intellectual and developmental disabilities the resources and confidence they need to make their own wellness decisions.

“We all find ourselves in the position with health-care providers where we don’t lead the discussion—often because we’re intimidated—and that can happen more often for someone with a disability,” says Bain.

“It is our hope that people who have access to this curriculum will be able to identify their healthcare goals and rights so they can build strategies for communicating with their healthcare providers,” says CDS project lead Ashley Steinbrecher.

This curriculum includes a suite of resources that was developed in close partnership with community groups. It is designed to promote self-determination and health literacy for people with disabilities.

The guide’s centerpieces are CDS’s My Health Care Plan and My Emergency Care Plan, which were developed with funding from the Delaware Developmental Disabilities Council.

“People can be active in their health and wellness,” Steinbrecher says.

Bain’s certain of it. “Once the teaching guide becomes readily available through CDS,” she says, “it will take on a life of its own.”
Spectrum Scholars turns out first graduates

Before enrolling at UD, Melissa Gatti says her family feared she’d get lost. “I wasn’t focused, I was struggling with my social skills, I wasn’t advocating for myself,” she says.

Andrew Martin feared he might “lock up.” “Before UD, I needed a paraprofessional,” he says. “I could get stuck or fail to do things in the order I needed to do them.”

That was then. Fortunately, they say, upon entering UD they also joined the CDS-run Spectrum Scholars program. Launched in 2018 in partnership with JPMorgan Chase & Co., it provides participating autistic undergrads with coaching, peer mentoring, social engagement, and career development opportunities.

Gatti and Martin graduated in May—the first students to complete the Spectrum Scholars program and the last people, anywhere, to lack confidence. “We embrace, never judge, our students,” says Program Manager Wes Garton. “They’ve got great abilities and potential. We encourage them, support them, and watch them grow.”

Today, Gatti coaches UD students with intellectual disabilities in a CDS program for neurodiverse students. She’s aiming for a master’s degree in computer science and perhaps a career in cybersecurity or software engineering. “Spectrum Scholars helped me interact with others, like the students I’m coaching,” she says. “I feel more accepted.”

Martin parlayed his Applied Molecular Biology & Biotechnology degree into a job working on monoclonal and polyclonal antibodies for a company in Newark. He lives, independently, in a nearby apartment. “I got organized, purposeful, and more skilled at seeking jobs with Spectrum Scholars,” he says. “Where I’m at is as good as I can imagine.”

Spectrum Scholars is supported with funding from JPMorgan Chase & Co.
I’m not afraid of new things

Jahlil Thorpe felt nervous; Mark Logan, a little worried. “Actually, I was very nervous,” says Thorpe, recalling when he first went to work two years ago for Logan at the Delaware Department of Transportation (DelDOT) in Newark.

“I didn’t know what I was doing. I wasn’t confident.”

“Yeah, Jay—we call Jahlil, ‘Jay’—was uncomfortable and shy around our guys,” says Logan. “But I needn’t have worried about him—not Jay, not in the least.”

Thorpe today is a confident mechanic’s apprentice, helping conduct annual DelDOT vehicle inspections when he isn’t changing vehicles’ oil, transmission filters, and tires. He’s a far cry from the eager-yet-anxious young man that DelDOT hired following his graduation from the CDS-led Career & Life Studies Certificate (CLSC) program for students with intellectual disabilities. Thorpe landed the DelDOT job after participating in an internship through CLSC at Sears Automotive in Price’s Corner.

“When Jahlil entered CLSC, he wanted to work in information technology, but after completing an IT internship, he was unsure if it was right fit for him,” says CLSC Program Manager Jay Sellers. “He loved working on cars, so he tried the internship at Sears Automotive where he gained experience to begin a career as a mechanic.”

“Never discredit someone with a learning disability,” says Logan. “There are strengths in people’s differences. I’ve never seen Jay have a bad day. Everybody here loves him.”

“I’ve grown,” says Thorpe. “I’m working with others and I like that. I’m not afraid of new things.”

Jahlil Thorpe (center) bonds with master mechanic Sal Hernandez (left) and automotive supervisor Mark Logan inside a DelDOT service center in Bear.
The Center for Disabilities Studies had an operating budget of $6,896,553 from July 1, 2022 through June 30, 2023.

**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 $589,500 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 2023**

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*This amount indicates what was spent from gift funds. New gifts to CDS in the 2022-2023 reporting year totaled $7,513.

**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 2023**

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<td><strong>Grand Total</strong></td>
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FUNDERS

FEDERAL GOVERNMENT AGENCIES

Federal Communications Commission
U.S. Department of Education
- Office of Elementary and Secondary 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 Developmental Disabilities Services
- Division of Medicaid and Medical Assistance
- Division of Services for Aging and Adults with Physical Disabilities
Delaware Department of Labor
- Delaware Statewide Independent Living Council
- 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
- Education Health & Research International, Inc.
- Freedom Center for Independent Living
- Independent Resources, Inc.
- JPMorgan Chase & Co.
- Organization for Autism Research
- TransCen, Inc.
- University of Delaware
- Wayne State University

DONORS

We would like to give special THANKS to those listed here for their generous support through gifts received in the year beginning July 1, 2022 and extending through June 30, 2023.

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Thea A. Calder '07 '09M
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Sonja L. Rathel
Sandra L. Walls

UNDERGRADUATE PROGRAM ENRICHMENT
Tracy L. Beird
Beth A. Mineo and Gary H. Heckert '72 '76

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The Center for Disabilities Studies is:

• One of 68 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 for eight consecutive years with enrollment this past year reaching 405 students from 37 majors across seven colleges at the University of Delaware.

In 2022–2023, CDS staff and faculty cultivated student learning by...

• Teaching or co-teaching 64 courses/course sections and independent studies, reaching a total of 143 graduate and 926 undergraduate students at the University of Delaware and two other institutions of higher education in Delaware.

In 2022-2023, CDS staff and faculty engaged with national, state and local communities by...

• Serving on 66 boards, committees and task forces external to the University (26% of these at the national level).
• Collaborating with 18 state agencies, 32 national and international agencies and organizations, 66 other units at UD, 92 community-based organizations and four other institutions of higher education.
• Contributing to media coverage about disability issues and the work of the Center in six online/print articles.

Delivering 14 guest lectures to 71 UD graduate students, 175 UD undergraduate students and 113 students at three other institutions of higher education.

• Offering 14 conference presentations and publishing seven journal articles, book chapters and other reports.
• Providing editorial support for 12 journals and serving as proposal reviewers for five funding agencies, three conferences and two other initiatives.

In 2022-2023, CDS staff and faculty fostered the development of new knowledge—and the translation of existing knowledge—by...

• Developing 34 project proposals internally and with external partners.
INDIVIDUALS WHOSE SERVICE CONCLUDED DURING THE PAST YEAR

STAFF AND FACULTY
John Airey
Elaad Anzili
Jill Blevins
Fiona Day
Najla Elgindy
Samantha Fields
Benjamin Green
Kathleen Harvey
Emma Huber
Charlene Johnson
Stephanie Kaznica
Sarah Mallory
Anthony Middlebrooks
Beth Mineo
Jillian Trabulsi

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Joyce Denman
Sharon DiGiralamo
Sue Dutton
Lauren Irwin
Tracy Long
Mary Ann Mieczkowski
Mary Norris

STAFF AND FACULTY
Blake Bossert
administrative assistant, welcomes visitors to CDS’s Newark office

At top: Blake Bossert, administrative assistant, welcomes visitors to CDS’s Newark office
At bottom: Edward Konigsberg (right), a student in CDS’s CLSC program, with his job shadow mentor, Jacob Wasserman, at the offices of Rep. Lisa Blunt Rochester
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 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, advocate
Alyssa Cowin, self-advocate
Terri Hancharkick, Endless Possibilities in the Community, parent
Susannah Eaton-Ryan, The Arc of Delaware

CAC MEMBERS
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Karl Booksh, University of Delaware, self-advocate
Charles Bryant, Division of Developmental Disabilities Services, parent
Selina Butcher, The Freedom Center, self-advocate
Anthony Carter, JEVS Support for Independence
Karen Doneker, parent
Deborah Dunlap, parent
Brigitte Hancharick, self-advocate
Kristin Harvey, Delaware Developmental Disabilities Council
Elisha Jenkins, Division of Vocational Rehabilitation
Nancy Lemus, parent

Jane Luke, parent
Dale Matusevich, Department of Education
Daniese McMullin-Powell, self-advocate
John McNeal, State Council for Persons with Disabilities, self-advocate
Melissa Smith, Division of Services for Aging and Adults with Physical Disabilities
Meedra Surratte, Parent Information Center of Delaware
Debbie Talley Beane, Division for the Visually Impaired
Pam Weir, Governor’s Advisory Council for Exceptional Citizens

MEMBERS WHOSE SERVICE CONCLUDED DURING THE PAST YEAR:
Kathy Hughes, family member
Ira Shepherd II, self-advocate
Laura Waterland, Disabilities Law Program
Despina Wilson, Independent Resources, Inc.
FRONT COVER: Shelvia and Stuart Neely (standing) with Selina Butcher at the 2023 closing ceremony for the Leadership in Neurodevelopmental and Related Disabilities program.

BACK COVER: Composite photos accompanying stories featured in the 2022-2023 annual report.