

# Lurie Institute for Disability Policy 2021 Annual Report (Text-Only Version)

## Who We Are

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

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

## Faculty, Staff, and Visiting Scholars

### **Faculty and Staff**

- Monika Mitra, Director
- Amy AbuShanab, Assistant Director
- Ilhom Akobirshoev, Research Scientist
- Joe Caldwell, Senior Scientist, Director of CLPC
- Finn Gardiner, Communications Specialist
- Miriam Heyman, Senior Research Associate
- Sandy Ho, Research Associate II
- Jennifer Lee-Rambharose, Research Associate II (joined Lurie in 2022)
- Frank Li, Research Associate II

- Nicole Lomerson, Research Associate II (joined Lurie in 2022)
- Teresa Nguyen, Research Associate II (joined Lurie in 2022)
- Serah Nthenge, Postdoctoral Fellow
- Wendy Peverill-Conti, Senior Department Coordinator
- Robyn Powell, Senior Research Associate
- Mel Ptacek, Communications Coordinator
- Lauren Smith, Research Associate II
- Kimberly The, Postdoctoral Fellow (joined Lurie in 2022)
- Anne Valentine, Research Associate II
- Marji Erickson Warfield, Senior Scientist
- Hussaini Zandam, Postdoctoral Fellow

### **Visiting Scholars and Scientists**

- Henry Claypool, Visiting Scientist
- Steve Kaye, Visiting Scientist
- Angel Miles, Visiting Scientist
- Ari Ne'eman, Visiting Scholar

### **Letter from the Director**

As we move into our fifteenth year, we hold true to our mission to improve the health and well-being of people with disabilities in the United States and worldwide. In this milestone year, we continue to embrace the impact of the Nancy Lurie Marks Family Foundation and the generous gift that makes all our work possible.

Although the continuing effects of the COVID-19 pandemic have caused us to rethink how we approach our work, define our research properties, and interact with our communities, COVID hasn't stopped

us from fulfilling our mission—in fact, we've been more active than ever. A few of the highlights of 2021:

- We've continued to research the disproportionate threats that the COVID pandemic has posed to people with disabilities, children with disabilities, and older adults.
- We launched the National Center for Disability and Pregnancy Research, which will develop research that policymakers and medical practitioners can use to support people with disabilities before, during, and after pregnancy. We're also proud to announce that the grant for the National Research Center for Parents with Disabilities has been re-awarded for another five years, meaning that we will continue to produce research on the needs and experiences of parents with disabilities—and how governments, researchers, self-advocates, attorneys, and others can work to improve policy and practice.
- Because our research focuses on real-world concerns like community living, civic engagement, healthcare, and parenthood, we refuse to keep our work inside the ivory tower. Although we haven't been able to hold events in person as we did before the pandemic, we have still found ways to connect with the community about the topics that matter the most. In particular, we enhanced our presence on social media, using our online webinars and community events to maintain the relationships we had before—and during—the pandemic.
- Our faculty and staff have received numerous accolades and awards throughout the year for their research, advocacy, and education.

My sincere gratitude goes to all the members of the Lurie Institute for working tirelessly throughout these unprecedented times. Their extraordinary commitment has ensured our continued progress toward our mission in improving the health and well-being of people with disabilities.

I am incredibly proud of what we have achieved throughout this difficult time.

Monika Mitra

Director, Lurie Institute for Disability Policy

Nancy Lurie Marks Associate Professor of Disability Policy

## Highlights

### **Research Highlights**

“It’s 2021 and still we’re finding that these disparities are an issue.” — Monika Mitra, “Pregnancy Outcomes and Disparities for Deaf and Hard-of-Hearing Mothers”

“Most states cap enrollment in their Medicaid home- and community-based service programs and maintain waitlists. Nationally, over 820,000 people are on HCBS waitlists.” —Community Living Policy Center, “Care Can’t Wait”

“Some disabled people spend more than half their money on housing.” —Community Living Policy Center, “Housing Problems for Disabled People”

### **New Grants and Centers**

- National Center for Disability & Pregnancy Research
- National Research Center for Parents with Disabilities
- Disparities in Perinatal Care and Outcomes among Black Women and Latinas with Physical Disabilities
- Racial Disparities in Home- and Community-Based Services Access and Utilization
- Supplemental Research on Home- and Community-Based Services through Medicaid Data (with the Community Living Policy Center)

- HopeWELL: RISE (Readiness, Inquiry, Scholarship, Education) Evaluation and Learning Partnership

## **Subawards**

- Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) at UMass Chan Medical School
- Strengthening the Collaboration between Aging and Disability Networks to Better Support Individuals with Intellectual and Developmental Disabilities and Their Families in Future Planning

## Research

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

Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research

Overview: The National Research Center for Parents with Disabilities conducts research on the needs and experiences of parents with disabilities, including healthcare, interactions with the legal and child welfare systems, pregnancy and childbirth, formal and informal support systems, and more.

To ensure that our research focuses on the real-world needs of parents with disabilities around the world and those who support them, our work is guided by an international consortium of disability-policy researchers, as well as a national advisory board composed of parents with a variety of disabilities, racial and socioeconomic backgrounds, and areas of expertise.

In 2021, we received another five-year grant to continue our research. Although much of our work from the previous grant will continue, we're also making several changes that will increase the scope and influence of our work.

First, we're excited to announce that Dr. Linda Long-Bellil of the University of Massachusetts Chan Medical School has joined us as the new co-principal investigator.

Dr. Long-Bellil's interest in disability and parenthood is both personal and professional: as an attorney and researcher, she has dedicated years to understanding the theories and practices that underlie policies affecting parents with disabilities in the United States—and as a mother and longtime disability advocate, she is deeply aware of the systemic exclusion and marginalization of parents with disabilities.

We're also expanding our research to include topics previously unexplored: studies on the racial and ethnic disparities affecting parents with disabilities, the development of a peer-support program for parents with intellectual disabilities and more. And that's not all—we will be increasing the reach of our work with a data and policy dashboard, an updated bilingual website, policy briefs and research summaries for policymakers and self-advocates, and toolkits to help parents with disabilities know and exercise their rights.

This year, we published scholarly articles and policy briefs about a wide range of topics including the needs of parents during the pandemic, health outcomes among fathers with disabilities, and the intersections between race, parenthood, and disability.

### Spotlight: State-of-the-Science Teleconference

"I'm a mother of a five-year-old daughter, and I grew up with absolutely no examples of disabled parents around me. And what we don't see, sometimes we can't fathom." —Nicole Lomerson, "Perspectives of Parents with Disabilities: Reflections from Advisory Board Members of the National Research Center for Parents with Disabilities"

"Parents with disabilities, whether or not they're in the child welfare system, are less likely to find tailored and appropriate services to meet their needs. And so typical parenting challenges may be that much harder." —Sarah Lorr, "Reimagining a Child Welfare System that Works for Parents with Disabilities and Their Families"

“One of the incredibly valuable things about peer support... is the fact that there is someone who understands your situation and understands that recovery is not a straight path and that there are ups and downs and is open to thinking about the possibilities and offering hope, which is so important.” —Joanne Nicholson, “Peers Have Much to Offer Parents: Leveraging the Benefits of Lived Experience”

Highlights from 2021 Research:

Compared with nondisabled parents, parents with disabilities were more likely to be referred to the child welfare system by social service providers. (“Who Refers Parents with Intellectual Disabilities to the Child Welfare System? An Analysis of Referral Sources and Substantiation”)

Legislators often had outdated, harmful ideas about disability and parenthood, including the misconception that parents with disabilities are inherently unfit. Because of these stereotypes, these legislators did not consider the rights of parents with disabilities a high priority. (“Advocates, Attorneys, and Legislators on Passing Legislation That Protects the Rights of Parents with Disabilities”)

Fathers with disabilities have needs and experiences distinct from those of mothers with disabilities or nondisabled fathers, but the lack of research about disabled fathers prevents researchers, service providers, and medical professionals from giving them the support they need to raise their children successfully. (“Fatherhood with a Disability: Health and Unmet Needs”)

## **Community Living Policy Center**

Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research

Overview: Though the *Olmstead v. L.C.* Supreme Court ruling established the right for all people with disabilities to live in the community, inconsistent policies and systemic discrimination have prevented many from enjoying that right. At the Community Living Policy Center, we research policies and programs that keep people with disabilities and older adults in the community with their families, friends, and neighbors—and out of institutions.

The COVID-19 pandemic has drawn renewed attention to the adverse health outcomes that many older adults and people with disabilities face. For instance, we found that people who need long-term services and supports—whether they receive those services in institutions or as home- and community-based services—have a greater risk than others of getting sick from, or dying of, COVID. In early 2021, we released a brief, “Elevated COVID-19 Mortality Risk among Recipients of Home- and Community-Based Services: A Case for Vaccine Prioritization,” that urged state governments to provide people with disabilities with vaccines in the earliest phases. In another study, we also learned that people who self-directed their services during the pandemic had better outcomes and fewer gaps in services.

Our research also highlighted the need for increased federal investment in home- and community-based services, which we covered in our briefs, *The Better Care Better Jobs Act and Home- and Community-Based Services and Care Can’t Wait: How Do Inadequate Home- and Community-Based Services Affect Community Living and Health Outcomes?*, as well as peer-reviewed journal articles, including “Relationship between Unmet Need for Home- and Community-Based Services and Health and Community Living Outcomes.”

Our research team has been working closely with Lived Experience Experts to conduct focus groups to evaluate the policies of One Care, a demonstration program that brings principles of independent living into Long-Term Services and Supports for people in Massachusetts who receive both Medicare and Medicaid. We also interviewed dozens of care managers and consumers to evaluate service plans for person-centered care.

To share our work with the community, we also held a series of webinars about a variety of topics, including the inequitable effects of COVID-19 on people with intellectual and developmental disabilities, the provisions of the Biden–Harris administration’s historic proposal to invest \$400 billion in Medicaid HCBS, and the continued use of shock and pain as treatment for people with disabilities at the Judge Rotenberg Center in Canton, Massachusetts. Another CLPC webinar featured the showing and discussion of the documentary *6,000 Waiting*, which described the struggle of three people on Georgia’s



waiting list to receive the services and supports they need to live independently in the community.

## Highlights from Our Research

Two-thirds of people on HCBS waiting lists have intellectual or developmental disabilities. (“The Better Care Better Jobs Act and Home- and Community-Based Services”)

The number of people on waiting lists has more than doubled over the past decade. (“The Better Care Better Jobs Act and Home- and Community-Based Services”)

When disabled people’s needs for home- and community-based services went unfulfilled, their relationships, health, and community participation suffered. (“The Relationship between Unmet Need for Home- and Community-Based Services and Health and Community Living Outcomes”)

Respondents identified staff coercion as a barrier to self-determination. (“Who’s In Control?”: Control over Community Services for People with Disabilities—published jointly by ASAN and CLPC)

## CLPC Webinars: Quotes & Insights

“When we decide to subject people to electric shocks to control their behavior, we’re saying that the end—that is, compliance—justifies these torturous and inhumane means.” —Finn Gardiner, Panelist & Lurie Institute Communications Specialist, “Pain and Shock in America: A Conversation on the Use of Pain and Shock on People with Disabilities,” a discussion with author Jan Nisbet

“If nobody knows about your story, if nobody knows who you are, then the likelihood of you ever getting out of a nursing home is slim.” — Nick Papadopoulos, Panelist whose story was featured in *6,000 Waiting* screening and discussion

“We cannot recover from this economic crisis . . . [and] COVID if we do not look at the crucial caregiving infrastructure in this country, and that includes the home- and community-based service system that helps people with disabilities and older adults live in their own communities, as well as the formal and informal caregiving workforce.”

—Alison Barkoff, Panelist and Principal Deputy Administrator of the Administration for Community Living, “The Biden–Harris Administration’s Caregiving Initiative: Investing in Medicaid HCBS”

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

Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research

Overview: The National Center for Disability and Pregnancy Research, or NCPDR, was established in 2021 to conduct research about pregnancy, family planning, and reproductive health among people with disabilities. Since people with disabilities are wrongly assumed to be uninterested in—or incapable of—making decisions about reproduction and pregnancy, researchers and public health practitioners have often neglected their needs. We want to learn more about the health disparities that people with disabilities encounter before, during, and after pregnancy so that policymakers and medical practitioners can use our findings to improve services and outcomes.

“I work in the pregnancy and prenatal area, and every time I say this, people always assume it’s parents of children with disabilities—as if parents can only be able-bodied... The assumption is that a person cannot have a disability and take care of someone else.” —Monika Mitra, as quoted in the Los Angeles Times

We are collaborating with partners at research institutions, including the Oregon Health & Sciences University, the University of Michigan Medical School, the University of Toronto, Cincinnati Children’s Hospital, the University of Minnesota, and Magee-Womens Hospital Research Institute & Foundation to conduct cross-disability, multidisciplinary research—and to share our findings with a wide audience. To make sure that our research puts the community’s needs first, we’ve formed an advisory board that will guide our research, education, and training.

The Center includes five research projects that will contribute to our understanding of pregnancy experiences, perinatal risks, complications, and outcomes in people with disabilities through rigorous population-based research:

- Expanding the Evidence Base on Perinatal Disparities in Disability Populations
- Developing Preconception Education for Women with Mobility Disabilities
- Accessibility Pregnancy Action Plan
- Reimagining Healthcare Design for Maternal and Infant Health for People with Disabilities
- Edinburgh Postnatal Depression Scale for People with Intellectual and Developmental Disabilities

### **Additional Research Projects**

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 Lurie Institute for Disability Policy researching the relationship between addiction, disability, and service provision to support people with disabilities who also have opioid use disorders.

Funded by National Institute on Disability, Independent Living, and Rehabilitation Research.

Maternal and Child Health Field-Initiated Research Program - Birth, Parenthood, and Health Behaviors of Father's Disability

This study investigated fatherhood, health, and health behaviors among U.S. fathers with disabilities.

Funded by Health Resources and Services Administration.

Improving Pregnancy Outcomes of Women with Intellectual and Developmental Disabilities

This research project uses population data to investigate pregnancy outcomes, complications, and inpatient costs among women with intellectual and developmental disabilities in the United States.

Funded by National Institutes of Health.

## 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. In this study, we are using primary and secondary data—structured interviews, national data sets, and surveys—to learn from Deaf and hard-of-hearing mothers and the clinicians who work with them.

Funded by National Institutes of Health.

## Supportive Services Available to Parents with Disabilities

This project was the first national-level examination of supportive services that parents with multiple disabilities receive during their involvement with the child-protection system.

Funded by Brandeis University, Office of the Provost.

## **Selected Papers and Presentations**

### Papers

The ParentingWell Learning Collaborative Feasibility Study: Training Adult Mental Health Service Practitioners in a Family-Focused Practice Approach. Nicholson, J., English, K., & Heyman, M. in the *Community Mental Health Journal*

Mental Health Impacts of COVID-19 on People with Disabilities: A Call to Action - Mitra, M., & Turk, M. in the *Disability & Health Journal*

The Compounding Effect of Having HIV and a Disability on Child Mortality among Mothers in South Africa. - Akobirshoev, I., Zandam, H., Nandakumar, A., Groce, N., Blecher, M., & Mitra, M. in the *Public Library of Science*

Contraceptive Provision and Quality Care Measures for Insured Individuals in Massachusetts Who Are Deaf or Hard of Hearing. Wu, J. P., Zhang, J., McKee, M., Akobirshoev, I., McKee, K. S., & Mitra, M. in the *Obstetrics and Gynecology Journal*

Severe Maternal Morbidity and Maternal Mortality in Women with Intellectual and Developmental Disabilities. *American Journal of*

Preventive Medicine, Mitra, M., Akobirshoev, I., Valentine, A., Brown, H., & Moore Simas, T. in the *American Journal of Preventive Medicine*

Pregnancy and Neonatal Outcomes among Deaf and Hard of Hearing Women: Results from Nationally Representative Data, Mitra, M., McKee, M. M., Akobirshoev, I., Ritter, G. A., & Valentine, A. M. in the *Women's Health Issues Journal*

The Relationship Between Unmet Need for Home and Community-Based Services and Health and Community Living Outcomes, Chong, N., Akobirshoev, I., Caldwell, J., Kaye, H. S., & Mitra, M. in the *Disability and Health Journal*

Infectious Diseases-Related Emergency Department Visits among Non-Elderly Adults with Intellectual and Developmental Disabilities in the United States: Results from the National Emergency Department Sample, 2016, Zandam, H., Mitra, M., Akobirshoev, I., Li, F. S., & Ne'eman, A. in the *Journal of Population Health Management*

## Presentations

Communication and Relationship: How the Two Constructs of Relational Coordination Relate to Family Caregivers' Well-Being - Marji Erickson Warfield

Disability Data - Learning Together: Connecting Research and Lived Experience - Monika Mitra

The Americans with Disabilities Act and Termination of Parental Rights Cases - Robyn Powell

The Risk of Child Mortality among Women with and without Disabilities in South Africa - Ilhom Akobirshoev & Monika Mitra

The Role of Resilience among Mothers with Physical Disabilities - Serah Nthenge

The Use of Modern Contraceptives at the Intersection of HIV and Disability - Hussaini Zandam

## Education

### **Postdoctoral Program**

The Lurie Institute for Disability Policy offers a two-year postdoctoral fellowship in disability and health research for emerging scholars interested in disability justice, social policy, and public health. The Postdoctoral Program began in 2015 with funding from National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Lurie Institute for Disability Policy, and the Lurie Institute received renewed funding in 2020.

“Through the fellowship I have learned valuable skills for my career development. I gained experience on how research, when conducted with people in mind, can be a powerful tool for a meaningful change.”  
—Hussaini Zandam, Lurie Institute Postdoctoral Fellow

“My postdoctoral experience at the Lurie Institute for Disability Policy helped sharpen my research skills. This was enhanced by working with a dynamic team that embraces diversity both in research and the work environment.” —Serah Nthenge, Lurie Institute Postdoctoral Fellow

### **Hon. Jonathan Brant '68 Endowed Doctoral Fellowship**

Intended for doctoral students affiliated with the Lurie Institute, the Brant Fellowship provides tuition and other financial assistance to support their dissertations and policy advocacy. Through the Brant Fellowship, the Lurie Institute encourages promising students to apply their research and advocacy prowess to ensuring the full social and legal equality of people with disabilities across the United States and worldwide.

“I chose to come to Heller in part because I knew I wanted to center my research around disability, and receiving the Hon. Jonathan Brant '68 Endowed Doctoral Fellowship has helped make me feel confident that I made the right choice. As a disabled researcher, being awarded a fellowship that specifically supports students in conducting work that advances the rights of disabled people is both personally and professionally meaningful.” —Ian Moura, Hon. Jonathan Brant '68 Endowed Doctoral Fellow

### **Undergraduate Fellowship in Disability Policy**

## 2020–2021 Fellows and Mentors

- Michael Atkins & Joe Caldwell
- Anna Cass & Ilhom Akobirshoev
- Sabrina Chow & Frank Li
- Aishwarya Khanna & Lauren Smith
- Zoë Pringle and Rachel Sayko Adams
- Luca Swinford and Miriam Heyman

## 2021–2022 Fellows and Mentors

- Maytal Bach & Ilhom Akobirshoev
- Joelle Galatan & Lauren Smith
- Roe Keshet & Miriam Heyman
- Allie Mundis & Hussaini Zandam
- Micah Rothkopf & Joe Caldwell
- Zach Williams & Frank Li

“This fellowship was the highlight of my time at Brandeis. It provided me with the policy knowledge, research skills, and connections necessary to . . . begin a career in disability policy. I enjoyed that this fellowship had a blend of meetings, talks, presentation opportunities, and ways to do real work in disability policy.” —Michael Atkins

“The fellowship has been a wonderful opportunity to delve into the world of the disability community and the meetings with the community leaders were really wonderful. It wasn’t until I filled out a job application and saw my experience on a list of things that ‘count’ as disabled that I had even considered identifying as disabled.” — Undergraduate Fellow

## **Repair the World**

We partnered with Repair the World to provide internships for undergraduate students and recent graduates interested in disability policy.

“The most meaningful part of my experience with Repair the World was doing disability policy research. I learned a lot—more than I ever realized—about how complicated things are, how very privileged I am to be where I am and that I take myself and the life I’ve been dealt for granted sometimes.” —Repair the World Fellow

### **Classes, Lectures, and Seminars**

#### Selected Classes & Lectures Taught by Lurie Faculty and Staff

Monika Mitra

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

Joe Caldwell

- Independent study: Home- and Community-Based Services: Past, Present, Future
- Racial and Ethnic Equity in Home- and Community-Based Services
- Intersection of Immigration and Disability Policy

Marji Warfield

- HS 334F 1 Disability Policy: Intersections with Health, Poverty, Education and Family Policy

Finn Gardiner

- Seminars for Leadership and Education in Neurodevelopmental Disabilities (LEND) Fellows at the University of Massachusetts Chan Medical School: Identity-First Perspectives; Intersectionality & Disability; “Getting It Write” : Writing Well & Inclusively about Disability

Amy AbuShanab



- Guest lecture: Visualizing Data: Storytelling with Your Data

### Selected Guest Speakers and Seminars

Kara Ayers, Assistant Professor, Associate Director University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD) Cincinnati Children's Hospital Medical Center

- Addressing Ableism in Healthcare Inequities Experienced by People with Disabilities

Nora Groce, Leonard Cheshire Chair of Disability and Inclusive Development Epidemiology; Public Health Institute of Epidemiology & Health

- The Evolving Field of Global Disability Studies: Where Have We Been, Where Do We Go Next?

Ari Ne'eman, Visiting Scholar, Lurie Institute

- Disability and Scarce Resource Allocation: Who Gets What When There's Not Enough to Go Around?

Angel Miles, Health/HCBS Policy Analyst, Access Living

- Doing Intersectional Disability Research: What You Should Know

Christina Nicolaidis, Professor and Senior Scholar in Social Determinants of Health, School of Social Work, Portland State University

- Participatory Research with Autistic Adults: What It Takes; What It Offers

## Community

### **Social Media**

We translate complicated research findings into understandable formats—infographics, videos, and pull quotes—for community members, advocates, and nonprofits.

Twitter graphics:

“People with disabilities should be able to marry without losing benefits. #BetterCareBetterJobsAct”

“[Informed consent] is a crucial component that must be discussed before the pregnancy stage before the baby arrives. —Adrianna Smart”

“Share your favorite end-of-year traditions. Submit blogs by Jan. 10.”

A graphic with the words “special needs,” “handicapable,” and “differently abled” all crossed out. Written underneath is “DISABLED” and the hashtag #SayTheWord.

Social Media Statistics:

In 2019, the Lurie Institute Twitter account had 1,566 followers. In 2020, this number increased to 1,858. By 2021, we had 2,002 followers.

In 2019, the National Research Center for Parents with Disabilities had 1,376 followers. This grew to 1,663 in 2020, and as of 2021, we had 1,921 followers.

The Community Living Policy Center had 117 followers in 2019. In 2020, the number of followers grew to 238—more than double. In 2021, we doubled the number of followers again, ending with 533.

### **Events, Webinars, & Lectures: Selected Excerpts**

“Historic disenfranchisement of people with disabilities has its roots from the same tree as Jim Crow policies.” — Rebecca Cokley, Richman Distinguished Fellow in Public Life, “Achieving an Inclusive Democracy: What It Means for Every Voice to Count”

“My transition to the workforce as an adult has been challenging and complex compared to school and college... I believe employers [are well-intentioned] and are committed to their company’s productivity. The disconnect, however, comes when they are faced with disabled employees who may need additional accommodations that conflict with

workplace norms.” — Anonymous, “Envisioning a World Where Employers Trust Disabled Employees,” Disability@Work National Disability Employment Awareness Month Blog Series

“For disabled folks to truly have access, it needs to be part of the [work] culture, not just an individual accommodation.” — Anonymous, “We Need to See It’s Okay to be Disabled,” Disability@Work National Disability Employment Awareness Month Blog Series

“I’m very, very happy to be a dad, and I think that both [my wife] and I having disabilities and growing up with our disabilities ... has helped inform our parenting as parents of a child with a disability.” —Kevin Irvine, Panelist, “The Role of Disabled and Deaf Fathers in the Family”

“Another thing that has come out of [COVID-19] that was really good was I started a Facebook group specifically for other high-risk moms or moms who are in families that have high-risk children, elder grandparents, etc... we’ve been able to find support with this subset of people in our town. That’s been a really great source of support.” — Nicole Lomerson, Panelist, “Coping with COVID: Parenting with a Disability during a Pandemic”

“Approximately 70% of nursing homes are for-profit, and [they] are more likely than nonprofit to be understaffed, overcrowded, and to invest in fewer resources and care for residents. Black and Latinx people are more likely to be in these facilities, and not only are they subject to subpar care, but they’re increasingly at risk for contracting and dying of COVID-19.” —Angel Miles, Panelist, “Unfair and Unequal: COVID-19 and People with Intellectual & Developmental Disabilities”

## **Lurie in the Media**

### Selected Articles

Ari Ne’eman, Lurie Institute Visiting Scholar

- “Commentary: People with disabilities need services in the community,” *Bloomberg Opinion*, July 25, 2021.
- “What if Disability Rights Were for Everyone?,” *New York Times*, October 1, 2021.

Monika Mitra

- Sonja Sharp, “Disabled mothers-to-be face indignity: ‘Do you have a man? Can you have sex?’,” *Los Angeles Times*, September 30, 2021.

Finn Gardiner and Monika Mitra

- Kayla Hui, “Appeals Court Overturns FDA’s Ban on Electric Shock Device,” *Verywell Health*, July 23, 2021.

Henry Claypool, Lurie Institute Visiting Scientist

- Eric Galatas, “Disabled Community Urges Congress to Boost Home-Care Infrastructure,” *Public News Service*, August 12, 2021.

Sandy Ho

- “73 Questions with Judy Heumann,” *The Heumann Perspective*, September 9, 2021
- “Disability Civic Engagement” & “Disability and Intersectionality,” *Included: The Disability Equity Podcast*, October & November 2021.

“...Mentorship is... a two-way street, right? And I think that’s something people can sometimes forget, is that when seeking out mentorships, I’m learning just as much from, say, the undergraduate fellows who are being mentored by researchers at Lurie Institute, as much as they are hopefully learning about research from us.” —Sandy Ho

## **Selected Faculty and Staff Awards**

Heller Award for Diversity, Equity, and Inclusion

Finn Gardiner

ASAN Ally of the Year

Sandy Ho

Bill Allan Award for Grassroots Disability Advocacy

Sandy Ho

Disability Mentoring Hall of Fame

Sandy Ho & Finn Gardiner

Gibbs Leadership Prize: Best Manuscripts of 2021 in Women's Health Issues

Monika Mitra

Inaugural Peg Nosek Award for Research Contributions for Women with Disabilities or Other Underrepresented Populations in Disability Research, American Public Health Association Disability Section

Monika Mitra

NARRTC Commendation Award for Excellence in Research, Teaching, and Advocacy

Monika Mitra

National Association of Rehabilitation Research and Training Centers (NARRTC) 2021 Best Paper Award

Monika Mitra & Eun Ha Namkung

## **Advisory Boards**

Advanced Rehabilitation Research and Training Postdoctoral Fellowship

- Sharon Applegate
- Cheryl Cumings

- Colleen Flanagan
- Dennis Heaphy
- Bill Henning
- Jeff Keilson
- Colin Killick
- Holly Pearson
- Jean Luc Pierite
- Jessica Podesva
- Leo Sarkissian
- Brenda Vezina
- Heather Watkins

#### National Center for Disability and Pregnancy Research

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

#### National Research Center for Parents with Disabilities

- Earl Allen
- Judith Brown
- Patrick Cokley

- Morénike Giwa-Onaiwu
- Keith Jones
- Nicole Lomerson
- Julie Petty
- Tana Pradia
- Jennifer Senda
- Laura Stout
- Heather Watkins

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

- Marjorie Aunos
- Susan Collings
- Maurice Feldman
- Gabrielle Hindmarsh
- Helen Leonard
- Gwynnyth Llewellyn
- Nomfundo Moroe
- Carmit-Noa Shpigelman
- Margaret Spencer
- Karin van Doesum

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

- Sarah Arana
- Adrianna Smart
- Melissa Elmira Yingst
- Joann (JoJo) Skowzgird Forbes

- Jamie L. Maes-Eishen
- Robert C. Nutt
- Christa Williams
- Timothy R. B. Johnson
- Kim Kelstone
- Rosalyn Maben-Feaster
- April Lyon
- Karen M. Duguid

### Community Partners

- ADvancing States
- Access Living
- American College of Obstetricians and Gynecologists
- American Council of the Blind
- American Foundation for the Blind
- American Network of Community Options and Resources
- The Arc of the United States
- Association of Maternal & Child Health Programs
- Association of University Centers on Disabilities
- Autistic Self Advocacy Network
- Autistic Women & Nonbinary Network
- Centene Corporation
- Center for Public Representation
- Child Welfare League of America
- CityMatCH
- Disability Policy Consortium



- Disability Rights Education & Defense Fund
- Disability and Aging Collaborative
- Hearing Loss Association of America
- Justice in Aging
- Little People of America
- Mental Health America
- National Association of Councils on Developmental Disabilities
- National Association of the Deaf
- National Council on Aging
- National Disability Rights Network
- National Perinatal Association
- Psychiatric Rehabilitation Association/Psychiatric Rehabilitation Foundation
- Topeka Independent Living Resource Center
- United Spinal Association
- Maternal and Child Health Organizations

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- Massachusetts Department of Public Health

- National Institute on Disability, Independent Living, and Rehabilitation Research
- National Institutes of Health

## **In Memoriam**

The faculty, staff, and students of the Lurie Institute would like to remember Dr. Marty Krauss, PhD'81, for her instrumental role in establishing the institute and supporting our work.

## **Credits**

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- Twitter: [twitter.com/NatRCPD](https://twitter.com/NatRCPD)
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### **Community Living Policy Center**

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