Brandeis | THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT

Lurie Institute for Disability Policy

2024 Annual Report

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Welcome Letter from the Director

Dear Friends of the Lurie Institute for Disability Policy,

I am delighted to share the 2024 Annual Report for the Lurie Institute. Over the past year, we have continued to grow, innovate, and deepen our commitment to advancing disability policy. Below are some key highlights of our work in 2024.

We launched two interactive data dashboards—the Community Living Dashboard and the Parents with Disabilities Dashboard—to make disability data more accessible. Historically, data about people with disabilities have been difficult to find, navigate, and interpret. These dashboards provide advocates, policymakers, and researchers with user-friendly, visually engaging insights. Developed with direct input from disabled stakeholders, they are designed to be both practical and effective.

In September, the Community Living Policy Center (CLPC) began a five-year partnership with the University of Illinois Chicago's Family Support Research and Training Center (FSRTC). Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), this initiative will address critical gaps in family caregiving support, with a particular focus on aging, disability, and underrepresented families. In addition, CLPC has continued its research on two pressing issues: the direct care workforce shortage and the affordable housing crisis—both of which significantly impact community living and healthcare access. Our current work explores the experiences of direct care workers, focusing on strategies to improve recruitment and retention.

Recognizing the urgent need for more inclusive perinatal care, we received new funding from the National Institute of Child Health and Human Development to develop an online training program for obstetric providers. Through focus groups and interviews, we will identify key strategies to help providers recognize and address ableism in perinatal and postpartum care. The training will be tested with 200 providers to assess its impact on attitudes, clinical practices, and knowledge. This his five year research project is being conducted in collaboration with colleagues at Massachusetts General Hospital.

We are also thrilled to announce renewed funding from the NIDILRR for our National Center for Disability and Pregnancy Research. Over the next five years, in partnership with Oregon Health & Science University, we will continue our efforts to improve pregnancy and postpartum care for disabled people.

To support the next generation of disability policymakers, researchers, and practitioners, we launched the Student Fellowship in Disability Policy in 2019. This fellowship provides Brandeis undergraduate and graduate students with hands-on research training, allowing them to develop critical skills and deepen their understanding of disability policy. This year, we welcomed a new cohort of eight students.

None of this work would be possible without your support. Thank you for being part of our journey as we continue to advance disability rights, access, and justice.

With gratitude,

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

Who We Are

The Lurie Institute for Disability Policy, based at Brandeis University's Heller School for Social Policy and Management, is a leading research and education center dedicated to shaping policies, programs, and practices that improve the lives and well-being of people with disabilities.

Our work is organized into three core areas: Research and Policy, Education, and Mentorship, and Community Engagement, each playing a vital role in advancing disability equity and justice.

Research and Policy Work:

The Lurie Institute is home to four federally funded research centers, each led by nationally recognized experts in disability research and policy:

Community Living Policy Center

Community Living Equity Center

National Research Center for Parents with Disabilities

National Center for Disability and Pregnancy Research

Our research addresses critical issues such as poverty, unemployment, inequitable access to healthcare, discrimination, and community exclusion. Using both qualitative and quantitative methods, we generate data-driven insights to inform policies and programs. We collaborate with the disability community, advocacy organizations, policymakers, clinicians, and other stakeholders to ensure our research leads to meaningful, lasting change.

Education and Mentorship

Lurie Institute faculty and staff teach graduate and undergraduate courses on disability policy and provide mentorship opportunities at multiple levels. Our fellowships support the next generation of disability scholars and leaders:

- Student Fellowship in Disability Policy
- Hon. Jonathan Brant Endowed Doctoral Fellowship
- Lurie Postdoctoral Fellowship in Disability and Health Policy
- Carrie Buck Distinguished Fellowship

Community Engagement

Grounded in Disability Justice, our work is deeply collaborative. We partner with the disability community through our various advisory boards and partnerships with national and local community organizations to ensure our work centers the experiences of the most impacted. To make our work accessible, we produce plain language explainers of our research findings, host public talks and webinars, share our findings through social media, provide bilingual resources in English and Spanish, and partner with disability organizations to ensure our knowledge reaches and benefits the broader community.

Our Legacy

Founded in 2007 through a generous gift from the Nancy Lurie Marks Family Foundation, the Lurie Institute has spent 17 years conducting cross-disciplinary research on real-life issues affecting disabled people. Our work spans health and healthcare, parenting, home- and community-based services, and more—all with the goal of fostering a more just and equitable society.

2024 by the Numbers

16 Webinars

62 Conferences, Presentations, & Lectures

50+ Research Articles & Peer-Reviewed Publications

17 Conferences Attended

12 Reports & Briefs

12 Awards & Honors

Research & Policy

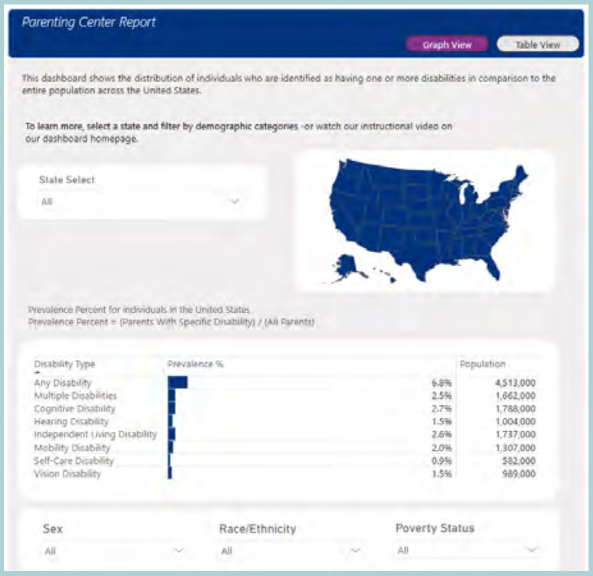
2024 Highlights

Launching Our Disability Data Dashboard

On December 3, 2024, International Day of People with Disabilities, we launched two data dashboards—two interactive tools designed to make disability data more accessible. Historically, data about people with disabilities and their experiences have been difficult to access, navigate, and understand. Our data dashboards offer a user-friendly solution, presenting key information in visually engaging and accessible formats for advocates, policymakers, and researchers. Developed with direct input from stakeholders with disabilities, the dashboards are designed to be both effective and accessible for the communities we serve. The two primary dashboards are

The Community Living Dashboard
The Parents with Disabilities Dashboard

By equipping advocates with easy-to-use, data-driven tools, we hope to further the rights, access, and inclusion of disabled people. Explore the dashboards at DisabilityDataDashboard.com.

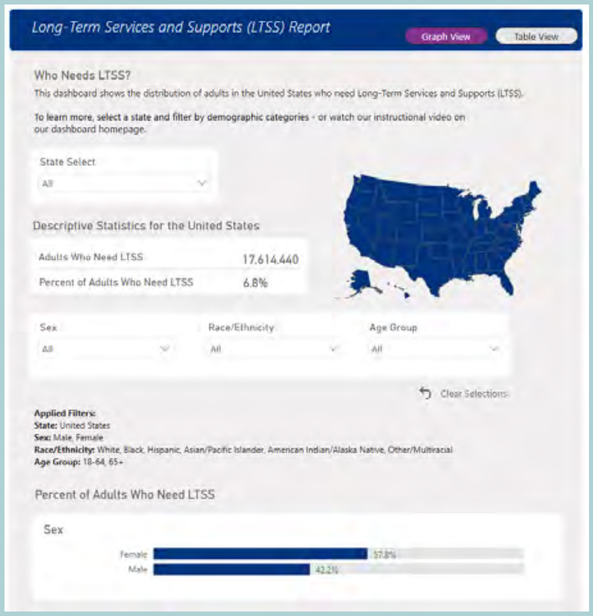


This dashboard shows the distribution of individuals who are identified as having one or more disabilities in comparison to the entire population across the United States.

To learn more, select a state and filter by demographic categories -or watch our instructional video on our dashboard homepage.

Prevalence Percent for individuals in the United States
Prevalence Percent = (Parents With Specific Disability) / (All Parents)

Disability Type	Prevalence %	Population
Any Disability	6.8%	4,513,000
Multiple Disabilities	2.5%	1,662,000
Cognitive Disability	2.7%	1,788,000
Hearing Disability	1.5%	1,004,000
Independent Living Disability	2.6%	1,737,000
Mobility Disability	2.0%	1,307,000
Self-Care Disability	0.9%	582,000
Vision Disability	1.5%	989,000



Who Needs LTSS?

This dashboard shows the distribution of adults in the United States who need Long-Term Services and Supports (LTSS).

To learn more, select a state and filter by demographic categories - or watch our instructional video on our dashboard homepage.

Descriptive Statistics for the United States

Adults Who Need LTSS	17,614,440
Percent of Adults Who Need LTSS	6.8%

Applied Filters:
State: United States
Sex: Male, Female
Race/Ethnicity: White, Black, Hispanic, Asian/Pacific Islander, American Indian/Alaska Native, Other/Multiracial
Age Group: 18-64, 65+

Percent of Adults Who Need LTSS

Sex

2024 Highlights

FSRTC

Family Support Research &
Training Center

Partnership Creates The Family Support Research & Training Center

In September 2024, the Community Living Policy Center (CLPC) launched a five-year partnership with the University of Illinois Chicago's Institute on Disability and Human Development's Family Support Research and Training Center (FSRTC). Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, the FSRTC will address critical gaps in family caregiving support systems, with a particular focus on aging, disability, and underrepresented families.

CLPC is leading two key research projects for the FSRTC: analyzing national datasets on family support and conducting policy research to improve family caregiving programs. The FSRTC will create a national resource center for families and caregivers, offering training, technical assistance, and evidence-based information to caregivers, healthcare professionals, and policymakers.

Advancing Equitable Perinatal Care for Disabled Women

Many obstetricians lack the training needed to provide quality care for disabled women, contributing to stark disparities in maternal and child health outcomes. Barriers such as inaccessible facilities, inadequate clinician education, and ableist attitudes disproportionately impact disabled women of color.

In 2024, we received new funding to address this gap by developing an online training program that helps obstetric providers recognize and combat ableism in perinatal and postpartum care. Through focus groups and interviews, we will identify key topics and effective teaching strategies to equip providers with the knowledge and tools needed to deliver inclusive, equitable care. This training will be tested with 200 obstetric providers, assessing its impact on attitudes, clinical practices, and knowledge.

This research study is funded by the National Institute of Child Health and Human Development and conducted in collaboration with colleagues from Massachusetts General Hospital. Additionally, we are also proud to partner with the American College of Obstetricians and Gynecologists (ACOG), who will help share this training with their members. Every pregnant person deserves a fair chance at a healthy pregnancy, and this project is a big step toward making that a reality.

ACOG
The American College of
Obstetricians and Gynecologists

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Lurie Institute for Disability Policy

2024 Highlights

National Center for Disability and Pregnancy Research: Securing Five More Years of Funding

We are thrilled to announce renewed funding from the National Institute on Disability, Independent Living, and Rehabilitation Research for our National Center for Disability and Pregnancy Research. This continued funding allows us to expand our work to ensure disabled people receive the perinatal care and support they deserve. In partnership with colleagues from Oregon Health and Science University, our work over the next five years will focus on five key objectives:

Analyzing national data to examine perinatal risks, care, and outcomes by disability status, type, and race/ethnicity.

Scaling up and testing the efficacy of a preconception education curriculum for women with mobility disabilities.

Developing and piloting an accessible online prenatal education program for Deaf pregnant people.

Investigating the impact of Medicaid coverage for doula care on perinatal experiences and outcomes for disabled people.

Establishing quality indicators and an e-learning module for mental health providers to improve perinatal mental health care for disabled women.

Community Living Policy Center

Funding provided by the National Institute on Disability, Independent Living, and Rehabilitation Research.

Research on Community Living Policy

The CLPC conducts research on the provision and quality of Home- and Community-Based Service (HCBS) programs for people with disabilities in the United States. The Center played a lead role in the implementation of the first standardized core set of HCBS quality measures and examined factors influencing direct care workforce compensation, which is essential for sustaining access to services for disabled people and their families. Researchers are leveraging Medicaid Claims Data (T-MSIS) to analyze individual-level characteristics of HCBS beneficiaries, with a focus on racial and ethnic disparities in access. The CLPC research team also conducted one of the first studies examining the relationship between person-centered planning and community living outcomes, such as community participation and personal autonomy. In collaboration with partner researchers, the CLPC has provided policy recommendations on implementing the HCBS Settings Rule, the role of social housing for disability access, and the importance of coordinated transportation systems in supporting community participation.

Upcoming Research on the Direct Care Workforce, Housing, and Olmstead

The CLPC is conducting several studies examining the impact of the direct care workforce shortage and the affordable housing crisis on community living and access to healthcare. A new study is underway to explore the experiences and perspectives of direct care workers, with a focus on identifying strategies for recruitment and retention. Additionally, partner researchers are investigating policy approaches, including the role of state Olmstead advocacy, in addressing the shortage of affordable, accessible housing for disabled people and older adults seeking to remain in their communities.

Research Briefs

Association of Person-Centered Planning with Improved Community Living Outcomes

Person-centered planning was linked to peoples' increased participation in the community, feeling more in control of their life, and satisfaction with how they spent their days.

The HCBS Settings Rule: Looking Back and Forging Ahead

Generally, when people have access to safe, reliable HCBS, they choose more integrated options that optimize their opportunities to interact in the community as they would like.

Beyond the Minimum: How Social Housing Can Fully Include Disabled People

As social-housing initiatives in the U.S. gain momentum, disabled people must understand their underlying structure and benefits and actively engage with critical stakeholders to center their economic, structural, design, and programmatic requirements.

Community Living Equity Center

Funding provided by the National Institute on Disability, Independent Living, and Rehabilitation Research.

Highlights

Community Living Data Dashboard

Accessing reliable data on community living services remains a challenge due to data quality concerns. The new Community Living Dashboard centralizes key information on who needs Long-Term Services and Supports (LTSS), who receives Medicaid LTSS, and existing disparities in access to Home and Community-Based Services (HCBS). The Community Living Data Dashboard is comprehensive, accessible, and designed for ease of use. Learn more: DisabilityDataDashboard.com

Peer & Community-Led Research

CLEC incorporates Disability Justice principles and adopts a Participatory Action Research (PAR) approach, recognizing that the knowledge gained from lived experience is essential to effective research. Through partnerships with Lived Experience Experts and peer researchers, CLEC generates new insights, develops systems-change initiatives, and serves as a national resource on community living.

National Thought Leaders

CLEC continues to serve as a national leader in community living and participatory research. Our team presented at four major conferences, sharing research on expanding access and inclusion: the National Conference on Self-Direction, the American Association on Intellectual and Developmental Disabilities conference, the National Council on Independent Living conference, and the HCBS (Advancing States) conference.

Webinars & Engagement

Our Lived Experience Experts partnered with the Reality Poets to host a screening and panel discussion on Fire Through Dry Grass, a documentary highlighting the community living advocacy of Black and brown disabled artists during the COVID-19 pandemic.

CLEC Director Teresa Nguyen participated in a panel discussion reflecting on key milestones in Olmstead policy and future directions to advance community living policy.

Implementing Elements of Effective Participatory Action Research

Selection

Choosing multiply marginalized people who have the skill and knowledge to navigate societal systems

Training

Education about how to practice research, collect and organize data, and share findings

Mentorship

Collaboration with existing researchers who can provide support and guidance as they develop skills and navigate projects

Payment

Compensation for lived experience shared and time spent performing research activities is essential

National Research Center for Parents with Disabilities

Funding provided by the National Institute on Disability, Independent Living, and Rehabilitation Research.

Highlights

Parents with Disabilities Dashboard

Approximately 7% of parents in the U.S. have a disability, yet the rights of disabled parents continue to be challenged. In 2024, we launched the Parents with Disabilities Dashboard to provide free, accessible, and user-friendly data on disabled parents and the state of their parental rights based on geographic location. Learn more at DisabilityDataDashboard.com

Conferences

Our focus on research on disabled parents has led to a number of conference presentations at the American Public Health Association Annual Meeting, where the Parenting Center team presented findings from their research on housing stability among disabled parents.

Legal Education

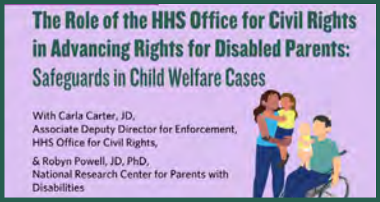
The Parenting Center is working to educate legal professionals about the rights of disabled parents as well as the biases that they face in the justice system. Linda Long-Bellil's presentation, Keeping families together: Training attorneys to use disability law to defend the rights of disabled parents involved in the child welfare system provided attendees with best practices to support disabled parents in legal proceedings.

Webinars & Trainings

In 2024, we conducted several webinars and training sessions aimed at enhancing understanding and support for disabled parents, providing professionals with the tools and knowledge necessary to better serve this community:

Living with Anxiety as a Disabled Parent

Moderator: Nicole Lomerson, MPH
Panelists: Judith Brown & Jenny Senda



The Role of the HHS Office for Civil Rights in Advancing Rights for Disabled Parents: Safeguards in Child Welfare Cases

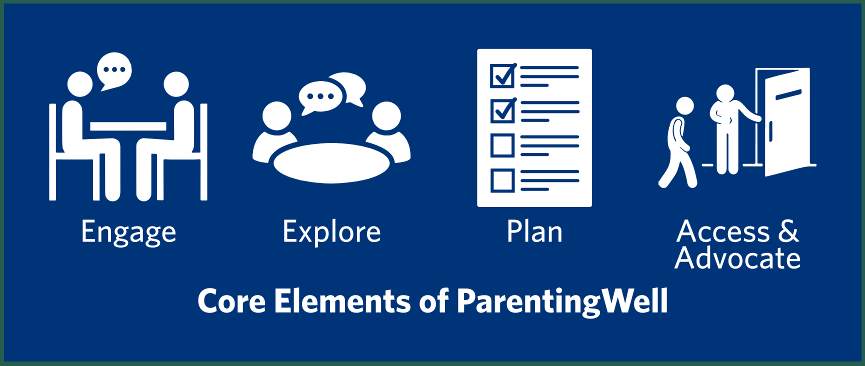
With Carla Carter, JD,
Associate Deputy Director for Enforcement,
HHS Office for Civil Rights,

& Robyn Powell, JD, PhD,
National Research Center for Parents with Disabilities

'I challenge them a bit': Encounters Between Parents with Disabilities and the Medical Institution in Chile

Speakers:
Florencia Herrera and Andrea Rojas
Wednesday, March 6, 2024
12:00pm ET
Heller 163 and via **Zoom**
Lunch will be provided

Expanding ParentingWell Use



Core Elements of ParentingWell

Our study, The ParentingWell Practice Approach: Facilitating implementation in U.S. adult mental health services, examined the early implementation of ParentingWell in Massachusetts. We found that coaching sessions and self-care practices were instrumental in supporting mental health practitioners in integrating family-focused care. Our findings underscore the need for continued training and institutional support.

National Center for Disability and Pregnancy Research

Funding provided by the National Institute on Disability, Independent Living, and Rehabilitation Research.

Highlights

Newly Funded Research

We are excited to announce that the Pregnancy Center has been awarded five more years of funding to further our overall goal of understanding the pregnancy-related experiences and outcomes of pregnant women with disabilities. This research includes investigating the impact of Medicaid coverage for labor and delivery doula care on disabled women, identifying key components of preconception health care for women with mobility disabilities, creating accessible prenatal care education for deaf and hard of hearing women, and developing quality indicators for perinatal mental health care for disabled women.

Outreach to Deaf and Hard of Hearing Community

As part of our recent dissemination efforts, we have focused on the deaf and hard of hearing (DHH) community. Through these efforts, we aim to raise awareness of the research conducted by our Pregnancy Center and enhance the health and well-being of DHH women during pregnancy and postpartum. Collaborating with Deaf researchers, advisory board members, and community leaders, we have created dissemination products in American Sign Language. Some key products include:

A video brief on our research on the increased risk for severe maternal morbidity (SMM) among DHH women.

A three-part video series with Estefani Arevalo from That Deaf Family discussing the joys and challenges of motherhood, the need for in-person interpreters at medical appointments, practical breastfeeding tips, and insights from an interview with another expectant Deaf mother.

Webinars

In 2024, we provided several webinars designed to equip healthcare professionals, researchers, and community leaders with the knowledge and tools needed to address the unique challenges faced by disabled women during pregnancy and postpartum:

Webinar

Addressing Perinatal Health Inequities Among Deaf and Hard of Hearing Individuals through Clinical, Research, and Community Insights

Tuesday, April 30 @ 12pm Eastern

Presented by Drs. Angela Earhart & Michael McKee
Moderated by Norma Morán

Pregnancy and Physical Disability:
A discussion for people with physical disabilities who are pregnant or thinking about pregnancy

Thursday, January 18, 2024
12:00 PM ET

Panelists:
Nicole Lomerson
Laura Stout

Research Findings of Note

We published several research papers that highlighted critical disparities and challenges faced by disabled women in pregnancy and postpartum care.

49% higher

The prevalence of unintended pregnancies among Non-Hispanic White with disabilities was 49% higher than among their counterparts without disabilities.

Women with cognitive and/or multiple disabilities experienced the greatest risk for poor preconception health among disabled women.

Women who are DHH experience heightened risk for Severe Maternal Morbidity (SMM) during delivery and postpartum compared to non-DHH women.

Ongoing Grants and Projects

Disparities in Perinatal Care and Outcomes Among Black People and Latina/xs With Physical Disabilities

As part of this National Institutes of Health-funded research project, four peer researchers–Black women or Latinas with lived experience of physical disabilities–conducted qualitative interviews with Black and Latina/x individuals with physical disabilities who had given birth in the last ten years. The peer researchers, alongside the Lurie research team, began qualitative analysis of the interview data. Additionally, the team developed materials for interviews with pregnancy care providers and performed quantitative analyses using state-level data from Massachusetts, California, and South Carolina. Their studies revealed critical disparities. One study found that Black individuals with physical disabilities faced a compounded risk of maternal mortality. Another found that Black, Latinx, and American Indian/Alaska Native mothers with disabilities had 10-16 times higher risk of assault-related hospital visits than White nondisabled mothers.

BIPOC moms with disabilities had **10-16x higher risk** of assault-related hospital visits than white nondisabled mothers

Addressing Sexual and Reproductive Health Care Disparities and Barriers Among Adolescents and Young Adults With Disabilities

In 2024, the research team for this National Institutes of Health-funded study continued developing interview materials for youth and young adults about sexual and reproductive health. Advisory Board members contributed by testing and revising the interview guide. The team also advanced work on an online sexual and reproductive health toolkit for adolescents and young adults, conducting an environmental scan of existing programs to identify gaps the toolkit could fill. The team developed manuscripts focused on the utilization of sexual and reproductive health services among female youth with and without disabilities, the utilization of sexual and reproductive health services among male youth with and without disabilities, and sexual experiences of female youth with and without disabilities.

Do you have a disability?

We want to know how you take care of your sexual health!

Brandeis University is doing a research study with young people with disabilities.

Scan the QR code to learn more:

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Lurie Institute for Disability Policy

Ongoing Grants and Projects

Developing Lived Experience Expert Research Frameworks

People with disabilities are often underrepresented in academia and research. They are frequently the subjects of studies rather than the ones leading them. This is especially true for disabled people of color. Drawing on themes from Disability Justice and Community-Based Participatory Research practices, we are using a peer researcher model for a qualitative study about pregnancy in Black women and Latinas with physical disabilities. The process is described in a journal article titled Inclusion of Black and Latina Parents With Physical Disabilities in a Qualitative Research Study: A Peer Researcher Training Model. This model differs from typical research practices because we contracted, trained, and compensated disabled people of color—who were not already working in academia—as peer researchers. This approach has shown notable benefits, including rapport with participants and robust analysis discussions. We hope that, through the development of this model, more research institutions will collaborate directly with marginalized disabled people and value the lived experience, knowledge, and expertise of the disability community.

Lurie Institute Served as Third-Party Evaluator for Crucial Disability Protection Program

The Massachusetts Disabled Persons Protection Commission (DPPC)

is a key independent state agency dedicated to protecting people with disabilities from abuse and neglect through investigation, oversight, public awareness, and prevention. The Lurie Institute served as a third-party evaluator reviewing the DPPC's data of reports of abuse and neglect made between 2020 to 2023.

Our evaluation team began with an analysis of the demographics of people with disabilities in Massachusetts included in DPPC’s database. We then compared this data with the broader population of people with disabilities in the state to assess whether DPPC was reaching a proportionate group of people. We also evaluated the effectiveness of the DPPC's processes, including the number of investigations conducted, the duration of these investigations, and the availability of evidence supporting their findings. Overall, our analysis concluded that the DPPC was meeting its targets and the needs of the disability community.

Selected Publications

Pregnancy

- Attitudes, beliefs, and assumptions of obstetric care clinicians regarding pregnancy care of women with intellectual and developmental disabilities.
- Wait, what? What's going on?— Pregnancy experiences of deaf and hard of hearing mothers who do not sign.
- Preconception health risks by presence and type of disability among U.S. women.
- Severe maternal morbidity and other perinatal complications among Black, Hispanic, and White birthing persons with and without physical disabilities.
- Intersectional inequities in maternal mortality: Examining the compounded risks for black birthing individuals with physical disabilities.

Parenting

- Experiences with and perceptions of the child welfare system during the perinatal period of mothers with intellectual and developmental disabilities.
- The impact of ableism on the sexual, reproductive, and parenting rights of people with intellectual disabilities.
- The ParentingWell practice approach: Facilitating implementation in U.S. adult mental health services.
- Child welfare system inequities experienced by disabled parents: Towards a conceptual framework.

Research Methods

- Inclusion of Black and Latina parents with physical disabilities in a qualitative research study: A peer researcher training model.
- Experiences of faculty and scientists with disabilities at academic institutions in the United States.
- A participatory action research project with people with disabilities and seniors in China during the COVID-19 pandemic.

Community Living Policy

- Unmet needs for long-term services and supports and associations with health outcomes.
- Self-directed home- and community-based services improve outcomes for family caregivers: A systematic review.
- Housing and long-term services and supports for people with intellectual or developmental disabilities from racially and culturally minoritized communities.
- Intersectional inequalities: How socioeconomic well-being varies at the intersection of disability, gender, race-ethnicity, and age.

Community Engagement

Conference Presentations

Pregnancy

- Perinatal Health and Outcomes at the Intersection of Physical Disability and Race or Ethnicity: A Retrospective Cohort Study.
- Accessible Pregnancy Action Plan.
- Maternal Health and Well-being: A Comparison Between Latina and White Mothers of Children with IDD.

Parenting

- “The System is Stacked Against Them”: Intersectional Oppression and Disabled Parents Involved with the Child Welfare System.
- Housing Stability for Disabled Parents in the United States: Estimates from American Community Survey Data.
- Institutional Ableism in Child Welfare: Insights from Attorneys Representing Disabled Parents.
- Preconception, Prenatal, and Postpartum Assault of Massachusetts Mothers with Physical Disabilities by Racial/Ethnic Background.
- Surveilling Disabled Parents and Their Children.

Research Methods

- Participatory Action Research to Advance Community Living Equity.
- Talking With and Talking Through: Disability Inclusive Qualitative Interview Strategies.
- People Power! Working towards Truly Inclusive Disability Community Research Partnerships.
- Pregnancy Experiences of Black and Latina Mothers with Physical Disabilities: A Peer Researcher Model.

Community Living Policy

- “I never got that before”: Explorations of the Long-Term Supports Coordinator Role in Managed Care for People Who Are Dually Eligible for Medicare and Medicaid.
- Psychotropic Utilization and Polypharmacy Among Adults with IDD: Residential Disparities Across Institutional-LTSS and HCBS During the COVID-19 Pandemic.
- HCBS Quality Measures and Stakeholder Engagement - The Medicaid Access Rule and HCBS Participant Rights.
- What Does Race and Culture Have to Do With Self-Direction?
- Dimensions of Person-Centered Planning in HCBS and Associated Social Inclusion Outcomes.

Select Conference Presentations

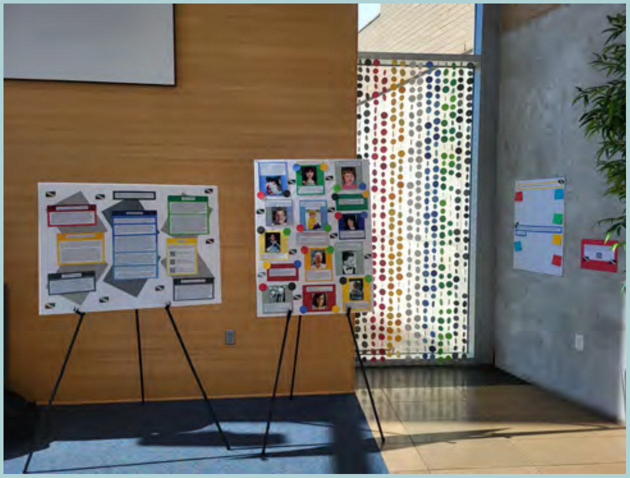
Joe Caldwell, Monika Mitra, and Teresa Nguyen at National Association of Rehabilitation Research and Training Centers conference

Jennifer Lee-Rambharose presenting at American Association on Intellectual and Developmental Disabilities conference

Jennifer Lee-Rambharose, Joseph Caldwell, Bevin Croft, Tim Jin, and Felix Guzman

Events and Webinars

Disability Day of Mourning



In March, the Heller School's Disability Working Group installed a week-long display to honor individuals with disabilities who were killed by family members and caretakers in the United States—a tragic act known as filicide.

At the heart of the display was a striking centerpiece of hanging paper circles, each bearing the names of one of the 200 victims from the Northeast. Some circles were intentionally left blank to represent those whose names and stories remain undocumented. The installation also highlighted photos and stories of victims from Massachusetts along with information and resources about Disability Day of Mourning.

Over the course of the installation, Brandeis staff, students, and faculty engaged with the display, deepening their understanding of the Disability Day of Mourning and the urgent need for justice for those we have lost.

#TeachDisabilityHistory - October 2024

The movement to integrate U.S. disability history in classrooms is gaining momentum. In October, representatives from Easterseals Massachusetts visited the Lurie Institute to discuss their educational campaign promoting disability history. This collaborative event fostered an exchange of knowledge between staff from the Heller School, Lurie Institute, and Easterseals. Together, we strengthened connections that will advance our shared commitment to education, accessibility, and a more inclusive future.

Easterseals Massachusetts presentation

Lurie Staff watches presentation hosted by Easterseals

Joe Caldwell and Kaitlin Stober chat with presenters

Public Lectures, Guest Talks, & International Lectures

In 2024, Dr. Mitra presented to disability researchers and advocates in Santiago, Chile and Valencia, Spain

In 2024, Dr. Monika Mitra engaged with disability researchers, advocates, and partners across the globe, strengthening international collaborations and advancing conversations on disability policy and research. She presented her work and connected with experts in Santiago, Chile and Valencia, Spain, fostering new partnerships and sharing insights on Disability Justice, health equity, and inclusive policy development. These engagements reflect the Lurie Institute's commitment to global dialogue and knowledge exchange in the field of disability research.

Dr. Mitra visits Universitat de València, Valencia, Spain

Dr. Mitra visits Pontificia Universidad Católica de Chile, Santiago, Chile.

Dr. Mitra visits Ministry of Health in Chile

Education and Mentorship

Carrie Buck Distinguished Fellowship

Each year, the Lurie Institute awards the Carrie Buck Distinguished Fellowship to a distinguished activist, scholar, or community organizer with disabilities whose work advances the intersection of disability and reproductive justice. This Fellowship honors Carrie Buck, the plaintiff in the infamous *Buck v. Bell* Supreme Court case, which upheld the involuntary sterilization of people with disabilities and had lasting repercussions on reproductive autonomy.

In 2024, we were honored to select Robin Wilson-Beattie as the Carrie Buck Distinguished Fellow. A dynamic speaker, writer, and advocate, Robin has transformed the landscape of sexual health education by challenging norms and empowering individuals to recognize and embrace their unique sexual identities. During her week-long residency at the Lurie Institute, she delivered insightful guest lectures and participated in a thought-provoking discussion with Rebecca Cokley (Ford Foundation) about her work and the broader field of disability and reproductive justice.

We are deeply grateful to the Ford Foundation for supporting this Fellowship and helping to amplify the voices of Disability Justice leaders.

Distinguished Fellow Robin Wilson-Beattie.

Robin Wilson-Beattie and Rebecca Cokley.

Lurie Student Fellowship in Disability Policy

As society's understanding of disability policy evolves, so do the research questions about the needs, experiences, and unmet needs of people with disabilities. Addressing these questions requires innovative approaches that consider disability as a social, political, cultural, and medical experience. To cultivate the next generation of disability policymakers, researchers, and practitioners, the Lurie Institute for Disability Policy created the Student Fellowship in Disability Policy in 2019. This fellowship offers Brandeis University undergraduate and graduate students with hands-on research training, allowing them to develop critical research skills and deepen their knowledge of disability policy. Our eight 2024-25 fellows work closely with established Lurie Institute investigators, engaging in research that addresses pressing policy issues and advances disability rights and justice. Through this program, students gain invaluable experience while contributing to meaningful change.

2024–25 Lurie Fellows with Mentors and Staff.

Back row from left to right: Tori Lajous, Sophie Glassman, Sam Larue, Elana Regan, Jeremy Evans, Ilhom Akobirshoev, Miriam Heyman, and Lauren Smith

Front row from left to right: Sydney Charron, Christina Waring, David Cahn, Monika Mitra, Janelle Mills, and Amy AbuShanab

Hon. Jonathan Brant Endowed Doctoral Fellowship

The Hon. Jonathan Brant Endowed Fellowship was established by Dr. Renee Tankenoff Brant ’68 in memory of Judge Jonathan Brant ’68, a Brandeis alumnus, Cambridge District Court judge, and tireless advocate for people with disabilities. This fellowship supports doctoral students affiliated with the Lurie Institute who are dedicated to disability research that addresses the complex challenges of disability policy and advocacy.

Arielle Papalimberis is the 2024-25 Honorable Jonathan Brant Endowed Fellow. As a research assistant at the Lurie Institute, she is working on two projects supporting parents with disabilities. Through this fellowship, Arielle is deepening her commitment to disability equity and inclusion, with a focus on ensuring that policies and programs are designed to support the rights and well-being of disabled individuals and families.

Arielle Papalimberis

Postdoctoral Fellowship in Disability and Health Policy

Our two-year Postdoctoral Fellowship is an innovative disability and health research program designed for emerging scholars committed to Disability Justice, social policy, and public health. The Fellowship provides mentorship, partnership, connections to the disability community, and advanced training in knowledge translation, scientific writing, and grant proposal writing. Fellows participate in research across a wide range of topics important to the disability community, such as access to healthcare and community-based services. In 2024, LuanJiao Aggie Hu, Dalton Stevens, and Weiwen Zeng continued their work as Lurie Postdoctoral Fellows, contributing valuable research and scholarship to the field.

Dr. LuanJiao Hu

Dr. LuanJiao "Aggie" Hu completed her two-year Fellowship in 2024. During her time at the Lurie Institute, she served as a peer reviewer for the Journal of Disability and Health, submitted manuscripts about disabled parenting, pregnancy, and disability to journals, and started and led a collaborative research project on immigrants with disabilities in the United States.

Dr. Dalton Stevens

In 2024, Dr. Dalton Stevens began his critical Switzer research on multiple cause of death data, age at death, and data error trends for people with varying disabilities. He also led studies on the sexual and reproductive health of girls and women with disabilities. Beyond his research, Dalton provides training to peer researchers involved in some of our studies.

Dr. Weiwen Zeng

In 2024, Dr. Weiwen Zeng completed his postdoctoral fellowship early and moved on to become an assistant professor at the University of Texas at Arlington. He continued his work at the Lurie Institute by collaborating with Dr. Miriam Heyman and her team at the National Research Center for Parents with Disabilities on a longitudinal study investigating maternal stress among mothers with intellectual disabilities and borderline intellectual functioning over a period of 15 years.

Lurie Scholars Awarded ACL Switzer Research Fellowships

We are thrilled that three Lurie Institute scholars—Dalton Stevens, Elad Daniels, and Ian Moura—have been awarded Switzer Research Fellowships. This prestigious program, funded by the Administration for Community Living, aims to strengthen research capacity by supporting highly qualified individuals, including those with disabilities, in advancing research on the rehabilitation and well-being of people with disabilities. We are proud of their achievements and look forward to the impact of their work on disability policy and practice.

Elad Daniels

Psychotropic Utilization in Medicaid Home and Community-Based Services for People With Intellectual and Developmental Disabilities.

Ian Moura

Examining the Impact of Algorithmic Decision-Making Tools on the Disability Community.

Dalton Stevens

U.S. Disability Mortality Trends Across Disability Status, Type, Sex, Race, and Ethnicity, 2017-2021.

Awards

Elad Daniels

- Merit Switzer Research Fellowship for Doctoral Dissertation Research
- Retirement and Disability Research Consortium Dissertation Grant

Jennifer Lee-Rambharose

- American Society on Aging RISE Fellowship

Ian Moura

- Robert Wood Johnson Foundation Health Policy Research Scholars Dissertation Award
- Merit Switzer Research Fellowship for Doctoral Dissertation Research
- APHA Disability Section Student Award
- Marjorie S. Trotter Doctoral Fellowship
- Heller School Teaching Assistant Award

Robyn Powell

- Association of American Law Schools 2024 Chai Feldblum Award, Section on Law Professors with Disabilities and Allies
- Yale Law Journal 2024 Emerging Scholar of the Year
- University of Oklahoma College of Law 2024 Order of the Coif

Dalton Stevens

- Switzer Research Fellowship for Post Doctoral Research

Acknowledgements

Our Staff

Faculty and Staff

Monika Mitra, Director and Nancy Lurie Marks Professor of Disability Policy
Amy AbuShanab, Associate Director for Administration and Engagement
Ilhom Akobirshoev, Senior Scientist and Director of Research
Laurin Bixby, Research Scientist
Joseph Caldwell, Senior Scientist and Director of the Community Living Policy Center
Maddie Crowley, Communications Specialist
Elad Daniels, Data Analyst
Mark Davis, Data Analyst
Miriam Heyman, Research Scientist
LuanJiao Aggie Hu, Postdoctoral Fellow
Jennifer Lee-Rambharose, Research Associate
Frank S. Li, Data Scientist I
Nicole Lomerson, Research Associate
Janelle Mills, Research Associate
Teresa Nguyen, Senior Research Associate and Director, Community Living Equity Center
Wendy Peverill-Conti, Senior Department Administrator
Sydney Pickern, Senior Research Associate
Robyn Powell, Senior Research Associate
Mel Ptacek, Communications Specialist
Ruby Siegel, Research Associate
Lauren Smith, Associate Director of Research Operations
Rajan Sonik, Associate Research Professor
Dalton Stevens, Postdoctoral Fellow
Ryan Suh, Graphic & Data Visualization Designer
Luci Swinford, Research Associate
Kimberly The, Senior Research Associate
Anne Valentine, Research Scientist
Marji Erickson Warfield, Senior Scientist
Weiwen Zeng, Postdoctoral Fellow

Visiting Scholars

Henry Claypool, Visiting Scholar
Taline Alonso Da Silva, Visiting Scholar
Joan Beasley, Visiting Scholar
Anjali J. Forber-Pratt, Visiting Scholar
Alex Green, Visiting Scholar
John Harris, Visiting Scholar
Dennis Heaphy, Visiting Scholar
Sonya Rudra, Visiting Scholar
Maggie Sheets, Visiting Scholar

Our Staff

Student Research Assistants

Natalie Chong
Fernanda Escobar
Sarah Jerome
Gabrielle Katz
Ebenezer Kwapong
Ian Moura
Kaitlin Stober
Kartik Trivedi
Michael (Mike) Vetter

Peer Researchers

Anne-Marie Gomes
Tyree Brown
Timotheus "T.J." Gordon Jr.
Sherria Young
Valerie Novack
Heather Watkins
Nancy Garr-Colzie
Maria Palacios
Jennifer Senda

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Ayesha Elaine Lewis
Renee Bracey Sherman

415 South Street MS 035
Waltham, MA 02453

This report was written by Madeline Crowley, Communications Specialist, and Eben Kwapong, Communications Intern. It was designed by Ryan Suh, our Graphic & Data Visualization Designer.