

2019 Annual Report

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



Welcome Statement from Department Head

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The 2018-2019 year has been an exciting and productive time for the Department of Disability and Human Development (DHD) as well as its Institute on Disability and Human Development (IDHD). We are delighted to share some highlights and accomplishments in this year's Annual Report.

We are so proud of our continuously growing academic programs and offerings. Over 2,200 students were enrolled in DHD courses in the Fall and Spring semesters taking our 23 courses. Our Assistive Technology Certificate program became only the second of its kind in the country to earn accreditation from the Commission on Accreditation of Allied Health Education Programs (CAAHEP). This upcoming year, we welcome five new faculty to our DHD team who are ready to guide and inspire students, including tenure-track faculty Kristin Berg, Yochai Eisenberg, and Delphine Labbé as well as clinical faculty Daniel Cochrane and Jennifer Skalitzky.

We continue to prioritize training and research projects that address timely issues for the disability community in Illinois and beyond. Recently, DHD faculty Fabricio Balcazar and Sarah Parker Harris received federal funding for a 5-year project on promoting entrepreneurship among low-income youth with disabilities. This project will partner with the Youth Connection Charter School and the Illinois Division of Rehabilitation Services to support transition-aged individuals. Existing efforts to educate future healthcare professionals through a grant (led by Kiyoshi Yamaki) from the Illinois Council on Developmental Disabilities, on how to serve people with disabilities has been expanded throughout Chicago and greater Illinois.

We've supported many students, trainees and fellows to attend conferences such as the Association of University Centers on Disabilities (AUCD) annual conference and the Disability Policy Seminar. We are pleased to see the impact both our current students and alumni have had on disability rights and policy at a state and national level. As we highlight our accomplishments of the past year, we also reflect on what more needs to be done for people with disabilities in Illinois, the United States, and around the world. We are excited to continue our role in the fight for inclusion and justice for the disability community in years to come.



Dr. Tamar Heller, Disability and Human Development Department Head

Tamar Heller

Research Spotlight

Accessibility of Pathways for People with Disabilities

The Americans with Disabilities Act requires localities to ensure the accessibility of pathways for all people. More specifically, sidewalks need to be wide, flat, unbroken, and have ramps to connect sidewalks and streets at intersections. Cities are required to create transition plans to identify issues with pathways and to plan how to make them easier for people with disabilities to use, but little is known about these transition plans, including how many communities actually have them and how robust these plans are. Research examining pathways accessibility for people with disabilities found that many localities do not have transition plans. Of those localities with plans, the overall quality was low, with localities missing requiring parts of the plan. Furthermore, of the communities studied, half of the sidewalks require updating in order to be accessible to people with disabilities. Additionally, while many communities allowed for public input, they didn't do much outreach, and only a few specifically elicited input from disability groups. Involving people with disabilities in transition plans can help localities develop plans and prioritize community locations that matter most. For more information about the research, please contact Dr. Yochai Eisenberg at yeisen2@uic.edu.

Disability Rights Research Takes an International Approach

A study analyzed policy approaches to disability rights and justice in the US and Uganda, focusing on the right to employment. The study found that while both Uganda and the US have similar legal frameworks to prevent employment discrimination, both continue to experience low labor market participation of people with disabilities. However, while the laws are similar, their policy approach are substantially different in three key areas: the cultural meaning of disability, application of the law to support hiring people with disabilities, and the national level of support for implementation. Both countries have strengths in their approaches: the US system has the ability for people with disabilities to challenge discrimination through the court system, while Uganda has policies such as reserved seats in Parliaments for people with disabilities. For more information, please see the Open Access article: Ojok, P., & Gould, R. (2019). A comparison of disability rights in employment: Exploring the potential of the UNCRPD in Uganda and the United States. *Disability and the Global South*, 6(2), 1698-1718. For more information about the research, please contact Dr. Robert Gould at rgould3@uic.edu.

Institute on Disability and Human Development

DHD/IDHD is home to many centers, programs, and units. They include:

Academic Programs:

Director of Graduate and Undergraduate Studies: Sarah Parker Harris, skparker@uic.edu, 312-996-5485

Office of Student Affairs: Maitha Abogado and Maris Fujiura, dhdosa@uic.edu, 312-996-1508

Advocacy and Empowerment: Fabricio E Balcazar, fabricio@uic.edu, 312-413-1646

Assistive Technology Unit: Glenn Hedman, atu@uic.edu, 312-413-9065

Center for Health Promotion: Yochai Eisenberg, yeisen2@uic.edu, 312-413-9410

Evaluation and Public Policy Unit: Kueifang (Kelly) Hsieh, hsieh@uic.edu, 312-413-1530

Developmental Disabilities Family Clinic: Tamar Heller, theller@uic.edu, 312-413-1647

Great Lakes ADA Center: Robin Jones, guinness@uic.edu, 312-413-1407

LEND Program: Kruti Acharya, acharyak@uic.edu, 312-413-1495

Program on Disability Art, Culture and Humanities: Carrie Sandahl, csandahl@uic.edu, 312-996-1967

Family Support Research and Training Center and Research: Tamar Heller, theller@uic.edu, 312-413-1647

Training Center on Developmental Disabilities and Health: Tamar Heller, theller@uic.edu, 312-413-1647

Cultural Exchange Fellowship at IDHD

This past November, the Institute on Disability and Human Development welcomed two visiting fellows from Uganda as part of the Association of University Centers on Disabilities Professional Fellows Program for Inclusive Disability Employment.

Led by Dr. Gould, fellows Esther Allen Nakamwa and Peter Ogik participated in a four-week program centered on disability, employment and policy in the United States. Nakamwa, a principal at the Heritage Kindergarten and Daycare, and Ogik, the director of the Source of the Nile Union of Persons with Albinism (SNUPA), participated in home-stays with DHD faculty and attended various DHD classes. Both fellows attended The Chicagoland Opportunity Summit, a conference on disability inclusion in the workforce, and met with Equip for Equality and Access Living. DHD faculty, staff and students enjoyed showcasing cultural happenings across Chicago, attending a Chicago Bulls game and a Blues club.

Following their Chicago experience, Nakamwa founded Embrace Inclusive Employment, an NGO based in Kampala, and Ogik developed new videos on the media representation of persons with Albinism for his organization, SNUPA.

Dr. Gould had the opportunity to travel to Uganda and provide additional support to Ogik and Nakamwa as they dedicated themselves to these endeavors this past Spring. Dr. Gould also met and shared resources with other Ugandan organizations including the National Union of Disabled Persons of Uganda, Legal Action for Persons with Disabilities, and Humanity and Inclusion.

While there, Dr. Gould connected with friend and UIC alumnus Dr. Ojok and met with the Honorable Esther Anyakyn, a parliament member, and the Honorable Jacob Oulanyah, the Deputy Speaker of the Uganda Parliament, during deliberations on a new disability bill (PwD Bill of 2018). Dr. Gould shared his expertise on the Americans with Disabilities Act of 1990 and provided insight into the strengths and limitations of the Ugandan bill as it was presently drafted.

Dr. Ojok also hosted Dr. Gould in his childhood home, a rural village, where they met with leaders at the Awach Primary School, where Dr. Ojok attended as a child. Dr. Gould has used his connection with Dr. Ojok and the AUCD fellows to pioneer a cross-continental partnership between UIC and Kyambogo University in Uganda.

Dr. Gould will continue working to provide technical assistance and guidance with Dr. Ojok as Kyambogo University starts a graduate degree program on Disability Studies and Inclusive Development, the first of its kind.



Dr. Rob Gould and DHD Alum Dr. Patrick Ojok visit Uganda's parliament. Pictured from left to right The Honorable Esther Anyakun, Patrick Ojok, Honorable Jacob Oulanyah - Deputy Speaker of the Ugandan Parliament, and Dr. Rob Gould.



Esther Nakamwa and Peter Ogik visiting with Dr. Gould in his undergraduate course "Disability in World Cultures."

“ Cultural exchange programs open up doors for collaboration, reciprocal learning, and mutual respect. Working with the different fellows from Uganda has been a transformative experience and an incredible privilege. ”

-Dr. Rob Gould

New Faculty Highlight

Delphine Labbé, PhD *Assistant Professor*

Dr. Labbé joins DHD as an Assistant Professor from the University of British Columbia where she worked as a postdoctoral fellow in Occupational Science and Occupational Therapy. Dr. Labbé is interested in participation of people with disabilities by looking at interactions between the person and their environment, and developing interventions that promote inclusive communities. Dr. Labbé's research is grounded in the social model of disability while incorporating an ecosystemic approach. Her work has looked at different environments, including housing and public spaces like shopping malls and neighborhoods and how these spaces facilitate or introduce barriers for people with disabilities. Another interest of Dr. Labbé's is health promotion of people with disabilities through adaptive leisure, sports, and recreational physical activity. Her organizational partnerships focus on universal access, rights advocacy, and leisure. Her research highlights interdisciplinary teams and uses various qualitative and mixed methods approaches such as interviews, photovoice, Q-methodology, and surveys.



Dr. Delphine Labbé

Yochai Eisenberg, PhD *Assistant Professor*

Recent UIC Health Policy and Administration PhD graduate, Dr. Yochai Eisenberg, continues on with DHD, transitioning from his role as a senior research specialist to Assistant Professor. Dr. Eisenberg's work focuses on the intersection of disability, urban planning, and public health. More specifically, Dr. Eisenberg uses a combination of data analysis, policy evaluation, and community engaged research to understand how neighborhood environments, local policies, and systems impact the health behaviors and outcomes of people with disabilities. Dr. Eisenberg developed a tool called the Community Health Inclusion Index (CHII) for communities to use to increase the participation of people with disabilities in health-promotion activities. The tool has been used nationally and internationally to examine community health inclusion. In his teaching and research, Dr. Eisenberg uses Geographic Information Systems (GIS) and Global Positional Systems (GPS) tools. Dr. Eisenberg has taught graduate classes in the Urban Planning department at UIC.



Dr. Yochai Eisenberg

Kristin Berg, PhD *Associate Professor*

DHD welcomes Dr. Kristin Berg from the University of South Dakota where she acted as Assistant Director of the South Dakota UCEDD. Prior to her role in South Dakota, Dr. Berg served as an assistant professor in the College of Public Health at Temple University and as the LEND Self Advocate/ Research Co-Director at the Children's Hospital of Philadelphia. Her background is in social work and her dissertation was one of the first studies to document victimization experiences of youth with disabilities in the child welfare system, along with its impact on mental health and community participation. In a former role, Dr. Berg examined the intersection of early childhood adversity and service access disparities among young with autism spectrum disorder. Dr. Berg has also been involved with target program innovations that work to improve access to and quality of services for people with disabilities through her involvement with different entities and organizations.



Dr. Kristin Berg

Students in the Spotlight

Drew Egli



3rd-year PhD student, Drew Egli, stands among the Wolfensberger Archives in Omaha, Nebraska.

Drew Egli is a third year PhD candidate in the DHD. While working with UIC's IDHD, Drew was selected through funding by Joan Wolfensberger to spend the summer exploring and documenting findings in the Wolfensberger Archives of the McGoogan Library of Medicine in Omaha, Nebraska. Wolf Wolfensberger (1934-2011) is an important figure in the Disability field, known for his contributions to the deinstitutionalization movement and community inclusion.

However, Drew noticed that Wolfensberger's work and professional considerations extended beyond the disability community and that Wolfensberger was devoted to the empowerment of various marginalized communities. Drew commented, "If Wolf was still alive today I would first thank him for his influence on not just people with disabilities, but also for the potential of his influence on other marginalized groups." In collaboration with the University of Nebraska Medical Center, DHD plans to send a PhD student, like Drew, each summer to continue working in the archives.

Drew's personal research interests include the different predictors of self-determination within the intellectual and developmental disability (IDD) community. Drew is currently writing his dissertation proposal about how improvisation has the potential to foster decision-making skills and self-determination in individuals with IDD. He plans on collecting his own data while conducting improvisation classes in the community, and possibly developing a curriculum that could be implemented in group homes.

Academic Program-FY2019

BS Major

Enrollment 66

Graduates 17

<https://go.uic.edu/DHDBachelor>

BS Minor

Enrollment 153

Graduates 65

<https://go.uic.edu/DHDMinor>

MS

Enrollment 3

Graduates 3

PhD

Enrollment 63

Graduates 5

<https://go.uic.edu/DHDPhD>

Assistive Technology Certificate

Enrollment 64

Graduates 19

<https://go.uic.edu/DHDATCP>

Ethics Certificate

Enrollment 11

Graduates 3

<https://go.uic.edu/DHDDECP>

Megan Schoonveld

Each state has a developmental disabilities council (DD council) which works to promote advocacy, capacity-building, and systemic change for their citizens by investing in projects that benefit people with intellectual and developmental disabilities and their families. DHD major and sociology minor, Megan Schoonveld, interned with the Illinois Council on Developmental Disabilities (ICDD) and said, "Working with ICDD was one of the best experiences of undergrad." During her time with ICDD, Megan worked with ICDD staff to determine which policies and programs other DD councils had found to be successful (and also unsuccessful).

Working with ICDD allowed her to apply the knowledge she had accumulated about disability over the years in DHD. Taking classes in DHD helped Megan understand that disability wasn't just a physical condition and that many environments pose accessibility issues for people with all types of disabilities and health conditions.

Megan hopes to continue her work in disability as she heads to Tulane University in New Orleans to get her masters in public health with a concentration in maternal and child health. Megan wants to work with mothers and children of minority and underserved populations, including mothers and children with disabilities, acknowledging that there's a lack of information available for these populations.



Megan Schoonveld holding her diploma post-graduation from UIC.

“ Megan was an outstanding intern for the Illinois Council on Developmental Disabilities. Her hard work and research help guide our approach to systems change and “big picture” impact in Illinois. We look forward to continuing to work with the outstanding students in DHD and wish Megan the best for her future!

– Mariel Hamer, ICDD Staff

DHD Students Recognized with Awards

DHD is fortunate to present a number of student scholarship awards every year. Donors have established these generous scholarships in honor of distinctive individuals. In May 2019, DHD held its annual awards ceremony to present five awards to students.

Ann & Edward Page-EI, M.D. Scholarship

Hailee Yoshizaki-Gibbons

Hailee Yoshizaki-Gibbons won the Ann & Edward Page-EI, M.D. Scholarship this year. Dr. Page-EI was involved in the fields of neurology and developmental disabilities throughout his career and adopted a patient-centered decision-making approach before it became more widely accepted. The award supports educational opportunities for graduate students who are interested in social or medical aspects of neurological disabilities.

Anne Hopkins Scholarship,

Katie Arnold & Elizabeth Harrison

Disability Studies PhD candidates Katie Arnold and Elizabeth Harrison received the Annie Hopkins Scholarship this year. The Annie Hopkins Scholarship was established in memory of former DHD student, Annie Hopkins, to support educational opportunities for graduate students interested in disability and sexuality, relationships and dating, the social model of disability, and/or social entrepreneurship.

Charlotte A. Tate Multidisciplinary Research Award,

Hailee Yoshizaki-Gibbons & Yovia (Yue) Xu

The Charlotte A. Tate Multi-Disciplinary Research Award honors Dr. Tate's distinguished and varied career in the applied health sciences. The award supports students who show a multidisciplinary approach to health, society, and disability. Disability Studies PhD candidates, Hailee Yoshizaki-Gibbons and Yovia (Yue) Xu, were the award recipients this year.



One of the recipients of the Charlotte A. Tate Multidisciplinary Research Award, Yovia Xu, presents at the Student Awards Ceremony.

Neal H. Gottlieb Memorial Scholarship Award

Noah Ohashi

The Gottlieb award was recently established in memoriam of Neal Gottlieb, whose experience with multiple sclerosis led him to become an advocate for workplace accommodations and assistive technologies. The award is intended for students with physical disabilities. This year's winner was undergraduate student, Noah Ohashi.



Neal H. Gottlieb Scholarship Award recipient Noah Ohashi stands with Dr. Tamar Heller holding a plaque.

Carlos Drazen Memorial Scholarship, Sumithra Murthy

Carlos Drazen received a MS degree from DHD and was working on a PhD in Disability Studies when she passed away in 2011. In Carlos Drazen's honor, The Carlos Drazen Memorial Scholarship supports educational opportunities for graduate students who are interested in the intersection of race and disability. This year's winner was Disability Studies PhD candidate Sumithra Murthy.

If you would like to contribute to these scholarship funds, or to DHD in general, please visit <https://go.uic.edu/givetodhd> and choose a DHD fund from the list provided.

DHD Continues to Influence Alumni Work

Jessica Kramer



Dr. Jessica Kramer

Prior to getting her PhD in Disability Studies at DHD, Dr. Kramer graduated with bachelor's and master's degrees in Occupational Therapy (OT). Dr. Kramer began to work in schools with children ages 3-20 with significant disabilities. One school Dr. Kramer worked at focused on community participation and measuring students' progress as they reached their Individualized Education Program, or IEP, goals. She became interested in measurement, specifically of student progress when students did not map onto traditional understanding of development. Her impetus for her master's degree in OT was to learn more about measurement. During her master's classes, she became struck by ideas of advocacy, empowerment, and disability theory, as she had never been exposed to these ideas in her previous studies. However, these ideas resonated with her clinical experiences as an OT, which then led her to pursue a PhD in Disability Studies.

After receiving her PhD from UIC in 2008, Dr. Kramer moved to Boston to do a Postdoctoral Fellowship and then worked as a faculty member in the Department of Occupational Therapy at Boston University. She has created self-report measures for children and youth with disabilities as a way for them to share their lived experiences. Jessica and her research team also initiated Project TEAM, an intervention to teach youth with disabilities to systematically evaluate environmental barriers and supports, identify needed supports, and request environmental modifications and reasonable accommodations to facilitate participation. Throughout her research, she has partnered with youth with disabilities to build these tools from the ground up and to help ensure the tools are relevant and important to youth. Dr. Kramer's Disability Studies background has shaped her research and she hopes it has supported others to integrate Disability Studies into their clinical rehabilitation practices.

Henan Li

Dr. Henan Li is a 2015 graduate from DHD's PhD program in Disability Studies. Henan is originally from Ganzhou, China where he received a bachelor's degree in Sport/Applied Psychology. Henan came to the United States in 2008 for graduate studies in Disability and Movement, Kinesiology, Statistics, and Health Surveys. Soon after, Henan became interested in the intersection of disability and health. Henan's mentor at the time said to him, "If you want to truly 'understand' disability—live and breathe disability—UIC is the place to be." Henan began his PhD in Disability Studies in the Fall of 2010.

During his time at UIC, Henan was a research assistant on a number of federally-funded research studies, such as the Longitudinal Health and Intellectual Disability Study (LHIDS) and the "Caring for Myself" Caregiver health study.

After graduating from DHD in 2015, Henan completed a two-year postdoctoral training program at Brandeis University. He currently works at Human Services Research Institute (HSRI), a nonprofit research organization in Cambridge, MA. At HSRI, Henan is a team member of the National Core Indicators (NCI), which is an ongoing data collection and quality improvement initiative of people with intellectual and developmental disabilities with 46 participating states nationwide. He provides statistical and methodological expertise so that the more than 20,000 in-person surveys collected yearly can be analyzed, summarized, and disseminated into reports and benchmarks. HSRI's clients, state developmental disability departments, then use the reports to better understand the status and needs of their constituents, as well as the performance and standing of their service system compared to those of other states.



Dr. Henan Li



It was an invaluable experience. I did literature reviews, manuscript writing, survey data cleaning, analysis and reporting, all of which I am still doing today at HSRI. Being immersed in disability research at UIC DHD really prepared me for later opportunities and challenges. - Dr. Henan Li



Disability Training for Medical and Healthcare Students

There is a shortage of healthcare providers and medical professionals who are equipped to meet the needs of patients with intellectual and/or developmental disabilities (IDD). In part, this is because very few academic programs include training about patients with IDD in their curriculums, so students who become providers often report being uncomfortable serving this community. The discomfort or lack of preparedness among providers contributes to a disparity in healthcare access and health outcomes between people with IDD and the general population.

For the past 8 years, Research Associate Professor Dr. Kiyoshi Yamaki has addressed this problem by educating third-year students at UIC's College of Medicine through a short selective course in partnership with Dr. Maureen Gecht, the Associate Director of Medical Student Education. Past participants have described how this course profoundly impacted their practice and perspectives relating to disability.



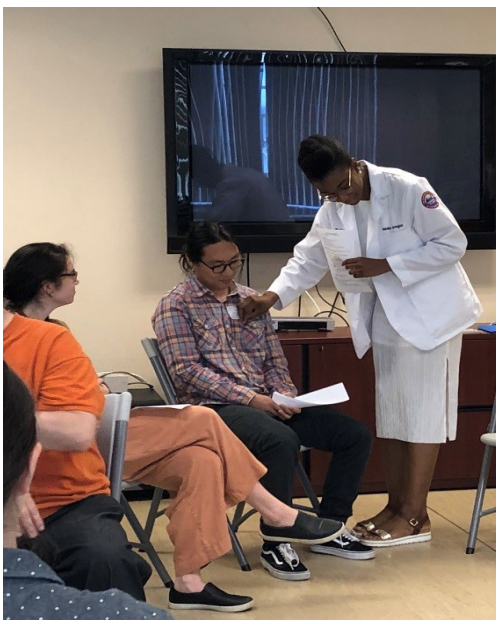
Dr. Kiyoshi Yamaki (left) and Dr. Maureen Gecht (right) stand with a second cohort of UIC third-year medical students.



I realized the importance of education in helping people with disabilities and the true harm of ignorance.
- Student Participant



In 2019, Dr. Yamaki was awarded a grant from the Illinois Council on Developmental Disabilities to expand this work and provide pre-service training to over 500 medical and health professional students in and beyond Chicago. As a result, IDD-specific training is being embedded within the curriculums at various medical schools including the University of Illinois at Chicago, University of Chicago, Northwestern University, Southern Illinois University (SIU), as well as the Illinois Leadership Education in Neurodevelopmental and related Disabilities (LEND) program, housed under UIC's Department of Disability and Human Development.



UIC medical students act out a skit on doctor visits.

All participating students learn about the rights of patients with IDD, disability etiquette, issues regarding continuum of care, and disability support services that are available. Each training also includes an interactive component where self-advocates with IDD and family members share their experiences and perspectives with students. For example, medical students at UIC go on multiple site visits to UCP Seguin of Greater Chicago, a community-based service provider, where they speak with adults with IDD and learn about their health concerns. Training at SIU, Northwestern and University of Chicago include interactive panel discussions with adults with disabilities, family members, and healthcare professionals.

Beyond pre-service training, Dr. Yamaki plans to establish a network of university programs that can continue to collaborate and contribute to a depository of instructional resources about healthcare provision for the IDD community. With these tools, a new generation of healthcare providers can facilitate better access and health outcomes for people with IDD.

ATU Supports Colbert Consent Decree

The Assistive Technology Unit (ATU) continues to provide mobile services throughout northern Illinois, through a fleet of 8 mobile units. During the past year, services to Colbert Consent Decree class members have kept the ATU extremely busy.

The Colbert Consent Decree provides individuals with disabilities who currently reside in a nursing home in Cook County the opportunity to move back into the community. While a move to an apartment is most common, a move to a rental single-family residence is also possible, based on the client's needs.

The ATU works across three phases of services in the Colbert initiative. In Phase 1, an ATU occupational therapist or physical therapist sees the client in the nursing home to determine if there are any needs regarding mobility or activities of daily living equipment. The required accessibility components of the apartment are also identified.

Phase 2 services involve an ATU architect or engineer viewing the client's potential apartment to determine what accessibility work needs to take place before the move. For extensive work, the ATU performs a bid process with local accessibility contractors.

Phase 3 services occur after the move. Here, an ATU occupational therapist visits the client in their home to determine if any instrumental activities of daily living equipment is needed. The performance of equipment identified in Phases 1 and 2 is also rechecked at this time.

The ATU provides services to approximately 400 Colbert class members annually. State management of the Colbert Consent Decree Implementation Plan is currently performed by the Illinois Department on Aging, transitioning to the Illinois Department of Healthcare and Family Services during Fiscal Year 2020.

While annual contracts enable Colbert class members and clients of the Illinois Department of Human Services - Division of Rehabilitation Services (Home Services and Vocational Rehabilitation) to receive services, the ATU also has one-at-a-time referral relationships with other third-party payers.

Anyone interested in ATU services is encouraged to contact ATU Case Management at **312-413-9065** or **atu@uic.edu**.



ATU occupational therapists visit a Colbert class member's home.



ATU occupational therapist checks daily living equipment.

Assistive Technology Certificate Program Earns CAAHEP Accreditation

In June of 2019, the UIC Assistive Technology Certificate Program earned accreditation from the Commission on Accreditation of Healthcare Education Programs (CAAHEP), a partnership that the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) began last year.

UIC's program became the second accredited program in the country and remains one of only three accredited options. While DHD has been offering a graduate certificate in assistive technology for a number of years, the accredited curriculum now includes an Assistive Technology field experience so all students can gain hands-on experience in the field.

Students who are already working professionals may complete this field experience in their own work setting if preferred. Students also have the option to take a lab-based fabrication course at UIC's campus, or online students can work with UIC faculty to create and conduct alternative assignments. If desired, the entirety of this certificate program could be completed online.

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For more information on the Assistive Technology Graduate Certificate Program you can contact:

DHD's Office of Student Affairs: dhdosa@uic.edu

Glenn Hedman,
Director of ATU:
ghedman@uic.edu

Family Clinic Coalition for Autistic and Neurodiverse Students (CANS)



Helen Rottier (left) and another student engage in a discussion while making post cards for a ban on GED shock devices.

Other services offered by the Family Clinic include:

- Individual and group counseling therapy
- Diagnostic services
- Autism screenings
- Social skills groups for children 8+ years
- Behavioral consultation
- Early intervention diagnostic and therapy services for children 0-3 years
- Autism therapy and diagnostics
- The Autism Program (TAP) Webinars
- Partner with *Grupo SALTO* - support groups for mothers and fathers
- For more information, go to <https://go.uic.edu/dhdfamilyclinics> or email familyclinic@uic.edu.

The Developmental Disability Family Clinic has served adults and children with developmental disabilities since 1992, with a strong focus on underserved populations. There are variety of services available for people with developmental disabilities, along with services to support their families. The Clinic continues to enhance services through clinical research and community training. Over the past year, Helen Rottier, a now second-year MS/PhD student in Disability Studies and a graduate research assistant collaborated with counselor Susan Kahan to reimagine The Coalition for Autistic and Neurodiverse Students (CANS). CANS is a peer mentoring program for autistic and neurodivergent students at postsecondary education programs in the Chicagoland area.

CANS' roots are clinical, but Helen, who identifies as an autistic student herself, wanted to remove the clinical focus and transition meetings to community spaces. Currently, twelve students from Chicagoland colleges regularly engage in monthly meetings. The meetings mix business and pleasure. The first-half of the meetings focus on sharing of personal and professional experiences along with support, resources, and strategies. Discussions establish group guidelines and goals, address difficult classes and roommates, and often include the topic of a mutual interest in superheroes. The second-half of the meetings include fun activities to connect and strengthen relationships among the group. Social events, such as bowling, movies, and outdoor pizza parties are particularly useful during the summer months when school is out so that group members can continue to build their relationships. As Helen continues to transform CANS into a diverse and inclusive group, she plans to incorporate workshops to educate non-autistic students and faculty about autism, an art installation to raise awareness about CANS experiences, and outreach to autistic high school students regarding postsecondary education options.



CANS group members, including Helen Rottier, stand with facilitator Susan Kahan.

Leadership in Neurodevelopmental and Related Disabilities Program

LEND Engages with Research, Education, and Policy

IDHD is proud to host the Illinois Leadership in Neurodevelopmental and related Disabilities (IL LEND) Program. With 4 training sites across the state, this 1-year interdisciplinary training program prepares future leaders who will serve children with neurodevelopmental and related disabilities and their families. In FY 2019, 29 trainees from 13 different disciplines including Special Education, Pediatrics, Family, and Self-Advocacy completed the IL LEND fellowship.

As part of the curriculum, trainees are required to complete a research/leadership project. Several of these projects have taken an interdisciplinary approach to directly impacting local area service providers and families. This year, two of these projects focused on different aspects of health care transition (see Research Spotlights). Trainees also learn about policy in an applied way. In pairs, they prepare a policy brief about disability-related legislation. This year, trainees presented their policy briefs to David Applegate, Special Projects Manager at the Office of Senator Tammy Duckworth and Tran Nguyen, US Senate Aide at the Office of Senator Dick Durbin. IL LEND also provided support for trainees and faculty members to attend the 2019 Disability Policy Seminar in Washington DC where they were able to educate congressional leaders about the importance and impact of the LEND program.



Top row: Tom Wilson, Dr. Brian Grossman (Disability Studies Faculty), Tanuja Kothinti (Pediatrics), IL Congressman Sean Casten, Zoie sheets (Public Health), & Micki Coppel (Illinois Arc). **Bottom row:** Penny Hartwell (Pediatrics), & Susan Aarup (Self-Advocate) meeting with U.S. Representative Sean Casten in DC.

Trainee Spotlight: LEND Trainees adapt Parents Taking Action for Latino Parents of Pre-Adolescents with Autism



LEND Trainee, Mariana, presents a poster about the curriculum.

One of the most complicated gaps in terms of support for Latino parents of children with Autism Spectrum Disorder (ASD) are the stages of puberty and pre-adolescence, especially because they experience physical, along with psychological, emotional and social changes. This project was an educational program for Latino parents of pre-adolescents with ASD and included information, resources and basic strategies to improve transitions. This interdisciplinary effort included IL LEND trainees from Disability Studies, Social Work, and Applied Behavior Analysis. Mariana, Alicia and Natalia developed an 8-module Spanish curriculum targeting important issues such as changing strangers, mood changes, and the Internet.

In collaboration with Grupo SALTO, an independent support group for Latino families who have children with disabilities, 11 families received a total of 9 hours of training divided into 3 sessions. Each session was delivered in Spanish and included topics from the newly developed curriculum in addition to discussions, practice of strategies, and a safe space to discuss and share experiences about the new challenges that come with adolescence. Mariana plans to use this curriculum as part of her doctoral work in Columbia. She will provide the intervention to 3 groups in Bogota and 1 in Paipa (rural area) in Columbia.

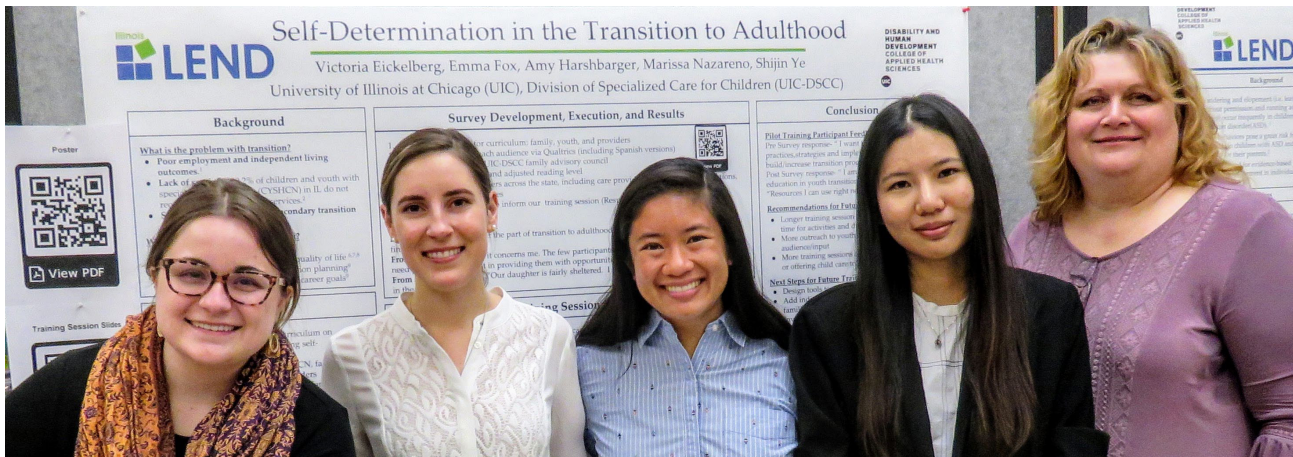
Talking about adolescence and sexuality in the Latino community is often considered taboo, resulting in cultural barriers that need to be addressed. Educational programs tailored for Latino families could be a feasible approach to provide tools, strategies, and knowledge to parents who are the primary care takers and educators of these youth.

Research Spotlight: LEND Trainees Research Self-Determination in the Transition to Adulthood

Astonishingly, 90.2% of children and youth with special healthcare needs (CYSHCN) in Illinois do not receive adequate transition services (i.e. services that families need to facilitate the transition to adulthood in areas such as post-secondary education, moving from pediatrics to adult healthcare, and preparing for employment). For their research and leadership project, Amy Harshbarger (Family), Emma Fox (Public Health), Marissa Nazareno (Family), Shijin Ye (Nursing) and Vickie Eickelberg (Public Health) teamed up to address this largely unmet need.

Trainees partnered with the UIC Division of Specialized Care for Children (DSCC) to create a train-the-trainer curriculum on supporting CYSHCN in building self-determination skills during the transition to adulthood. This evidence-based and strengths-based curriculum focused on 3 elements of self-determination, including self-awareness, self-advocacy, and decision-making. Featured in the curriculum were real-life examples, group discussions, take-home activities, and case scenarios. Trainees hosted a pilot session at 2 sites (UIC and Bloomington-Normal), which were connected via video conferencing. Attendees included 29 participants (3 CYSHCN, 10 family members, and 16 service providers).

One survey respondent said, “I am just beginning my education in youth transition and this was perfect” in response to the pilot training. Recommendations for future trainings included longer training sessions, more outreach to youth, and more training session times. Next steps for future trainees were identified as designing tools to measure behavior changes, adding individualized breakout session for youth/families/providers, and inviting youth with disabilities to share their experience with self-determination. The DSCC at UIC will continue to build on this work.



From left to right: Emma Fox (Public Health), Vickie Eickelberg (Public Health), Marissa Nazareno (Family), Shijin Ye (Nursing) and Amy Harshbarger (Family) presenting at the 2019 IL LEND Open House. Visit LEND website <https://www.illinoislend.org/>

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Advocates and Allies: DHD in the Community!

Disability Pride Parade

Students, staff and faculty from the Department on Disability and Human Development and its Great Lakes ADA Center braved a Chicago heat wave to celebrate at this year's annual Disability Pride Parade. The parade theme "Disability Pride is Social Justice" aligned well with DHD's commitment to the promotion of disability rights and positive policy change. For the first time in parade history, the Mayor of Chicago, Lori Lightfoot, gave a speech at the post-parade celebrations in Daley Plaza. Commissioner Karen Tamley of the Mayor's Office for People with Disabilities and the parade Grand Marshal, Ginger Lane, also gave speeches highlighting efforts to improve access and inclusion for the disability community in Chicago. Sporting "I Heart DHD" t-shirts with the 3E Love logo, many DHD volunteers passed out resources and fun giveaways to the parade attendees.



DHD volunteers are pictured at the DHD booth at the Disability Pride Parade 2019.

Chicagoland Disabled People of Color Coalition



TJ Gordon holds a sign at the Disability Pride Parade 2019.

This year, Timotheus "TJ" Gordon, a recent graduate from UIC's Master's degree in Disability Studies program, founded the Chicagoland Disabled People of Color (DPOC) coalition.

This organization has three central goals:

- 1) to promote disability justice and celebration among disabled people of color
- 2) to provide education on disability access and inclusion in communities of color
- 3) to provide a safe space for disability people of color to collectively learn and celebrate themselves

Along with IDHD Community Education and Training Coordinator, Jae Jin Pak, TJ hosts monthly meetings where disabled, deaf, autistic, and/or neurodivergent people can come together under this coalition. If you would like to learn more about DPOC, please contact TJ Gordon at tgordo7@uic.edu.

Going Home Coalition

This past May, IDHD staff and students travelled to Springfield, Illinois to participate in the Going Home Advocacy Day. For the sixth year in a row, this event highlighted the rights of individuals with developmental disabilities to live within the community, and the need for Illinois to close state institutions. IDHD research specialist and PhD student Caitlin Crabb supports the community living movement in Illinois by evaluating the implementation of the Ligas Consent Decree in her work at DHD. She was excited to attend the rally, explaining “Illinois is behind the times, especially compared to national de-institutional efforts. It’s important for our government representatives to hear how important community living is for our fellow Illinois citizens with disabilities.” The Going Home campaign started off this all-day event by rallying in the Illinois State Capitol Rotunda with speeches, poster-making, and chants. After lunch, the Illinois Network of Centers for Independent Living led the charge with more speeches and calls for change. IDHD staff participated in letter-writing campaigns, and delivered postcards to the offices of our Illinois State representatives.



Going Home Advocacy Day 2019 attendees listen to presentations in the Illinois Capitol Building Rotunda.

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