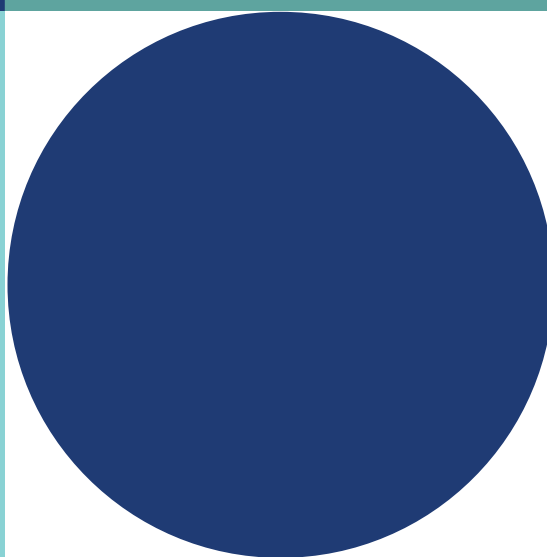


ANNUAL  
REPORT

2023



Brandeis

THE HELLER SCHOOL  
FOR SOCIAL POLICY  
AND MANAGEMENT  
Lurie Institute  
for Disability Policy

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# INTRODUCTION

The Lurie Institute for Disability Policy at Brandeis University's Heller School for Social Policy and Management leads research that helps shape policies, programs, and practices that improve the lives of people with disabilities across the lifespan.

We partner with people with disabilities, community organizations, policymakers, and clinicians to produce research that addresses the critical issues that disabled people and their families face. Our research incorporates qualitative and quantitative methods that are informed by the disability community and grounded in disability justice. Our research team includes established academic scholars, postdoctoral fellows, professional research staff, and student research assistants.

The Lurie Institute was created by a generous gift from the Nancy Lurie Marks Family Foundation in 2007. Over the past 16 years, we have conducted cross-disciplinary research on real-life topics affecting people with disabilities, including health and healthcare, parenting, home- and community-based services, and more.



# MESSAGE FROM DR. MITRA

Dear Friends of the Lurie Institute for Disability Policy,

It is with great pleasure that I present the 2023 Annual Report of the Lurie Institute for Disability Policy. The past year has been particularly exciting as we embarked on new projects and collaborations and continued our innovative and community-driven disability research and policy analysis.

In March 2023, Laurie Bertram Roberts was appointed the first Carrie Buck Distinguished Fellow. Her public lecture, “Advocacy and Action at the Intersection of Disability and Reproductive Justice,” drew attendees from across Brandeis, the Boston area, and nationwide. Funded by the Ford Foundation, this annual fellowship honors Carrie Buck, a poor, disabled woman who was involuntarily sterilized in 1927.

Our collaborations with community and international partners have continued to expand. Last year, we received renewed funding for the Community Living Policy Center, partnered on a new project with the Massachusetts Disabled Persons Protection Commission, and launched a new study focused on understanding systemic barriers for potential recipients of Supplemental Security Income. We also strengthened collaborations with researchers in the U.S., Chile, Netherlands, and Israel, and from countries across the Global South.

Our four federally funded research centers—the National Research Center for Parents with Disabilities, the National Center for Disability and Pregnancy Research, the Community Living Policy Center, and the Community Living Equity Center—are thriving and receiving well-deserved recognition for their work. The respective researchers continue to partner with and are guided by disabled community advisors, ensuring that their work remains inclusive and relevant.

**Our funders and supporters are crucial to our successes in community-driven and policy-relevant disability research. Your generosity permits us to continue and expand our work.**

Thank you for your contributions and support as we advance disability rights and inclusion.

Monika Mitra  
Director, Lurie Institute for Disability Policy  
Nancy Lurie Marks Professor of Disability Policy





# OUR TEAM



**Monika Mitra**  
Director



**Amy AbuShanab**  
Associate Director of  
Administration and  
Engagement



**Ilhom Akobirshoev**  
Director of Research



**Laurin Bixby**  
Research Scientist



**Joe Caldwell**  
Director, Community  
Living Policy Center  
(CLPC)



**Elad Daniels**  
Data Analyst II



**Mark Davis**  
Data Analyst II



**Miriam Heyman**  
Research Scientist



**Jessica Hoyle**  
Postdoctoral Fellow



**Luanjiao Hu**  
Postdoctoral Fellow



**Jennifer Lee-  
Rambharose**  
Research Associate II



**Frank Li**  
Data Scientist I



**Nicole Lomerson**  
Research Associate II



**Janelle Mills**  
Research Associate



**Teresa Nguyen**  
Director, Community  
Living Equity Center  
(CLEC)



**Wendy Peverill-Conti**  
Senior Department  
Coordinator



**Sydney Pickern**  
Senior Research  
Associate



**Robyn Powell**  
Senior Research  
Associate



**Mel Ptacek**  
Communications  
Specialist



**Lauren Smith**  
Associate Director of  
Research Operations



**Rajan Sonik**  
Associate Research  
Professor



**Dalton Stevens**  
Postdoctoral Fellow



**Ryan Suh**  
Graphic & Data  
Visualization Designer



**Luca Swinford**  
Research Associate



**Kimberly The**  
Senior Research  
Associate



**Anne Valentine**  
Senior Research  
Associate



**Marji Erickson  
Warfield**  
Senior Scientist



**Hussaini Zandam**  
Postdoctoral Fellow



**Weiwen Zeng**  
Postdoctoral Fellow

# OUR RESEARCH

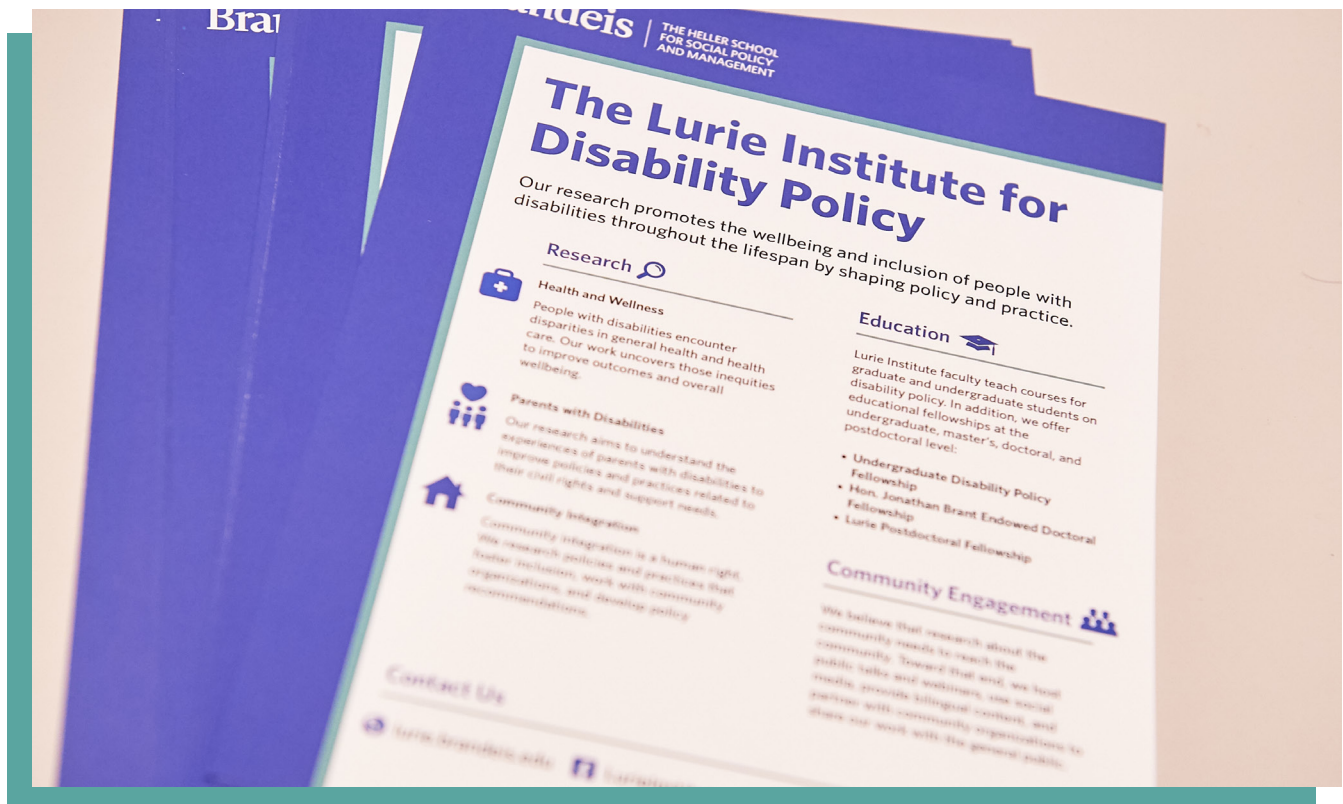
## New Projects:

In 2023, the Lurie Institute launched three newly-funded projects.

The Lurie Institute received a new 5-year grant to continue the **Community Living Policy Center's research**, which examines state and federal policies that enable people with disabilities to live in the community.

Lurie researchers began working on a project funded by the **Social Security Administration** to understand the barriers preventing eligible disabled people from successfully completing the SSI application and appeal process.

In collaboration with the **Massachusetts Disabled Persons Protection Commission (DPPC)**, a new project aims to identify criminal abuse and neglect of disabled adults. Lurie researchers are assisting DPPC Adult Protective Services (APS) in evaluating reports of abuse or neglect of disabled adults.



# NATIONAL RESEARCH CENTER FOR PARENTS WITH DISABILITIES (NRCPD)

The 2023 NRCPD research projects included examining how state policies on parental termination laws affected disabled parents, including those from racial and ethnic minority groups. In addition, the ParentingWell Learning Collaborative for diverse practitioners successfully hosted a four-part virtual event in Philadelphia, with Spanish interpretation.

NRCPD released an international companion to its U.S. data compendium, establishing a comprehensive framework for research on parents with disabilities globally. The Compendium of International Data Sources for Parents with Disabilities includes data sources from China, India, Israel, Australia, and other countries, making it a crucial contribution to global knowledge on disability experiences.

Over the past year, the NRCPD hosted several well-attended webinars, including “Parents and Parenting with Disabilities: Perspectives from Chile,” which resulted in the Lurie Institute hosting Chilean disability researchers in March 2024. Additional webinars focused on disabled immigrant parents, disabled parents in multigenerational families, and parents with psychiatric disabilities involved with the child welfare system.

The NRCPD designed and conducted specialized trainings aimed at preparing U.S. attorneys to support and defend disabled parents in child welfare cases. The training session titled “Keeping Families Together: Preparing Attorneys to Defend Disabled Parents in Child Welfare Cases” was attended by eighty attorneys.

**National Research Center for Parents with Disabilities**  
September 6, 2023 ·

<https://zuri.co/4RbB>

Level up your skills! **#NoCost #attorney #training** by experts on using **#disabilitylaw** in **#childwelfare** cases! Fill out surveys to show impact & **#win** a chance for \$250 gift card! Sponsored by Brandeis U & UMass Chan Med School. Info [taylor.merk@umassmed.edu](mailto:taylor.merk@umassmed.edu)

**NO COST WEBINAR**  
**Keeping Families Together**  
Attorney training to defend disabled parents in child welfare cases

October 5 & October 12, 2023  
2:00 - 3:00 PM EDT

UMASS CHAN IRB# 00000963

**National Research Center for Parents with Disabilities**  
October 4, 2023 ·

Researchers from the Lurie Institute for Disability Policy will provide background info about the disproportionate representation of parents with psychiatric disabilities within the child welfare system & issues that these parents frequently confront. Registrations are now open!

**Strategies to Support Parents with Psychiatric Disabilities with Child Welfare Involvement: Perspectives from Staff Providing Legal Services**

Presenters: Miriam Heyman, Robyn Powell, Ron Ayler, and Alex Dutton

Thursday, October 19, 2023  
3:00 PM ET

**SCAN TO REGISTER**

This program has been approved by the National Association of Social Workers (Approval #986142820-8097) for 1 continuing education contact hour.

**Nat'l Research Center for Parents w Disabilities**  
@NRCRPD

Webinar on June 10: Parents & Parenting with Disabilities: Perspectives from Chile

Panelists @mfho, Jimena Luna & Soledad Del Carmen Véliz Córdova will discuss their work, experience, and perspectives. **#DisabledParenting #ParentsWithDisabilities #Chile**

[zuri.co/Azm6](https://zuri.co/Azm6)

**ing Webinar** **rio web en inglés**

and Parenting with Disabilities: **y padres con discapacidad: ives from Chile ivas desde Chile sobre la crianza**

**ATTN: 10:00 AM ET** **ATTN: 10:00 a.m. ET**

# COMMUNITY BLOG POSTS

The NRCPD periodically invites community members to contribute blog posts for distribution on our website and social media channels, amplifying the voices of disabled parents. Selected excerpts are featured below:

“The thing I recently realized is that by missing those activities, and the walks and car rides that get my family there, I’m also missing out on family conversation and bonding time. I miss stories that my daughters tell their dad. I miss funny jokes. When I’m sitting on the bench and see them walking away laughing, it hurts me inside. But I don’t want them to stop living their happy lives because of my health issues.”

— Alisha McMillen, “Trying to pass as ‘normal’ can be exhausting.”

“I gave birth during a time when COVID-19 measures in international travel between China and the U.S. were still strict and it was almost impossible for my parents to travel and support me in person. My partner and I were privileged (though it should be the norm) that we had jobs with paid m/paternity leave and supportive work environments. We shared the childcare responsibilities without any sitters or nannies. Our parents were able to fly in later to stay with us and provided additional support for a time. Yet none could stay with us for a long time because they do have their lives overseas to return to.”

— Luanjiao Aggie Hu, “Mothering at the intersection: My experience as an immigrant woman with a physical disability.”

“I want my children to enjoy time with friends. I sometimes dread the anxiety that accompanies these interactions. I wish I could make the awkwardness disappear but the kids, mine and their friends, are worth the discomfort. I want a more accessible and inclusive future. One in which I could show up knowing I could expect access. Until we get there, we can figure out workarounds together.”

— Kara Ayers, “Playdates as a Disabled Parent.”

DECEMBER 5, 2023

Trying to pass as “normal” can be exhausting

by Alisha McMillen



Trying to pass as “normal” can be exhausting

“The thing I recently realized is that by missing those activities, and the walks and car rides that get my family there, I’m also missing out on family conversation and bonding time. I miss stories that my daughters tell their dad. I miss funny jokes. When I’m sitting on the bench and see them walking away laughing, it hurts me inside. But I don’t want them to stop living their happy lives because of my health issues.”

— Alisha McMillen

AUGUST 14, 2023

Mothering at the intersection: My experience as an immigrant woman with a physical disability (Part 1)

by Luanjiao Aggie Hu

Part 1 of 2



“...I observed how my motherhood experience is closely entangled with my immigration, race/ethnicity, and disability statuses, and how becoming a mother reminded me of my multiple identities all at once.”

— Luanjiao Aggie Hu, “Mothering at the intersection”

JANUARY 29, 2023

Playdates as a Disabled Parent

by Kara Ayers



“... I don’t remember playdates being “a thing” as a child. When I had friends over, it was almost always at my house because it was accessible for my wheelchair.”

— Kara Ayers, “Playdates as a Disabled Parent”



# NATIONAL CENTER FOR DISABILITY AND PREGNANCY RESEARCH (NCDPR)

In 2023, the NCDPR conducted research focusing on disparities in perinatal healthcare and preconception education among people with disabilities, accessible pregnancy planning, maternal and infant health for people with disabilities, and postpartum depression among women with intellectual and developmental disabilities.

The NCDPR disseminated their research findings through various formats. Two plain-language research summaries were published; one highlighting pregnancy care for women with intellectual and developmental disabilities (IDD), based on Dr. Monika Mitra's research examining the risk of maternal mortality and severe maternal morbidity among this group of women; the other discussing insights from qualitative interviews with clinicians providing perinatal care to women with IDD, addressing barriers to optimal care and policy implications.

Additionally, in 2023, the NCDPR released four videos aimed at women with intellectual and/or developmental disabilities who are preparing for pregnancy, thinking about pregnancy, or recently gave birth. They also published ASL videos summarizing research findings on the pregnancy and postpartum experiences of deaf and hard-of-hearing mothers. Their latest video release provided a comprehensive overview of health risks for deaf and hard-of-hearing people during and immediately after birth, with recommendations for improved care.

The NCDPR conducted numerous webinars addressing perinatal care for pregnant people with physical disabilities and the reproductive and perinatal healthcare needs of people with IDD.





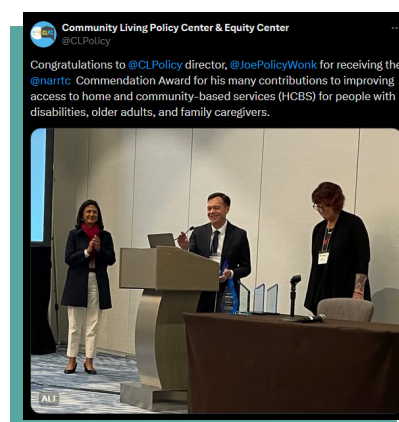
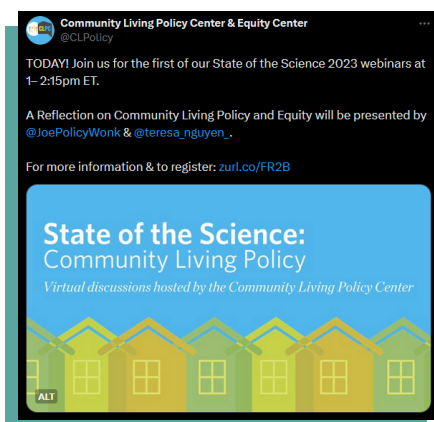
# COMMUNITY LIVING POLICY CENTER (CLPC)

The Community Living Policy Center has been awarded renewed funding through 2028 following a competitive grant application process. This grant will support the CLPC in its ongoing research on state and federal policies that promote community living for people with disabilities in the U.S. Additionally, CLPC director, Joe Caldwell, was awarded the prestigious National Association of Rehabilitation Research and Training Centers Commendation Award in recognition of his significant contributions to disability research and policy.

Over the past year, the CLPC has maintained a robust research agenda, collaborating on numerous research projects with partner organizations. Research topics include the need for affordable and accessible housing, barriers to transitioning from institutional to the community settings, ongoing COVID-19 impacts, and the need for person-centered planning in healthcare.

The CLPC hosted a comprehensive three-part series on “State of the Science 2023: Community Living Policy,” which featured an overview of the CLPC achievements, discussions on future research priorities, and summaries of stakeholder roundtable discussions. Additional CLPC webinars focused on topics such as affordable, accessible housing and equity in home and community-based services (HCBS) policies at the state level.

The CLPC remains a sought-after resource for legislators and policymakers. In 2023, CLPC leaders engaged with staff from Senator Bob Casey’s office and the U.S. Senate Special Committee on Aging to discuss issues affecting older adults and people with disabilities. The CLPC continues to provide valuable insights through comments and policy analysis on federal legislation and regulations related to long term services and supports (LTSS) policy.



# COMMUNITY LIVING EQUITY CENTER (CLEC)

In 2023, the CLEC research team continued to investigate how systemic racism, ableism, and xenophobia in the U.S. contribute to significant inequities for disabled people of color.

We were thrilled that the CLEC Director, Teresa Nguyen, was invited to the White House in July of last year to speak with Vice President Kamala Harris and Secretary of Transportation Pete Buttigieg. This meeting, part of the Vice President's initiative with disability-rights leaders nationwide, focused on transportation accessibility via air travel.

In 2023, the CLEC held its first webinar, "Disability Identity and Pride in Equity Research," highlighting the voices and vital work of members from the CLEC Community Advisory Committee. This was followed by another webinar on addressing equity in HCBS at the state level.

CLEC's research agenda is robust, with five active research studies underway. These include examining the needs of racial and ethnic minority adults with long-term services and support at the national and state levels; investigating barriers to accessing Medicaid HCBS faced by disabled people of color; and identifying promising practices among peer-support models that address racial equity in HCBS from the consumer, family, worker, unpaid caregiver, and community perspectives. Additionally, CLEC researchers have established a workshop for people of color with disabilities who have experience in self-directing HCBS.



# ***DISPARITIES IN PERINATAL CARE AND OUTCOMES AMONG BLACK PEOPLE AND LATINA/XS WITH PHYSICAL DISABILITIES***

In 2023, the NIH grant funding this study entered its third year of funding. Researchers have been recruiting Black people and Latina/xs with physical disabilities who have had a baby in the last 10 years to participate in interviews about their pregnancy experiences. These interviews are being conducted by four peer researchers who identify as Black or Latina and have lived experience of physical disabilities. Peer researcher Heather Watkins and collaborator Linda Long-Bellil presented on the study at the American Public Health Association's annual meeting in Atlanta in November, 2023.

Lurie researchers are also conducting quantitative analysis using national data and state-based data from Massachusetts and California. Recently-acquired data from South Carolina will also be analyzed. Manuscripts on disparities in severe maternal morbidity and maternal mortality from national Healthcare Cost and Utilization Project data are in progress and have been presented at several national conferences.

## ***ADDRESSING SEXUAL AND REPRODUCTIVE HEALTH CARE DISPARITIES AND BARRIERS AMONG ADOLESCENTS AND YOUNG ADULTS WITH DISABILITIES***

In 2023, the research team for this NIH-funded study focused on developing materials for interviews with youth and young adults about sexual and reproductive health. A Work Group, composed of three youth and young adults with disabilities, developed the interview guide in collaboration with Lurie team members. The team also began work on an online sexual and reproductive health toolkit for adolescents and young adults, which includes an environmental scan of existing programs to identify gaps the toolkit could fill.

Additionally, the Lurie team is analyzing data from the National Survey of Family Growth to examine the utilization of sexual and reproductive health services, outcomes, and racial/ethnic differences in sexual and reproductive health outcomes among adolescents and young adults with and without disabilities.



# UNDERGRADUATE STUDENT FELLOWSHIP

As of spring 2024, our undergraduate fellowship program has trained nearly 40 undergraduate students in disability policy research. Last year, fellows attended and presented at the 2023 American Public Health Association annual meeting. These students are the future leaders of disability research and policy, and we are honored to support their development.

2023-2024 Undergraduate Fellows:

Logan Shanks, Rachel Bindman, Isabella Doulas, Leilani Segura, Elena Soranno



Group photo of Lurie staff and 2023-2024 fellows.

From left to right:

Back row: Logan Shanks, Miriam Heyman, Monika Mitra, Rachel Bindman, Isabella Doulas, Leilani Segura, Elena Soranno, Kim The, Amy AbuShanab.

Front row: Jennifer Lee-Rambharose, Nicole Lomerson.

# **HONORABLE JONATHAN BRANT ENDOWED DOCTORAL FELLOWSHIP**

The Brant Fellowship supports doctoral students affiliated with the Lurie Institute, by providing tuition and other financial assistance to aid in their dissertations and policy advocacy efforts. This fellowship aims to encourage promising students to apply their research and advocacy skills towards achieving full social and legal equality of people with disabilities in the U.S. and globally.

The 2023 Honorable Jonathan Brant Endowed Doctoral Fellowship was awarded to Kaitlin Stober.



**Kaitlin Stober**

“

During my fellowship tenure, I collaborated with past fellowship recipients on various Lurie projects and was supported by Lurie faculty and staff to develop my dissertation research around community living and engagement among people with disabilities. I strongly believe that the Hon. Jonathan Brant '68 Endowed Doctoral Fellowship has helped cultivate a community of student scholars who are dedicated to improving the lives of people with disabilities through research and evidence-based policy—I am thankful and proud to be part of this growing network.



# POSTDOCTORAL FELLOWSHIP

The Lurie Institute for Disability Policy offers a 2-year postdoctoral fellowship in disability and health research, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). This program supports emerging scholars focused on disability justice, social policy, and public health. Our postdoctoral fellows engage in diverse research projects, ranging from the sexual and reproductive health of adolescents and young adults with disabilities, and deaf and hard-of-hearing women's experience of pain management during pregnancy, to the transition of disabled young people to adulthood, and the improvement of person-centered care for Medicaid and Medicare enrollees with disabilities.



**Dr. Luanjiao Aggie Hu**

Dr. Hu is collaborating with researchers on a scoping review of the experiences of parents with disabilities and leading a paper on pain management during pregnancy for deaf and hard-of-hearing women. Additionally, Dr. Hu is conducting a community-based participatory action research project to understand the experiences of enrollees with disabilities in Medicaid and Medicare and to recommend policies for improving person-centered care plans.



I truly enjoyed working on different projects at Lurie, which have exposed me to diverse research methods and topics. My colleagues at Lurie have been nothing but supportive of my work here.

# POSTDOCTORAL FELLOWSHIP

Dr. Stevens's research at the Lurie Institute has focused on sexual and reproductive health experiences and outcomes among adolescents and young adults with disabilities; mortality trends among adults with physical, sensory, mental health, autism, and IDD; abuse and neglect reports in Massachusetts; and the transition to adulthood for disabled millennials. Dalton is preparing articles for publication, a state-level report, and a book manuscript. Next year, Dalton will join CLEC/CLPC staff to work on nursing home transitions, home and community-based services and supports receipt across states, and lived experiences of direct support professionals.



**Dr. Dalton Stevens**



As a Lurie Postdoctoral Fellow, I work on cutting-edge disability policy research, contributing to several projects at different stages and collaborating with leading experts in the field to advance the understanding of disability research and policy solutions to major barriers in the lives of disabled people.

# POSTDOCTORAL FELLOWSHIP



**Dr. Jessica Hoyle**

Dr. Hoyle is working on a series of papers related to an NIH-funded study on the sexual and reproductive health among adolescents and young adults with disabilities. The papers analyze data from the National Survey of Family Growth to compare outcomes of individuals with and without disabilities.



**Dr. Weiwen Zeng**

Inspired by his clinical experiences, Dr. Zeng's research focuses on identifying the mechanisms behind health challenges and disparities faced by minoritized families of individuals with autism/developmental disabilities across the lifespan. He aims to develop evidence-based interventions to address these disparities.

“

My postdoc experience at Lurie has been incredibly rewarding, thanks to the unwavering support and mentorship from the faculty, staff, and peer mentors, which has greatly enriched my research and career development.

# PUBLICATIONS

## Highlights

The 2023 Healthcare Cost and Utilization Project (HCUP) Outstanding Article of the Year Award, issued by the Agency for Healthcare Research and Quality (AHRQ) and AcademyHealth was awarded to Ilhom Akobirshoev, Sharon Reif, Rachel Sayko Adams, Frank Li, and Monika Mitra, for their article, “Opioid Use Disorder-Related Emergency Department Visits Among Deaf or Hard of Hearing Adults in the United States,” published in the Disability and Health Journal.

As part of the NIH-funded study on pregnancy outcomes and experiences of individuals with physical disabilities from Black/Latinx communities, Lurie Institute researchers trained four peer researchers to conduct interviews and qualitative analysis. They developed a research training model that places a unique and timely focus on the intersections of community-based participatory research and racial and disability justice, and emphasizes the importance of building capacity in Black and Latina disabled peer researchers. This training process was documented in the following peer-reviewed publication.

**Lee-Rambharose, J., Smith, L. D., The, K.,** Horner-Johnson, W., Long-Bellil, L., **Watkins, H., Senda, J., Garr-Colzie, N., Palacios, M. R., & Mitra, M.** (2024).

Inclusion of Black and Latina Parents with Physical Disabilities in a Qualitative Research Study: A Peer Researcher Training Model. International Journal of Qualitative Methods, 23. <https://doi.org/10.1177/16094069231207771>



# PUBLICATIONS

## *Other Publications:*

- Adams, R. S., Akobirshoev, I., Brenner, L. A., Katon, J. G., & Mitra, M. (2023). Pregnancy, fetal, and neonatal outcomes among women with traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 10-1097.
- Caldwell, J., Heyman, M., Katz, G., & Ho, S. (2023). Facilitators and barriers to person-centered planning from the perspectives of individuals receiving Medicaid home and community-based services and care managers. *Disability and Health Journal*, 101473.
- Cerilli, C., Katz, G., Volandes, A., Davis, A., Paasche-Orlow, M., James, T., & McKee, M. (2023). "There is no communication": A qualitative examination of Deaf signers' experiences with advance care planning. *Journal of Palliative Care*.
- Dembo, R. S., Mailick, M. R., Rudolph, A. E., Huntington, N., DaWalt, L. S., & Mitra, M. (2023). Social network diversity and mental health among mothers of individuals with autism. *American Journal on Intellectual and Developmental Disabilities*, 128(2), 101–118.
- Helm, K. V. T., Panko, T., Herschel, M., Smith, L. D., Mitra, M. & McKee, M. M. (2023) Maternal health experiences of Black deaf and hard of hearing women in the United States. *Women's Health Issues*, 33(6), 610–617.
- Heyman, M., Li, F., Swinford, L., & Mitra, M. (2023). Housing circumstances of disabled parents within the child welfare system. *Children and Youth Services Review*, 107089.
- Heyman, M., Li, F. S., Swinford, L., & Mitra, M. (2023) Life circumstances of diverse parents with disabilities with child welfare system involvement. *Child Welfare*, 100(5).
- Heyman, M., Powell, R., The, K., & Mitra, M. (2023) Experiences of parents with psychiatric disabilities with child welfare involvement. *Child Welfare*, 101(1).
- James, T. G., Panko, T., Smith, L. D., Helm, K. V., Katz, G. R., Caballero, M. E., ... & McKee, M. M. (2023). Healthcare communication access among deaf and hard-of-hearing people during pregnancy. *Patient Education and Counseling*, 107743.



# PUBLICATIONS

- McKee, M. M., Zhang, J., Akobirshoev, I., McKee, K., & Mitra, M. (2024). Antenatal emergency department and inpatient use among Massachusetts deaf and hard of hearing women: A retrospective cohort study. Research Square.
- Mellinger, T.J., Forester, B.P., Vogeli, C., Donelan, K., Gulla, J., Vetter, M., Vienneau, M., Ritchie, C.S. (2023). Impact of dementia care training on nurse care managers' interactions with family caregivers. BMC Geriatrics, 23 (16).
- Mitra, M., & Turk, M. A. (2023). DHJO looks to the future. Disability and Health Journal, 16(1).
- Mitra, M., & Turk, M. A. (2023). The power of advocacy in advancing disability and health research. Disability and Health Journal, 16(3).
- Namkung, E. H., & Mitra, M. (2023). Residency differences between fathers with and without disabilities in the United States. Family Relations.
- Ne'eman, A. & DeMartino, E. S. (2023). Disability rights and life-sustaining treatment: Building bridges between clinicians and advocates. CHEST Journal, 164(1), 203–205.
- Powell, R. (2024). Family Caregivers' Attitudes and Perspectives About the Sexual and Reproductive Health of Women With Intellectual and Developmental Disabilities: An Online Survey. American Journal on Intellectual and Developmental Disabilities, 129(2): 135–150.
- Powell, Robyn. (2023). Legal ableism: A systematic review of state termination of parental rights laws. Washington University Law Review, 101(2).
- Thomas, C. P., Stewart, M. T., Ledingham, E., Adams, R. S., Panas, L., & Reif, S. (2023). Quality of opioid use disorder treatment for persons with and without disabling conditions. JAMA Network Open, 6(3), e232052–e232052.
- Turk, M. & Mitra, M. (2023). Surveys and Research. Disability and Health Journal, 16(4):101522.
- Turk, M. A., & Mitra, M. (2023). The evolution of disability and health research and practice. Disability and Health Journal, 16(2), 101450.
- Zhang, W., Bjørnstøl, E., Ding, P., Gao, W., Liu, H., & Liu, Y. (2024). Disability, sexuality, and gender in Asia. Intersectionality, human rights, and the law. First edition. Routledge.

# ***SELECTED RESEARCH BRIEFS AND CASE STUDIES***

The following are selected research briefs and case studies published by Lurie researchers and their partners:

Parent-Centered Planning: A new model for working with parents with intellectual and developmental disabilities

Who reports parents with intellectual disabilities to the child welfare system?

Fatherhood with a disability: Health and unmet needs

Are reports of child abuse among U.S. parents with disabilities more likely to be substantiated?

The ParentingWell Practice Approach: Findings from recent research

Recurrence of substantiated reports of child maltreatment by low-income parents with disabilities: The importance of poverty and race

Map of state termination of parental rights laws that include parental disability

Prevalence of parents with disabilities in the United States

Enhancing employment opportunities and outcomes within Medicaid home- and community-based services

Strengthening the long-term support services coordinator role within One Care: A qualitative study and analysis of the One Care Massachusetts Health Plan

The Massachusetts Alternative Housing Voucher Program (AHVP): A case study

Needs and priorities for community living policy research: Summary of stakeholder roundtables and community living policy survey

# COMMUNITY ENGAGEMENT

## *First Annual Carrie Buck Fellowship*

The inaugural Carrie Buck Distinguished Fellow was Laurie Bertram Roberts, executive director of the Mississippi Reproductive Freedom Fund. The first lecture was a conversation between Laurie and Rebecca Cokley, program officer for the U.S. Disability Rights program at the Ford Foundation. Over 150 people attended the hybrid event, including Brandeis students, staff, faculty, and researchers, as well as community members from the Boston area, and nationwide.



**Laurie Bertram Roberts (Left) & Rebecca Cokley (Right)**

# COMMUNITY ENGAGEMENT

## *SHINE Program*

In 2023, the Lurie Institute formed a community-based partnership with SHINE, a Stoneham High School program providing high school and post-high school education for students with disabilities. A Lurie staff member and Lurie student fellows hosted SHINE students for student-centered activities to immerse them in the Brandeis community and college experience.

Lurie staff, student fellows, and SHINE students co-created an easy read guide about Massachusetts transportation and visited areas around campus, including the Spingold Theater and Rose Art Museum.





# COMMUNITY ENGAGEMENT

## *Disability Pride*

Staff members from the Lurie Institute enthusiastically joined the 2023 Disability Pride event in July 2023, hosted at the Massachusetts State House.





# COMMUNITY ENGAGEMENT

## *American Public Health Association Annual Meeting*

Several Lurie faculty, staff, and students presented at the 2023 Annual Meeting of the APHA.

Monika Mitra. Mothers with intellectual and developmental disabilities during the perinatal period: The prominence of the child welfare system in healthcare experiences and perceptions.

Ilhom Akobirshoev. In-hospital mortality involving COVID-19 in the U.S. among adults at the intersection of intellectual and developmental disability, race, and ethnicity: Evidence from nationally representative hospital discharge data.

Kaitlin Stober. Self-advocacy participation and choice-making among adults with intellectual disabilities.

Elad Daniels. Psychotropic medication utilization among adults with intellectual and developmental disabilities: Disparities across residence types in Medicaid long term services and supports.

Frank Li. Disparities in Internet access among parents with and without disabilities in the United States.

Robyn Powell. Surveilling disabled parents and their children.

Robyn Powell. Legal ableism: A systematic review of state termination of parental rights laws.

Samantha Shortall. Parenting stress of mothers with intellectual disabilities: A nationally representative, longitudinal study.

Luca Swinford. Eugenic logic, parental capacity, and parents with intellectual/developmental disabilities in New York termination of parental rights cases, 2014–2021.

Heather Watkins & Linda Long-Bellil. A peer researcher model for qualitative research on the intersections of disability, pregnancy, and race and ethnicity.

Lauren Smith. Obstetric clinician perspectives on providing perinatal care to d/Deaf and hard-of-hearing people.



# COMMUNITY ENGAGEMENT

## *Selected lectures by Director, Monika Mitra*

Dr. Monika Mitra was invited to present at several international forums including a talk on Reproductive Health of Women with Intellectual & Developmental Disabilities: A Call to Action at the Sungkyunkwan University, Seoul, South Korea and the Korean Society for Disability Studies, Seoul, South Korea.

She also gave the keynote lecture on Eliminating Disparities in Sexual and Reproductive Health among People with Disabilities at the Disability Access and Inclusion Conference, Tata Institutes of Social Sciences, Mumbai, India.



# COMMUNITY PARTNERS

*Thank you to our advisory board members, lived experience experts, dissemination partners, and others who have partnered with the Lurie Institute.*

## **Advanced Rehabilitation Research and Training Postdoctoral Fellowship**

- Cheryl Cumings
- Colleen Flanagan
- Darian Gambrell
- Dennis G. Heaphy
- Bill Henning
- Jeff Keilson
- Colin Killick
- Jean-Luc Pierite
- Jessica Podesva
- Brenda Vezina
- Heather Watkins

## **National Center for Disability and Pregnancy Research**

- Samantha Crane
- Joanne (JoJo) Forbes
- Morénike Giwa-Onaiwu
- Charity Heukstedt
- Norma Moran
- Jennifer Senda
- Laura Stout
- Heather Watkins
- Robin Wilson-Beattie

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## **Study on Pregnancy Outcomes and Experiences of Deaf and Hard-of-Hearing Women**

- Sarah Arana
- Karen M. Duguid
- Timothy R. B. Johnson
- Kim Kelstone
- April Lyon
- Rosalyn Maben-Feaster
- Jamie L. Maes-Eishen
- Robert C. Nutt
- Adrianna Smart
- Joann (JoJo) Skowzgird Forbes
- Christa Williams
- Melissa Elmira Yingst

## **National Research Center for Parents with Disabilities**

- Earl Allen
- Judith Brown
- Patrick Cokley
- Morénike Giwa-Onaiwu
- Keith Jones
- Linda Long-Bellil
- Julie Petty
- Tana Pradia
- Jennifer Senda
- Morénike Scheduler
- Laura Stout
- Robert Walker
- Heather Watkins



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## **International Consortium of Research on Parents and Parenting with Disabilities**

- Marjorie Aunos
- Jimena Luna Benavides
- Susan Collings
- Karin van Doesum
- Maurice Feldman
- S.R. (Sander) Hilberink
- Gabrielle Hindmarsh
- Helen Leonard
- Gwynnyth Llewellyn
- Nomfundo Moroe
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- Margaret Spencer
- Kinuko Sugiura
- Emiko Tanaka

## **Community Living Equity Center**

- Andy Arias
- Bernard Baker
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- LaWanda Cook
- Melody Cooper
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- TJ Gordon
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- Valerie Novack
- Janie Mejias
- German Parodi
- Jean-Luc Pierite
- Elaina Seep
- Sherria Young-Smith

# COMMUNITY PARTNERS

## **2023 Carrie Buck Distinguished Fellowship**

- Colleen Flanagan
- Morénike Giwa Onaiwu
- Mia Ives-Rublee
- Monica Porter
- Heather Watkins

## **Disparities in Perinatal Care and Outcomes among Black Women and Latinas with Physical Disabilities**

- Nancy Garr-Colzie
- Maria Palacios
- Jennifer Senda
- Heather Watkins

## **Addressing Sexual and Reproductive Health Care Disparities and Barriers among Adolescents and Young Adults with Disabilities**

- Diana Cejas
- Quinn Donover
- Alix Herer
- Dominic Mondon-Poirier
- Brittany Orians
- Ian Watlington

## **Lurie Institute for Disability Policy**

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