



delAware

A PUBLICATION OF THE CENTER FOR DISABILITIES STUDIES

Steps Ahead

Disability Studies at UD



WELCOME! It's a pleasure to provide you with this window on disability studies at the University of Delaware. Through it you'll discover why students majoring in subjects spanning education, psychology and even agriculture and communications say that minoring in disability studies gives them an advantage. (Hint: It helps them to better appreciate the one-in-five people who have a disability and their role in creating a more inclusive society. And, it enhances their marketability for advanced degrees and careers.)

You'll understand why this relatively young minor attracts more students than more established minors – and even some majors – on

campus. (Its lessons in accessibility and empowerment directly apply to fields as diverse as allied health and the arts, and it offers students as many chances outside their classes as in to further their education.)

And you'll appreciate as we do that to continue the minor's success, graduating students who will partner with people with disabilities to make communities responsive to them, the minor needs to keep exploring ways it can evolve. Disability studies at UD began as an experimental course, and we'll continue to experiment and innovate to remain relevant and lead.

Laura Eisenman

Disability Studies Faculty Coordinator

A PASSIONATE COMMITMENT

Administrators at the University of Delaware believed disability studies would annually serve some 20 students when they launched the minor in 1997. They were conservative in their estimate. Today, disability studies serves more than 400 students and in 2014, it became UD's most popular minor.

The extraordinary growth of disability studies on campus mirrors an increasing demand in the community for professionals who can support a rising percentage of the population identifying as having a disability. But that only partly explains the minor's success. If its growth were simply a byproduct of disability becoming more prevalent, disability studies would be thriving on campuses everywhere.

Only a relative few universities offer courses in disability studies, however. And fewer still offer disability studies as a minor to undergraduate students. The principal driver of its success at UD is the commitment that educators, community partners and students have made and continue to make to ensure that



Samantha Hitchell discusses public policy in her Senior Seminar class.

the minor supports the growing population of people with disabilities and their families.

"We felt that everyone should know about disabilities and the capacity of people with disabilities," says Michael Gamel-McCormick, a principal designer of the minor and now an executive at the Association of University Centers on Disabilities. "We thought everyone should know that it is the only minority group that anyone can enter at any time in their life; that more than 50 million Americans have disabilities; that much of the public thinks of the group as separate from the general population; and that people with disabilities have much to contribute."

So in 1992, educators and administrators from what now is UD's College of Education and Human Development, which offers the minor, and the Center for Disabilities Studies, which administers it, collaborated with advocates in the community to offer the experimental *Families and Developmental Disabilities* course. (It's one of the minor's few required courses.) Heightened interest from undergraduates and CDS-affiliated faculty across the university fueled the launch of the minor a few years later. The creation of the minor allowed UD "to infuse disability in undergraduate programs across as many disciplines as possible"

so that students would be mindful of people with disabilities in their future professions, Gamel-McCormick says.

The design of the minor also increased the probability of its success, says Gary Allison, an assistant professor in special education who teaches the minor's *Introduction to Exceptional Children* course. The minor's flexibility and breadth allows students to choose courses that match their personal, academic and professional interests, with classes delving into everything from how politics impacts disability to the importance of fostering mentoring relationships.

The minor's also about *doing* as much as it is about learning. One day students read about an issue, the next day they hear about the issue from leaders and experts, a day later they explore ways they can do something about the issue. Students conduct research and become involved in service learning, community service and other work experiences.

UD undergraduate Alyssa Marren says the minor enhanced her professional knowledge and marketability and should help her "interact better as a teacher with students who have disabilities." Kaitlin Mandel says the "interdisciplinary minor" offers students like her, from different parts of the UD community, the opportunity "to work together and learn from each other.

SUM OF ITS PARTS

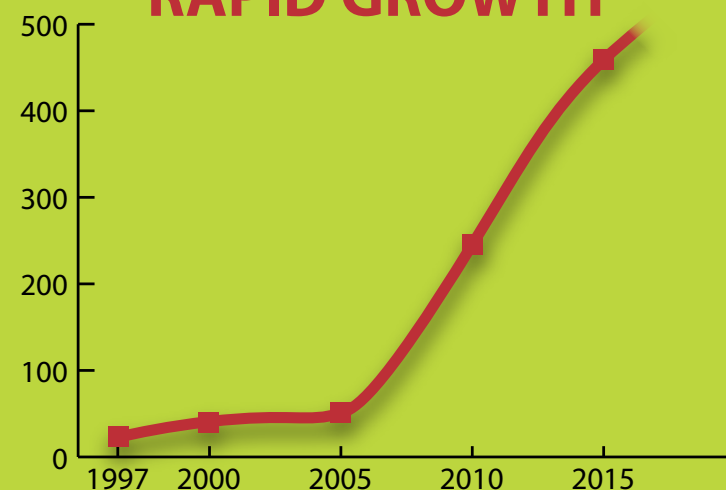
The minor draws students from many disciplines.

EXERCISE SCIENCE
NURSING HUMAN DEVELOPMENT ANIMAL SCIENCE
COMMUNICATIONS HISTORY FAMILY STUDIES NEUROSCIENCE
HEALTH SCIENCES MANAGEMENT PSYCHOLOGY SOCIETY
DIETETICS CRIMINAL JUSTICE PUBLIC POLICY
ENGLISH ED MUSIC ED
ELEMENTARY EDUCATION
HUMAN SERVICES
EARLY CHILDHOOD EDUCATION
COGNITIVE SCIENCE

It's a real benefit," she says, "to connect with peers from different majors who share a passion for disability studies."

See over the next several pages how other UD students and the community at-large are benefitting from the disability studies minor.

RAPID GROWTH



The disability studies minor grew from 20 to more than 400 students in less than 20 years.



Shari Paltrowitz (far right), alongside Nicole Davidson, asks at a campus forum about opportunities to volunteer in the community.

IN THE CLASSROOM

Julia Schmidt's devoted to elementary education, Emily Fritz to animal therapy, and Megan Johnson to exercise science. The disability studies minor and Senior Seminar in Disability Studies, the capstone of the program, helped them determine how they can readily support people in their respective field .



Julia Schmidt



Emily Fritz



Megan Johnson

I knew I wanted to major in elementary education with a concentration in special education when coming to the University of Delaware. Pursuing the disability studies minor seemed to make sense for my profession, but it became so much more holistic than that.

Senior Seminar expanded my knowledge of disabilities and made me more aware of the very real barriers that still exist today. By exposing me to experts in the field and individuals with disabilities, it allowed me to become personally invested in the issues, particularly where there is poor accessibility to health care for people with disabilities.

The seminar inspired me. I want to advocate to make a difference. I want to make those around me informed. The seminar and the minor made me realize how much we still have to change to become a more inclusive society. We not only have the responsibility to recognize problems, but to make improvements.

As an animal science major, I chose the disability studies minor because it was a great way to combine my interests: working with people with disabilities and working in animal therapy. The seminar introduced me to a new cohort of peers; coming from the College of Agriculture and Natural Resources, my discussions with people of diverse backgrounds were uniquely engaging.

Senior Seminar was the first course I took that really delved into the world of adulthood and disability, exploring the factors involved in transitioning. While I have significant experience with the disability community having an older brother with Down syndrome, I was shocked at how much I did not know about policy and practice – the supports that need to be in place for an individual's independence really hit home.

Because of this course, I feel better prepared to advocate for individuals with disabilities. Through service dog training, I will improve their quality of life.

My interest in a disability studies minor began when I set my sights on pediatric physical therapy. I'm an exercise science major. By reaching out to the community, *Seminar* helped me see how concepts we learned about directly impact real people every day. That's not something you get in many classes. Our final video project was particularly meaningful: interviewing students with intellectual disabilities from the Meadowood Transition Program, hearing about their hopes and transition goals for employment. Their dreams and our class discussions on accessibility resonated with me, inspiring me to want to help pave the way for my future young clients. I now find myself much more aware of accessibility issues in all environments.

The minor taught me that people with disabilities are competent individuals. As a PT, I will access the capabilities of each child with whom I work, provide the necessary support to foster independence and growth, and always assume ability, thanks to the *Senior Seminar*.

DIRECT CHALLENGES

Disability can't be exclusively book-taught or book-learned, say Beth Mineo and Cheryl Bates-Harris. Students need to meet individuals who are impacted and get involved in policy. Those opportunities are available throughout the minor, but no more so than through the *Senior Seminar*.

Mineo, director of UD's Center for Disabilities Studies and an associate professor who teaches the seminar, brings self-advocates and experts into class to challenge students to consider what they thought they knew in different ways. A course with few pat answers, the seminar motivates students to appreciate the complexity of issues, Mineo says.

Bates-Harris of the National Disability Rights Network is one of the seminar's self-advocate guest lecturers. Involved in a head-on collision with a motorcycle, she got fired from a job during her recovery, an injustice which sparked her fight for employee rights. Sparks fly when she engages *Seminar* students. "The students are passionate, understanding disability impacts lives everywhere," she says. With an assist from the seminar, it's also making advocates of the minor's students.

Beth Mineo (left) and Cheryl Bates-Harris.



Disability studies minor Rebecca Lloyd and CDS Associate Director Brian Freedman discuss their joint research initiative: a statewide survey for the National Core Indicators (NCI) project, a voluntary effort by public developmental disabilities agencies to measure and track their performance in providing services to individuals with developmental disabilities.

Rebecca: I'm proud to be a part of a research project that gives these individuals the opportunity to voice their opinions about services they receive. Having a disability myself, I know how important it is to have a say in your needs.

Brian: The voices of people with developmental disabilities are rarely heard. The National Core Indicators project is giving us a strong indication of what their lives are like from their own perspectives.

Rebecca: If we reach our goal this year, we'll collect 400 face-to-face surveys from individuals across Delaware.

Brian: That's right: surveys with information about their employment, rights, service planning, community inclusion, choice, and health and safety. We're able to conduct this research because in 2013, the Division of Developmental Disabilities Services

selected us to build interviewer teams to collect the data due to our relationships with students and self-advocates.

Rebecca: And I was recruited for this research project, and ended up doing my 400-hour internship for my major with NCI.

Brian: Effective communication has been a key to the success of the project, allowing us to maximize the participation of those being surveyed.

Rebecca: Yes. I created a picture card system for non-verbal participants. And in one interview, a man who was deaf read my lips as I asked questions, which was pretty neat.

Brian: All the research we do in connection with disability studies supports the growth of our students. And Rebecca, you brought everything to the table – a student from the university, a disability studies minor, and an individual with a disability.

Rebecca: My disability allowed me to better connect with participants. I am familiar with services from personal experience and I believe many individuals may feel more comfortable opening up to me because of this.

RESEARCH

Brian: This project lets students apply so much outside the classroom. You get to go into the community, meet people with disabilities and learn about their lives. This, in turn, helps students consider ways they can improve services and access for people with disabilities after college. It's a perfect illustration of what research through our minor does in our quest to create a more inclusive society. The data we collect is also being gathered in more than 40 states so researchers can explore solutions for people with developmental disabilities across the nation.

Rebecca: It's very exciting to be a part of research that will have a direct, immediate impact!

Brian: Through our research projects, Rebecca, we hope students like you not only will become better informed and involved in the field, but also become strong advocates. I have definitely seen this growth in you through your involvement in the NCI project.

Rebecca: The work I've done has definitely helped me reaffirm my career path. It has been a great experience.

SERVICE LEARNING

“Their faces, and ours, lit up.”



Devon Aleszczyk (right) and her sister, Kaley Marshall.

“I came to UD because I felt it would best prepare me for my ultimate goal of becoming an occupational therapist. By the end of my freshman year, I knew I wanted to minor in disability studies. I was interested in disabilities because of my sister, Kaley. She’s 10, she’s very loving and enjoys helping others. My sister is deaf and has a cochlear implant. She also has Smith Magenis syndrome, and we’re still learning about ways it affects her. To complement my personal experience with disabilities, I wanted to incorporate a professional experience through education. I knew it was a way to learn about assistive technology and mentoring individuals with disabilities.

Through the minor, I had the opportunity to be a part of UD’s service learning program. Service learning scholars work for 10 weeks in the Delaware community under the guidance of a UD faculty mentor. I’m very interested in research, and in finding new ways to treat people. It seemed like a great way to help the community.

In my project, we taught motor skills to children with intellectual disabilities using video modeling. Instead of telling someone how to throw a ball, we had a video that breaks the action down into steps.

Every day, students would come into the classroom individually and watch the video. We asked them to try the skill and tell us what they thought. My partners and I are actually in the videos – whatever we’d ask the students to do, they’d see us doing it in the videos. The videos are engaging. For some kids with disabilities, it’s easier to see a visual representation of what to do.

From what I observed, it directly benefited these students. These kids were learning, and we watched them improve every day. Sometimes they did things they hadn’t done before. Their faces, and ours, lit up when that happened. I saw changes happen right in front of me. We benefited academically, but they benefited in their lives.

It’s a valuable program because I gained professional experience with the community I hope to engage in my career. Personally, it’s meaningful because I enjoy witnessing the change and improvement in the students. You don’t get that from a textbook, you’ve got to learn that by working firsthand.”

COMMUNITY SERVICE

“With other minors you take a certain set of classes, you satisfy requirements and you’re done,” says Anthony Monaco, a cognitive science major who minored in disability studies. “With a disability studies minor, you find a community through the people in your classes and through the many interactions and relationships built outside the classroom – what you are learning is used and real.”

Anthony should know. He took advantage of community service opportunities through the disability studies minor involving policy, mentoring and creative outlets that, he says, “let me become closer to my community and form great friendships.”

Cases in point: Through the minor Anthony connected with Junior Partners in Policymaking, a weeklong program overseen by the Delaware Developmental Disabilities Council that offers students with and without disabilities classes that cover topics such as assertiveness, self-determination and understanding government processes. The program tops off with a visit to Legislative Hall in Dover. Through it, Anthony met students with intellectual disabilities who were participating in UD’s two-year Career and Life Studies Certificate (CLSC) program. Those encounters then led Anthony to becoming an academic and life skills coach for CLSC.

Anthony also volunteered at the Center for Disabilities Studies’ Artfest program, an annual creative workshop and community celebration hosted in conjunction with Art Therapy Express of Newport. “I was paired with a great young man named Sean; he has visual impairments and uses a wheelchair,” says Anthony. “We had an incredible day together.” Sean’s mother, Phyllis, says that “Anthony and Sean really hit it off! Anthony put Sean at ease and they both have a great sense of humor. They immediately connected and Sean enjoyed having a buddy and kindred spirit helping him with the activities.”

Chances to hear through the minor about opportunities to perform community service are practically limitless: Students can, for example, learn sign language, train dogs to support



Anthony Monaco (right) and Sean Guinivan at Artfest.

people with disabilities, offer exercise programs to people with limited mobility, provide household support to elderly and chronically ill members of the community, and raise awareness about epilepsy, autism, cerebral palsy and other disabilities.

Doing community service through the minor allows you to be “more aware and prepared to interact with all people; it makes you a better person,” Anthony says. “The minor shaped my academic and social experiences at UD. It will continue to shape my involvement and connection to my community throughout my life.”



Anthony (far right) with his Junior Partners in Policymaking pals.

INFLUENCE ON AND OFF CAMPUS

At and around the University of Delaware, the disability studies minor's pillars of inclusion, accessibility and service are becoming increasingly fixed in the community's foundation. There are the many registered student organizations on campus that support people with disabilities in the community – many of their members and faculty advisors come from the disability studies minor. There's the university's involvement each year in Spread the Word to End the Word, which has many students in the minor joining other students on campus to encourage everyone to end the verbal denigration of people with disabilities.

There was the campus panel discussion and library exhibition celebrating the benefits of the Americans with Disabilities Act on the occasion of its 25th anniversary, and the university shooting and posting to YouTube a captioned video of the state's festival in Dover commemorating the ADA. UD's annual sponsorship in Newark of Disability Mentoring Day has grown to where employers throughout the state now give students with disabilities a chance to personally connect with them that day – and opportunities to land jobs with them later. Disability studies students and staff played significant parts in the success of the ADA and DMD events.

Giving people with disabilities the opportunity to participate in the community requires a greater awareness of their needs – and “our disability studies minor increases this awareness,” says Lynn Okagaki, dean of UD's College of Education and Human Development at the time disability studies became UD's largest minor. Okagaki notes that what's taught through the minor finds expression elsewhere on campus. For example, engineering students are working with fashion majors to design clothing that enables children with limited mobility to stand and gain greater movement with their arms and legs. Health and



Lynn Okagaki



Carol Henderson



Andy Imparato

human service students are learning how to identify, assist and support people with physical, cognitive or emotional differences. And students in public policy are becoming more aware of how policies may affect vulnerable populations.

Carol Henderson, vice provost of diversity at UD, says the minor “encourages all of us to think about the ways we engage inclusion and equity on our campus.” It also “allows us to impact practices in the private and business sectors and in state and city agencies.” Yet for all that the minor offers or adds to the university and community, Henderson says, “I don't think we're where we need to be; we still have a lot of work when it comes to inclusion, equity and diversity.”

Other schools and communities have even more work to do. Given the myriad benefits colleges and communities can derive by practicing the tenets taught in a disability studies curriculum, it's surprising that so few universities offer a minor in disability studies.

Disability studies needs to be seen as a priority at more universities, says Andy Imparato, executive director of the Association of University Centers on Disabilities, of which UD's Center for Disabilities Studies is a member. Universities and colleges that don't offer courses or academic disciplines in disability studies should use UD as a model, he says.

“Look, all these graduates who minored in disability studies are going to be working in business environments, at nonprofits, pursuing additional degrees, taking what's taught in disability studies with them wherever they go. It will enable them to make more open and better decisions; the philosophy of inclusion will be with them wherever they go; many places where they work invariably will become more accessible.” That “ripple effect” would be positive for any society, he says. Which university, which community, wouldn't want to be part of that?

A NEED TO EXPAND AND DIVERSIFY

Despite the exponential growth of the disability studies minor, there's still room for expansion. Fewer than 5 percent of the minor's students disclose that they have a disability or special health care need. Fewer than 5 percent of students are male. Fewer than 10 percent identify their ethnicity as other than Caucasian. And students rarely come from UD's colleges of business and engineering.

Why hasn't the program attracted more minorities? Micah Bernard, a human services major and person of color who minored in disability studies, can't say with certainty. But she says that students, no matter their color, “select their minor based on what complements their major.” And that, she suggests, isn't necessarily the best approach. The program “isn't just for those who will work directly with individuals with disabilities,” she says. “It doesn't just add something to your degree. It adds something to you as a person. You learn cultural competence and barriers that people face every day. It's valuable material for everyone.”

Why hasn't the program attracted more men? Cullen Worsh, who minored in disability studies, majored in biology and expects to become a doctor, notes a particular obstacle. “It seems like a gender role barrier,” he says. “Many students in the minor are pursuing ‘helping professions,’ careers predominantly held by females,” such as teaching, occupational therapy and speech-language pathology.

But Cullen called selecting the minor “a natural choice,” and an area of study that will benefit him – and that could benefit anyone – professionally. “It taught me to look at the person as a whole, not just at the symptoms of their disabilities,” he says.



Micah Bernard

“It doesn't just add something to your degree. It adds something to you as a person. You learn cultural competence and barriers that people face every day.”

One of the relative few students with a disability in the program, Seth Logan says he'd like to see more people with disabilities participating in the minor. His own disability sparked his interest in the minor, he says. Later, lessons in policy and advocacy through the minor helped him gravitate toward a career in the disabilities field. A neuroscience major,

Seth says he hopes “to work in policy and create alternatives to the systems we now have in place for people with disabilities.”

Moving forward, Laura Eisenman, the minor's faculty coordinator, says she hopes to involve more students from colleges on campus that are underrepresented in the minor – “any one of whom has the potential to impact disability issues.” Recently, mechanical and biomedical engineering students at UD designed an adaptive device to help individuals with physical disabilities participate in rowing sports. Few students from the College of Engineering tend to minor in disability studies due to limited flexibility in their program, she says. But here was an example where UD students with no involvement in the program made a significant contribution to the disability field, which sparked an “aha moment” for program coordinators.

“We need to better educate students on why the minor can complement any program,” Eisenman says. To that end, she is reaching out to other university faculty and deans and encouraging them to inform more students about the benefits of the disability studies minor.

AFTER THE MINOR, MAJOR IMPACT

Some graduates strive to make their workplaces more accommodating to people with disabilities while others endeavor to make their communities more open to them. Still others make it their job to enhance the lives of their loved ones at home or at work. Here are how a few disability studies alumni are making a difference.

THE ADVOCATE

We would not be here without Lisa, says Monica Trojnar of Lisa Rathbun, a disability studies alum who helped Trojnar's son start school in a regular education classroom this year. "He is finally coming home to his own community," Trojnar says.

It could have been otherwise. Her nine-year-old son Grady has autism and had seen his speech therapy come to a halt due to severe tantrums, an outcome that lessened chances he would progress in school the way he and his mother had hoped. Enter Lisa, who landed a job after graduating UD as coordinator of services at Central Delaware Speech Language Pathology in Dover, where she acts as a liaison between the practice's clients and their health insurance companies.

Lisa secured approval from the Trojnar's insurance company for Grady to receive out-of-network behavioral therapy. Then she repeatedly called the insurance company to expedite reimbursement since the Trojnar's upfront had to pay the \$200-per-hour therapy charge. Lisa even tried to get their copays covered by Medicaid.

Lisa always thought "beyond the scope of her job" and was significantly "more sympathetic to the financial situation of a family" than other office administrators might have been, says Trojnar. Without the minor, Lisa says, she would not be as aware of the challenges that people with disabilities face every day. "Having that experience," she says, "really opened my eyes to the effect one person can have on a family."



Lisa Rathbun (left), Grady Trojnar and Monica Trojnar.

THE MATCHMAKER

During the disability studies minor's *Senior Seminar* course, Becky Clark, now a transition counselor at the Delaware Division of Vocational Rehabilitation, shadowed a young girl with a disability and her mother. Becky saw firsthand that a massive gap in service delivery existed for people with disabilities. "[The mother] was the one that had to go out and find the resources available" to her family; there was no one to help her navigate the system, Becky says.

Now, Becky does just that for young adults with disabilities looking to make the transition into employment. She matches her clients based on their interests and career goals with local companies that are hiring.

Laura Love of Computer Aid, Inc. in Newark says her company has found that individuals with autism often have a unique, detail-oriented skill set that predisposes them for success in IT careers. Over the past few years, Becky has connected CAI with numerous job-seekers on the autism spectrum who have gone on to excel in positions in data and software quality analysis.

I encounter "a lot of folks who were not aware of the resources that were out there until they were referred to Becky," says Love. After that, "it's like a whole new world has opened up for them."



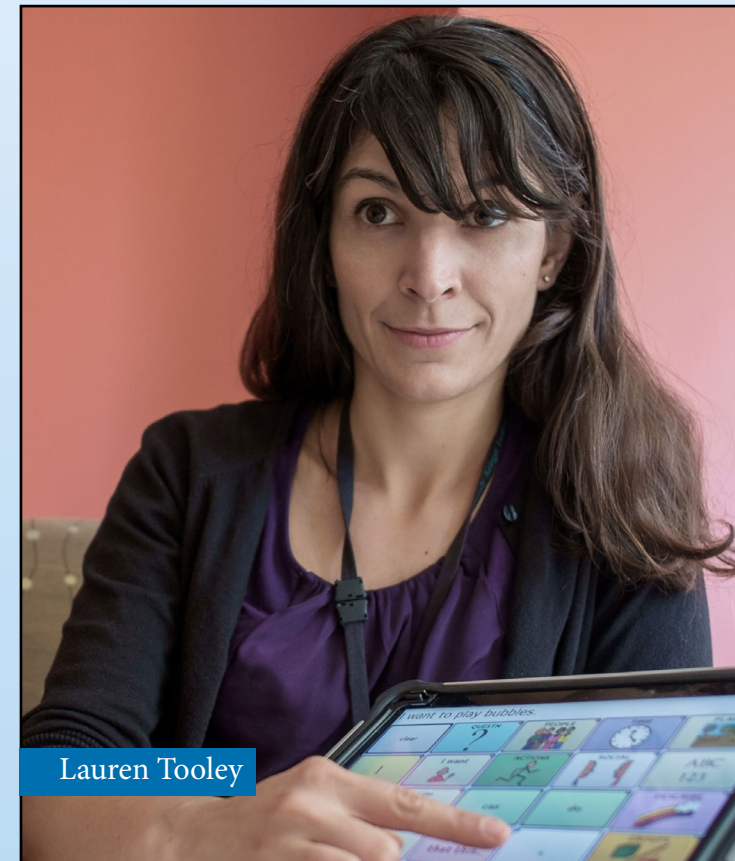
Becky Clark

THE MANAGER

Disability is something that Lauren Tooley, manager of the assistive technology clinic at the Kennedy Krieger Institute in Baltimore, Md., has been intimately aware of her entire life. Her mother is a physical therapist and her father has quadriplegia. But it wasn't until Lauren began taking courses as part of the disability studies minor at UD that she began to develop a more "holistic view" of people whose lives are affected by disability.

Lauren has a patient at the clinic who regularly misses her appointments. Rather than assume that her family is not invested in their daughter's treatment, Lauren considers the fact that they do not have a car that fits her wheelchair. Instead, they must use paratransit to travel to appointments, which can be an unreliable service in the Baltimore area.

Lauren says her experience in the minor helped her to consider "the many aspects of what's going on with a family that has someone with a disability" and not just what is immediately apparent. She says her studies in speech-language pathology provided her with invaluable knowledge of communication disorders, but the minor gave her a unique understanding of the social systems in which those disorders exist. What the minor teaches, Lauren says, "is not something you can just go and learn anywhere else."



Lauren Tooley

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Front cover Disability studies minor student Jackie Solomon (left), Conor Rifon, her mentee in UD's *Mentoring Students with Disabilities* class, and Debbie Bain, one of the class instructors.

Back cover Disability studies minor student Katie Mandel receives her diploma.

For more information about the disability studies minor and the Center for Disabilities Studies, visit www.udel.edu/cds



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