

Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT

Lurie Institute
for Disability Policy



2019

Lurie Institute for
Disability Policy

**ACHIEVEMENT
REPORT**

The Lurie Institute *for* Disability Policy



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 which improve the lives of people with disabilities across the lifespan. The Lurie Institute was created by a generous gift from the Nancy Lurie Marks Family Foundation in 2007. Over the past 13 years, we have conducted cross-disciplinary research on real-life issues affecting people with disabilities, including health and health care, parenting, home- and community-based services, and more.

Brandeis

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

A WORD FROM THE director

In 2019, the Lurie Institute for Disability Policy team continued to reflect our mission of ensuring equity for people with disabilities through our research, education, and community engagement projects. I am immensely proud to share this summary of the work our faculty, staff, and students have done to foster the inclusion, civil rights, and health of people with disabilities in the United States and worldwide.



Monika Mitra

Nancy Lurie Marks Associate
Professor of Disability Policy
Director, The Lurie Institute for
Disability Policy

faculty + staff



Monika Mitra
Director



Amy AbuShanab
Assistant Director



Ilhom Akobirshoev
Research Scientist



Joe Caldwell
Senior Scientist



Finn Gardiner
Communications
Specialist



Miriam Heyman
Senior Research
Associate



Sandy Ho
Research Associate



Frank Li
Research Associate



Eun Ha Namkung
Postdoctoral Fellow



Serah Nthenge
Postdoctoral Fellow



Wendy Peverill-Conti
Senior Department
Coordinator



Robyn Powell
Research Associate



Lauren Smith
Research Associate



Anne Valentine
Research Associate



Marji Erickson Warfield
Senior Scientist



Hussaini Zandam
Postdoctoral Fellow



Anne Womer
Research Project
Manager

Research

RESEARCH AT THE Lurie Institute

Research at the Lurie Institute spans a wide range of topics on the experiences and needs of people with disabilities, including health and health care, parenting with a disability, national and regional policies affecting people with disabilities, civic engagement, opioid use, community living, and caregivers' experiences. We maintain two major research centers, the National Research Center for Parents with Disabilities (NRCPD) and the Community Living Policy Center (CLPC). The Lurie Institute manages over \$10 million in funding from federal, local, and philanthropic grants to advance our mission.

Research Areas



Lurie Institute Research by the Numbers



15+

Peer-Reviewed
Journal Articles



10+

Policy Briefs



30+

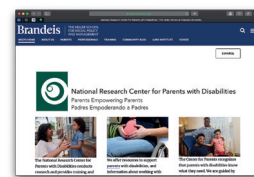
Posters and
Presentations

NATIONAL RESEARCH CENTER FOR parents with disabilities

The **National Research Center for Parents with Disabilities** (NRCPD) is a multi-year research program funded by the National Institute on Disability, Independent Living, and Rehabilitation Research designed to investigate the needs, challenges, and experiences of parents with disabilities. Our publications have covered multiple topics on parenting, reproduction, and disability, including pregnancy and childbirth, contraception, disabled parents' socioeconomic status, the needs of parents with intellectual and developmental disabilities, parents' experiences with the child welfare and legal system, and legal and community needs of parents with psychiatric disabilities. We work with an advisory board of parents with disabilities with extensive policy, advocacy, and legal expertise to ensure that our work prioritizes the needs of parents with disabilities.



National Research Center
for Parents with Disabilities



ParentingWell
PRACTICE PROFILE



To share our research with people with disabilities, practitioners, and the general public, we have created a bilingual website (centerforparentswithdisabilities.org) that offers information, training, and summaries of our research in English and Spanish. In addition to our research activities, we also provide technical assistance to researchers and service providers; hold webinars for self-advocates and practitioners, conduct trainings on disability, parenting, and the law for legal professionals; and offer a training framework, the ParentingWell® Practice Profile, for parents with psychiatric disabilities.

Facts and Figures from Our Research



Four out of five pregnant women with intellectual or developmental disabilities experience at least one birth complication.



Compared to parents without disabilities, parents with disabilities are more likely to be single parents, have fair or poor health, and have a high school education or less.



In 2019, Oregon passed a law protecting parents with disabilities from discrimination by courts, child welfare agencies, and adoption agencies. Alabama and Georgia also passed legislation to protect blind parents.



Parents with psychiatric disabilities reported benefiting from long-term, wide-ranging legal services, professional knowledge and understanding of psychiatric disabilities, and formal and informal community supports for themselves and their families.

COMMUNITY LIVING policy center



Community Living Policy Center

The **Community Living Policy Center**, or CLPC (communitylivingpolicy.org), focuses on the integration of people with disabilities and older adults in broader society, prioritizing three areas: home- and community-based service policies and programs, policy barriers and facilitators affecting community living and participation, and data and policy analyses that improve community living and participation.

The CLPC's projects address the transition of institutional residents from congregate sites to their communities; the provision of long-term services and supports for older adults and people with disabilities; and the impact of federal and state policies on the health, community integration, and overall wellbeing of people with disabilities and older adults. We collaborate with community advocacy organizations, including the Autistic Self Advocacy Network (ASAN) and the Disability Rights Education & Defense Fund (DREDF), to conduct our research and adapt it for policymakers, disability professionals, self-advocates, and the general public. Previously housed at the University of California–San Francisco, the CLPC moved to Brandeis University in 2018. The CLPC receives funding from the National Institute on Disability, Independent Living, and Rehabilitation Research.

Facts and Figures from CLPC Research

The Money Follows the Person program has helped over



95,000 people

return home from nursing homes and institutions. Findings from our research helped extend the program.

Autistic adults identified priorities for researchers studying community living policy and practice, including support for aging autistic adults, home-based services and supports, and accessibility.



Easy-read tools and resources helped state advocates implement a new federal regulation to increase access to home- and community-based services.



An expert workgroup's recommendations informed new federal legislation to improve housing, employment, transportation, and caregiver supports for older adults and people with disabilities.



SELECTED research projects



Civic Engagement and Philanthropy

In collaboration with the Ford Foundation and the Sillerman Center for the Advancement of Philanthropy at Brandeis University, we identified barriers to civic engagement for people with disabilities, and highlighted example cases of civic-engagement organizations developing disabled leaders and of disability organizations integrating civic engagement and leadership. We also developed recommendations for philanthropy and civic-engagement organizations to enhance disabled people's civic participation. In addition, we sought to address racial disparities in leadership among people with disabilities.



Pregnancy Outcomes and Experiences Among Deaf and Hard-of-Hearing Women

Women who are deaf or hard of hearing often encounter obstacles to receiving appropriate reproductive health services or information. This study—conducted in conjunction with the University of Michigan Medical School—intends to address these disparities through studies of national datasets, analyses of longitudinal health outcomes, a national survey, and structured interviews with deaf and hard-of-hearing mothers and the clinicians who work with them. This study will lead to a first-ever systematic understanding of pregnancy, infant health outcomes, and pregnancy costs for deaf and hard-of-hearing women.



INROADS (Intersecting Research on Opioid Misuse, Addiction, and Disability Services)

INROADS is a joint research program between Brandeis University's Institute for Behavioral Health and the Lurie Institute for Disability Policy that examines the intersection between addiction, disability, and service provision to address the rise of opioid use disorders among people with disabilities.



Understanding the Healthcare Needs and Experiences of Boston Children with Disabilities

This study uses data from the Boston Survey of Children's Health, a representative study of the health and wellbeing of children with disabilities, to examine children's healthcare access, service utilization, quality, and disparities among children with and without disabilities.

Education

DEVELOPING researchers + leaders

The Lurie Institute is dedicated to supporting a new generation of disability policy scholars through fellowships for undergraduates, doctoral students, and postdoctoral researchers; courses and seminars on disability, public policy, and public health; mentoring for students, recent graduates, and established researchers; and advising students who are working on their doctoral or master's theses.

Classes Taught by Lurie Faculty and Staff

In 2019, several Lurie Institute faculty and staff conducted classes, seminars, and guest lectures on salient topics related to disability and public policy, including reproductive health, disability law, intersectionality, data visualization, and community living policy.

Monika Mitra

Courses

Disability Policy (HSSP 128A)
Disability & Health Disparities Seminar (HS 607C)

Guest Lectures

Ableism in Sexual and Reproductive Health
Unconscious Bias and Disability-Related Disparities in Sexual and Reproductive Health
Integrating the Reproductive Rights of Women with Disabilities in Medical Curriculum
How I Lead: Reproductive Health, Rights, and Justice into Practice

Amy AbuShanab

Guest Lecture

Introduction to Data Visualization

Joe Caldwell

Guest Lecture

Community Living Policy for Individuals with Disabilities

Finn Gardiner

Guest Lectures

Intersectionality, Disability, Family, and the Community
Disability at the Intersections

Sandy Ho

Guest Lectures

Leadership in Disability Culture
Practicing Allyship: Intersectionality in our learning environments
Sociology of Disability
Access Is Love: Diversity & Inclusion
New Discourse in Disability Studies
Creating Access as Social Justice

Robyn Powell

Courses

Disability Law

Guest Lecture

Ensuring the Right to Parent with a Disability

Marji Erickson Warfield

Courses

Survey Research Methods (HS 407B)
Integrative Seminar on Health: Public Health in the U.S. (HSSP 110A)
Research Methods and Evaluation (HS 332A)
Child and Family Policy (HS 334A)



Mentoring and Advising

Lurie Institute faculty and staff supported postdoctoral fellows, PhD candidates, master's students, law students, undergraduates, and other scholars through active mentorship, advising, and degree supervision. While the majority of these mentees were students at Brandeis University, Lurie faculty and staff also mentored students at Boston University and the University of Illinois at Chicago.



Doctoral students photographed with Lurie Institute Director Monika Mitra

Monika Mitra

Postdoctoral



Irina Cain, Eun Ha Namkung, Serah Nthenge, and Hussaini Zandam

PhD



Robbie Dembo, Maia Hyary, Robyn Powell, and Kartik Trivedi

Master's



Annika Grassl

Other Mentorship



Linda Long-Bellil and Justine Wu

Ilhom Akobirshoev

Postdoctoral



Eun Ha Namkung and Irina Cain

PhD



Robbie Dembo, Marianne Pugatch, and Lyoung Hee Kim

Joe Caldwell

PhD



Caitlin Crabb
(University of Illinois at Chicago)

Robyn Powell

Degree Supervision



Maryrose Robson
(Boston University law student)

Marji Erickson Warfield

PhD



Sue Phillips, Heba Naim Ali, Milagros Ramirez, and Liam Honigsberg

Master's



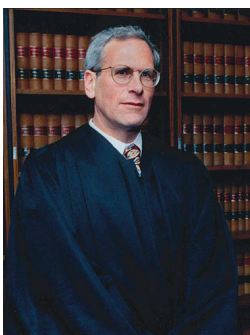
Tamayo Ishihara

Student Fellowships

Postdoctoral Fellowship

The Lurie Institute's Postdoctoral Fellowship is geared toward researchers who have recently completed a PhD in disability studies, sociology, public health, or related disciplines and want to use their expertise to conduct research that improves the lives and outcomes of people with disabilities and the people who support them. This program receives funding from the National Institute on Disability, Independent Living, and Rehabilitation Research.

Our fellows' research spans a variety of topics, including birth outcomes among women with disabilities, the interactions between people with disabilities and healthcare systems, social determinants of health, and prenatal and perinatal care for women with disabilities. In 2019, our postdoctoral fellows were Drs. **Irina Cain**, **Eun Ha Namkung**, **Serah Nthenge**, and **Hussaini Zandam**.



Judge Jonathan Brant



Robbie Dembo

Hon. Jonathan Brant Endowed Doctoral Fellowship

Named after Brandeis alumnus Judge Jonathan Brant, the Hon. Jonathan Brant Endowed Scholarship provides financial and academic support to Brandeis doctoral students working in disability policy.

The 2019-20 Brant Fellow is **Robbie Dembo**, a doctoral student and Lurie graduate research assistant. **Robyn Powell**, a doctoral student and Lurie research associate, was named the inaugural Brant Fellow in 2018.

Undergraduate Fellowship in Disability Policy

The Lurie Institute's Undergraduate Fellowship in Disability Policy provides undergraduate students at Brandeis the opportunity to gain research experience, learn about disability and public policy, and develop their skills to pursue a future career in disability policy.

The 2019-20 Fellows are **Carmela Belizaire, Anna Davidge, Shoshana Finkel, Maddy Pliskin, Jack Rubinstein, and Regina Tham**. The Spring 2019 cohort included **Julia Brown, Monika Chen, Shoshana Finkel, Shira Levie, Alanna Levy, Rachel Steinburg, Norma Stobbe, and Max Tang**.



2019-20 Undergraduate Fellows, pictured with Assistant Director Amy AbuShanab and Research Associates Robyn Powell and Lauren Smith



Spring 2019 Undergraduate Fellows

Student Research Assistants

Sasha Albert, Natalie Chong, Emily Crandall, Robbie Dembo, Annika Grassl, Lizbeth Hernandez, Jamie Jason, Gabrielle Katz, Jenny LaFleur, Thomas Moyers, and Kartik Trivedi

Student Spotlight



Shoshana Finkel, a Lurie Institute Undergraduate Fellow, co-authored a research poster with **Ilhom Akobirshoev** and **Monika Mitra** and presented it at the American Public Health Association's Annual Meeting in November 2019.

Robbie Dembo, the 2019-20 Brant Fellow, received the Best Student Abstract Award from AcademyHealth's Disability Research Interest Group. He also received the Best Poster award from the International Network for Social Network Analysis.



Doctoral student **Jenny LaFleur** received the Best Student Poster award from the AcademyHealth Disability Research Interest Group.



Research associate and master's student **Frank Li** completed his Master of Public Policy degree at the Heller School in 2019.



Community Engagement

LURIE INSTITUTE

community engagement

We firmly believe that research about real-life community issues should involve the communities we discuss in our work. We live out this principle through a robust community engagement program. Our community engagement activities have included interviews for public radio, websites, newspapers, and podcasts; panel presentations for local, national, and international policymakers; guest lectures from disability researchers and advocates; and sponsorship of events supporting the full inclusion of people with disabilities.

Community Engagement at the Lurie Institute



Guest Lectures



Interviews



Panel Discussions



Social Media



“ Parenting is one of our nation’s most fundamental rights. Nonetheless, it is not fully recognized for parents with disabilities. As a future mother with a disability, I cannot begin to tell you how terrifying this is. No one should have their parenting rights violated based on bias and speculation. ”

—ROBYN POWELL



“ The problem with subminimum-wage work is that it engenders stereotyping. It sends the message that if you are a worker with a disability who is deemed to be “less productive” than other members of society, then you are only worth being paid pennies on the dollar. ”

—FINN GARDINER

LURIE INSTITUTE

distinguished lectures

Our Distinguished Lectures provide an opportunity for researchers, advocates, activists, policymakers, and community members to learn together. Over the thirteen years of the Lurie Institute's existence, we have hosted policymakers, researchers, and disability advocates. In 2019, we hosted two guest lectures by Judy Heumann, a long-time disability rights activist and former State Department staffer; and Dr. Paul Shattuck, the director of the Life Course Outcomes Research Program at Drexel University's Autism Institute.



March 7, 2019

Judy Heumann

DISABILITY RIGHTS ACTIVIST, THE HEUMANN PROJECT

"The Journey to Achieving Equality:
Past, Present, and Future of Disability Activism"

“We need to be seeing ourselves as change agents, not just in disability, but in broader society.”

November 20, 2019

Paul Shattuck

DIRECTOR, LIFE COURSE OUTCOMES RESEARCH PROGRAM,
A.J. DREXEL AUTISM INSTITUTE, DREXEL UNIVERSITY

"Using Population Data to Inform Autism Policy in the U.S."

“If you want your work to have an impact, people have to know it exists.”



DISABILITY POLICY in the community

Throughout 2019, Lurie Institute faculty and staff shared our research, ideas, testimony, and experiences at community events, including state and federal hearings about disability policy, presidential candidates' question-and-answer sessions, awards dinners, media interviews, conferences, and more.



Lurie Institute Director **Monika Mitra** held a lecture on health literacy and clinical trials, “A Workshop on Health Literacy in Clinical Trials: Practice and Impact,” for the National Academies of Sciences, Engineering, and Medicine on April 11, 2019.



Lurie Institute Director **Monika Mitra** and Research Associate **Robyn Powell** attended a hearing at the Massachusetts State House on July 23, 2019, to provide expert testimony on the rights, experiences, and legal challenges faced by parents with disabilities.



The Lurie Institute sponsored a table at the Disability Policy Consortium's seventh annual awards dinner in October 2019. Assistant Director **Amy AbuShanab**, Research Project Manager **Anne Womer**, and Postdoctoral Fellows **Hussaini Zandam** and **Serah Nthenge** represented us at the event.

DISABILITY POLICY in the community



Research Associate **Sandy Ho** held an online town hall with presidential candidate Julián Castro on disability, public policy, and civic engagement on November 14, 2019. She is also the founder and lead organizer of the Disability Intersectionality Summit, a biannual conference that focuses on disability and its intersections with race, gender, class, culture, and more.

On November 25, 2019, Lurie Research Associate **Robyn Powell** appeared on WNYC's *The Takeaway* to discuss disability rights and employment policy, including fair pay for people with disabilities, systemic workplace discrimination, and ways to improve employment outcomes. She also conducted a roundtable on disability policy and health with graduate research assistant **Kartik Trivedi** at the American Public Health Association's annual meeting.



Lurie Communications Specialist **Finn Gardiner** addressed the U.S. Civil Rights Commission on November 15, 2019, to give testimony supporting fair wages for people with disabilities. Earlier in the year, he appeared on a panel at the United Nations' World Autism Day to discuss disability rights, policy, and advocacy.

COMMUNITY

partners + advisory boards

Organizations

ADvancing States
American Association of People with Disabilities
American Bar Association
American Council of the Blind
American Foundation for the Blind
Arc of the United States
Association of University Centers on Disabilities
Autism Women's and Nonbinary Network
Autistic Self Advocacy Network
Boston Center for Independent Living
Centene Corporation
Child Welfare League of America
Disability Policy Consortium
Disability Rights Education & Defense Fund
Employment Options, Inc.
Massachusetts Behavioral Health Partnership
Massachusetts Department of Mental Health
Massachusetts Bureau of Substance Addiction Services
MassHealth
Mental Health America
National Association of the Deaf
National Association of Social Workers
National Disability Rights Network
Psychiatric Rehabilitation Association
Topeka Independent Living Resource Center
Washington Division of Behavioral Health and Recovery
Washington Research and Data Analysis
Washington State Independent Living Council

People

Elizabeth Bostic
Lydia X.Z. Brown
Reid Caplan
Nikki Cherry
Henry Claypool
Kim Connor
Susan Connors
Jess Cuculick
Cheryl Cumings
Deborah Delman
Maryanne Frangules
Morénike Giwa-Onaiwu
Jill Hatcher
Melinda Haus
Dennis Heaphy
Barbara Herbert
Kevin Irvine
Julie Kegley
Jeff Keilson
Erin Krebs
Jennifer Lee
Linda Long-Bellil
Mike McKee
Spencer Milo
Mike Oxford
Susan Parish
Julie Petty
John Pirone
John Piselli
Tammy Rayess
Lisa Razzano
Roxanne Reddington-Wilde
Carmen Rosado
Roslynn Rubin
Mark Salzer
Leo Sarkissian
Nicole Lomerson
Shickling
Jennifer Senda
Denise Simon
Laura Stout
Susan Vaughan
Heather Watkins
Anne Whitman

acknowledgments

The Lurie Institute for Disability Policy would like to acknowledge funding support from:

Nancy Lurie Marks Foundation
Administration for Community Living
Deborah Munroe Noonan Memorial Research Fund
Ford Foundation
Massachusetts Department of Public Health
National Institute on Disability, Independent Living, and
Rehabilitation Research
National Institutes of Health—Eunice Kennedy Shriver National
Institute of Child Health and Human Development
Office of Minority Health

We are also grateful to Dean David Weil of the Heller School for Social Policy and Management and our Heller School colleagues for their unwavering support of our work.

Disclaimer

The contents of this report reflect the views of the authors and not our funders.



The Lurie Institute for Disability Policy

 lurie.brandeis.edu

 lurie@brandeis.edu

 [@LurieInstitute](https://twitter.com/LurieInstitute)

 facebook.com/LurieInstitute