

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

BRANDEIS UNIVERSITY

The Heller School

FOR SOCIAL POLICY AND MANAGEMENT

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.

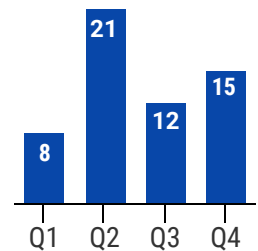
Dean David Weil, Heller School



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.

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A Word from the Director

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

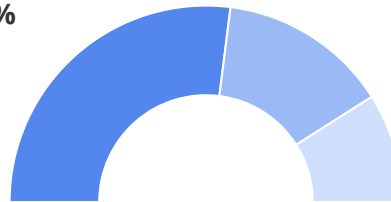
In 2018, the Lurie team worked to **shape the national conversation** concerning disability policy by publishing more than 23 peer-reviewed papers and 13 policy briefs, and by **engaging** in 56 presentations and conducting 7 webinars. These publications have appeared in a wide range of **leading** journals. 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

PUBLICATIONS

Akobirshoev, I., Mitra, M., Parish, S., Moore Simas, T.A., Dembo, R., & Ncube, C. N. (2018). Racial and ethnic disparities in birth outcomes and labour and delivery-related charges among women with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*.

Clements, K.C., Mitra, M., Zhang, J., & Iezzoni, L.I. (2018). Antenatal hospital utilization among women at risk for disability. *Journal of Women's Health*.

Crossman, M.K., Parish, S., Hauser-Cram, P., & Warfield, M.E. (2018). The influence of early intervention, informal support and the family environment on trajectories of competence for fathers raising children with developmental disabilities. *Research in Developmental Disabilities*.

Crossman, M.K., Warfield, M.E., Kotelchuck, M., Hauser-Cram, P., & Parish, S. (2018). Associations between early intervention home visits, family relationships and competence for mothers of children with developmental disabilities. *Maternal and Child Health Journal*.

Dembo, R. S., Mitra, M., & McKee, M. (2018). The psychological consequences of violence against people with disabilities. *Disability and Health Journal*.

Eagan, T.J., Teshale, S., Herrera-Venson, A.P., Ordway, A., & Caldwell, J. (2018). Participation in two evidence-based falls prevention programs by adults aging with a long-term disability: Case-control study of reach and effectiveness. *Journal of Aging and Health*.

Floyd, F.J., Mailick, M.R., Greenberg, J.S., Namkung, E.H., & Song, J. (2018). Families at midlife. *APA Handbook of Contemporary Family Psychology*.

Li, H., Mitra, M., Wu, J. P., Parish, S.L., Valentine, A., & Dembo, R.S. (2018). Female sterilization and cognitive disability in the United States, 2011–2015. *Obstetrics & Gynecology*.

Mitra, M., Akobirshoev, I., Clements, K., Parish, S. L., & Zhang, J. (2018). Antenatal hospitalization among US women with intellectual and developmental disabilities: A retrospective cohort study. *American Journal on Intellectual and Developmental Disabilities Research*.

Mitra, M., Akobirshoev, I., Rosenthal, E. & Moore-Simas, T.A. (2018). Postpartum hospital utilization among Massachusetts women with intellectual and developmental disabilities: A retrospective cohort study. *Maternal and Child Health*.

Mitra, M., Long-Bellil, L., & Powell, R. M. (2018). Public health ethics relating to persons with disability. In J. Kahn, N. Kass & A. Mastroianni (Eds.). *Oxford handbook of public health ethics*, Oxford: Oxford University Press.

Namkung E.H., Greenberg, J.S., Mailick M.R., & Floyd, F.J. (2018). Lifelong parenting of adults with developmental disabilities: Growth trends over 20 years in midlife and later life. *American Journal on Intellectual and Developmental Disabilities*.

Nicholson, J., & Valentine, A. (2018). Defining “Peerness”: Developing peer supports for parents with mental illnesses. *Psychiatric Rehabilitation Journal*.

Parish, S.L., Son, E., Powell, R.M., & Igdalsky, L. (2018). Reproductive cancer treatment hospitalizations of US women with intellectual and developmental disabilities. *Intellectual & Developmental Disabilities*.

Powell, R.M., Mitra, M., Smeltzer, S.C., Long-Bellil, L.M., Smith L.D., Rosenthal, E., & Iezzoni, L. (2018). Adaptive parenting strategies used by mothers with physical disabilities caring for infants and toddlers. *Health and Social Care in the Community*.

Powell, R.M., Mitra, M., Smeltzer, S.C., Long-Bellil, L. M., Smith, L. D., & Rosenthal, E. S. (2018). Breastfeeding among women with physical disabilities in the United States. *Journal of Human Lactation*.

Sannicandro, T., Parish, S.L., Fournier, S., Mitra, M., & Paiewonsky, M. (2018). Employment, income, and SSI effects of postsecondary education for people with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*.

Smeltzer, S.C., Mitra, M., Long-Bellil, L. M., Iezzoni L.I., & Smith, L.D. (2018). Obstetric clinicians' experiences and educational preparation for caring for pregnant women with physical disabilities: A qualitative study. *Disability and Health Journal*.

Sonik, R.A., Parish, S.L., Mitra, M., & Nicholson, J. (2018). Parents with and without disabilities: Demographics, material hardship, and program participation. *Review of Disability Studies*.

Sonik, R.A., Parish, S. L., Mitra, M. (2018). Inpatient Medicaid utilization and expenditure patterns after changes in Supplemental Nutrition Assistance Program benefit levels. *Preventing Chronic Disease*.

Warfield, M.E., Adams, R.S., Ritter, G., Valentine, A., Williams, T.V., & Larson, M.J. (2018). Health care utilization among children with special health care needs in military families. *Disability and Health Journal*.

Woodman, A.C., Demers, L.B., Crossman, M.K., Warfield, M.E., & Hauser-Cram, P. (2018). The influence of Part C early intervention dosage levels on growth in adaptive skills through adolescence. *Early Childhood Research Quarterly*.

Wu, J.P., Zhang, J., Mitra, M., Parish, S.L., & Reddy, G.K. (2018). Provision of moderately and highly effective reversible contraception to women with intellectual and developmental disabilities: Evidence from the Massachusetts All-Payer Claims Database. *Obstetrics & Gynecology*.

REPORTS/ BRIEFS

Gardiner, F. (2018). Advice and information for professionals working with parents on the autism spectrum.

Gardiner, F. (2018). Advice for professionals working with parents with intellectual disabilities.

Mitra, M., Long-Bellil, L.M., Iezzoni, L.I., Smeltzer, S.C., & Smith, L.D. (2018). Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy.

Mitra, M., Long-Bellil, L.M., Iezzoni, L.I., Smeltzer, S.C., & Smith, L.D. (2018). Self-Advocacy tips for pregnant women with physical disabilities.

Powell, R.M. (2018). Representing parents with disabilities: 10 tips for attorneys.

Powell, R.M. (2018). Changes in state legislation to protect the rights of parents with disabilities.

Powell, R.M., Mitra, M., Smeltzer, S.C., Long-Bellil, L.M., Smith, L.D., Rosenthal, E., & Iezzoni, L.I. (2018). Facilitators and barriers to breastfeeding among mothers with physical disabilities in the United States.

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.

Powell, R.M. (2018). Strengths and benefits of parenting with a disability.

Smeltzer, S.C., Mitra, M., Long-Bellil, L.M., Iezzoni, L.I., & Smith, L.D. (2018). Obstetric clinicians' experiences and educational preparation for caring for pregnant women with physical disabilities: A qualitative study.

Smeltzer, S.C., Mitra, M., Long-Bellil, L.M., Iezzoni, L.I., & Smith, L.D. (2018). Recommendations for clinicians working with pregnant women with physical disabilities.

PRESENTATIONS

Akobirshoev, I., Saitadze, I., Scutaru, T., Lomiashvili, T., & Marandici, I. (May 2018). *The PhD process*. Open Society Foundation North America Regional Conference, Washington, D.C., USA.

Akobirshoev, I., Mitra, M., & Dembo, R. (September 2018). *Inpatient hospital mortality among adults with autism spectrum disorder in the United States*. 2018 CityMaTCH Leadership and MCH Epidemiology Conference, Portland, OR.

Akobirshoev, I., Mitra, M., & Dembo, R. (November 2018). *Inpatient hospital mortality among adults with autism spectrum disorder in the United States: A retrospective analysis of U.S. hospital discharge data*. Annual meeting of American Public Health Associations, San Diego, CA.

Akobirshoev, I., Parish, S.L., Mitra, M., & Dembo, R. (November 2018). *Impact of medical home on health care of children with and without special health care needs: update from the 2016 National Survey of Children's Health*. Annual Meeting of American Public Health Association, San Diego, CA.

Cain, I. (February 2018). *Educational predictors and interventions for postsecondary community living*. Council of Exceptional Children Annual Conference, Tampa, FL.

Cain, I. (June 2018). *How does cultural and economic privilege influence disability labeling in special education programs?* American Association on Intellectual and Developmental Disabilities Annual Conference, St. Louis, MO.

Cain, I. (June 2018). *Community living as a means to promote full inclusion*. American Association on Intellectual and Developmental Disabilities Annual Conference, St. Louis, MO.

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.

Cain, I. (November 2018). *Impact of cultural and economic differences on disability labeling*. MA Council for Exceptional Children Annual Conference, Marlboro, MA.

Cain, I. (November 2018). *Impact of cultural and economic differences on disability labeling*. American Public Health Association Annual Conference, San Diego, CA.

Dembo, R. & LaFleur, J. (March 2018). *The ecology of exclusion: Community health contexts and suspensions of students with disabilities*. Impairment in the Social World Conference, Columbia University, New York.

Dembo, R. (June 2018). *Violence: A (possible) social determinant of health for people with disabilities; social determinants of health among individuals with functional impairments*. American Public Health Association and Association of University Centers on Disabilities, online conference.

Dembo, R., Akobirshoev I., & Mitra, M. (September 2018). *Violence against youth with disabilities: Residual physical and mental health symptoms*. 2018 CityMatCH Leadership and MCH Epidemiology Conference, Portland, Oregon.

Dembo, R., Akobirshoev I., & Mitra, M. (September 2018). *Violence against youth with disabilities: Residual physical and mental health symptoms*. American Public Health Association Annual Conference, San Diego, California.

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

Dembo, R., Mitra, M., & Akobirshoev, I. (June 2018). *System sequelae following violence against youth with disabilities*. AcademyHealth, Seattle, WA.

Dembo, R., Mitra, M., & McKee, M. (November 2018). *The psychological consequences of violence against people with disabilities*. 2018 Annual Meeting of American Public Health Associations, San Diego, CA.

Feingold, L., Goraya, D., Patkin, D., & Powell, R.M. (April 2018). *Disability and dispute resolution: Best practices and practical information for DR practitioners*. Workshop at the American Bar Association 20th Annual Section of Dispute Resolution Spring Conference, Washington, DC.

Long-Bellil, L.M. & Powell, R.M. (March 2018). *Breastfeeding among women with disabilities: Strategies and solutions*. Webinar for the New York State Department of Health.

Long-Bellil, L.M., Higgins, A., Higgins, J., Higgins, N., Ladau, E., & Ladau, E. (May 2018). *Raising our girls: Stories from mothers with disabilities and daughters who've been there*. Webinar for the National Research Center for Parents with Disabilities.

Mitra, M. (January 2018). *Need for inclusive prenatal care for women with physical disabilities*. National Association of County and City Health Officials, Health and Disability Meeting, Washington, D.C.

Mitra, M., Nicholson, J.N., & Powell, R.M. (March 2018). *The National Research Center for Parents with Disabilities: Initial findings inform next steps*. Tuesday Talks Series, Heller School for Social Policy and Management, Brandeis University.

Mitra, M. (May 2018). *Perinatal care for women with disabilities: Making the case for inclusion*. University of Michigan Medical School, Ann Arbor, MI.

Mitra, M., McKee M, Akobirshoev, I., & Valentine, A. (May 2018). *Pregnancy and neonatal outcomes among deaf or hard of hearing women*. AcademyHealth, Seattle, WA.

Mitra, M. (June 2018). *Unmet needs and barriers to perinatal care for women with disabilities: Making the case for inclusion*. Ohio Department of Health.

Mitra, M., (September 2018). *Prevalence and characteristics of violence victimization against men with disabilities*. Men and Violence: Engaging Men and Boys as Survivors, Advocates and Change Agents Conference, Virginia Dept. of Criminal Justice Services, Richmond, VA.

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.

Mitra, M. (October 2018). *Unequal access: confronting disability related disparities in perinatal health*. International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, UK.

Mitra, M., McKee, M., & Akobirshoev, I. (November 2018). *Pregnancy outcomes among women who are deaf and hard of hearing*. Annual Meeting of American Public Health Associations, San Diego, CA.

Mulzer, A., Lucas, C.A., & Powell, R.M. (March 2018). *Raising ADA claims to advocate for parents with disabilities in child welfare cases*. CLE webinar for the American Bar Association.

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.

Namkung, E. (June 2018). *Quality of relationships between aging parents and adult children with intellectual/developmental disabilities*. National Association of Social Workers (NASW) National Conference, Washington DC.

Namkung, E.H., Valentine, A., & Mitra, M. (September 2018). *Contraceptive use at first sex among adolescent girls and young women with disabilities: The role of formal sex education*. 2018 CityMatCH Leadership and MCH Epidemiology Conference, Portland, OR.

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.

Nicholson, J. (March 2018). *Family mental health begins with parents*. National Research Center for Parents with Disabilities. Webinar.

Pirone, J. & McKee, M. (June 2018). *Deaf parents' approaches to parenting*. Lurie Institute's National Research Center for Parents with Disabilities webinar.

Powell, R.M. (February 2018). *Representing parents with intellectual disabilities and their families: Strategies and solutions for attorneys*. Webinar for the National Research Center for Parents with Disabilities.

Powell, R.M., Ayers, K., & Andrews, E. (April 2018). *How Prospective Parents with Disabilities Can Prepare for Parenthood*. Webinar for the National Research Center for Parents with Disabilities.

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.

Powell, R.M. (June 2018). *ADA and parents with disabilities*. National Disability Rights Network Annual Conference; Baltimore, MD.

Powell, R.M., Mitra, M., Parish, S., & Nicholson, J. (June 2018). *Promoting adult relationships: Best practices for training social workers about working with parents with intellectual disability and their families*. American Association of Intellectual and Developmental Disabilities Annual Meeting, St. Louis, MO.

Powell, R.M. (July 2018). *Representing parents with intellectual disabilities and their families*. 41st National Child Welfare, Juvenile Justice, and Family Law Conference, National Association of Counsel for Children, San Antonio, TX.

Powell, R.M. & Lucas, C.A. (September 2018). *Representing parents with disabilities and their families*. Office of Respondent Parents' Counsel 3rd Annual Conference, Keystone, CO.

Powell, R.M., Andrews, E., & Ayers, K. (November 2018). *Improving access to perinatal health care for parents with disabilities in the United States*. American Public Health Association Annual Meeting, San Diego, CA.

Powell, R.M., Ayers, K., & Andrews, E. (November 2018). *Looking beyond barriers to identify strengths of parents with disabilities*. American Public Health Association Annual Meeting, San Diego, CA.

Powell, R., Mitra, M., Long-Bellil, L., Smeltzer, S., Smith, L., Rosenthal, E., & Iezzoni, L. (November 2018). *Adaptive parenting strategies used by mothers with physical disabilities caring for infants and toddlers*. American Public Health Association Annual Meeting, San Diego, CA.

Powell, R.M. & Yee, S. (December 2018). *Making connections: Reproductive justice, disability rights, and LGBTQ liberation*. National Health Law Program Annual Conference, Washington DC.

Shields, M., Akobirshoev, I., Parish, S.L., Mitra, M., & Dembo, R. (June 2018). *Self-injurious behavior among adults with and without Autism Spectrum Disorder: Comparing differences in hospital admissions, lengths of stay, and costs*. 2018 AcademyHealth's Disability Research Interest Group, Seattle, WA.

Smith, L. D., Hatcher, J., Wilbur, A., & Mitra, M. (July 2018). *Health care experiences of people who are Deaf and hard of hearing: A community health needs assessment*. National Association of County & City Health Officials Annual Conference, New Orleans, LA.

Swanson, S., Caldwell, J., Deere, D., Willis, W., & McMillan, E. (November, 2018). *Medicaid managed long-term services and supports: An opportunity for inclusion?* Association of University Centers on Disabilities Annual Meeting, Washington, DC.

Warfield, M.E. & Naim Ali, H. (June 2018). *Predictors of caregiver well-being in a consumer directed Medicaid waiver program*. State of the Science Conference, Washington, DC.

Warfield, M.E., Adams, R.S., Ritter, G., Williams, T.V., & Larson, M.J. (November 2018). *Health care utilization among children with special health care needs in military families*. American Public Health Association Annual Conference, San Diego, CA.

Wu, J., Li, H., Mitra, M., Parish, S., Valentine, A., Dembo, R. (November 2018). *Female sterilization by tubal ligation and hysterectomy among U.S. women with cognitive disabilities*. North American Primary Care Research Group Annual Meeting, Chicago, IL.

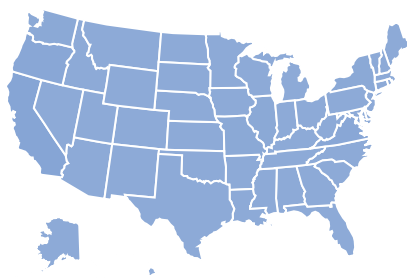
Wu, J., Zhang, J., Mitra, M., Parish, S., & Reddy, G. K. M. (November 2018). *Provision of reversible birth control to women with intellectual and developmental disabilities: Evidence from the Massachusetts All-Payer Claims Database*. North American Primary Care Research Group Annual Meeting, Chicago, IL.



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



**24 Media Articles +
10 Media Mentions**

Lurie staff published articles and were quoted in:

- Rewire
- Huffington Post
- ABC News
- Vice News
- Newsweek
- WPR



**9 New
Community
Partnerships**

Lurie's new Community Living Policy Center has ensured leadership of people with disabilities in research action.

**1,000+
Social Media Posts**

Lurie and The Center for Parents disseminated findings and engaged with SM users.



7 Webinars + 5 Events

Lurie featured the voices of parents with disabilities, students with disabilities, social workers, disability policy lawyers, policymakers, and researchers.



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
November, 2018. Brandeis University.

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 Policy Consortium Annual Meeting, October, 2018. Boston, MA.

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

Ho, S. (2018, August 2). Canfei to Canji: The freedom of being loud. *Bitch Media*.

Powell, R.M. (2018, January 3). Parents with disabilities face an uphill battle to keep their children. *Pacific Standard*.

Powell, R.M. (2018, January 12). Despite Republican claims, Medicaid work requirements would hurt people with disabilities. *Rewire.News*.

Powell, R.M. (2018, January 19). For people with disabilities, Trump's first year has threatened nearly every facet of life. *Rewire.News*.

Powell, R.M. (2018, February 8). Ohio's dangerous abortion ban pits disability rights against reproductive rights. *Rewire.News*.

Powell, R.M. (2018, February 22). When fear turned into fact: Congress' move to gut the Americans with Disabilities Act spurs protests. *Rewire.News*.

Powell, R.M. (2018, February 27). Trump says institutions are the solution for ending gun violence. He's wrong. *Rewire.News*.

Powell, R.M. (2018, March 7). What Hollywood gets wrong about disabilities. *Huffington Post*.

Powell, R.M. (2018, March 12). For parents around the country, having a disability can mean losing custody of their kids. *Rewire.News*.

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, March 27). The tributes to Stephen Hawking show what's wrong with how we talk about disability. *Rewire.News*.

Powell, R.M. (2018, May 31). People with disabilities are 'severely underrepresented in elected office.' These candidates hope to change that. *Rewire.News*.

Powell, R.M. (2018, April 3). Sen. Tammy Duckworth saves the Americans with Disabilities Act—for now. *Rewire.News*.

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, May 2). The Trump administration may have made it even harder for people with disabilities to access health care. *Rewire.News*.

Powell, R.M. (2018, May 17). For people with disabilities, earning pennies per hour is only part of the problem. *Rewire.News*.

Powell, R.M. (2018, May 18). Disability activists fight for the right to live in their communities. *Rewire.News*.

Powell, R.M. (2018, July 2). Kennedy's retirement will leave the rights of people with disabilities in danger. *Rewire.News*.

Powell, R.M. (2018, July 13). A looming family leave plan in Congress could harm parents with disabilities. *Rewire.News*.

Powell, R.M. (2018, July 26). Judge Kavanaugh's Supreme Court nomination could put the Americans with Disabilities Act in danger. *Rewire.News*.

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*.

Powell, R.M. (2018, September 11). 'Please do not vote to turn the clock back': People with disabilities testify against Kavanaugh. *Rewire.News*.

Powell, R.M. (2018, September 20). Now is an especially terrible time for Texas to stop teaching kids about Helen Keller. *Rewire.News*.

MEDIA MENTIONS

Monika Mitra was quoted in the following:

Jones, Lindsay. (2018, February 8). Advocates Focus on Inclusion to Improve Public Policy Affecting Individuals with Disabilities. *INSIGHT into Diversity*.

Smith, Adam. (2018, October 1). Prof: Victims with Disabilities Missing From Me Too. *Boston Disability Report News Blog*.

Robyn Powell was quoted in the following:

Ballesteros, C. (2018, February 15). House votes to gut the Americans with Disabilities Act to nip 'abusive lawsuit.' *Newsweek*.

Guyette, N. (2018, January 18). Parents with disabilities face obstacles to keep their children. [radio interview]. *WPR* (NPR affiliate).

Gyimah-Brempong, A. & Radke, B. (2018, July 10). What are the real tradeoffs of the straw ban? [radio interview]. *KUOW* (NPR affiliate).

Perry, D. (2018, February 14). Why Congress is so close to gutting a key provision of the ADA. *Pacific Standard*.

Plank, L. (2018, January 18). There's a lot of pressure on mothers to be perfect. Here's why that idea is toxic. *Divided States of Women* (Vox).

Quinlan, C. (2018, February 15). House votes to gut the Americans with Disabilities Act. *Think Progress*.

Ward, S.F. (2018, January 2). Disability rights movement's legislative impact sprang from on-campus activism. *ABA Journal*.

Watkins, H. (2018, January 4). Republican lawmakers assault disability rights. *Women's Media Center*.

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 Mentor, AcademyHealth's 2018 Annual Research Meeting, Robert Wood Johnson Foundation, Health Policy Research Scholars Program. Seattle WA

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

Dissertation: The Americans with Disabilities Act and parents with disabilities: An empirical review of appeals cases.

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, 2018-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.**



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.**