



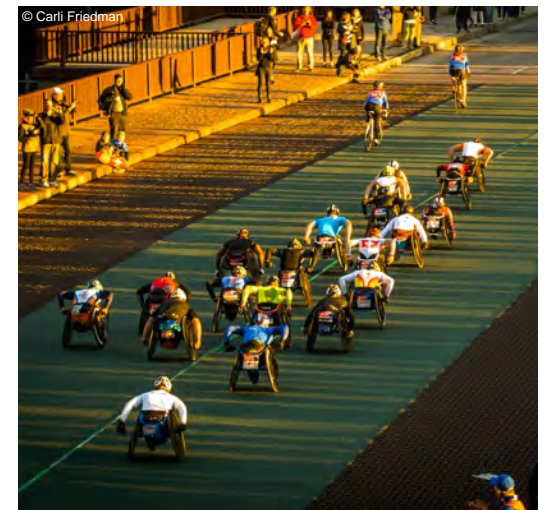
# 2016 INSTITUTE ON ANNUAL DISABILITY AND REPORT HUMAN DEVELOPMENT

UNIVERSITY OF ILLINOIS AT CHICAGO



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## Welcome from IDHD Director Tamar Heller

Greetings! The past year has been an exciting time for the Institute on Disability and Human Development (IDHD). July 25, 2015 marked the 25th anniversary of the Americans with Disabilities Act, and IDHD was involved in many local and national events relating to that celebration, including presenting research in Washington, DC on a **systematic review of the ADA**, sponsoring numerous cultural events relating to disability through the **Bodies of Work** program housed at IDHD, co-facilitating and evaluating a **Leadership Institute for People with Disabilities** sponsored by the Chicago Community Trust, and of course participating in Chicago's **2015 Disability Pride Parade**.

Our **academic programs** are thriving and rapidly expanding. In addition to our leading **PhD program in Disability Studies**, our undergraduate **minor in Disability and Human Development** is highly popular, with over 700 undergraduate students taking one of our courses each semester. During the next academic year, we will be introducing an **undergraduate major program in Disability and Human Development**. In addition to formal academic degrees, IDHD offers graduate certificate programs in assistive technology (**Assistive Technology Certificate Program**) and **Disability Ethics**. IDHD is also home to the recently refunded **Illinois Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** program, which provides an interdisciplinary training to pre-professionals, family members, and self-advocates for working in the autism and developmental disability field.

IDHD is a national and international leader in research relating to people with disabilities. Our faculty have obtained national research grants, notably from the **National Institute on Disability, Independent Living and Rehabilitation Research** which funds our **Rehabilitation Research and Training Center (RRTC) on Developmental Disabilities and Health** and the **Family Support Research and Training Center**. Another exciting new research program at IDHD is the **Chicagoland Entrepreneurship Education for People with Disabilities (CEED)** project, which promotes entrepreneurial skills and connects people with disabilities with community resources to start their own business. IDHD continues to conduct important evaluations for the state of Illinois, most recently evaluations of the **closure of Jacksonville Developmental Center** and the **implementation of the Ligas consent decree**.

Despite challenges relating to the lack of a state budget in Illinois, **IDHD's Family Clinics** and **Assistive Technology Unit** have strived to continue to operate and provide model services to people with disabilities and their families in Illinois, which include diagnostic services, support groups, mobile units that deliver assistive technology in the community as opposed to a clinic setting, and modifications needed for people with disabilities to move from nursing homes back to the community. However, due to the cutbacks, we have a need for alternative funding, donations, and, hopefully, reinstatement of state funding to enable us to continue the many services that we provide particularly for underserved families and services not typically reimbursed by insurance.

I hope that this annual report gives you an idea of the wide range of services, research and evaluation, training, technical assistance, and information dissemination that IDHD provides. If you would like further detail on any of the projects highlighted in this report or if you have any questions or suggestions, I encourage you to contact me at [idhd@uic.edu](mailto:idhd@uic.edu). I look forward to working with you to continue to work towards improving the lives of people with disabilities and their families in Illinois and across the globe! **-Tamar**

# Disability Studies Program Helps Graduate Student Hailee Gibbons Succeed

## Graduate Students



**66**  
Students in  
the MS & PhD  
programs



**55**  
Publications by  
trainees in FY16



**117**  
Presentations by  
trainees in FY16

The Department of Disability and Human Development (DHD) in the College of Applied Health Sciences at University of Illinois at Chicago is home to internationally and nationally acclaimed leaders in the field of disabilities and is dedicated to the interdisciplinary study of disability with the goal of removing barriers to the advancement of disabled persons in society. DHD offers the following programs:

- PhD in Disability Studies
- MS in Disability and Human Development
- BS in Disability and Human Development (new Fall 2017!)
- Undergraduate minor in Disability and Human Development
- Certificates in Assistive Technology and Disability Ethics

**Hailee Gibbons**, MS, is a fourth-year PhD student in Disability Studies at DHD. A gerontologist by training, Hailee came to DHD because of its intersectional nature and because as a person with a psychiatric disability she felt disability studies empowered her personally. For her dissertation, she plans to conduct an ethnography of dementia units in nursing homes in Chicago. She is particularly interested in "understanding how a disability studies lens might inform and transform how we understand dementia and treat people with dementia. This includes considering how disability studies may help us rethink the ways we segregate people with dementia in (and within) institutions, and the impact this has on their lived experiences."



As a graduate student at DHD, Hailee has had the opportunity to teach a number of undergraduate courses. Hailee explains her favorite part of teaching in DHD "is the 'aha!' moments that students have. Disability studies is a transformative field – it challenges the dominant narrative that disability is an individual, medical issue that is always, 'bad and sad.'" She describes feeling privileged "to witness students as they begin to understand that disability is socially constructed and a social, political, and cultural phenomenon. For many students, it is eye-opening, empowering, and even life changing. Disability touches so many people's lives; this course material isn't abstract or purely theoretical – it's deeply personal, and students understand and feel its relevance for themselves, their families, their friends, and their communities. "

Hailee loves the creative freedom that comes with DHD's interdisciplinary nature. In addition to nurturing her diverse interests, the department provides her with the opportunity to learn from faculty and peers with different backgrounds. She credits this feature of DHD with greatly enriching her education. Hailee also values her time at DHD tremendously for the opportunities it has provided. She explains, "I have felt incredibly supported by the faculty and peers in DHD, and also have been provided with numerous opportunities that have helped me develop professionally. Through my assistantships, I have gained experience in large-scale research projects and teaching undergraduate courses."

## Making an Impact One Person at a Time: Undergraduate Alumni Sara Burnett Believes DHD Can Help Change the World

DHD is extremely proud to announce that we will launch an undergraduate Bachelor's of Science in Disability and Human Development. Taking an interdisciplinary approach, the new major examines various aspects of society — healthcare, culture, politics, economics, history, legislation, and social attitudes — that uniquely impact the experience and development of people with disabilities.



While pursuing a Bachelor's in Psychology at UIC **Sara Burnett** (15') double minored in Sociology and Disability and Human Development. She recently reached out to to thank DHD for the impact the program had on her personal and professional life. In her letter Sara explains, "before taking DHD classes I had the stereotypical view of people with disabilities, which I am ashamed to admit. If it were not for the DHD program I would have carried my previous ignorance into my career working with people with disabilities. Instead I was able to gain an amazing understanding of disability culture, history, and rights which I was then able to pass on to others."

After moving to Colorado, Sara started a job as a special education paraprofessional. However, she quickly found she was "embarrassed" by the program's lack of funding and "understanding and education." She explains, "the administration had little respect for the special education department, which then negatively affected how the team could help the students." Sara resigned from her position to look "for work elsewhere to grow personally and professionally."

Sara is now "super excited to have the opportunity to work with a social services company called Sample Supports located in Northern Colorado. They believe everyone has a right and space in the community and no one should be institutionalized... They never say 'no' to taking on new clients, no matter the prior behaviors or offenses, and truly believe in protecting and respecting every client's human rights."

Appreciative of the undergraduate program at DHD, Sara explains, "as I continue down this professional path I know for a fact I would not be able to provide this community with the support I do if it were not for the DHD program at UIC. Personally, I think every person should have to take at least one DHD course because it could change the world! Until then I will personally try to provide trust, confidence, and happiness to every person I work with and to educate the general public in the process. The work DHD does is making an impact one person at a time and I am so thankful for what you have provided for me!"

### Undergraduate Students



**154**

Students in the undergraduate minor



**718**

Students in DHD classes

**64**  
Undergraduate minor alumni



**22**  
Undergraduate courses in disability and human development



## IDHD's Diversity Fellowship Expands Cultural and Linguistic Competency

IDHD received a grant from the Administration on Intellectual and Developmental Disabilities' (AIDD) Administration on Community Living (ACL) to develop a program that enhances diversity, expands cultural and linguistic competence, and promotes leadership among underrepresented groups. To this end, IDHD supported two exceptional diversity fellows in FY 2016: Miguel Morales and Kat Perez.



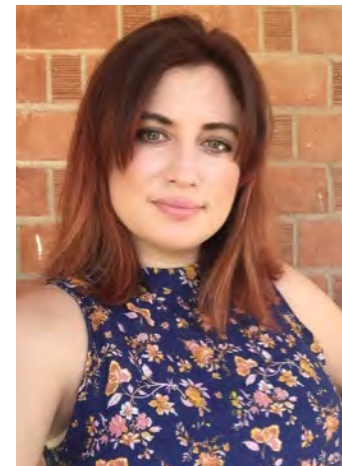
In addition to being the Assistant Director of the Family Support Research and Training Center, **Miguel Morales**, MPH, is one of IDHD's Diversity Fellows. Prior to coming to IDHD, Miguel was a program manager for HIV/AIDs and obesity prevention programs. While completing a Masters in Public Health at UIC, Miguel focused on Epidemiology because of his interest in racial and ethnic health disparities. As an IDHD Diversity Fellow Miguel is researching whether there are ethnic and racial health disparities among adults with intellectual and

developmental disabilities (IDD). He and his research team found that among adults with IDD, Latinos had a higher odds of reporting diabetes compared to Whites. They also found among Latino adults, those with IDD were more likely to be obese and have diabetes compared to those without IDD.

He is grateful for the leadership opportunities provided to him by the Diversity Fellowship. He explained, "this is an important aspect of the fellowship—developing diversity in leadership. Diversity is not an accident. Given historical, institutional, and societal barriers, it has to be actively and intentionally cultivated, developed and sustained."

He also credits the IDHD LEND program with helping him understand Disability Studies and apply it to Public Health. As a result, he believes he became better-rounded in his knowledge of and experiences with autism diagnosis, services, and public policy and research. He loves how DHD has exposed him to talented researchers and professionals from a wide array of disciplines who are unified by the disabilities studies perspective. He notes, "I feel privileged to be here."

**Kat Perez**, JD, is a fourth-year PhD candidate and IDHD Diversity Fellow. In addition to having a sister with an intellectual disability and autism, Kat personally identifies as disabled. Prior to coming to IDHD, Kat went to law school because she wanted to be a disability rights attorney. Although grateful to her law training for helping her advocate for services for her sister, she found few opportunities to study disability law in law school. Thus, she came to DHD to get her PhD in Disability Studies.



Kat's dissertation will be a critical analysis of how Burger Supreme Court (1969-1986) made disability decisions. This Court was the first to interpret disability rights Federal statutes and laws. She is also writing about litigation strategies under the ADA Title I regarding fighting discriminatory employment practices. Finally, her work also centers on the intersections of race and disability. As a part of her diversity fellowship Kat helped organize a disability/Latinx conference in Chicago. The conference aimed to help promote leadership and build coalitions in this area. While a Fellow, Kat also worked with the Congressional Hispanic Caucus Institute (CHCI) to help them train their fellows on disability policy.

After graduating from DHD, Kat hopes to litigate as a disability attorney as well as do critical disability legal theory. She ultimately hopes to work for the federal government. Kat explains, the professors at IDHD have taught her the critical disability skills necessary to merge disability with her legal training. She also appreciates the sense of community and belonging in the department; calling it "invaluable" she credits IDHD with helping strengthen her disability identity.



# DHD Alumni Improve the Lives of People with Disabilities Around the World



Students enroll in DHD for a variety of reasons and with a variety of goals for when they graduate. Some students go into academic positions, while others work in disability policy and advocacy, and others work in the visual or performing arts. DHD alumni have found positions as: Director of Long-Term Services and Supports Policy at the National Council on Aging (Joe Caldwell), President and CEO of the Council on Quality and Leadership (Mary Kay Rizzolo), and Director of Research and Evaluation at the Arc (Amie Lulinski) to name a few. Vladimir Cuk and Ryan Parrey-Munger are two recent graduates who have also found great success in their current positions.



**Vladimir Cuk** earned a MS degree from DHD in 2007. He is currently the Executive Director for the International Disability Alliance (IDA) based in New York. IDA is an alliance of over 1,100 organizations from 14 global and regional networks that encompass 180 countries that works to promote the rights of people with disabilities, particularly the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) and the 2030 Agenda on Sustainable Development within the United Nations framework. As the Executive Director, Vladimir supervises staff in New York and Geneva as they work together to promote the rights of people with disabilities, provide technical assistance, and provide a unified message regarding human rights and disability across multiple stakeholders, including the UN and its member states, civil service organizations, and various disability organizations.

Vladimir came to DHD because the department's multidisciplinary approach helped increase his ability to advocate for people with disabilities internationally. He appreciated the breadth of academic approaches that the department offered while focusing on disability. Vladimir credits DHD for the opportunity to get a formal degree related to disability because of the recognition and credibility that it offers. The degree helped him obtain his current position and his experiences in DHD improved his confidence to work in a variety of different settings. The knowledge and experience that he received in DHD will continue to be integral to Vladimir's success in advocating on an international level for the human rights of people with disabilities.

**Ryan Parrey-Munger** earned a PhD in Disability Studies from DHD in 2013. He is currently a Lecturer and Acting Director of the Disability Studies Certificate program at Eastern Washington University (EWU). In his current position, Ryan helped develop a Disability Studies minor at EWU while continuing to develop new course offerings. He is also involved in building relationships with community partners and developing service-learning projects with those organizations. Describing himself an activist-scholar, Ryan's research interests are in social interactions between people with and without disabilities.

Ryan believes DHD helped him to grow as a Disability Studies academic. He credits the interdisciplinary setting at DHD with developing a teaching style that works with people from a variety of disciplines and with diverse career trajectories. He appreciated being able to work with and beside scholars, activists, and professionals with such varied backgrounds, which has helped him network with colleagues across his campus.



# Professor Sandy Magaña Loves Educating DHD's Social Justice Oriented Students

IDHD has 22 faculty positions and 125 staff from a wide range of fields, including but not limited to: English, law, psychology, social work, sociology, and rehabilitation sciences. IDHD's faculty and staff are constantly being recognized for their excellence in the fields of research and teaching!

**52**  
Research  
and  
training  
projects



**258**  
Publications

**65** Journal  
articles

**27** Books and  
book  
chapters

**34** Fact sheets  
and  
brochures

**28** Monographs  
and  
technical  
reports

**470**

Presentations  
to local, state,  
regional, &  
international  
audiences  
reaching  
**33,000 people.**



**Sandy Magaña**, who has a PhD in Social Policy and an Master's in Social Work, is a professor at DHD who focuses on the intersection between autism spectrum disorders (ASD), and Latino families. She is the Director of the Family Support Research and Training Center (FSRTC) which examines the needs of families, which are often overlooked.

Sandy's past work as a community organizer and case manager for families of children and adults with developmental disabilities led her to her current research path. Many of the families she worked with were Spanish speaking and she noticed there was very little research literature about them. This inspired her to study Latino families of adults with intellectual disabilities for her dissertation research. As Sandy describes, her interaction with families keeps her going because she learns so much from them about their strengths, needs, and challenges.

Today, Professor Magaña is currently involved in several research projects that are aimed at identifying racial and ethnic disparities for children and adults with autism and developmental disabilities and their families. Her most recent study found that Latino and African American adults with intellectual and developmental disabilities (IDD) had worse health and mental health outcomes than White adults with IDD.

Sandy also teaches undergraduate and graduate students in the DHD class "Disability in Latino Communities." As a mentor to students she guides them through the world of academia. She finds it exciting that her classes often attract Latino students who are eager to learn about disability and social justice. She feels that, "teaching in an area that underrepresented minority students can relate to can bring their attention to the important field of disability and disability studies."

Sandy enjoys being in DHD because of its interdisciplinary nature and its focus on the social model of disability. She explains, she is learning a lot about different aspects of disability studies, which is different than her previous training. She believes social work as a profession often takes a social justice perspective, but does not really explore disability in the way it should. She explains, "my experience here involves learning as well as teaching!"



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## LEND Postdoc Sandra Vanegas Improves Services for Diverse Families

The **Illinois Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** Program which was recently funded for another five years by Maternal and Child Health (MCH) is a one year interdisciplinary training program incorporating both didactic and hands on learning in clinical and community-based settings. LEND aims to prepare future leaders who will serve children with neurodevelopmental disabilities (including related disabilities and autism) and their families through coordinated, culturally competent, and family-centered care, as well as public health services and policy systems change. Key partners include Rush University, University of Chicago, Southern Illinois University (Carbondale and Springfield Medical School), University of Illinois at Urbana Champaign, The Autism Program, and Easter Seals of Peoria.



**27** long term trainees



**11** different disciplines



**18**  
sites  
across  
the state



**Sandra Vanegas**, PhD, was the 2014-2016 Illinois LEND Postdoctoral Research Associate. While at IDHD her research has focused on bilingual language development among people with autism spectrum disorder (ASD). While previously studying at the University of Rochester, Sandra became involved with the Studies to Advance Autism Research and Treatment (STAART) Center where she learned about the challenges families faced when their child was diagnosed with ASD. Reflecting on her own experience growing up in a Spanish-speaking household, she wanted to understand ASD in diverse families.

Based on these experiences and her mentorship at IDHD's LEND, Sandra is currently conducting research which involves reviewing 10 years of medical records of children with ASD who visited the IDHD Family Clinics with the aim of focusing on children and families that are typically under-represented in research on ASD. In another project, Sandra is assessing the validity of measures of language in capturing the language abilities of monolingual and bilingual children with ASD. She explains, "we know from the literature on typically developing bilingual children that standardized assessments may underestimate the child's true abilities. Thus, if we find the similar pattern emerge for bilingual children with ASD, this can have a significant impact on treatment recommendations."

Sandra explains, the diversity of work conducted at IDHD/LEND has enabled her to have a much broader understanding of issues that affect individuals with disabilities and their families. She loves that LEND is a national network of professionals with similar missions in supporting individuals with disabilities and their families. The experiences Sandra's has had through IDHD/LEND have helped her develop her own research program by thinking about research questions that are not only scientifically relevant but also relevant to children with ASD, their families, and their communities. By framing her research into a broader context, she feels that she is on her way to having a rewarding career.

Sandra believes IDHD is unique in that faculty, staff, and students are not restrained by their respective disciplines but rather bring together their knowledge and skills to address significant issues that individuals with disabilities face. She thinks this helps promote work that has a direct and lasting impact on the fundamental needs of individuals with disabilities, particularly within highly diverse communities.

# The Assistive Technology Unit's Cutting Edge Technology Expands Independence

IDHD offers comprehensive clinical services including interdisciplinary diagnostic assessment, individual and group therapy, and family support services through the Developmental Disabilities Family Clinics and the Assistive Technology Unit.



**Mobile ATU units  
for community-  
based service  
delivery**



**292  
ATU Consumers  
receiving home  
accessibility  
services**



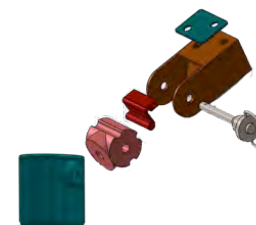
**90%  
were in the  
community**

Our interdisciplinary **Assistive Technology Unit (ATU)** has been providing services to underserved individuals with developmental disabilities in northern Illinois for the past 20 years. The ATU holds an Adaptive Equipment Clinic at a local transition program two to three times a month. At the transition program, students, such as one named Lauren, take classes and learn independent living skills such as hiring aides, managing money, and daily living skills. Lauren came to the ATU's Adaptive Equipment Clinic requesting assistance with several daily living tasks she was hoping to have greater independence.

The first request from Lauren was to assist her with equipment that would allow her to independently operate the elevators. Lauren needs to access four floors throughout her typical day for classes, meals, and getting to and from her room. Lauren is a person of short stature and her reach is limited. Through the Adaptive Equipment Clinic, the ATU designed an Elevator Access Stick for Lauren. The Elevator Access Stick is made from a lightweight aluminum rod and incorporates a 3D-printed hand grip at one end of the stick, a 3D-printed center grip, 3D-printed flexible rubber endtip for "gripping" the elevator button, and 3D-printed attachment to her wheelchair. Lauren also had the ATU incorporate a 3D-printed hook, into the grip end of the aluminum rod, so now she can use the elevator stick to access handles for pulling open drawers within her room.

The second request from Lauren was for a cup holder to access water independently and maintain hydration throughout the day. Standard cup holders placed a cup outside of Lauren's reach. A 3D-printed cup holder with custom, lightweight, 3D-printed locking mechanism for a swing arm was designed to allow Lauren to access water as needed, but also swing the cup holder out of the way so she can transfer out of her wheelchair.

The third request from Lauren was for a phone holder. Lauren is a very social person and as a avid smartphone user likes having access to her smartphone at all times. Prior to coming to the clinic, she kept her smartphone in her lap but she was concerned with it dropping. The ATU designed a 3D-printed phone holder that attached to her wheelchair. It provides a place for Lauren to store the phone on her wheelchair when she is not using it, access it when she needs it, and prevent the phone from being dropped.



## The Developmental Disability Family Clinics Provides Clients and their Families with Seamless Support and Services

**10,000**

Service hours  
provided in  
the Family  
Clinics in  
FY16



**1167**

Persons  
served in  
the Family  
Clinics in  
FY16



**500**

Latino/a  
families of  
children  
with autism  
served by  
Grupo SALTO  
in FY16

Established more than 25 years ago, the **Developmental Disabilities Family Clinics** have provided quality clinical and family support services, as well as community education and training for individuals with developmental disabilities, including autism, and their families. Their services include comprehensive interdisciplinary diagnostic assessments, specialized individual and group therapies, and family support in Spanish and English with a strong commitment to minority populations. The clinics emphasize the value of family, resources within the community and a multidisciplinary approach in providing services. As such, the Family Clinics provide diagnostic and family support services to a culturally diverse population through programs spanning from early childhood through adulthood. In addition to its diagnostic, treatment, and family support programs it has three speciality programs: 1) the Hispanic Diagnostic and Family Support Program; 2) the Autism Clinic and Training Center; and 3), Child and Family Development Center.

Many families find that the services and workshops provided by the Family Clinics benefits their family members with disabilities. For example, after attending a Family Clinics workshop on autism, Octavia spoke with one of our clinic psychologists about her son Felix. She had always felt that he had autism but he had never been diagnosed. Felix was living at home and Octavia wanted help getting him adult services. The psychologist from the Family Clinics worked with Octavia to gather records and bring her son in for an evaluation, where he was officially diagnosed with autism. Octavia is grateful to the Family Clinics and the services Felix received because “the evaluation helped Felix get his diagnosis of autism documented to expedite his transition to adult services.” Because of this Felix is now able to participate in a day program where he enjoys learning and socializing with his peers.

Recently another mother of a client, Sam, who was referred to the Family Clinics for an autism evaluation reached out to IDHD to thank the Clinics for its services. Sam’s mother, Rachael, explained, “the best thing about the program was that the therapists really stuck with me. When my son needed an evaluation, the Early Intervention therapists helped me get an appointment at the clinic.” Since Sam aged out of Early Intervention, he has been seen by a Speech Therapist at the clinic. Rachael professes, “It was great that there are services available for my son no matter what age he is. The transition from Early Intervention to early childhood therapy was seamless.” Rachael feels that her son’s ability to be successful in school has a lot to do with the programs. She notes, “Sam really hit the ground running at school. The skills he learned with his therapists made going to school and learning a lot easier than it is for some of the other kids who didn’t get that head start.”

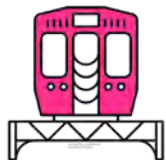


# The CEED Project Reduces Employment Barriers Faced by People with Disabilities

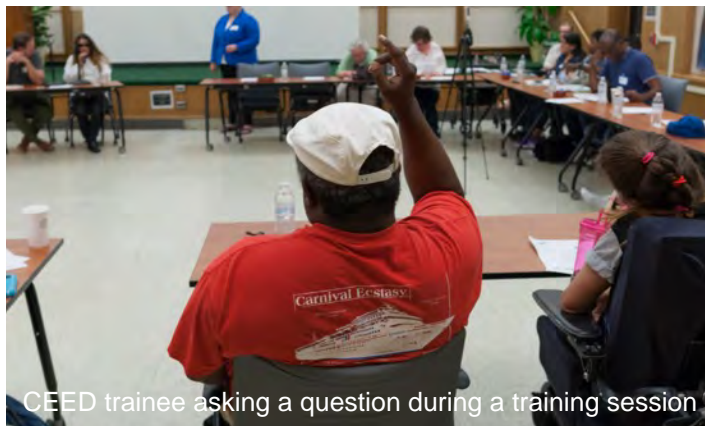


Supporting advocacy efforts and promoting systems change are core values of IDHD. As such, IDHD is home to a large number of research programs which fulfill the unique needs of Chicago and Illinois.

The values of cultural diversity, consumer choice and self-determination are emphasized across the life span in all IDHD research centers.



CEED trainees



CEED trainee asking a question during a training session



CEED staff Kate Caldwell (left) and Sarah ParkerHarris (right) with speakers Chef Laura Martinez (center-L) and Andrew Fogaty (center-R)

The **Chicagoland Entrepreneurship Education for People with Disabilities (CEED)** project is one of IDHD's community-based research and training initiatives. CEED is an interdisciplinary effort to support people with disabilities in pursuing entrepreneurship as a pathway to employment. People with disabilities can become a powerful source of social innovation in addressing the needs of their community through social entrepreneurship. However, the main barriers to entrepreneurship affecting people with disabilities, such as lack of education and training opportunities, need to be addressed.

CEED developed comprehensive evidenced-based training programs and curriculum, which have been written in plain language and uses a universal design approach to be as accessible as possible. By the end of the entrepreneurship training, people with disabilities will have a CEED plan that takes into consideration both business needs, and disability services and support needs. Participants in the provider training will have a CEED policy by the end of their training that they can begin implementing in their organization. The CEED project is also producing a curriculum that can be replicated so that anyone can have access to entrepreneurship education and training no matter where they live!

The CEED project's success is in part due to its incorporation of key IDHD values, such as promoting diversity, and collaboration across disciplines, into its training program. As such, the CEED project has included people with disabilities across all levels of their program, from the project team to its advisory committee. They have also intentionally collaborated with key figures in the fields of disability studies and entrepreneurship studies. The success of these valuable components of the program is reflected in the CEED project's findings that upon completion of the program participants are much better informed and prepared to advocate for their needs in the community.

## ADA Research and Training Project Champions Leaders with Disabilities

The 25th anniversary of the Americans with Disabilities Act (ADA) was on July 26, 2015. The Chicago Community Trust was the primary sponsor of a year-long celebration of the anniversary in 2015 in the Chicago area, known as ADA 25 Chicago, designed to continue to raise awareness of disability. IDHD was highly involved in many of these activities. Director of the Great Lakes ADA Center and IDHD Instructor Robin Jones was on the ADA 25 Chicago steering committee. The Bodies of Work project, led by IDHD Associate Professor Carrie Sandahl, co-sponsored many cultural events and performances by people with disabilities throughout the city.

One of the legacy projects of ADA 25 Chicago is **ADA 25 ADVANCING LEADERSHIP**, which is a leadership program designed to promote the inclusion of people with disabilities in board, commission, task force, and other leadership positions in the region. One of its primary activities was to host the inaugural Leadership Institute for People with Disabilities in early December 2015. Seventeen diverse people with disabilities were included as Fellows for the three and a half day leadership retreat.

IDHD Professor Carol Gill was a co-facilitator of the training, particularly focusing on the disability identity and history content areas. IDHD Interim Associate Director and Research Assistant Professor Randall Owen was a participant-evaluator for the first Leadership Institute for People with Disabilities, meaning that he was a full participant in the leadership retreat, but also conducted an extensive evaluation of the Leadership Institute.

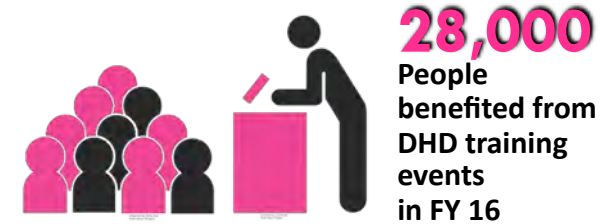
The primary outcome from the evaluation was the development of a strong rapport amongst the Fellows, who continue to support one another in their leadership development. Several Fellows have reported success in advancing their leadership positions in the community, despite the relatively short amount of time following the retreat. The full evaluation can be accessed on IDHD's website. ADA 25 ADVANCING LEADERSHIP continues to provide networking and educational opportunities for its members to encourage their leadership development. IDHD will continue their evaluation in 2016-17 with a goal of following up on the inaugural Fellows, as well as conducting an evaluation of the next Leadership Institute retreat, which Randall is helping to plan by serving on the design team committee.





## Future Planning Trainings Encourage Smooth Transitions for Aging Caregivers

IDHD places great emphasis on research-oriented activities and training opportunities. Many research-related activities are integrated across community services projects thereby creating a direct link between research and practice. At IDHD, technical assistance is not seen as a discrete activity, but rather as a logical and natural extension of all our work. Therefore, virtually all staff and faculty in the IDHD research centers and programs are involved in some form of technical assistance at the local, state, regional and national levels.



IDHD staff members partnered with The Arc of the United States, an advocacy organization for people with intellectual and developmental disabilities (IDD) and their families, to conduct several trainings on **future planning for professionals** working with people with disabilities. Funded through The Retirement Research Foundation, the trainings focused on the need for aging caregivers to be equipped to work with their family members with disabilities in order to ensure a seamless transition after the caregiver becomes unable to provide care.

Planning for the future is a daunting task, and it can be particularly overwhelming for aging caregivers who provide direct support for their sons and daughters with IDD. Surveys of caregivers show that the first step in future planning is often the most difficult, and that fear is the greatest barrier to initiating planning. Professionals including staff from the local Arc chapters are important, but underutilized, resources in successful future planning. The trainings focused on how to promote and develop self-advocacy skills in a future planning context, covered core areas of future planning and emphasized how professionals can identify and solve common barriers that families experience. Participants were empowered to initiate outreach to families, use resources from The Arc's Center on Future Planning and state-specific resources, and act on the understanding that future planning ultimately improves outcomes for people with disabilities and their families.



Tia Nelis, IDHD Self-Advocacy Specialist, and Lex Owen, IDHD Research Specialist, worked with The Arc staff members to develop and deliver the full-day training in North Carolina and Kentucky. Tamar Heller, IDHD Director and DHD Department Head, also provided professionals training at the American Association on Intellectual and Developmental Disabilities Annual Meeting in Atlanta, Georgia. Participants enthusiastically responded to the training material and particularly appreciated the opportunity to role play and practice skills central to helping families navigate the financial, legal, housing-related, and social aspects of future planning. IDHD anticipates future similar collaborations in the future that impact overall quality of life for individuals with IDD and their families.



# IDHD Project Develops Tool to Promote Health Initiatives in the Community

IDHD's Center on Health Promotion Research for Person with Disabilities' latest project, the **Community Health Inclusion Index (CHII)**, aims to design a set of survey tools used to help communities gather information on the extent to which there are healthy living resources that are inclusive to all members of the community, including persons with disabilities.

Community health initiatives often do not provide enough supports for people with disabilities to fully participate in healthy, active living opportunities. People with disabilities are more likely to be physically inactive, have greater health problems, and experience more barriers to taking part in physical activity and maintaining good nutrition compared to people without disabilities.

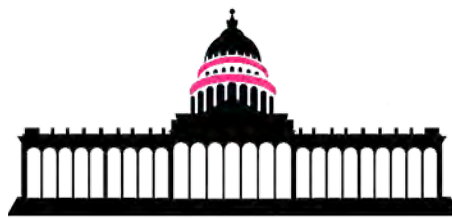
The CHII is the first instrument to incorporate community health inclusion into a comprehensive assessment tool that can be used by public health professionals and community coalitions to examine the critical supports needed for improving healthy, active living among people with disabilities.

The CHII can be used to adjust, enhance, and/or develop strategies for adults and children with disabilities that will modify the environment to reduce or remove barriers to physical activity and healthy food choices. Lastly, it provides an opportunity for communities to develop active living resources that are inclusive of people with disabilities through a process where public health professionals and members of the disability community work together.

The next phase for the CHII is for it to be used in communities by local public health departments and community coalitions. The CHII is currently part of a larger project being run by the National Association of Chronic Disease Directors and CHII is being used during the assessment phase in 10 communities in 5 states to focus on to improve access to healthy living resources. It will be disseminated nationally through the National Center on Health Physical Activity and Disability, who has integrated it into a larger inclusive community building process.



## Self-Advocacy Specialist Tia Nelis Recognized by President Obama at ADA 25 Celebration



Tia Nelis with Vice President Joe Biden

IDHD self-advocacy specialist **Tia Nelis** was personally invited to the White House to celebrate the 25th anniversary of the Americans with Disabilities Act (ADA). In his speech honoring the ADA anniversary, President Obama specifically noted Tia's accomplishments in self-advocacy! He remarked, "I want to thank some of the activists who are here -- folks like Ricardo Thornton and Tia Nelis. In 1999, the Supreme Court ruled that institutionalizing people with disabilities -- isolating them, keeping them apart from the rest of the community -- is not just wrong, it is illegal. Ricardo and Tia have pushed to make sure that ruling is enforced."

Tia was also spotlighted as one of the leaders of the Disability Rights Movement by tech giant Google. Google published a story and video about Tia's pivotal role in the self-advocacy movement for people with intellectual and developmental disabilities. Google also had Tia's image painted up a set of stairs in Washington, D.C. (image to the left) to mark the advances made by people with disabilities since the passage of the ADA. The painting of the stairs was a nod to the the historic capitol hill crawl where disability activists crawled up the steps of the capitol building in order to get the ADA passed.



## IDHD Initiative Makes Research Accessible for Everyone

IDHD is excited to announce our new **accessible research summary series**! Recognizing the importance of access for a variety of audiences, including families and people with disabilities, we have produced accessible research summaries (and audio versions) of our journal publications. By summarizing research in plain language the series aims to increase the accessibility of IDHD's research for families and people with disabilities. Over 40 briefs covering a wide variety of topics, from advocacy to health to employment, are already available on our website!

The briefs can be accessed here:  
<http://ahs.uic.edu/dhd/facultyresearch/publications/#accessible>





# The Family Support Research and Training Center Meets the Needs of Families

IDHD's **Family Support Research and Training Center (FSRTC)** is important because families represent the largest form of support and long-term care for people with disabilities, yet their needs are overlooked by policy and service systems.

The aim of the center is to develop and disseminate family support research and training to inform more cohesive policies and practices related to family support. The FSRTC's goals are to:

- Define the state of science in family support;
- Generate new knowledge in the critical policy areas of self-direction and managed care and in culturally competent peer-to-peer family interventions;
- Generate and implement a vision for policy and practice in family support through a national resource center.

One outcome of the center has been the implementation of the "Need to Know" campaign that they conducted with Easter Seals. The FSRTC engaged stakeholder including caregivers, people with disabilities, service providers, advocates and researchers in telling them what research topics are important to them in the area of family support. The FSRTC will be publishing a report with the results of this campaign this summer.

The FSRTC is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the Administration on Community Living (ACL).



## IDHD Programs and Research Centers:

In addition to the FSRTC, IDHD programs and centers, which are listed below, fulfill unique needs throughout Chicago and Illinois.



- Assistive Technology Unit (ATU) [www.ahs.uic.edu/cl/atu/](http://www.ahs.uic.edu/cl/atu/)
- The Center for Capacity Building on Minorities with Disabilities Research (CCBMDR) [ccbmdr.ahslabs.uic.edu/](http://ccbmdr.ahslabs.uic.edu/)
- The Center on Health Promotion for People with Disabilities (CHP) [chp.ahslabs.uic.edu/](http://chp.ahslabs.uic.edu/)
- Chicago Center for Disability Research (CCDR) [ahs.uic.edu/dhd/facultyresearch/centersprograms/ccdr/](http://ahs.uic.edu/dhd/facultyresearch/centersprograms/ccdr/)
- The Great Lakes ADA Center [www.adagreatlakes.com](http://www.adagreatlakes.com)
- The Evaluation and Public Policy Unit [ahs.uic.edu/dhd/facultyresearch/centersprograms/evaluationandpublicpolicyunit/](http://ahs.uic.edu/dhd/facultyresearch/centersprograms/evaluationandpublicpolicyunit/)
- The Family Clinics [www.ahs.uic.edu/cl/familyclinics/](http://www.ahs.uic.edu/cl/familyclinics/)
- The Family Support Research and Training Center [fsrtc.ahslabs.uic.edu/](http://fsrtc.ahslabs.uic.edu/)
- The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program [www.ahs.uic.edu/dhd/aboutidhddhd/whatislend/](http://www.ahs.uic.edu/dhd/aboutidhddhd/whatislend/)
- The Program on Disability Art, Culture, and Humanities (PDACH) [www.ahs.uic.edu/dhd/pdach](http://www.ahs.uic.edu/dhd/pdach)
- Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD) [www.rrtcadd.org](http://www.rrtcadd.org)



## Global Lecture Fund Fosters Innovative Ideas



Renowned scholar **Gary Albrecht**, PhD has made a generous donation to IDHD to establish the Albrecht Global Lecture on Disability Fund. The purpose of the Fund is to invite leading disability scholars to UIC. The goals of this lecture series are to foster innovative ideas regarding sociology, social policy and human rights; develop international collaborations; and raise the prestige and awareness of the doctoral program in disability studies. In addition to a lecture, the speaker will meet with students and faculty to discuss research and provide mentoring.

## Donation Helps Provide Clinical Services to Those Who Need it Most

The **National Greek Orthodox Ladies Philoptochos Society** recently made a significant philanthropic contribution to IDHD, particularly for the Autism Clinic and Training Center. The donation will help fund The Social Skills Groups which allows us to provide important social skills group experiences and training to underserved individuals with autism and their families. The donation also helps support parent workshops to underserved families where we provide training to parents and professionals on a variety of autism related topics, such as an introduction to autism, positive behavior management, social skills development, use of visual supports, transition to adulthood, and “make and take” sessions where parents are supported in creating teaching materials for their children.



## Promoting Student Opportunities through Scholarships and Awards

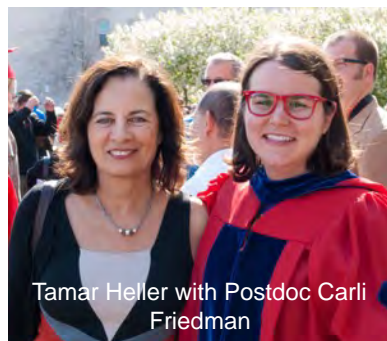
Through the help of thoughtful contributions IDHD is also able to offer the following selective fellowships and scholarships to its students:

- Ethel Louise Armstrong (ELA) Endowed Ph.D. Fellowship - women with physical disabilities
- Carlos Drazen Memorial Scholarship - scholarship on the intersection of race and disability
- Anne Hopkins Scholarship - scholarship on disability, and sex and relationships; social model of disability; social entrepreneurship
- Ann & Edward Page-El, M.D. Scholarship - scholarship on social or medical aspects of neurological disabilities
- Charlotte A. Tate Award - scholarship with a multidisciplinary approach across health, society, and disability

To contribute to IDHD please email [IDHD@uic.edu](mailto:IDHD@uic.edu) or visit our website at [ahs.uic.edu/dhd/support](https://ahs.uic.edu/dhd/support)



LEND trainees



Tamar Heller with Postdoc Carl Friedman



Student Timotheus Gordon presenting his work



Ellyn McNamara (center-right) winning the 2016 Page El Award





Sumithra Murthy, Program Coordinator for the Rehabilitation Research and Training Center on Developmental Disabilities and Health, & Susun Xiong, PhD student in Disability Studies



# INSTITUTE ON DISABILITY AND HUMAN DEVELOPMENT

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Education



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#### Advocates & Family Members

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- Marty Fox
- Michael Grice
- Nora Handler
- Stevie Hopkins
- Laurie Jerue
- Elbert Lott
- William Owens Jr.
- Leanne Roth
- Vincent Smith
- Monica Thorns
- Lindsay Tonyan
- Tara Wickey
- Francisco Alvarado, *Division of Rehabilitation Services*
- Russell Bonanno, *The Autism Program of Illinois (TAP)*
- Kathy Carmody, *Institute on Public Policy for Persons with Disabilities*
- Greg Fenton/Kathy Ward, *Division of Developmental Disabilities*

#### Organizational Representatives

- Donald Dew, *Habilitative Systems, Inc.*
- Art Dykstra, *Trinity Services*
- Zena Naiditch/Melissa Picciola, *Equip for Equality*
- Teresa Parks, *Illinois Guardianship and Advocacy Commission*
- Tony Paulauski, *The Arc of Illinois*
- Kris Risley/Karen VanLandeghem, *Community Health Sciences/MCH UIC School of Public Health*
- Dorelia Rivera, *Blue Cross Blue Shield*
- Sandy Ryan/Margie Harkness, *Illinois Council on Developmental Disabilities*



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