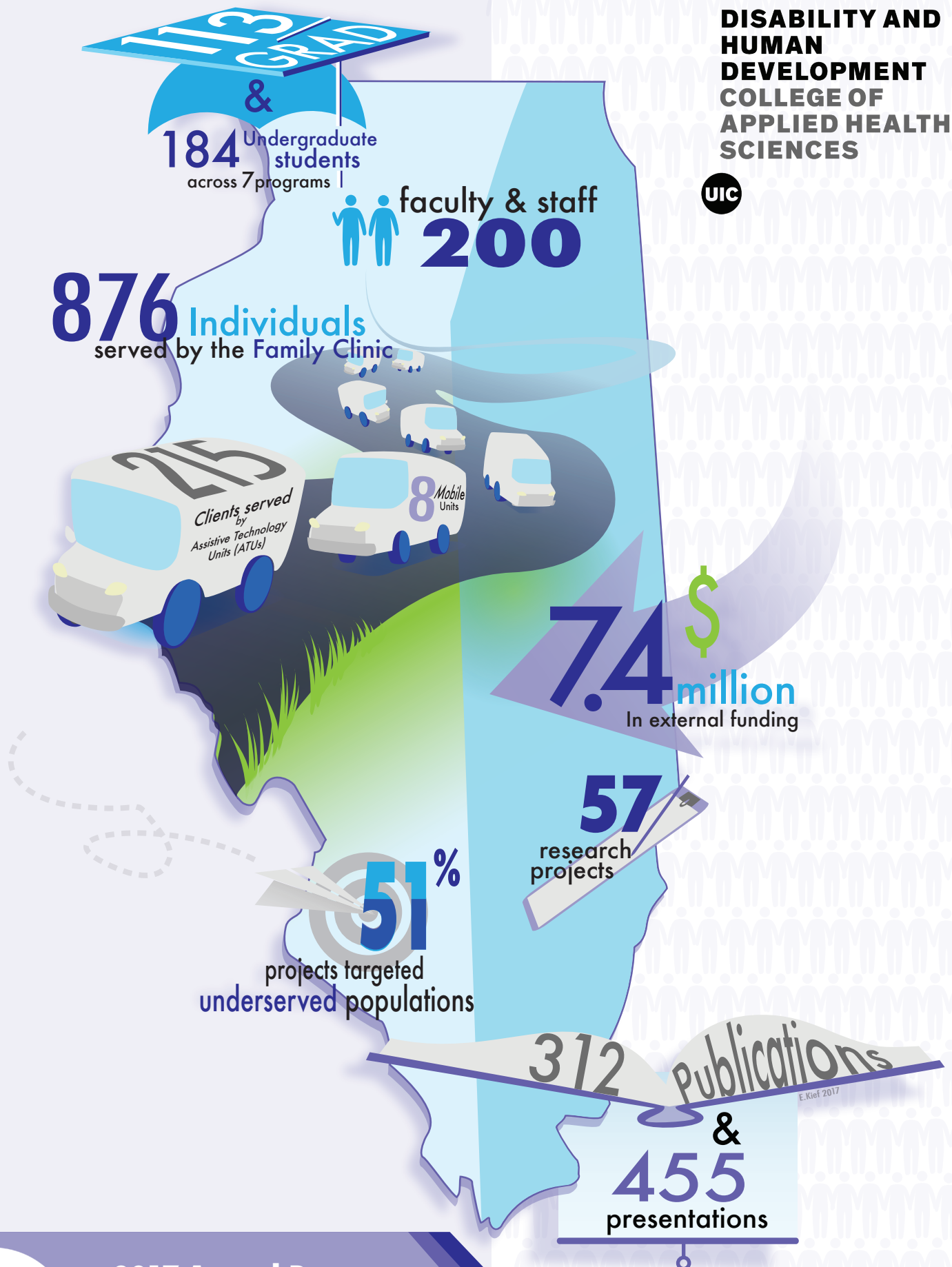


**DISABILITY AND
HUMAN
DEVELOPMENT
COLLEGE OF
APPLIED HEALTH
SCIENCES**



2017 Annual Report

Department of Disability and Human Development
Home to the Institute on Disability and Human Development

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Welcome Statement

We are pleased to present the 2016-2017 Annual Report for the Department of Disability and Human Development (DHD) and its Institute on Disability and Human Development (IDHD). It has been an exciting year for DHD as we now offer a full range of academic programs, from an undergraduate minor and major to a PhD program in Disability Studies and graduate certificates in Assistive Technology or Disability Ethics. We are attracting over 600 students to our courses each semester. Additionally, we are now able to offer teaching assistantships to our doctoral students.

With the mission of "breaking down barriers for people with disabilities," it has been a year of challenges at both the state and national levels as we advocate for the health and long-term services and supports that people with disabilities need. We have contributed to advocacy through our research on policies and practices and through our training and technical assistance activities. In this report, we highlight several projects and national centers, including the Great Lakes ADA Center and the Rehabilitation Research and Training Center on Developmental Disabilities and Health. Our Leadership in Neurodevelopmental and Related Disabilities (LEND) program continues to train students and fellows across many disciplines with partnerships across the state. To advance diversity in leadership in the disability field we have obtained funding for 3 diversity fellows in 2016-2017.

I would like to thank our donors who have contributed to our clinical services and to our student scholarships, including a new one for undergraduate students, the Neal H. Gottlieb Memorial Scholarship Fund. Thank you to all of you who have supported our work!



Tamar Heller, PhD
Distinguished Professor, Head and Director



Post-Doctoral Program Trains Tomorrow's Leaders



Photo: DHD 2016-17 Postdoctoral Research Associates

DHD has an active and thriving group of Postdoctoral Research Associates who work on various research and teaching activities. In 2016-17, DHD had five postdocs in the department who collaborate with faculty and others around the College of Applied Health Sciences. Four of these postdocs are profiled above (see page 8 for a profile on the fifth, Kate Caldwell).

Robin Dodds began as a postdoctoral research associate at UIC in 2016 after completing her PhD in Special Education from the University of California at Santa Barbara. Her dissertation is entitled, "The Development of a Measure of Readiness to Volunteer as a Peer Support Provider for an Organization Serving Parents of Children with Special Needs". Robin's interests are around supporting families of children with autism spectrum disorder and related developmental disabilities in underserved communities, primarily through parent-to-parent social support and parent-mediated interventions for social communication. Robin is also on the executive committee of Parent to Parent USA.

E-mail: rdodds@uic.edu

Haleigh Scott came to UIC as a Postdoctoral Fellow in June 2017. She is a graduate of The Ohio State University's Intellectual and Developmental Disability Psychology program. Haleigh's research, including her dissertation entitled, "Social support, physical activity and stress as determinants of well-being in adults with intellectual disability", focuses on the well-being of

people with intellectual and developmental disabilities (IDD). Specifically, she is interested in how psychosocial factors influence mental and physical health outcomes and measurement issues in obtaining health-related information from people with IDD. Clinically, she is interested in people with IDD and mental health/behavioral health issues.

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Angel Miles is a graduate of the University of Maryland – College Park and her dissertation is entitled, "Barriers and facilitators to homeownership for African American women with physical disabilities" and highlights how education,

economics, architecture, and discrimination interact with personal identity and self-esteem which create barriers to homeownership for African American women. Angel's research examines the intersections of race, class, gender, and ability related to disparate social and economic outcomes for women and minorities with disabilities. Angel's postdoctoral position is a joint program between the Occupational Therapy Department and DHD and she will focus on community-based participatory research.

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Lieke van Heumen is a graduate of the Disability Studies PhD program (2015). Lieke began a postdoctoral research associateship soon after completing her dissertation entitled "Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective". Lieke received both her undergraduate and master's degrees in psychology with a specialization in gerontology from Radboud University in the Netherlands. Lieke regularly provides trainings for community agencies related to aging and intellectual and developmental disabilities along with supports for people with dementia. Lieke also teaches in the Department and won the Applied Health Sciences Student Council Excalibur Award for Teaching Excellence in 2017.

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PhD Students Expand their Horizons Internationally

DHD offers the world's first, interdisciplinary PhD program in Disability Studies. As such, our graduate students represent the best of the field of Disability Studies from across the globe.

Nell Koneczny Explores Exclusion in Poland



Photo: Nell Koneczny

Nell Koneczny entered the PhD program in Disability Studies in 2015. Prior to that, she obtained her Bachelor's degree in Anthropology and European Studies at Vanderbilt in 2014 and spent a gap year working as a paraprofessional in special education at a junior high school. Nell's research interests revolve around minority-majority relationships,

the dynamics of inclusion and exclusion, and how dehumanization occurs. Nell's focus is on disability inclusion/exclusion in certain environments, specifically how people with disabilities are excluded from Polish society. She is examining national historic sites in Poland to identify how they include or exclude people with disabilities, how Polish people with disabilities relate to those state narratives, and what it means to be Polish in general. Dr. Sandy Sufian is Nell's advisor.

Nell has a strong background in advocacy and organizing, having founded many clubs at Vanderbilt, and she has continued that work within DHD. She has been an instrumental part of the Disability and Human Development Student Association (DHDSA), especially with the newly-established peer mentoring program that kicked off in the fall 2017 semester. Nell believes it is important to nurture relationships with students in order to create a community and provide a supportive environment. This approach also makes her an effective undergraduate teaching assistant for DHD courses.

Chih-Chieh (Jay) Hsu Wins Taiwanese Literature Award



Photo: Jay Hsu

Chih-Chieh (Jay) Hsu is a PhD candidate in Disability Studies. Within DHD, Dr. Sarah Parker Harris is Jay's academic advisor, and his work focuses on social policies, notably employment policies and rights in Taiwan. However, Jay also excels outside of DHD, especially when writing literature.

Recently, Jay was awarded first place in the 4th Han

Bang Literature Award by the Blind of Taiwan, his home country. The award raises public awareness about visual impairment in Taiwan through sharing ideas about blindness through prose, poetry, and short novels. Jay's novel is about a blind hip-hop singer, and through the story he discusses and reflects on the stereotypes and barriers that people with visual impairments encounter in Taiwan. Jay wanted to communicate about why identity matters and illuminate the social barriers that people with disabilities encounter in Taiwan. Jay also advocated for accessibility in the competition by submitting large-printed versions of the novel, digital fields for audio description, and suggesting that more reviewers with visual impairments be included. He hopes that through his participation in the award, following awards can be more accessible with disability rights in the center of the process.

DHDSA Conference Focuses on "Disability and Violence"

Students in DHD have formed the Disability and Human Development Student Association (DHDSA). Originally for graduate students in the program, with the expansion of undergraduate degrees, DHDSA is an organization devoted to supporting students within DHD, advocating for disability across campus, and navigating college or graduate school and the job process. Each spring, DHDSA hosts the Chicago Disability Studies Conference at UIC. The theme for this year's conference was "disability and violence." The conference included presenters from UIC's graduate and undergraduate programs, along with presenters from other universities in Chicago. Access Living's Advance Youth Leadership Power (AYLP) provided the keynote presentation for the conference.

First Undergraduate Student Graduates from DHD's Major

DHD received approval for an undergraduate Bachelor of Science degree in Disability and Human Development in the fall of 2016. With the addition of this undergraduate major, DHD now offers a full range of academic programs, from an undergraduate minor and major to a PhD program in Disability Studies and graduate certificates in Assistive Technology or Disability Ethics. Although the DHD major only began in the fall, one undergraduate student, **Irada Flores**, began that program and became the first to be awarded the BS degree in Disability and Human Development from the University of Illinois at Chicago.

The undergraduate program is among the first of its kind in the nation. The program has a strong interdisciplinary focus with a comprehensive curriculum that fosters understandings of disability as a social, political, historical, cultural, and environmental phenomenon, not just a medical or biological condition. DHD has long been a leader in disability research, scholarship and teaching. Our strength lies in the interdisciplinary nature of our department, with access to diverse faculty mentors and resources in the health fields, social sciences and humanities.

"It's an honor to be the first graduate."
- Irada Flores

Flores began his studies at UIC in biological sciences, planning to become a physical therapist. A course in disability and human development changed his direction. "Disability studies intersects with so much in our lives: policy, public health, medicine, and social services," Flores said.

When the new undergraduate program in disability and human development was announced, he extended his time at UIC so he could earn degrees in both majors. It was no small decision, because he was working full time to pay for school. He later added a part-time job at a day program for young adults with developmental and intellectual disabilities.

A Bachelor's degree in Disability and Human Development prepares individuals to meet the increasing demand for skilled employees able to foster the fuller inclusion of people with disabilities in all aspects of cultural, social, economic and political life. Graduates are further prepared for advanced training and education in a variety of fields including disability studies and professional health programs. After graduation, Flores plans a career in social services. He is especially interested in working on issues related to disability in the Mexican-American community.

To read more about Irada and his journey in DHD, read the full story in the UIC College of Applied Health Sciences newsletter at <http://go.uic.edu/FirstDHD>.



Photo: Irada Flores at UIC Commencement

DHD Office of Student Affairs (207 DHSP)

For more information about DHD's academic programs, please contact DHD Office of Student Affairs:

Email: dhdsaa@uic.edu

Phone: 312-996-1508

Undergraduate Studies in DHD

Major in Disability and Human Development

Apply to DHD's newest academic program and the first of its kind in the nation. For more information, please visit:

go.uic.edu/DHDBachelor

Minor in Disability and Human Development

To learn more about the undergraduate minor in DHD, please visit:

go.uic.edu/DHDMINor

Graduate Studies in DHD

PhD in Disability Studies

Applications due January 15, 2018. Visit go.uic.edu/DHDPHD for more information.

Graduate Certificate Programs

Assistive Technologies Certificate Program (ATCP)

The ATCP gives you hands-on, practical training in assessing and implementing assistive technologies. The 12 credit-hour program is available online or on campus. For more information, visit: go.uic.edu/DHDATCP

Disability Ethics Certificate

Earn a Disability Ethics Certificate at UIC with four 3-credit hour courses designed to develop independent scholarship and critical thinking. Learn more at: go.uic.edu/DHDECP

IL LEND Trainees Learn by Doing



IDHD is proud to host the **Illinois Leadership in Neurodevelopmental and Related Disabilities (IL LEND)** program in the state of Illinois. This unique postgraduate interdisciplinary training fellowship prepares trainees from across the state to take on leadership roles in their respective fields, with the ultimate goal of improving outcomes for people with autism and other developmental disabilities and their families. In FY 2017, 31 trainees from 15 different disciplines, including Special Education, Pediatrics, Occupational Therapy and Self-Advocacy, completed an IL LEND fellowship. IL LEND trainees attended weekly seminars, clinical sessions, developed individual leadership projects, and worked in a community-based setting. For example, Robin Dodds, the IL LEND Postdoctoral Fellow, with guidance and support from Ann Cutler, IL LEND Clinical Training Director, initiated a series of "pop-up" autism screenings in the community. In collaboration with the Developmental Disabilities Family Clinic, Robin and Ann held five screenings in unserved or underserved areas, providing access to autism screening to over 25

families who would not otherwise be able to have their child screened for autism.

The IL LEND program is also one of the first in the country to develop a distinct Self-Advocacy discipline to include Self-Advocacy trainees and dedicated Self-Advocacy faculty.

Self-Advocacy as a IL



Photo: IL LEND Self-Advocacy Discipline Coordinator Tia Nelis and US Senator Tammy Duckworth

LEND discipline is growing in popularity as others discover the wealth of knowledge and unique perspective that self-advocates offer. For example, self-advocates help people understand about the preferred language that should be used to talk to and talk about people with disabilities. Self-advocates also serve as role models and help support parents who have often been told that their child will not be able to accomplish much. Self-advocates also benefit from being IL LEND trainees by learning the medical aspects of disability and how a diagnosis is made. With this knowledge, self-advocates will better be able to partner with physicians.

IL LEND trainees are asked to write about their experiences through an ongoing blog series (<http://lendblog.ahslabs.uic.edu>). This past year, Self-Advocacy Trainee Michael Grice wrote the following blog post:

"My name is **Michael Grice** and I am going to be talking about a Springfield trip that I took with Access Living on May 25th. Access Living took approximately 33 individuals. There were 2 primary reasons Access Living took this trip to Springfield.

The first issue was in regards to the overtime regarding the home services program. Self-advocates have had a very difficult time in working with their managed care companies as far as their home service hours and their personal care assistants.

Access Living and other organizations have been working on this overtime issue for over a year now. The reason we met with a lot of different legislators was to let them know how important the home service program is to the disability community. Because the average consumer needs more than 45 hours a week of home service hours, it also affects the personal care assistants. If they have to support their family members out of their home services wages they make, it is not a livable wage. That was the first issue.

The second issue was that we truly want the important legislators in Springfield to pass a budget so that a lot of community based agencies, centers, independent living centers can get back the money that they lost in the last two and a half years. There have been some independent living centers that had to close their doors due to this budget impasse and they will not be able to re-open their doors. So many of those consumers are scrambling to find programs and services where they can stay in the community. So, once again, on May 25th, we encouraged all the legislators that the staff and consumers meet with to pass a budget.

We did get the overtime bill through the senate and the house. Now we're just waiting for the governor to sign it. But we pretty much know what the governor is going to do with that bill when it comes to overtime issues. So the fight's not over yet. Stay tuned. There's more to come."



Photo: IL LEND trainees Jessica Edison (left), Michael Grice (front), and Timotheus Gordon (right) with Rep. Danny Davis in his DC office

DHD Promotes Systems Change Through Training and Advocacy

HOW STAKEHOLDERS CAN IMPACT SYSTEMS CHANGE: THE HCBS-ACT PROJECT

How do state and federal policy changes impact people with disabilities and their families? This question sparked the development of a training project called **Home and Community Based Services-Advocates Creating Transformation (HCBS-ACT)** funded by the Illinois Council on Developmental Disabilities. IDHD staff members Lex Owen, Irma Hernandez and Jessica Schultz collaborated with the Council on Quality and Leadership to create and deliver trainings about the 2014 federal changes to Medicaid HCBS Waiver programs. Each state must enact these changes, which lay out how HCBS settings can and should maximize participant self-determination, autonomy and dignity, by 2022.

"Agencies are great, but they just say, okay here's a day program, or "let's go here." But that really doesn't get you where you want to be. We talk about having a lock on your door in case you want privacy, or having someone, having a girlfriend spend the night. And not having the agency say, you can't do that. That's all part of the CMS rules, the process is already beginning. But that really doesn't get you where you want to be."

-Robert Peterson, HCBS-ACT Leadership Fellow

As each state prepares to make these changes, stakeholders such as people with disabilities and their families can play an important advocacy role in the state's implementation. The first step in this advocacy is education. The project team has conducted over 50 trainings across the state, facilitated two webinars, and developed several accessible materials for advocates' use. The project also featured a group of 14 Leadership Fellows who participated in year-long training and mentorship relationships. The Fellows learned about HCBS policy and initiated trainings and other outreach in their local communities. As the State works to establish updated policies, educate providers on the changes, and update legislation, it is important that people with disabilities and their families know what is coming, and advocate for systems that work for them. A central part of IDHD's purpose is to provide education about policies to the people who are most impacted by those policies, equipping them for advocacy at every level.



Photo: Self-Advocates prepare for a Training

THE SIBLING LEADERSHIP NETWORK CELEBRATES TEN YEARS

IDHD has the privilege of hosting the **Sibling Leadership Network**, a national nonprofit organization dedicated to providing siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promoting the issues important to them and their entire families. This June, the SLN held their sixth national conference in Hartford, Connecticut, welcoming 125 attendees from 31 states, as well as Australia and Taiwan. Conference-goers attended sessions on timely topics including future planning, family dynamics, supported decision-making, and cops, safety, and the dignity of risk; heard from leaders in the sibling movement; and participated in relationship-building throughout the weekend. One participant wrote:

"This conference has been life changing for us! We learned new coping mechanisms, support opportunities, disability laws and future planning tools. We met people just like us from all over the country, Taiwan and Australia. The weekend was full of many different sessions to choose from and each one was jam packed full of good information. It was difficult to select just one! The keynote speakers were fabulous! We laughed, we cried, and felt so understood."

Attendees also celebrated the 10th anniversary of the SLN, complete with cake and celebratory toast! SLN Executive Director Katie Arnold, who is also seeking her PhD in Disability Studies at UIC, gave the opening remarks, which highlighted the unique role siblings can and do play in each others' lives. The SLN has grown to 26 state chapters and is a growing presence through speaking engagements, grants, and online forums and resources. For more, go to siblingleadership.org.

DHD Awards Three Trainees Diversity Fellows

In fiscal year 2017, DHD received a Diversity Fellowship Program grant from the Association of University Centers on Disability (AUCD) and the Administration on Intellectual and Developmental Disabilities (AIDD). This program provides funding to trainees who identify with at least one of the following categories defined by AIDD: (1) Individuals from racial and ethnic minority backgrounds; (2) Individuals with limited English proficiency; (3) Individuals from underserved geographic areas (rural or urban); (4) Different disabilities; and/or (5) Lesbian, Gay, Bisexual, and Transgender. The Fellows participate in training activities related to disability, diversity, empowerment, and leadership while developing and conducting a capstone project. They also work closely with the Director and Associate Director of IDHD and attend the AUCD national conference. The Fellows for 2017 were:

Kate Caldwell completed her PhD in Disability Studies in DHD and stayed in the department as a Postdoctoral Research Fellow. Kate's diversity fellowship project works to expand inclusive entrepreneurship to look at race, gender, and disability. Kate will continue working on this project as part of a larger research program in her new role as clinical assistant professor in DHD. Kate's research interests in employment and social policy have largely focused on people with intellectual and developmental disabilities (IDD) in particular and Kate is credited with developing the technique for conducting Dyadic interviews with people with IDD, an approach informed by critical disability studies. Through her work, Kate is able to bridge the fields of Disability Studies and entrepreneurship studies informed by feminist theory, citizenship theory, and social justice. Additionally, Kate developed the best practice recommendation for AUCD for creating plain language summaries of academic articles.

Angélica Martínez Pérez was born and raised in Puerto Rico. She came to Chicago for her master's in Public Health and is now a Ph.D. student in Disability Studies. Angelica became interested in disability when she realized that disability was often not included public health courses. She also noticed that Latinos were not often referred for Assistive Technology (AT) services, especially compared to other ethnic/racial groups. As a Diversity Fellow, her project focuses on making AT more accessible to the Latino community. This includes translating documents and developing a bilingual guide about AT to distribute to various Latino groups in the Chicagoland area. Angelica plans to continue the project after the fellowship ends by developing material in Spanish for the The Autism Program resource room at UIC and other community agencies servicing Latinos such as Grupo Salto and "Lo que puede venir." Going forward with her work, Angelica plans to advocate

for AT resources to be readily available for Spanish speaking communities. In addition, she is interested in integrating the fields of Disability Studies and Public Health.

Timotheus "TJ" Gordon is a current doctoral student in Disability Studies at UIC. TJ will work on creating a survey that targets autistic people of color. TJ explores issues that autistic people of color face in their communities along with the intersection of autism and people of color and how to address those issues on a collective basis. TJ's research interests more generally are around examining the means of promoting acceptance of autism and culture in the African Diaspora, which includes black communities. After completion of the Diversity Fellowship, TJ would like to hold a panel on autistic identity with various autistic people of color nationwide. TJ advocates for combating police brutality directed towards people of color with disabilities and saving special education in public schools. TJ is a self-advocate, writer, and also the creator of the blog, the Black Autist, that focuses on disability/autism acceptance in black communities.



Photo: DHD 2016-17 Diversity Fellows

DHD Alumni as Leaders in Policy and Practice



Photo: Joe Caldwell

DHD's interdisciplinary approach to studying disability yields dividends for its alumni, who go on to propel their fields forward. These rewards aren't only for alumni, however. **Joe Caldwell** (PhD '05), for instance, credits his time at DHD with helping him understand how **"to apply research to make a difference in people's lives."** He is well-positioned to improve the lives of people with disabilities and their

families in his current role as the Director of Long-Term Services and Supports Policy at the National Council on Aging (a national non-profit organization focused on improving the lives of older adults). As part of his job, Joe partners with multiple universities to conduct research related to home and community-based services and family caregiver supports, provides his expert perspective on the intersection of disability and aging, and works in coalition with other national aging and disability organizations to advance federal policy on these issues.

While completing his graduate work at DHD, Joe's passion for policymaking took root after pursuing Washington-based fellowships, including time spent as a Disability Policy Fellow at the Association of University Centers on Disabilities. He then received the Joseph P. Kennedy, Jr. Fellowship, where he worked for the Senate Health, Education, Labor, and Pensions (HELP) Committee during the passage of the Affordable Care Act. Throughout his career, Joe has used his background in Disability Studies to critically examine policy through a disability lens and explore how policies communicate underlying societal values, meanings, and messages about disability. Joe's work directly impacts the lives of people with disabilities and their families at every level, whether he is advocating for policies, facilitating national research projects, or providing technical assistance to other aging and disability organizations.

Another field-innovating alumnus is **Jenna Heffron**. Jenna, who earned a PhD in Disability Studies from DHD in 2016, is currently an Assistant Professor in the Occupational Therapy Department at Ithaca College in New York. Jenna is passionate about infusing the professional field of Occupational Therapy with a growing awareness that Occupational Therapists have disabilities, too. In an on-going participatory action research project, Jenna, her students, and two co-

"I really benefitted from the interdisciplinary nature of the program, which gave me new ways of understanding and experiencing disability."

- Jenna Heffron, PhD '16

researchers from DHD work to support occupational therapy practitioners with disabilities while also challenging the profession to engage in critical discussions about its perceptions of and approaches to disability. Her service on Ithaca College's Diversity and Inclusion Committee provides an opportunity to bring issues of disability identity, justice, culture, and community to the table.

Jenna came to DHD as an Occupational Therapist to better understand and confront the institutional and systemic barriers experienced by disability communities. While in graduate school, Jenna said she "really benefitted from the interdisciplinary nature of the program, which gave me new ways of understanding and experiencing disability." For Jenna, the mentorship she received at DHD empowered her to apply Disability Studies principles with the goal of improving healthcare education and practice. She is now actively engaged with this goal every day in her work as a faculty member. She teaches courses related to occupational and social justice, group work and group dynamics, and community-based practice, as well as teaches a series of research courses in which students join her in conducting research on topics at the intersection of Disability Studies and Occupational Therapy.



Photo: Jenna Heffron and her advisor, Joy Hammel

Assistive Technology Unit Promotes Independence for People with Disabilities

A cup holder, a cellphone mount, a tray just right for a laptop - to Nicholas Guarino, 20, these are more than handy little devices. They're keys to a future that includes college, his own place and a career as a writer. Guarino has limited use of his right hand, so it's important to have everything he needs in a convenient place.

For more than 25 years, the Assistive Technology Unit (ATU) has maximized individual independence through person-centered therapy, design and engineering. The ATU is the largest mobile assistive technology program in the nation, serving clients in 13 counties in Northeast Illinois. With eight mobile vans, "we can go where the client is," said Glenn Hedman, ATU director and clinical associate professor of Disability and Human Development.



Photo: ATU Staff talk with Nicholas Guarino

The ATU's staff consists of 20 full and part-time staff including engineers, architects (including three graduate students), occupational therapists,

physical therapists and speech-language pathologists. ATU members travel to homes, schools, work sites and day programs, teaming up in different combinations depending on the case. They adapt, adjust or create devices and tools—from cup holders or software apps to contractor-ready drawings for making a home accessible. Several ATU devices have been licensed for commercial production. The people who work in the ATU like problem-solving. They also like the direct feedback from clients. "The work we do can have a real positive impact on someone's life," said Ron Schon, ATU architect and retired associate director of the UIC Office of Capital Programs.

"That's what's so strong about our clinic. We have the ability to customize what the individual needs,"

- Kathy Hooyenga, ATU occupational therapist and clinical assistant professor

The ATU also increases awareness of assistive technology by educating teachers, therapists, UIC students and others. "Disability issues are social issues,

manifested in the built environment," said Hedman. The ATU offers undergraduate and graduate-level courses and a certificate program in assistive technology.

A new federally funded, five-year program in collaboration with the College of Education is training Illinois elementary, middle and high school teachers as leaders in assistive technology implementation, assessment and policy. "There aren't enough experts. We want to get away from the expert model and have more leaders throughout the state," said Pat Politano, co-principal investigator of Project ATLIS (Assistive Technology in Special Education) with Daniel Maggin, assistant professor of special education. "The more people we can train, the more students can benefit from assistive technology," she added.

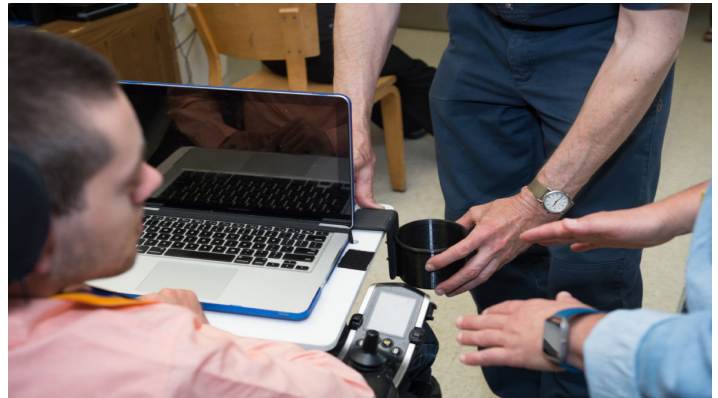


Photo: ATU Staff adjust Guarino's equipment

Moving Forward

Technology continues to advance, bringing new tools that increase independence for people with disabilities. There's a problem, though: who pays for this new technology? For example, insurers will cover "dedicated" computer and tablet-based devices that have communication apps with no access to the internet or other functions. But iPads, which cost significantly less, are not considered "durable medical equipment," so insurers won't pay for them. "The technology is out there. The research is out there," Hedman said. "The question is, how to fit developing technologies into systems such that third-party payers will cover them." "The state's dire budget situation has also impacted the ATU. Cuts in funding from the Illinois Department of Human Services means some services are no longer covered. In the meantime, the ATU continues its mission to overcome challenges, big and small. "What we do makes such a difference for people," Hooyenga said. "It's the best part of the job."

This story is an excerpt from a larger piece in the College of Applied Health Sciences news. For more information, see: <http://ahs.uic.edu/disability-human-development/news/life-hack/>.

**Assistive Technology Unit
Director: Glenn Hedman
Email: ghedman@uic.edu
Phone: 312-802-3141
Website: UICATU.org**

Family Clinic Provides Community Based Programs

The **Developmental Disability Family Clinic** has been a part of IDHD since 1992. The Clinic has offered a range of services for people with intellectual and developmental disabilities and their families over the years, all with a deep commitment to providing quality services and supports to unserved and underserved families throughout Illinois. Though this commitment has been tested in the last few years due to funding cuts, the Clinic has continued to offer services across the lifespan for individuals with intellectual and developmental disabilities (IDD) and their families.



Photo: Family Clinic intern works with children

At the Family Clinic, the work does not end at the clinic door. Instead, clinicians are active in community-based programs and projects, providing their unique and experience-tested insights in a variety of contexts. For example, clinicians have provided comprehensive special education consultations for multiple school districts, drawing on observation, interviews and chart review to facilitate solutions that benefit students, families and schools. Clinicians have also provided consultations for investigators at the State's Attorney's office, the Department of Children and Family Services, forensic interviewers, and the Children's Advocacy Center. In addition, clinicians provide support on

The DD Family Clinic offers a variety of services. These include:

- individual and group counseling therapy
- diagnostic services
- autism screenings
- social skills groups for children 8+
- behavioral consultation
- early intervention diagnostic and therapy services for children 0-3
- autism therapy and diagnostics through The Autism Program (TAP)
- webinars
- Grupo SALTO
- support groups for mothers and fathers

For more information, go to <http://go.uic.edu/DHDFamilyClinics> or email familyclinic@uic.edu. To make an appointment, contact Marlene Garcia at mgarci70@uic.edu or call 312-413-1490

"We offer more than just therapy. Our goal is to maximize independence and individuality, and we provide resources for families as well. As we work with families to accept a diagnosis, we try to overcome myths and misperceptions about autism and developmental disability."

**- DD Family Clinic Therapist
Susan Kahan**

clinical issues for a variety of research and training projects. For example, Susan Kahan, LCPC, provides mental health consultations for individuals that are a part of the state's Short Term Stabilization Homes demonstration project, and Irma Hernandez and Jessica Schultz have served as mentors in a stakeholder education and leadership development training grant about the HCBS final settings rule. Clinicians including Mati Ovalle provide the educational portion of a community-based group of families called Grupo Salto. Over 500 strong, this Latino family support group for families with children with IDD provides social support, education about policies and services that impact them, and ongoing advocacy efforts.

The Family Clinic aims to extend its influence by training students to be outstanding clinicians in their work with individuals with IDD and their families. Many clinic staff are also LEND faculty, and the Family Clinic is a primary training and observation site for Illinois LEND. This year, clinicians will teach LEND trainees to do autism screenings. The ethos of the Family Clinic, anchored in bringing hope to families through counseling, support and education, has left an indelible mark on its clients, and will continue to do so as the Family Clinic becomes better integrated into the UI Health system in FY18.



Photo: Parents make sensory objects for children with autism

Faculty Committed to Scholarship and Activism

FACULTY MEMBER AKEMI NISHIDA JUGGLES DUAL ROLES; COMMITMENT TO DISABLED STUDENTS



Photo: DHD Assistant Professor Akemi Nishida

Assistant Professor Akemi Nishida knows a thing or two about systems. As a cross-departmental cluster hire with a focus on “Racialized Bodies,” Nishida has dual appointments in Disability and Human Development and Gender and Women’s Studies. Nishida has appointments in two different Colleges (Applied Health Sciences and Liberal Arts and Sciences) and has learned to navigate two different departmental systems as she teaches courses in both departments. Across departments, she enjoys teaching courses about activism and politics, where students come to understand how different systems of oppression and identity, including racism, ableism, classism and sexism, work in society. Nishida asks her students to “grow in critical thinking—in other words, to learn how to make ethical and politically informed decisions.”

Nishida is committed to supporting students throughout their academic careers, and emphasizes that graduate work “isn’t designed to go through alone. You need a support system.” She has been impressed by the Department of Disability and Human Development’s commitment to supporting disabled students and disability activism. She urges students, particularly students from marginalized communities, to recognize how higher education is often steeped in racism, ableism, and other forms of social injustices, and to be aware of these institutional inequalities as they continue with their studies. Nishida encourages students not only to understand systems of power, but to work to change them. She challenges students to think about how their own work “can lift the conditions of disabled people.”

Nishida practices her own advice to students through her involvement with the Disability Justice Collective, a national activist organization. Since moving to Chicago, she has also taken an active role in Advance Youth Leadership Power (<https://www.accessliving.org/AYLP>). AYLP uses community organizing strategies to create social change, particularly focusing on police brutality against disabled people of color in Chicago and beyond. Nishida’s work with students and work

with community organizations like AYLP also relate to her research.

Nishida’s in-progress book manuscript explores the issue of care injustice and disability activism. In it, she points out how the impact of public healthcare’s focus on profit over needs of lower-income disabled people and their caregivers, who are often migrant women of color. “Many people only talk about how carers are exploited, but disabled people are also exploited.” She addresses the relational dynamics between disabled people and their carers, pointing out that while these relationships can lead to power differentials, they can also be spaces of solidarity. Other chapters explore community-based care collectives and “bed activism.”

As Nishida does the work of disability studies through teaching, research and organizing, she hopes that knowledge from community sources will become increasingly recognized and valued in different ways, leading to what she calls “holistic accessibility,” which would include not just ramps, but temporal and emotional flexibility and support.

RRTCDD Promotes the Health of People with IDD

DHD is home to the Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD). Dr. Tamar Heller is the Principal Investigator of the Center, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), which includes several research, technical assistance, dissemination and training projects related to the health and function of people with developmental disabilities.



HealthMatters Scale-Up Initiative

The HealthMatters Scale-Up Initiative is a 5-year project within the RRTCDD that aims to achieve widespread transformation of policy, fiscal budgets, and services to support health promotion for people with intellectual and developmental disabilities (IDD) and their supports through outreach, adoption, implementation, and maintenance across 6 states (Alaska, Illinois, Kentucky, Maryland, Missouri, and North Carolina). The goal is to build capacity to successfully implement health promotion activities throughout community based organizations. The HealthMatters Initiative employs the evidence-based HealthMatters Train the Trainer Webinar for Instructors and the 12-Week HealthMatters Program for People with IDD to (1) improve fiscal and policy capacity supporting health and wellness (e.g. CBOs, local communities, states); (2) increase community and organizational capacity for Health-Friendly Services; and (3) support attainment of health goals and improved health status among people with IDD where they live, learn, work, and play.

Currently, 70 community based organizations are participating in the Initiative across 6 states. Over 350 staff members have been trained and certified and over 1,000 people with IDD have participated in the evidence-based 12-week HealthMatters Program. Initial results from the HealthMatters Initiative show increased health promotion activities within participating organizations and among people with IDD.

For more information on the HealthMatters program, visit www.HealthMattersProgram.org

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RRTCDD Co-Hosts Partnering to Transform Healthcare with People with Disabilities (PATH-PWD) Conference

The RRTCDD partnered with Rush University to host the Partnering to Transform Healthcare with People with Disabilities (PATH-PWD) conference on March 23 and 24, 2017. At the conference, funded by grants from the Agency for Healthcare Research and Quality (AHRQ) and the Special Hope Foundation (now renamed as WITH Foundation), leaders on disability rights and disability health care from around the country gathered to discuss and recommend research and training agendas, and to collaborate on best practices and innovations in acute care, primary care, transitions, and health promotion for people with disabilities.

Over 130 people attended the conference, which included a keynote presentation by Dr. Lisa Iezzoni, panel presentations, small group work sessions, and two cultural events.

The workgroups recommended:

- 1) Involve people with disabilities in all aspects of health promotion and health care ("nothing without us").
- 2) Develop, implement and disseminate training for health professionals, providers, people with disabilities and their families in health care needs, and rights.
- 3) Increase access to quality health care and health promotion, including through reforms to healthcare models and payment structures, representation of people with disabilities in the workforce, health literacy, universal design, and cultural competency.
- 4) Develop, research, and scale up evidence based programs that result in positive health outcomes for people with disabilities.
- 5) Identify and develop valid, reliable, practical and sensitive instruments to measure outcomes relevant to persons, systems, and providers.
- 6) Improve communication, planning, and support in transitions from emergency services, discharge from acute care, transitions from one setting to another, and to life course transitions through end of life care.
- 7) Identify and analyze data sources to better understand definitions of disability; service needs, use, experiences, and outcomes; and social determinants of health and healthcare disparities.

Continuing the Legacy of the Americans with Disabilities Act (ADA) by Bridging Research, Training, and Education

The Great Lakes ADA Center provides technical assistance and disseminates information on the ADA within the States of Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin. Its mission is to promote voluntary compliance with the ADA to audiences including but not limited to business, employers, local and state governments, educational institutions, social service organizations, disability advocates, persons with disabilities and their family members.

DHD faculty often come together from across disciplines to bridge research, policy, and practice. The Great Lakes ADA Center provides one venue for such multi-disciplinary collaboration. The Great Lakes ADA Center's mission is to increase awareness and knowledge with the ultimate goal of achieving voluntary compliance with the Americans with Disabilities Act. The center's research, training, and technical assistance support the ADA's mission to "make it possible for everyone with a disability to live a life of freedom and equality." The Great Lakes Center is a member of the ADA National Network and has worked since 1991 to advance disability rights knowledge since shortly after

ADA 27
Celebrate the
Americans with
Disabilities Act years

the law's passage.

Recently, the center launched a new research program aimed at improving understanding and overall implementation of the ADA.

The research team

includes faculty and staff from a diverse range of backgrounds and areas of expertise including Robert Gould, who has a PhD in Disability Studies; Robin Jones, who is an Occupational Therapist and holds a Masters in Public Administration; Sarah Parker Harris, who holds a PhD in Sociology; Yochai Eisenberg, who has a Masters in Urban Planning; and Janet Peters, who has a Masters in Education.

Two of the projects are focused on improving best practices for youth with disabilities in relation to their assistive technology use and their use of online social/professional tools as they transition to employment. A third project involves assessing municipal ADA implementation plans to identify best practices and develop a tool that entities can use to evaluate their own plans. Lastly, the research team will also look closely at the process of ADA implementation by collecting "success stories" of organizations that have excelled in their efforts to advance the goals of the ADA in their policies and practices. The research team will begin recruiting organizations for interviews in the spring of 2018.

Great Lakes Director Robin Jones received the 2017 NARRTC (formerly known as the National Association of Rehabilitation Research and Training Centers) Commendation Award. It is awarded for excellence in research, teaching, service, or advocacy in the field of disability for specific, focused activities or achievements. Commendations recognize important contributions that strategically or creatively advance the field of disability.



Photo: Great Lakes ADA Center staff member Ancel Montanelli

The Great Lakes ADA Center provided 37 audio conferences and webinars on various topics and the archives can be found at: <https://www.accessibilityonline.org/ada-tech>.

Do you have success stories about how your organization has thrived in its ADA compliance or disability inclusion efforts? We would love to hear from you! Please contact Robert Gould rgould3@uic.edu, to hear about the Research of the Great Lakes ADA Center or to share your story.

Students Recognized for their Achievements

DHD currently awards four internal scholarships or research awards to current students. These awards are named after past students or administrators in the program.

The **Carlos Drazen Memorial Scholarship** honors Carlos Drazen, who passed away in 2011. Carlos was a graduate of the MS in DHD program and was close to finishing her PhD in Disability Studies. Because Carlos was a strong advocate for including non-white perspectives in the field of Disability Studies, the award is intended for graduate students who are interested in the intersection of race and disability. This year's winners were PhD students **Ellyn McNamara** and **Yue Xu**.

The **Annie Hopkins Scholarship** was established by her family and the memory of Annie Hopkins, who earned a MS in DHD was pursuing a PhD in Disability Studies and she passed away in 2009. Annie was well known for her outgoing personality and community advocacy. The award supports educational opportunities for graduate students who are interested in topics including disability and sex, relationships and dating, the social model of disability, and/or social entrepreneurship. PhD student **Nell Koneczny** and the PhD candidate **Janie Mejias** were awarded this year's scholarship.

The **Ann & Edward Page-El, M.D. Scholarship** is named for Dr. Page-El, a medical doctor who was instrumental in the development of the DHD Family Clinic. Dr. Page-El was active in the intersection of neurology and people with developmental disabilities throughout his career and was well known for the patient-centered decision-making approach, before it was more widely accepted. The award supports educational opportunities for graduate students who are interested in social or medical aspects of neurological disabilities. PhD students **Katie Arnold** and **Timotheus Gordon Jr.** were awarded this scholarship in FY17.

The **Charlotte A. Tate Multi-Disciplinary Research Award** honors Dr. Tate's distinguished and varied career in the applied health sciences. As the past Dean of the College of Applied Health Sciences, Dr. Tate witnessed the growth of DHD and its academic programs. This award is intended to support students that demonstrate a multidisciplinary approach to health, society, and disability. **Alfiya Battalova**, who recently graduated with a PhD in Disability Studies was selected to receive the award for FY17.



Photos: Yue Xu (left) and Alfiya Battalova (center-left) present their work and DHD students Katie Arnold and TJ Gordon (center-right) and Janie Mejias and Nell Koneczny (right) poses with DHD Director and Head Tamar Heller during the annual student awards presentation



During FY17, DHD was honored to receive a gift from the family of Neal H. Gottlieb. Neal was diagnosed with multiple sclerosis, which gradually decreased his mobility, leading him to retire from his job at the GAO. Subsequently, he became an advocate for workplace accommodations and assistive technologies. In honor of Neal, this donation established a scholarship intended to help students with physical disabilities further their education. The inaugural winner of this award will be selected during this academic year.

The Department of Disability and Human Development is home to the Institute on Disability and Human Development (IDHD), Illinois' only federally designated University Center of Excellence on Developmental Disabilities (UCEDD). IDHD is funded through the Administration on Intellectual and Developmental Disabilities and is a member of a network of 67 UCEDDs across the United States.

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