

Mute

Stop Video

Security

Participants

Chat

Share Screen

Record

Closed Caption

Breakout Rooms

Reactions

End



UNIVERSITY OF  
ILLINOIS CHICAGO

Institute on Disability  
and Human Development



APPLIED HEALTH  
SCIENCES

Department of Disability and  
Human Development

# Annual Report 2020

# Welcome Statement from Department Head

The unprecedented challenges felt around the world this year have reverberated within our University of Illinois Chicago and Chicagoland communities. As the ongoing COVID-19 pandemic robs the health and lives of our neighbors, we have needed to change the way we live and learn. At the same time, we continue to witness the systemic racism, political strife, and violence that has affected our country. We recognize the disproportionate impact on both the disability community and people of color and the need to strengthen our commitment to social justice.

We are very proud of the students, staff, and faculty within our Department of Disability and Human Development (DHD) as well as its Institute on Disability and Human Development (IDHD) for their perseverance in the face of such challenges and for their commitment to helping our community and community members. In this year's annual report, we are pleased to highlight just some of these many efforts and accomplishments. For instance, DHD developed a COVID-19 guidance and resource webpage which is updated regularly to keep people with disabilities, their families, and providers informed with the most up-to-date information. Current and former PhD candidates, Dr. Sandie Yi and Alison Kopit, spearheaded a mask-making effort under their Crip & Ally Care Exchange initiative. Both our students and faculty have quickly pivoted to online learning with as much grace as possible. With our support and leadership, the Chicagoland Disabled People of Color Coalition (DPOCC) has been active in promoting disability justice and celebrating people of color with disabilities through education, arts, and culture.

Despite the lack of time we have physically been able to spend together, there was no shortage of accomplishments fueled by teamwork and togetherness. We will continue working together in solidarity with our community as we enter the new year of 2021, with the goal of facilitating healing and justice for all.

Sincerely,



Tamar Heller



*Dr. Tamar Heller*

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# IDHD Researchers Publish on Health & Disability

IDHD and DHD has continued their commitment to research and dissemination amidst the pandemic. Included here are summaries of three recently published papers that stemmed from two different projects, the Longitudinal Health and Intellectual and Development Study (LHIDDS) and the Managed Care Study. Both these projects were housed in the Research and Rehabilitation Training Center on Developmental Disabilities and Health.

## Associated Risk Factors for Depression and Anxiety in Adults With Intellectual and Developmental Disabilities (IDD): Five-Year Follow Up

The first paper entitled “Associated Risk Factors for Depression and Anxiety in Adults With IDD: Five-Year Follow Up” explored factors associated with depression and anxiety in people with IDD. Understanding these factors is important so service providers, clinicians, and researchers can be provided with guidelines and improve the diagnostic process.

The study analyzed data from 758 adults with IDD and their support people who supplied information at four specific points in time across a 5-year period. The overall occurrence of depression within this sample remained steady at about 11% over time. However, the occurrence of anxiety within this sample increased over time, rising from 12% in year one, to 15% in year five.

Certain patterns and trends were discovered. For instance, female participants reported having depression at a higher rate than male participants. Older participants, and participants who identified as having autism or a hearing impairment were more likely to have anxiety than participants who did not fall into these categories. Lastly, participants with chronic health conditions reported having anxiety and/or depression more often than their peers without chronic health conditions. Like the general population, this research confirmed that big life changes or stressful events, such as moving to a new home or changing jobs is associated with a greater risk for anxiety.

It is important for service providers and health professionals be aware of and sensitive to different factors like these that may increase a person’s chance of also experiencing depression and/or anxiety. This study has echoed others by confirming that anxiety and depression are common concerns for people with IDD, and more work needs to be done to learn what treatments may be most effective for this population.



Dr. Kelly Hsieh

### Reference:

Hsieh, K., Scott, H. M., & Murthy, S. (2020). *Associated Risk Factors for Depression and Anxiety in Adults With Intellectual and Developmental Disabilities: Five-Year Follow Up*. *Am Journal on Intellectual and Developmental Disabilities*, 125(1), 49-63. doi: 10.1352/1944-7558-125.1.49

### More Research on Health and Disability is Underway with New Projects Funded in 2020

Dr. Beth Marks is serving as Principal Investigator on two new projects funded in 2020: “People with intellectual and Developmental Disabilities Healthy Brain Initiative” (funded by CDC, NCCDPHP, and NHBI), and the “COVID-19 Rapid Response for Clinical and Translational Sciences.”

Dr. Kelly Hsieh is serving as Principal Investigator on the “We Walk 4 Health” study (funded by NIDLRR, ACL) and the “We Walk Plus Study” (funded by the National Institute on Aging).

# IDHD Researchers Publish on Health & Disability

## Examining Association between Reported High Cholesterol and Risk Factors in Adults with IDD



Sumithra Murthy

### Reference:

Murthy, S., Hsieh, K., & Heller, T. (2021). *Examining Association Between Reported High Cholesterol and Risk factors in Adults With Intellectual and Developmental Disabilities (IDD): A Five Year Follow Up.*

The published paper explored the relationship between physical activity, obesity, diabetes, and cholesterol levels among adults with intellectual and developmental disabilities (IDD). Adults with IDD have a higher risk for developing high cholesterol than the general population, which also increases their likelihood of cardiovascular disease. This research used data from the LHIDD dataset, which included information about over 1,600 adults with IDD. Data was collected four times over a 5-year period so researchers could understand changes over time.

Results showed that as the participants aged, the prevalence of high cholesterol increased. There were also various categories associated with increased rates of high cholesterol. For instance, participants who lived in group or foster homes reported more occurrences of high cholesterol than participants who lived by themselves or with family. Both obesity and diabetes were associated with a high cholesterol status across all time-points, and having diabetes was found to have a partial-mediating effect. The authors concluded that further research studies are needed to advance our knowledge on the complex mechanisms behind the intersection of diabetes, obesity, high cholesterol. There is also a need to improve and prevention efforts, including health education and health promotion strategies for adults with IDD.

## Longitudinal Appraisals of Family Caregiving for People with Disabilities Enrolled in Medicaid Managed Care

The published paper examined how family supports impacted caregiver's feelings of burden, satisfaction, and self-efficacy over a two-year period. This paper was part of a larger study that evaluated the transition of people with disabilities and older adults in Illinois from fee-for-service Medicaid to Medicaid managed care. Only surveys completed by Medicaid managed care enrollees with disabilities who live with family caregivers were analyzed.

Results from the survey showed that family members who had more unmet family support needs, in that they weren't getting supports that they needed, had higher caregiving burden, lower caregiving satisfaction, and lower caregiving self-efficacy. Family members can sometimes be paid for the support they provide to their family member with a disability. The study found that families who provided a greater amount of unpaid care had higher caregiving burden. Parents, however, had lower caregiving satisfaction and caregiving self-efficacy than family members who were not parents, like a brother or sister. The study shows the importance of providing families with supports to help them feel better about their caregiving experiences which ultimately impacts the person receiving the support.



Dr. Caitlin Crabb

### Reference:

Crabb, C., Owen, R., Stober, K., & Heller, T. (2020). *Longitudinal appraisals of family caregiving for people with disabilities enrolled in Medicaid managed care. Disability and Rehabilitation*, 42(16) 2287-2294. doi:10.1080/09638288.2018.1557266

# Dr. Kate Caldwell Talks “Lead On” Project

Dr. Kate Caldwell has served as a Clinical Assistant Professor within UIC’s Department of Disability and Human Development since 2017. Prior to the onset of the COVID-19 pandemic, Dr. Caldwell received multiple grants and fellowships including an Interdisciplinary Pilot Grant from the College of Applied Health Sciences (AHS) for her research project *Lead On: Leadership and Women with Disabilities in Government*, and a faculty fellowship with UIC’s Inclusive Classroom Initiative to develop a module “Developing a Disability Inclusive Toolbox.” Dr. Caldwell (KC) sat down with IDHD researcher, Kaitlin Stober (KS), to talk about her Lead On project specifically. Abridged sections from this conversation follow:



*Dr. Kate Caldwell*

**KS: Why did you develop the Lead On project?**

**KC:** I noticed that we had this influx of women with disabilities working in governments, and I kept hearing about strategies that they were using, not just to get a seat at the table, but to make sure theirs and other women's voices were being heard—women of color, LGBTQ+ women, plus people with disabilities—making sure that these conversations were reflective of the community.

**KS: And what did you hope to accomplish?**

**KC:** I wanted to capture what was going on right now among this group of women with disabilities who had been doing this movement making, and to learn because a lot of times they aren't even aware of the progressive strategies that they've developed to make their voices heard and to do "the work." So I wanted to analyze their experiences to pull out those strategies and experiences.

**KS: Can you tell me more about the research process?**

**KC:** We did interviews with 31 women with disabilities working in government, and that includes transwomen with disabilities, at the local, state and federal level. It's a very intersectional analysis. We've got a large representation across different races and, also at different levels—political appointees, elected officials, civil service employees... And we had a huge variety of disabilities pretty much across the spectrum, including some individuals with intellectual and developmental disabilities.

**KS: How, if at all, did the pandemic impact your project?**

**KC:** We didn't set out to collect data on COVID, it just happened because we were talking to these women in the very early stages of responding to COVID in their communities. Some of the themes that came up were about workplace culture. In particular, while during the pandemic the workload for women with disabilities had not gotten bigger, it was more intense having to juggle responsibilities and given the expectations around their gender and disability. There is also additional labor for women with disabilities working in government to provide access. There needs to be someone willing to take on that additional responsibility, and oftentimes that ended up being the person requesting access, whether it was for themselves, or for their constituents. Perhaps most concerning [of the themes found] was the considerable amount of ableism that many of these women were experiencing as they were trying to respond to the pandemic in their communities – colleagues joking and refusing to wear masks and, therefore, putting colleagues with disabilities at risk. One of the wonderful things that we saw, were these mutual aid and care networks that women with disabilities working in government have been involved in developing and contributing to those networks to try and fill in the gaps and make sure the needs of their communities are being met. These interviews also highlighted, however, just how unprepared local, state, and federal gov't are when it comes to inclusive disaster and emergency response. Whereas many of the women with disabilities we spoke with were uniquely prepared, several having lived through them before. We are glad that our research can highlight those experiences to provide direction for policymakers going forward to improve preparedness and response efforts impacting the disability community.

**KS: So what's next for this project?**

**KC:** We're going to be doing a huge knowledge translation push so that we're getting these findings out there, but also developing tools that people can use it to apply these findings. We want to make sure that we're doing knowledge translation in a way that reaches not just other researchers, scholars, and policymakers, but also folks in the community. I think it's really going to make a difference and we'll be able to benefit from the strategies these women have mobilized over the years.



## PhD Student Explores Creole Experience in Dissertation

Andrea Cooke defended her dissertation virtually in May 2020. Andrea's dissertation partly grew out of a 2014 pilot study ("Creole People: Identity and Mental Health") in which she conducted semi-structured interviews with a convenience sample of 14 Creole people recruited from a conference in Illinois. Andrea used her findings from this pilot project to shape interview questions in her dissertation. Creole people are people of color with intergenerational mixtures of French and/or Spanish and/or Native American backgrounds and African heritage. Her dissertation looked at how Creole people of color form their identities and how racial stress impacts their mental health. Andrea conducted a focus group, a group interview, and 18 individual semi-structured interviews with people who identified as Creole. Andrea, a Creole woman of color, connected with her participants and felt that they had many similar experiences to the ones that she had. This is an important component of qualitative research: building rapport with study participants. She also discovered that the experiences of identity formation within Creole people of color differ from other multiracial people and that their identity is more salient than other multiracial individuals.



*Dr. Andrea Cooke*

## Undergraduate Students Create Art to Celebrate Disability Culture

Last year, DHD held an art contest for undergraduate students who were DHD majors, minors, or enrolled in DHD courses. The art contest had the theme, Creating Disability Culture. The winning art pieces included "Fatigue" by **Jordan Alcantar** (left, page 5), "Raw" by **Alkebuluan Merriweather** (top, page 6), and "Selma Blair and Her +1, Her Cane" by **Karla Velasco** (bottom, page 6).



**Jordan Alcantar, Fatigue**

**Want to learn more about our academic programs?**

**DHD Office of Student Affairs**

Email: [dhdosa@uic.edu](mailto:dhdosa@uic.edu)

Phone: 312-996-1508

**Undergraduate Studies in DHD:**

Major: [go.uic.edu/DHDBachelor](https://go.uic.edu/DHDBachelor)

Minor: [go.uic.edu/DHDMINOR](https://go.uic.edu/DHDMINOR)

**Graduate Studies in DHD:**

PhD in Disability Studies: [go.uic.edu/DHDPhD](https://go.uic.edu/DHDPhD)

**Graduate Certificate Programs**

Assistive Technologies Certificate Program (ATCP)

[go.uic.edu/DHDATCP](https://go.uic.edu/DHDATCP)

Disability Ethics Certificate: [go.uic.edu/DHDDECP](https://go.uic.edu/DHDDECP)

# DHD Students Shine: Art Show

## Undergraduate Students Create Art to Celebrate Disability Culture



Alkebuluan Merriweather, *Raw*



Karla Velasco, *Selma Blair and Her +1, Her Cane*



# DHD Alumni Impact: Across the Country and Around the World



*L to R: Dr. Randall Owen, Cade Owen, & Dr. Lex Owen*

## Drs. Owen Roll the Dice and Move to Reno

Dr. Lex Owen and Dr. Randall Owen, both alumni of our PhD in Disabilities Studies program and former leaders within IDHD, have recently taken their skills and devotion to the field to new positions.

Lex is now serving as a Practice Fellow for the National Technical Assistance and Training Center on Disability Inclusion in Emergency Preparedness, a project of AUCD's National Center on Disability in Public Health. In this role, Lex conducts program evaluation and will develop a sustainable playbook for maximizing partnerships to increase disability inclusion.

Randall is now an Associate Professor in the College of Education and Human Development as well as the new Director of the Nevada Center of Excellence in Disabilities (NCED), Nevada's UCEDD. Randall's years and experience leading IDHD, Illinois' UCEDD, will serve him well. We wish them and their family the best of luck on their new adventures in Nevada!

## Japanese Student Influences Disability Work Here and in Japan

Born in Fukushima prefecture, Japan, with a neurodiverse disability, Noah attended public high school in Japan but moved to the US to practice Judo professionally. Due to his progressive muscular dystrophy, Noah moved back to Japan and lived in several hospital, residential, and institutional settings specifically for people with disabilities. On March 11, 2011, Noah's life changed: he was forced to evacuate to Osaka due to the catastrophic earthquake that devastated northern Japan. There, he discovered the Center for Independent Living "MUCHU" and has been managing their advocacy team ever since. At the same time, Noah began work as a commentator and director of the TV show, "Barrier-Free Variety Show" – a show for disabled people, by disabled people. In May 2020, Noah graduated with a Bachelor of Disability Studies from UIC. Post-graduation, Noah wishes to go to graduate school to learn about Disability Studies in more depth. Noah would like to use research to understand how culture affects identity and to collaborate with a variety of disability organizations in the US and internationally. Noah currently juggles a number of roles: in addition to his work for MUCHU, Noah is a board member of the World Independent Living network (WIN) and president of Connecting Dots International (CDI).



*Noah Ohashi*



# Assistive Technology Unit

## ATU Leads Effort to Update Evacuation Device Performance Code

Assistive Technology Unit (ATU) Director and Rehabilitation Engineer Dr. Glenn Hedman, Chair of the RESNA Assistive Technology Standards Committee on Emergency Stair Travel Devices used by Individuals with Disabilities (ESTDs), spearheaded an effort to update the only performance code which exists for these critical devices. ESTDs are used to assist in evacuation downstairs in any building where stairs are a part of the evacuation route. The new edition of the standard, ANSI / RESNA ED-1:2019, opens up compliance testing to all device design types: carry-type, track-type, and sled-type. Devices are tested for weight capacity, forward and lateral stability, and maneuverability. The ATU has also assembled the required ESTD testing stations and is currently testing fourteen commercially-available devices. For more information, contact **Dr. Glenn Hedman** at [ghedman@uic.edu](mailto:ghedman@uic.edu).



*ESTD maneuverability test*



## ATU Services during COVID-19

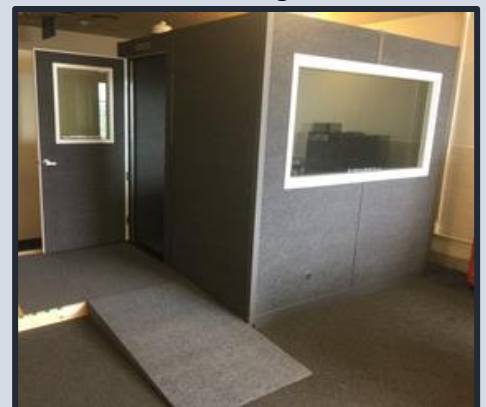
ATU services shifted to telehealth options for service delivery as COVID-19 procedures went into place in March 2020. As of September 2020, community-based services returned, with procedures and personal protective equipment (PPE) designed to keep clients and staff safe.

*(Photo left) ATU clinicians Kathy Waldera (OT) and Lori Peculis (PT).*

## Assistive Technology Certificate Program Evolves in Response to COVID-19

UIC's Assistive Technology Certificate Program (ATCP) is one of only three Assistive Technology (AT) training programs accredited by the Commission on Accreditation of Allied Health Education Programs (CAAHEP), and the only one with a distance learning focus. The ATCP currently has over 50 active students, mostly working professionals across the United States. The ATCP's required Field Experience has usually been achieved by providing AT services to clients in their geographic area, supervised by a local RESNA-certified Assistive Technology Professional (ATP). During COVID-19, opportunities for direct service provision have been greatly reduced. Clinical faculty members Daniel Cochrane, Jennifer Skalitzky, Fani Lee, and Rebecca Miller helped develop alternate options to enable the working professionals to demonstrate their knowledge and skill base in the delivery of quality AT services. ATCP students can now select an Investigation/Observation or Case Study option. The Investigation option requires an analysis of AT service availability in a geographic area. The Observation option includes an analysis of referral information and an in-the-room observation of evaluation, implementation, or follow-up services. The Case Study option enables students to present a case of their own, spelling out the service plan for the client. The ATU also constructed a Vocal Booth recording studio

to permit clinical supervisors to interact with ATCP students with privacy and in a soundproof setting.



*ATCP recording booth assembly*

DHD is proud to lead the Illinois Leadership in Neurodevelopmental and Related Disabilities (IL LEND) Program. With four training sites across the state, this one-year interdisciplinary training program prepares future leaders who will serve children with neurodevelopmental and related disabilities and their families. In FY2020, 28 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 educated about policy and advocacy through didactic sessions, a policy project, and advocacy opportunities.

## Former Trainee Spotlight: Jae Jin Pak

Jae Jin has continued to be an advocate since completing his LEND fellowship in 2014 and has served as the LEND Self-Advocacy training coordinator since 2017. He is the Chair for the Statewide Independent Living Council and provides support for Centers of Independent Living across Illinois. In 2019, he helped form the Disability Immigration Taskforce of Illinois (DITI) to empower and support immigrants, refugees, and asylees with disabilities and their families to access culturally and linguistically appropriate services. He works to develop strategic goals and objectives as part of DITI's steering committee, and he has also developed materials and workshops as part of the Education and Training committee. When House Bill 3299 which requires individuals living in a developmental disability facility to have access to sex education was passed, an interdisciplinary committee was formed to assist providers serving people with I/DD with guidelines and tools on providing access to sexual education. Jae Jin serves on both the Oversight and Curriculum committees.



*Jae Jin Pak*

## Research Spotlight: Behavioral Health Care Access for Youth with Autism



*Dr. Kristin Berg*

IL LEND Social Work Faculty, Dr. Kristin Berg, researches the social determinants of health impacting individuals with autism and developmental disabilities (DD), focusing on adversity in the health and well-being of youth. Adolescents with disabilities are two to five times more likely to have mental, emotional, and behavioral (MEB) comorbidities and more severe symptoms in comparison to their nondisabled peers. Comorbid MEB is associated with long term impacts on functioning, hospitalization, independence, and transition to adulthood outcomes, above and beyond adolescents' DD. Despite the impact of untreated MEB, youth with disabilities are less likely to access mental health supports.

Approximately 25% of youth with chronic disabilities have an unmet mental health care need and this number has increased substantially over recent years. Dr. Berg found that mental health care was the most

commonly reported health care need for youth with autism age 11-17 years. One significant barrier is the limited availability of evidence-based interventions and strategies to address MEB disparities and improve behavioral health care access. Dr. Berg seeks to address this research gap by focusing on development, implementation, and evaluation of innovative approaches to behavioral health care.



*LEND class of 2019-2020*

# A New Clinic within the Family Clinic

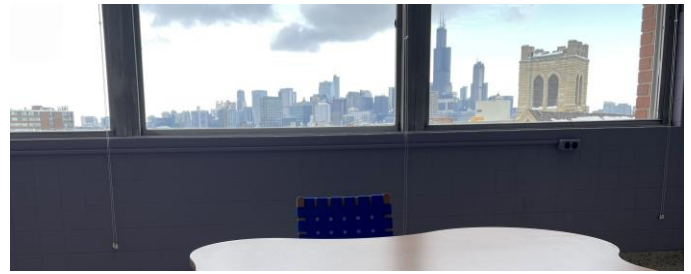
Amidst the chaos of the pandemic this year, new members of the DHD community created the Cognition, Behavior, and Mindfulness Clinic (CBM Clinic) as part of DHD's Developmental Disabilities Family Clinic. Directed by the highly talented Dr. Mark R. Dixon, and supported by Jessica Hinman (MS, BCBA) and Zhihui Yi, (MS, BCBA), this program started up and has been delivering services daily, despite COVID, to children with autism.

Each word in the Cognition, Behavior, and Mindfulness Clinic's name stands for a series of interventions that individuals can receive in order to learn new skills and limit behaviors that impact learning and independence. The primary goals for clinicians are to teach language and communication skills, provide behavioral consultations, offer training to families and caregivers of autistic individuals, and promote value-based behavior change through acceptance and commitment therapy.

The scientific core of CBM rests upon applied behavior analysis. Dr. Dixon was the founding president of the Illinois Association for Behavior Analysis and has been the editor of multiple top scientific journals in the field. But according to Dr. Dixon, all those academic accomplishments are useless if they cannot directly help the people who need it the most. His two protégés Zhihui and Jessica agree- as doctoral students in UIC's Rehabilitation Science program, they have years of experience working in the field.

Clients are already raving about the services being provided by the CBM Clinic. One such parent mentioned to the team that she seldom saw positive outcomes that had such life-changing effects, but that the therapy received at the CBM Clinic is proving to be one of those moments.

After keeping the program small during the fall semester, a few rumors started spreading about how amazing the services were: ***"We went from literally one client for a few months to getting calls every day. Some of that is surely pandemic related, but once word got out, we keep getting inquiries"***, says Zhihui.



*The CBM Clinic space overlooks the Chicago Skyline*

***"Although we have had to change our service delivery model due to the pandemic, we are still seeing incredible results. I have been providing mindfulness-based, behavioral services via telehealth and love seeing our clients learn to be more mindful, focusing on their values, and learning to be more psychologically flexible even amidst a global crisis"***, says Jessica.

Zhihui adds, ***"Besides offering quality care to clients and families, we also offer internship opportunities to UIC students. Undergraduate students looking to expand their educational experience can enroll in fieldwork credits and work with us for a full semester. Students who are interested and want to get more involved in ABA and research are also welcome to volunteer at the CBM clinic. A few awesome students are already signed up to join our team for spring 2021."***

Regardless of the timeline back to "normal", the CBM Clinic will be delivering services face-to-face and via telehealth. Dr. Dixon looks back at this year, his recent move, and the CBM "start up" as one intense adventure, saying, ***"I knew building a new program during the pandemic and trying to get people in the door or online would be challenging. But I love the challenge and the outcomes are worth the gamble."***



*A teen practices meditation in the sunlight*



# DHD's COVID-19 Resources and Research

## DHD Develops and Distributes COVID Resources

DHD created a COVID-19 Guidance and Resources web page to provide support for people with disabilities, their families, and support providers during the pandemic. <https://ahs.uic.edu/disability-human-development/coronavirus-disease-covid-19-resources/>

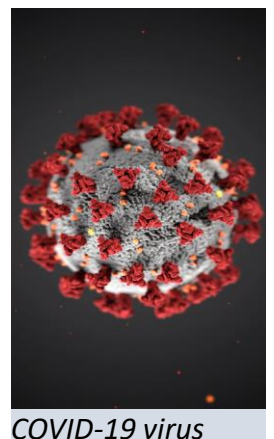
The engagement opportunities and educational materials guidance and resources categories are specific to the disability community and complemented by federal, state, and municipal resources for the general population and people with disabilities. Pandemic resources are compiled from partnering agencies' communications and the UIC tools, studies, and engagement opportunities. New resources are added every month.

A high-risk population for serious symptoms of COVID-19, people with disabilities and their families experience adult day centers closures, limited visitor access due to hospital policies during the initial stages of the pandemic, an increase in family caregiving in the home, major changes in daily routines, the move to remote service delivery, and distance learning. The DHD COVID-19 Guidance and Resources ease the burden on the disability community by equipping people with disabilities, their families, and support providers with knowledge, guidance, and support to manage a new normal during the pandemic. There are plain language materials and social stories on how to stay safe; guidelines to make testing sites and telehealth materials accessible; where to find respite resources; how to manage changed routines; and how to schedule, prepare, and participate in telehealth. Many of these resources are also available in Spanish. Resources include COVID-19 reports on people with disabilities in the areas of benefits access and enrollment, healthcare access, and employment. Live and archived webinars discuss ways to manage in this challenging environment.

For those looking to participate in supporting people with disabilities and their families during the pandemic, the engagement opportunities category within resources has volunteer opportunities, surveys to relay COVID-19 experiences, a link to order a smile mask, a sign-up survey to be an urgent backup caregiver for a person with disabilities, a downloadable checklist to prepare for a COVID-19 hospitalization, and the opportunity to register for a new COVID-19 webinar. We share our affiliated organizations' (ADA Great Lakes, Chicagoland DPOCC, and the Arc) COVID-19 resources lists. We will continue to disseminate, organize, and update pandemic resources for the disability community to facilitate moving through a challenging time.

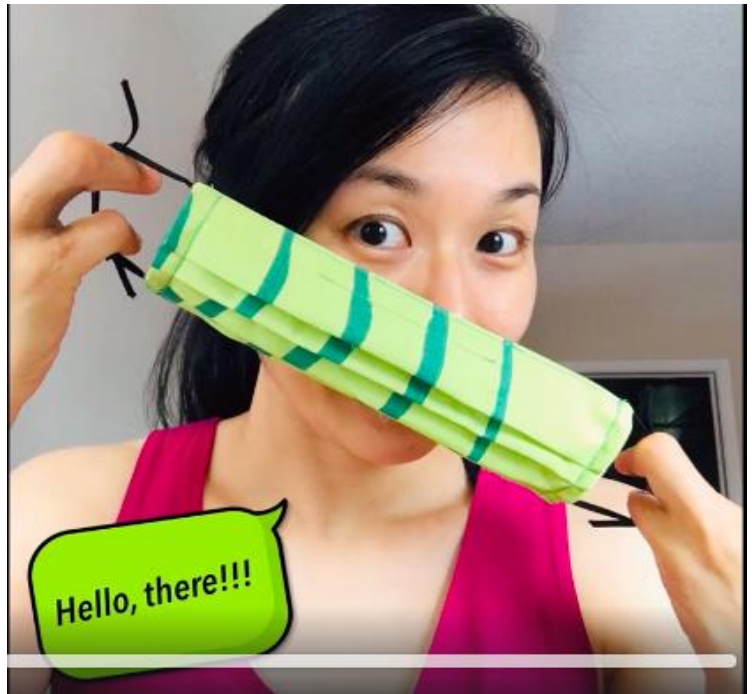
## Student Conducts Needs Assessment of People with Disabilities in China

A volunteer network of disability self-advocates, journalists, and nonprofit organizations serving people with disabilities emerged in February 2020 during the peak of COVID-19 to respond to the urgent needs of people with disabilities (PWD) in China. DHD PhD candidate Yue Xu served as the needs assessment advisor of this group where she helped design a brief survey for PWD. The network served over 200 people with disabilities by distributing masks, feminine care packages, telehealth gift cards, and providing sign language interpreting. Yue also helped Minority Voice, an online grassroots disability peer support group led by people with disabilities, design a survey to evaluate personal emergency preparedness among PWD in China. The organization collected 248 valid surveys and the results showed that PWDs with a physical disability and those from Hubei province in Central China are less likely to be ready for emergency evacuation. People with disabilities who feel confident in evacuation and are part of an online disability peer-support group are more likely to prepare for an emergency evacuation. Yue also partnered with Minority Voice to receive a grant (\$9,200) from the Raoul Wallenberg Institute of Humanitarian Law to do a needs assessment on emergency preparedness for PWD and senior citizens in China.



# Masks for Crips

Masks for Crips was co-created by Dr. Chun-Shan (Sandie) Yi, a DHD alumnus and Alison Kopit, current PhD candidate in DHD. Sandie and Alison are disabled artists. While quarantining at the onset of the pandemic, they noticed how volunteer mask-making efforts were making bulk mask donations to institutional settings and hospitals, but many local disabled people living in the community did not have access to PPE or homemade masks. Sandie practiced mask designs, several of which were used in Taiwan's COVID response. Together, they developed a system in which disability community and their care teams in the Chicago area could request masks. Masks for Crips worked to fill this need, supporting their community, and by extension, the Independent Living Movement, between the month of March and July of 2020.



*Dr. Sandie Yi poses with a mask*

The start of the project in March was critical to the local disability community, as the state of Illinois put its stay-in-home order in place on March 20. The availability of masks, directives for mask wearing, and acceptance of wearing masks was in its infancy at that time. Furthermore, Illinois state law did not and still does not require personal care assistants to wear a mask as a preventative measure to reduce the spread of COVID-19. Sandie and Alison understood distributing masks as both a practical way to curb the spread of the virus and a symbol of their love and sustained connection to disability community.

In their collaboration, Sandie managed the production side while Alison managed the administration side. They developed a mask making team and a mask delivery team as their project grew. They were grateful to feel an abundance of support from the community in the form of monetary donations, mask contributions, and reliable delivery. Keeping the project local allowed them to fulfill need while staying realistic about their own capacity as a small operation with a small budget. At the time of their last delivery in July, they delivered almost 300 masks. Masks for Crips took a Disability Justice approach, incorporating principles such as sustainability, collective access, and coalition-building.



*Masks for Masks for Crips*

# IDHD in the Community!

## ICDD 5-Year State Plan

Over the past few years, IDHD has worked closely with the Illinois Council on Developmental Disabilities (ICDD) in a review of their past projects and in developing their new five-year state plan, which sets objectives and guides the Council's activities over the next five-year period. IDHD has been assisting in the data collection effort to inform the plan, by researching Illinois and national data and by facilitating input sessions with various ICDD stakeholders including self-advocates with disabilities and service providers. These input sessions have been instrumental in the formation of the plan but have also offered an outlet for stakeholders to voice frustrations in the state during this difficult time.

## Census Project

IDHD received a sub-contract from Habilitative Systems Inc. to promote the census to people with disabilities in Illinois, with a focus on underserved areas. People with disabilities make up a quarter of the US population but have been identified by the US Census Bureau as a hard-to-count population, and therefore risk being undercounted in the census. The census is important for bringing money to communities to invest in their services and supports, so it's especially important to make sure people with disabilities are counted so that their communities receive these resources to help support them. IDHD participated in a variety of activities to help promote the census to people with disabilities in Illinois. One tactic was to widely promote the census through our social media outlets: Facebook, Instagram, Twitter, and our listservs. Our team leveraged Facebook Live to provide a virtual Q&A with staff from the Chicago Census Office about the census that was widely re-shared by viewers! Our team participated in socially-distant in-person events, like Community Blitz Days, in which census partners would go into the community to distribute flyers, educate people about the census, and assist them in finding information or answering any questions.

## Chicagoland Disabled People of Color Coalition (DPOCC)

In 2020, disabled people of color faced many additional challenges that threatened their livelihood and their communities, such as COVID-19, police violence, civil unrest, and reactions to the 2020 presidential elections. During this time, Chicagoland DPOCC remained committed to serve and empower disabled people of color in the Chicagoland area. In partnership with the Illinois Self Advocacy Alliance, we created a plain-language COVID-19 resource guide for people with disabilities in marginalized communities.

Additionally, Chicagoland DPOCC also made a brief plain-language document on ways to cope with the historic 2020 elections. In another important initiative, Chicagoland DPOCC created the #IAmCounted social media campaign. The purpose of the #IAmCounted campaign was to encourage disabled people to complete the 2020 US Census and educate on how the census can impact the disability community. When people completed the census, they would use pictures with the #IAmCounted campaign logos to show they completed the Census and encourage others to do so. The logos were also available as Facebook profile picture frames. In addition, Chicagoland DPOCC partnered with IDHD and UIC College of Applied Health Sciences to create the UIC DPOCC Fund which Chicagoland DPOCC can use to finance its operating expenses, including accessibility and accommodations for events.

The DPOCC Fund will also be used to support research that promotes intersectionality in the disability community and give scholarships to disabled UIC students of color. For information on the UIC DPOCC Fund, or if you would like to contribute to the fund, visit

<http://ahs.uic.edu/alumni/give-to-ahs/where-to-give>.



DPOCC founder TJ Gordon



# “Code of the Freaks” Documentary Debuts

2020 brought us the long-anticipated debut of *Code of the Freaks*, a full-length documentary on Hollywood’s representation of disability in the film that was co-produced and co-written by our faculty Drs. Carrie Sandahl and Aly Patsavas. The documentary’s team also included playwright Susan Nussbaum, who served as a producer/writer, and filmmaker Salome Chasnoff, who served as director/writer.

To illustrate the time and passion poured into the project, Dr. Sandahl points out the years of research and community development the project undertook through trips to film archives, town-hall discussion, and salon-style screenings.



A still frame of Dr. Aly Patsavas in *Code of the Freaks*

*Code of the Freaks* gets its name from the 1932 Tod Browning film feature *Freaks* – rare in its portrayal of the pride, solidarity, and defiance of the central troupe of disabled characters – and the tagline pays homage to Browning’s characters, jovially asserting “offend one and you offend them all.”

Like its namesake, this documentary finds few presentations of disability in film worth celebrating over the past century. *Code of the Freaks* delves into the many, misguided stereotypes surrounding disability by showcasing everything from classic films like *The Hunchback of Notre Dame* and to more recent blockbusters like “Wonder Woman.” In doing so, this documentary critiques the tired tropes that Hollywood has employed in relation to disabled characters and their plotlines.

But this documentary does so much more than merely criticize stereotypes and critique tropes. Unlike the movies analyzed within, *Code of the Freaks* is driven by the voices and experiences of actual disabled people. Featured critics, including DHD alumnus TJ Gordon, reflect on the impact that Hollywood’s representations of disability have had on both the lived experiences of disabled people as well as the understanding (or misunderstandings) about disability by nondisabled people. This community response shines through and directly contrasts the tendency of Hollywood to isolate disabled characters. Drs. Patsavas and Sandahl revealed their hopes for the film in a virtual, UIC alumni gathering.

Dr. Patsavas explains, “we need more critical gaze, and we hope our film gives people the tools to do that in relation to representations of disability.”

Dr. Sandahl added that she hopes educators will use this film in their classroom, and a recently awarded creative activity grant is going towards curriculum-making efforts that can be spread far beyond DHD. *Code of the Freaks* has been featured in a number of virtual film festivals this year, including ReelAbilities Film Festival and the Southern Circuit Tour.



A still frame of Dr. Carrie Sandahl in *Code of the Freaks*

You can follow *Code of the Freaks* on Facebook or visit their website—<https://www.codeofthefreaks.com/> to find future screening opportunities or get your own copy.

# PhD Students Lead Inclusive Dance Workshop Series

DHD doctoral students Maggie Bridger and Sydney Erlikh were selected for the distinguished Schweitzer Fellows Program for their founding and continuation of The Inclusive Dance Workshop Series, a series of creative movement workshops for children and adults with disabilities at Access Living and other local disability organizations. The workshops support dancers in developing their own artistic voice, provide a safe space to explore different forms of movement, and build artistic community for people with disabilities and their allies. So far, this project has reached 380 community members of various ages and embodiments. In addition to weekly workshops at Access Living and other Chicago-based organizations, Bridger and Erlikh have brought their project to Counter Balance, an annual integrated dance event, as well as the Art Institute of Chicago's Open House.

This project centered on the weekly classes, which focused on different components of inclusive dance each week. Together, dancers explored various dancemaking tools and concepts, techniques, and improvisational scores. Bridger and Erlikh took care to plan their weekly lessons in ways that addressed some of the strengths, interests, and areas for growth they witnessed in previous weeks' sessions. The classes, which typically have about 10-13 attendees each week, fostered a close-knit and inclusive community of disabled adults and allies.



*Workshop participants extend both their arms outward*

The workshops also encouraged participants to consider disability culture and the disability experience as a valuable platform from which to build community and art. While most dance spaces remain inaccessible and unwelcoming to diverse bodies and experiences, the Inclusive Dance Workshop Series holds diversity as a necessary and exciting opportunity to create dance and build strong relationships. By centering the disability experience, participants were able to explore and affirm their own emotions. One of the dancers expressed anxiety about returning to their “regular” dance classes after having experienced a workshop centered on their own movement. Bridger and Erlikh encouraged conversation on how affirming disability-centered spaces are and how it can be hard to leave them and go back into the rest of the world.



*A group of workshop participants crowd together in dance*

Bridger expanded, “It felt like a really wonderful moment where the dancer felt comfortable enough to share some of their anxieties about their work and the outside dance world and provided us an opportunity to affirm and work through some of those feelings together.”

This series has had a lasting impact on participants, with 83% of participants saying they would feel comfortable taking dance beyond these workshops and 66% saying they feel that they are a part of a disability community.

# The ADA Turns 30!

In 2020, The American with Disabilities Act (ADA) commemorated 30 years of progress in access and inclusion for people with disabilities. The Great Lakes ADA Center is one of the ten federally funded regional technical assistance centers on ADA, serving Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. The mission of the Center is to promote voluntary compliance with the ADA. The Center was established in 1991 shortly after the implementation of the ADA.



2021 marks the 30<sup>th</sup> anniversary of the ADA National Network and the Great Lakes ADA Center. The Center and Network provide technical assistance and consultation regarding the requirements of the ADA as well as conducting training to architects/designers, businesses, government entities, educational entities, employers, service organizations, and people with disabilities and their families. The Center responds to over 1,000 inquiries per month via telephone, website, and email and conducts training for over 3,000 individuals each month via its robust webinar offerings.

As part of the 30<sup>th</sup> Anniversary of the ADA, the Center collaborated with its affiliate organizations across the six states served to identify key advocates who were willing to share their stories in response to the tag line “Thanks To The ADA”. Over 30 interviews were conducted and video recorded across all six states.



ADA Mask

These videos have been distributed via the Center’s social media over the past several months in recognition of the 30<sup>th</sup> Anniversary. The Center also held a Trivia Quiz game with key figures in the ADA enforcement community. You can view both the interview and the Trivia Quiz video at the links below:

“ThanksToTheADA” Interview Video:

<https://tinyurl.com/y2ocz8k>

ADA Trivia Quiz Video:

<https://tinyurl.com/yvd23u7g>.

During the ADA 30 celebration, masks were given out so access and inclusion could be commemorated safely.

More information on the many services and resources available are at:  
[www.adagreatlakes.org/](http://www.adagreatlakes.org/)

The Center also sponsored a series of webinars during July 2020 highlighting the 30<sup>th</sup> Anniversary including its ADA Legal Webinar Series entitled, “The 30th Anniversary of the ADA: A Review of the Most Important ADA Cases” and its Accessible Tech Webinar Series entitled, “Digital Accessibility: What have we learned and what does the future hold?” In addition to marking the 30<sup>th</sup> Anniversary they also provided information to address disability and COVID-19 in various settings as well as the accessibility of the 2020 election.



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