2018

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 was created in 2007 with a generous gift from the Nancy Lurie Marks Family Foundation.

Visit our website at lurie.brandeis.edu
our year in review.

...a vibrant institute that uses a participatory approach with people with disabilities, researchers, clinicians, community based organizations, policymakers, undergraduates, graduate students and postdoctoral fellows to provide the critically needed research and policy support for the many issues facing people with disabilities, and their families.

Dean David Weil, Heller School

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23 Peer Reviewed Publications

48% People of Color
24% People with Disabilities

56 Presentations

Exploration

We conduct groundbreaking research that informs policies critical to the health and well-being of millions of people with disabilities in the United States and globally.

Partnership

Lurie has fostered new partnerships with over 10 local and national organizations in 2018, fostering real change in the community.

Mentorship

We are committed to developing the next generation of researchers. In addition to established graduate and postdoctoral mentorships, we’ve created a new undergraduate program.
I’m so pleased to share this summary of the 2018 activities and accomplishments of the Lurie Institute for Disability Policy. Our team’s research and publications bridge the lived experiences of disabled people with policymakers, service providers, and community leaders at the local, state, national, and global levels.

While our staff has grown and our Institute is thriving, we remain grounded in our mission of advancing a more equitable society for people with disabilities and their families.

Monika Mitra
RESEARCH
FUNDING, PUBLICATIONS, PRESENTATIONS

In 2018, the Lurie team worked to shape the national conversation concerning disability policy by publishing more than 23 peer-reviewed papers and 13 policy briefs, and by engaging in 56 presentations and conducting 7 webinars. These publications have appeared in a wide range of leading journals. The Lurie Institute manages research associated with over $10 million in funding from over fifteen grants, partnering with numerous research centers, academic institutions, disability policy and advocacy organizations, and disabled people from across the US and many countries around the world.

Sources of Funding

NIH: 54%
NIDILRR: 28%
Other: 18%

Looking Back at 2018...

EXPANDED AREAS OF STUDY

Community Living Policy Center with the Administration for Community Living

Health Care Needs of Boston Children with the Deborah Munroe Noonan Memorial Research Fund

Shared Living for Youth Transitioning to Adult Services with the Deborah Munroe Noonan Memorial Research Fund

Application of ADA in Child Welfare with the Brandeis Provost Office

Youth Transitioning to Independent Living with the Switzer Research Fellowship by NIDILRR

Legal Supports for Parents with Psychiatric Disabilities with Temple University

Intersecting Research on Opioid Misuse, Addiction, and Disability Services a joint research program between Brandeis University’s Institute for Behavioral Health and the Lurie Institute


REPORTS/ BRIEFS


Powell, R.M. (2018). What foster care and adoption agencies have to do when working with parents with disabilities.

Powell, R.M. (2018). What makes breastfeeding easier or harder for mothers with physical disabilities in the United States?

Powell, R.M. (2018). The legal obligations of foster care and adoption agencies when working with prospective parents with disabilities.


PRESENTATIONS


Cain, I. (September 2018). Pearls, possibilities, and pitfalls: writing successful grants and manuscript submissions. ACRM Annual Conference, Dallas, TX.

Cain, I. (September 2018). Predictors for postsecondary residential status. American Congress of Rehabilitation Medicine Annual Conference, Dallas, TX.

Cain, I. (September 2018). Impact of cultural and economic differences on disability labeling. American Congress of Rehabilitation Medicine Annual Conference, Dallas, TX.


Dembo, R. & LaFleur, J. (June 2018). The ecology of exclusion: Community health contexts and suspensions of students with disabilities. AcademyHealth, Seattle, WA.


Mitra, M., Mckee, M., & Akobirshoev, I. (September 2018). Maternal characteristics, pregnancy complications, and birth outcomes among Massachusetts women who are deaf or hard of hearing. CityMatCH Leadership and MCH Epidemiology Conference, Portland, OR.


Namkung, E. (June 2018). Differential quality of relationships aging parents have with their adult child with and without intellectual and developmental disabilities. Academy Health Annual Research Meeting Disability Interest Group Pre-Conference, Seattle, WA.


Nicholson, J. & Valentine, A. (May 2018). Family-focused parent peer supports in the USA. Think Family Symposium, Health and Social Care Board and Queen’s University, Belfast, Northern Ireland.


Powell, R.M. (June 2018). Best practices for teaching social workers about working with parents with intellectual and developmental disabilities. The American Association on Intellectual and Developmental Disabilities Annual Conference, St. Louis, MO.


ENGAGEMENT
EVENTS, COMMUNITY PARTNERSHIPS, MEDIA

The Lurie Institute has informed and expanded the local community’s understanding of issues facing people with disabilities through lectures, films, forums, panel discussions, and webinars. Through the creation of websites, social media campaigns, and online videos, the Lurie Institute has shared relevant research findings and best practices directly to people with disabilities, their families and caregivers, as well as to local and national disability advocacy and policy organizations.

The Lurie Institute’s presentations have spanned the US and beyond.

Changing the narrative through...

Being a disabled woman is an important part of who I am, and it is not something I am ashamed of. It’s time nondisabled people realize that too.

Robyn Powell, Research Associate, published in Rewire

1,000+ Social Media Posts
Lurie and The Center for Parents disseminated findings and engaged with SM users.

24 Media Articles +
10 Media Mentions
Lurie staff published articles and were quoted in:
- Rewire
- Huffington Post
- ABC News
- Vice News
- Newsweek
- WPR

7 Webinars + 5 Events
Lurie featured the voices of parents with disabilities, students with disabilities, social workers, disability policy lawyers, policymakers, and researchers.

9 New Community Partnerships
Lurie’s new Community Living Policy Center has ensured leadership of people with disabilities in research action.

The erasure of disabled people is one of the most common international crimes against humanity.

Sandy Ho, Research Associate, published in Bitch Media
BRANDEIS EVENTS

Deis Impact Festival of Social Justice Film Screening and Panel Discussion
*Sound and Fury*
February, 2018. Brandeis University. [Co-sponsored]

Performance and Discussion
Nataly Zukerman
*The Other Body*
March, 2018. Brandeis University. [Co-sponsored]

Lurie Institute Lecture
Marsha Mailick, PhD.
*Aging and Autism: Changes in the Autism Behavioral Phenotype and Health*
April, 2018. Brandeis University.

Lurie Annual Distinguished Lecture
U.S. Senator Tom Harkin (retired)
*True Integration: Meaningful Work for People with Disabilities*

Beyond Inclusion: Disability, Empowerment, and Intersectionality at Heller
A panel conversation honoring the UN international day of people with disabilities
December, 2018, Brandeis University, Waltham, MA [Co-sponsored].

EXTERNAL EVENTS

AcademyHealth, Disability Research Interest Group annual research meeting, June 2018. Seattle, WA.


Disability & Intersectionality Summit, October, 2018. Boston, MA.

Worcester Recovery Center and Hospital (WRCH) Deaf Mental Health Symposium, October, 2018. Worcester, MA.

The Arc of Massachusetts, Older Caregivers Forum, October, 2018. Waltham, MA.

American Public Health Association, Disability Section Business Meeting, November, 2018. San Diego, California

MEDIA ARTICLES


Powell, R.M. (2018, March 23). The FDA won’t ban electric shock on adults & kids with disabilities, & these activists are determined to change that. *Romper.*


Powell, R.M. (2018, April 10). Disabled women’s equal pay struggles often go unheard—but you can help include them. *Bustle.*

Powell, R.M. (2018, May 1). No, Donald Trump, the Paralympic Games are not ‘tough to watch.’ *Huffington Post.*


Powell, R.M. (2018, September 4). Wednesday’s lawsuit is Republicans’ next chance to gut the ACA—But it won’t be their last. *Rewire.News.*


**MEDIA MENTIONS**

**Monika Mitra** was quoted in the following:


**Robyn Powell** was quoted in the following:


**AWARDS/HONORS**

Cain, I. NIDILRR ARRT Fellow in the Young Investigators Symposium for the 2018 American Congress of Rehabilitation Medicine meeting

Dembo, R. Duke University Social Networks and Health Fellowship, 2018–2019

Dembo, R. AcademyHealth Disability Research Interest Group (DRIG) Best Student Presentation, 2018


Mitra, M. Invited to Advisory Council, Disabled Persons Protection Commission, Sexual Assault Response Unit, Advisory Council, 2018–Present

Powell, R. M. Disability Section Student Award, American Public Health Association, 2018

Powell, R. M. Hon. Jonathan Brant ’68 Fellowship, 2018

Powell, R. M. Student/Early Career Professional Scholarship, American Association on Intellectual and Developmental Disabilities, 2018

**NEW PARTNERSHIPS**

**Community Living Policy Center**

Association of University Centers on Disabilities (AUCD)

Autistic Self Advocacy Network (ASAN)

Disability Rights Education & Defense Fund (DREDF)

Disability Policy Consortium (DPC)

Centene Corporation

National Association of States United for Aging and Disabilities (NASUAD)

National policy expert, Henry Claypool

Topeka Independent Living Resource Center

University of California San Francisco (UCSF)
MENTORSHIP
FELLOWSHIPS, EMPLOYMENT, TEACHING

A central mission of the Lurie Institute is the education and development of students who will shape the future of disability policy through their research, advocacy, and teaching. In 2018, faculty and senior researchers mentored future disability policy researchers at the postdoctoral, doctoral, masters, and undergraduate levels, and taught numerous classes on and off campus. We advised students through their research and meaningful work at the Institute, and established the Hon. Jonathan Brant Endowed Fellowship to support dissertations and policy advocacy.

100%
Lurie staff engaged with undergrad/grad level student workers

6
Classes on disability policy, disability law, and disability activism

4
Doctoral students employed as Graduate Research Assistants

Looking forward to 2019...

Lurie’s impact will only continue to grow as we approach the close of the decade. Today, more than ever, we are committed to conducting research that helps shape policies, programs, and practices which improve the lives of people with disabilities across the lifespan.

Establish Starr Fellowship program, providing 8 undergraduates with direct research experience

Continue expansion of scope of research to global sphere

Contribute to Brandeis’s disability education program through multiple new courses

Collaborate with advocates and philanthropy to strengthen civic engagement in the disability community

I’m proud to combine my lived experience as a person with a disability and my professional expertise as a researcher and advocate to help advance disability rights at the Lurie Institute.

Finn Gardiner, Research Associate
MENTORSHIP

Postdoctoral Fellows

Irina Cain, PhD
Research area: Identifying services and practices associated with postsecondary quality of life
Lurie role: Mitra, Primary Advisor, 2017-present

Eun Ha Namkung, PhD
Research area: Intergenerational relationships in families of adults with disabilities
Lurie role: Mitra, Primary Advisor, 2018-present

PhD Students

Tara Casebolt, MSW, MPH
Doctoral Student, Gillings School of Public Health, UNC Chapel Hill
Research area: sexual, reproductive health, women with disabilities, Global South
Completed: Anticipated 2021
Lurie role: Mitra, Committee Member: 2018-Present

Robbie Dembo, MA
Research area: Health, social, and economic outcomes for families with children with developmental disabilities; Disability and barriers to work
Completed: Anticipated 2020
Lurie role: Mitra, Mentor, 2017-present

Maia Hyary, MPA
Dissertation: The impact of food insecurity on gender roles in the household
Completed: Anticipated 2019
Lurie role: Mitra, Committee Member, 2017-present

Susan Phillips, JD
Dissertation: Family & communities ties foster care in Connecticut -- the first year: Foster parent commitment and other outcomes for youth
Completed: Anticipated 2019
Lurie role: Parish, Committee Chair, 2013; Warfield, Committee Chair, 2014–present

Robyn Powell, MA, JD, Lurie Doctoral Fellow
Completed: Anticipated 2019
Lurie role: Parish, Committee Chair, 2016–present; Mitra, Committee Member, 2016–present

Kartik Trivedi, MPA
Research area: workplace inclusion, career pathways, and economic self-sufficiency as related to persons with disabilities
Completed: Anticipated 2023
Lurie role: Mitra, Mentor, 2016–present

Anne Valentine, MPH
Research area: Mental health and substance abuse services research; healthcare disparities; social and behavioral determinants of health status; behavioral economics and obesity
Completed: Anticipated 2020
Lurie role: Mitra, Mentor 2017-present

Master’s Students

Finn Gardiner, BA
Area of interest: Public Policy
Completed: 2018
Lurie role: Mitra, Faculty Advisor 2016–present

Annika Grassl, BA
Area of interest: Sustainable International Development
Completed: Anticipated 2019
Lurie role: Mitra, Mentor 2017-present
EMPLOYMENT

**Staff**

Monika Mitra, PhD, Director, Nancy Lurie Marks Associate Professor  
Amy AbuShanab, Assistant Director  
Ilhom Akobirshoev, PhD, MSW, Research Scientist  
Joe Caldwell, PhD, Senior Scientist  
Marji Erickson Warfield, PhD, Senior Scientist  
Irina Cain, PhD, Postdoctoral Fellow  
Finn Gardiner, MPP, Research Associate  
Eun Ha Namkung, PhD, MSW, Postdoctoral Fellow  
Sandy Ho, Research Associate  
Frank Li, MS, Research Associate II  
Kerry Patenaude, MS, Research Associate  
Wendy Peverill-Conti, MPA, Senior Department Coordinator  
Robyn Powell, MA, JD, Research Associate  
Lauren Smith, MPH, Research Associate  
Christine Thielman, Senior Communications Specialist  
Anne Valentine, MPH, Research Associate

**Students**

**Graduate Research Assistants**  
Robert Dembo  
Annika Grassl  
Lizbeth Hernandez  
Lyoung Kim  
Jennifer LaFluer  
Jacqueline Lewy  
Kartik Trivedi  
Morgan Shields

**Undergraduate Office Assistants**  
Jamie Jason  
Jennifer Manzano  
Delaney Palma  
Lucy Pugh-Sellers
A glimpse into Lurie Institute Centers

Lurie is home to two major centers: The National Research Center for Parents with Disabilities, established at Lurie in 2016, and the Community Living Policy Center, established at Lurie in 2018.

National Research Center for Parents with Disabilities

Conducts research and provides training and technical assistance to improve the lives of parents with disabilities and their families.

centerforparentswithdisabilities.org

- Our website is published in both Spanish and English, expanding the reach of impact to diverse audiences.
- Quarterly webinars engage parents with disabilities, social workers, attorneys.
- Our interactive and comprehensive website provides an online hub of resources for parents, practitioners, and advocates.

Community Living Policy Center

Supports and develops policies and practices that help people with disabilities of all ages live at home, in their communities, rather than in institutions.

communitylivingpolicy.org

- Policies which promote home and community-based services.
- Reducing barriers to community-based services, such as long wait lists and lack of appropriate housing.
- Rapid, timely data analysis used to inform policy recommendations.