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# Lurie Institute for Disability Policy 2022 Annual Report (Text-Only Version)

## Introduction

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 disabled people and their families face. Our research incorporates qualitative and quantitative methods 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.

The Lurie Institute was created by a generous gift from the Nancy Lurie Marks Family Foundation in 2007. Over the past sixteen years, we have conducted cross-disciplinary research on real-life topics affecting people with disabilities, including health and healthcare, parenting, home- and community-based services, and more.

## Message from the Director

Dear Friends of the Lurie Institute for Disability Policy,

It is with great pleasure that I present the 2022 Annual Report of the Lurie Institute for Disability Policy. Our faculty, staff, and students have worked tirelessly to conduct groundbreaking research on disability policy, engage with our community partners, and offer innovative programming. Our research has tackled important issues facing people with disabilities such as the experiences of individuals self-directing their HCBS during the COVID-19 pandemic, the risk of infectious disease among adults with intellectual and developmental disabilities, and the impact of the COVID-19 pandemic on disabled adults' access to medical care services.

One of our major accomplishments this year has been the launch of the Community Living Equity Center (CLEC). This Center aims to address

knowledge gaps about inequities in community living and participation experiences and outcomes faced by disabled people of color. We also established the Carrie Buck Distinguished Fellowship to honor Carrie Buck's memory. The Fellowship, funded by the Ford Foundation, is intended for activists, scholars, and community organizers with disabilities whose work draws national attention to systemic ableism in reproductive health policy.

We have continued to expand our community outreach efforts through partnerships with local and national disability advocacy organizations and government agencies. Our community partners have been instrumental in shaping our research agenda and ensuring that our work is responsive to the needs of disabled people.

I would like to express my gratitude to our funders and supporters, whose generosity has allowed us to continue our important work. Your contributions make it possible for us to expand our research and offer innovative solutions to the complex issues facing disabled people today.

As we look to the future, we are more committed than ever to advancing disability rights and promoting disability inclusion. Our work has never been more important, and we are excited to continue pushing the boundaries of what is possible in the field of disability policy.

Thank you for your continued support and partnership.

Monika Mitra

Director, Lurie Institute for Disability Policy

Nancy Lurie Marks Associate Professor of Disability Policy

## Our Team

- Monika Mitra, Director
- Amy AbuShanab, Assistant Director
- Ilhom Akobirshoev, Director of Research
- Joe Caldwell, Director, CLPC
- Elad Daniels, Data Analyst II

- Mark Davis, Data Analyst II
- Miriam Heyman, Senior Research Associate
- Luanjiao Hu, Postdoctoral Fellow
- Jennifer Lee-Rambharose, Research Associate II
- Frank Li, Data Analyst II
- Nicole Lomerson, Research Associate II
- Teresa Nguyen, Director, CLEC
- Wendy Peverill-Conti, Sr. Dept Coordinator
- Sydney Pickern, Senior Research Associate
- Robyn Powell, Senior Research Associate
- Mel Ptacek, Communications Coordinator
- Lauren Smith, Senior Research Associate
- Kimberly The, Senior Research Associate
- Anne Valentine, Research Associate II
- Marji Erickson Warfield, Senior Scientist
- Hussaini Zandam, Postdoctoral Fellow

## Research

Aligned with the mission of the Heller School for Social Policy and Management, we are committed to conducting research and sharing knowledge to advance social justice. Our research incorporates diverse methods and approaches to gain a deeper understanding of the needs, experiences, and policy priorities of individuals with disabilities. Our portfolio includes a broad range of research topics, such as addressing knowledge gaps related to inequities in community living outcomes faced by disabled people of color, examining the needs and experiences of parents and

prospective parents with disabilities, and investigating the pregnancy experiences and outcomes of disabled individuals.

Over the past few years, we have established several national research centers, including the Community Living Policy Center (CLPC), the National Research Center for Parents with Disabilities, and the National Center for Disability and Pregnancy Research. In 2022, we launched the Community Living Equity Center (CLEC) to further our commitment to advancing disability rights and justice through research and advocacy.

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

Conducting research and providing training and technical assistance to improve the lives of parents with disabilities and their families. Funding is provided through the National Institute on Disability, Independent Living, and Rehabilitation Research.

### *Data Compendium*

Lurie researchers published a list and description of datasets so that researchers can investigate questions related to the prevalence and life circumstances of disabled parents.

### *Prevalence of Parents with Disabilities in the U.S.*

Researchers compiled accurate, detailed, and up-to-date information about the prevalence of disabled parents in order to support disabled parents and their families. This brief includes data about specific disability types, as there are unique circumstances associated with specific disabilities.

### *Map on U.S. State Laws Terminating Parental Rights Based on Parent's Disability*

Current laws in many U.S. states include parental disability as grounds for the termination of parental rights. Our map displays the types of disabilities that states currently allow as grounds for terminating parental rights.

### *Community Blog Posts*

"I find that my immigrant identity, in addition to my disability status, has affected my experience notably."

— Luanjiao (Aggie) Hu, “My experience as an immigrant and expectant mother with a physical disability”

“I’m fully vaccinated and boosted, but the truth is that if I get COVID, I’m much more likely to die than the average able-bodied person. I’d leave three children six and under motherless, and I’m only 34. As the world moves on, I feel like my community views my family as disposable....”

— Ariel, “Homebound”

## **Community Living Policy Center**

Researching policies and practices that keep people with disabilities in the community. Funding is provided through the National Institute on Disability, Independent Living, and Rehabilitation Research.

### *Experiences of Individuals Self-directing Medicaid Home and Community-based Services During COVID-19*

The study examined how home- and community-based services (HCBS) users felt about the help they received during the pandemic, how they protected themselves from the coronavirus, and how they stayed healthy. We released two accessible videos summarizing findings with the peer-reviewed article.

### *States and Territories Encouraged to Apply for Money Follows the Person Funding*

A Lurie undergraduate fellow and graduate student assistant created a fact-sheet emphasizing the importance and impact of Money Follows the Person, a federally funded program that helps transition people out of nursing homes and other institutions.

### *Excess Deaths of Medicaid Home and Community-Based Services Recipients During COVID-19*

Researchers calculated excess mortality rates for Medicaid home- and community-based services recipients during March–December 2020. For younger recipients, excess mortality was 7.4 times that of other community-dwelling Medicaid beneficiaries and 26.6 times that of the general population.

At least 1.2 million people use self-directed home- and community-based services. People using self-directed HCBS have control over hiring and supervising their workers.

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

Improving disabled people's pregnancy experiences and outcomes through research, training, and education. Funding is provided through the National Institute on Disability, Independent Living, and Rehabilitation Research.

### *End of Roe is a Health Risk for Disabled People*

Featured in the *Tampa Bay Times*, Dr. Mitra spoke of health risks for disabled people associated with the end of Roe. "Forcing disabled people to carry a baby to term could put their health at risk and also increase economic hardship since people with disabilities typically earn less than their able-bodied peers... In a post-Roe America where abortion is expected to be legal in some states and not others, people with disabilities may also struggle to be able to afford to travel for the procedure."

### *Disabled Women of Color Are at Especially High Risk of Adverse Pregnancy Outcomes*

Our researchers recommend addressing the preconception health needs of a diverse population of women with disabilities as a strategy to optimize pregnancy outcomes and maximize health of women and infants.

### *Experiences of Women of Short Stature During and After Pregnancy*

Researchers interviewed nine women of short stature. One participant expressed, "one of the best things that I found is that I actually have a really strong support network of other moms with dwarfism."

### *Unequal Care, Unequal Outcomes*

Black disabled women have worse pregnancy care and outcomes than their white disabled peers:

- 38% of Black disabled women compared to 35% of white disabled women responded to the following statement: "I report my prenatal health as fair or poor."

- 18% of Black disabled women compared to 13% of white disabled women responded to the following statement: “I don’t have health insurance.”
- 63% of Black disabled women compared to 38% of white disabled women responded to the following statement: “I don’t have enough social support.”

### *Culturally Competent Preconception Care*

Competencies to demonstrate:

1. Grounding in conceptual models of disability and the history of discrimination that compounds disability
2. Consideration of social determinants of health
3. Recognition of disability as a dimension of human diversity

### *Biases for Clinicians to Eliminate*

1. Women with disabilities are non-sexual and cannot or should not have children
2. Valuing the fertility of white women over women of color

## **Community Living Equity Center**

The Community Living Equity Center (CLEC) was founded in late 2022 with the aim to address gaps in our knowledge about inequities in community living and participation experiences and outcomes faced by disabled people of color. We develop interventions to address equity by leveraging existing and new data sources and create new policy and systems change initiatives through active dissemination of findings and trainings for stakeholders. Funding is provided through the National Institute on Disability, Independent Living, and Rehabilitation Research.

### *Meet the Director: Teresa Nguyen*

“I am thrilled to be leading the work of the Community Living Equity Center. As a disabled, Vietnamese American woman, I recognize there has been a historical need in my community for the research and data that the Center



will be working on. The CLEC is taking a community-based participatory approach in our work and I'm really excited to have the disability community's perspectives and experiences help inform the research and information that we will put forth on equity in community living."

### *Logo Created by the Community*

The CLEC invited individuals from the disability community to submit their ideas for a logo that illustrates community living, equity, and people with disabilities! In alignment with the White House Executive Order on Advancing Equity, we define equity as, "the consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment."

### *Community Advisory Committee*

The community advisory committee consists predominately of disabled people of color with expertise to guide our research and knowledge translation activities.

### *Our Research Consists of Five Major Activities*

1. Racial and ethnic disparities in HCBS access and utilization
2. Barriers and facilitators in access to HCBS for people of color
3. Self-direction and community living outcomes for people of color
4. Promising practices in peer support models to advance equity in community living outcomes for people of color
5. Policy analysis and development to advance community living equity

## **New & Continued Initiatives**

### **Carrie Buck Distinguished Fellowship**

To honor Carrie Buck's memory and to take steps to rectify the injustice to which she and thousands of other people in the United States have been subjected, the Lurie Institute for Disability Policy has established the Carrie Buck Distinguished Fellowship. The fellowship, funded by the Ford

Foundation, is intended for activists, scholars, and community organizers with disabilities whose work draws national attention to systemic ableism in reproductive health policy.

### **New Project Funded by Robert Wood Johnson Foundation**

A team led by Dr. Caldwell will examine disabled people of color's experience with structural racism/ableism barriers in accessing Medicaid home- and community-based services.

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

This study addresses health disparities through research of national datasets, analyses of longitudinal health outcomes, administration of a national survey, and structured interviews with Deaf and hard-of-hearing mothers and the clinicians who work with them.

### **Disparities in Perinatal Care and Outcomes Among Black Women and Latinas with Physical Disabilities**

This mixed-methods study uses existing and new data to systematically examine perinatal disparities impacting Black women and Latinas with physical disabilities and develop targeted recommendations to address these disparities.

### **Advanced Rehabilitation Research and Training**

Our postdoctoral fellowship focuses on racial, ethnic, and disability-based health disparities affecting children and adults with disabilities.

Fellows improve the health of people with disabilities through state based public health programs.

Lurie researchers partner with the Massachusetts Department of Public Health, Health and Disability Program to explore the health needs of disabled Massachusetts residents.

## Engagement

The Lurie Institute for Disability Policy is committed to engaging the broader community about disability policy and advocacy, and disseminating our research findings to communities who are most impacted by the research. This year, through funding from the Ford Foundation, we established the Carrie Buck Distinguished Fellowship for activists, scholars, and community organizers with disabilities whose work draws national attention to systemic ableism in reproductive health policy. Our engagement took many other forms as well.

### **Lurie @ APHA**

Lurie researchers, postdoctoral fellows, graduate students, and undergraduate fellows presented at the annual meeting of the American Public Health Association in November 2022.

#### *Presentations:*

*Assault-Related Injury Among Deaf and Hard-of-Hearing Women in an Emergency Department Sample*, Frank Li

*Disabled Parents: ACS Estimates of Prevalence and Life Circumstances*, Miriam Heyman

*Ensuring the Rights of Parents With Substance Use Disorder Involved With The Child Welfare System: A Disability Rights Law Approach*, Robyn Powell

*Experiences of ASL Interpreters in Perinatal Care Settings*, Lauren Smith

*Food Insecurity at the Intersection of Disability and Race and Ethnicity in the U.S.*, Alexandra Mundis

*Living under a Microscope: The Social and Community Experiences of Disabled Parents*, Robyn Powell

*Minority Health and Issues Related to Intersectionality*, moderated by Gabrielle Katz

*Perspectives for Disabled Parents*, moderated by Nicole Lomerson

*Perspectives of Adults with Disabilities and Opioid Misuse: Qualitative Findings Illuminating Experiences With Stigma and Substance Use Treatment, Emily Ledingham*

*Severe Maternal Morbidity Among U.S. Women: Disparities at the Intersection of Physical Disability and Race or Ethnicity, Ilhom Akobirshoev*

*Severe Maternal Morbidity by Maternal Disability Status and Type in the U.S.: Evidence from Nationally Representative Data, Ilhom Akobirshoev*

*Honors:*

*Early Career Award, APHA Law Section: Robyn Powell*

*Disability Section's Career Enhancement Student Scholarship award: Mike Vetter*

*Posters:*

*Disability and Vulnerable Groups Inclusion in COVID-19 Policy and Planning: Analysis of Documents from Selected Sub-Saharan African Countries, Hussaini Zandam*

*Estimating the Effect of Care Recipient Hospitalizations on Weekly Hours of Informal Care in the Presence of Dementia, Mike Vetter*

*Gulf of a Distance: Communication and Accommodation Experiences of Deaf and Hard-of-Hearing People for Perinatal Care, Gabby Katz & Lauren Smith*

*Informal Caregiving Hours Provided to the Elderly 65+ With and Without Dementia by Spouses and Daughters, Mike Vetter*

*Sepsis-related Emergency Department Visits Among Elderly Adults with Intellectual and Developmental Disabilities, Hussaini Zandam*

## **Webinars**

The Lurie Institute for Disability Policy held numerous webinars in 2022, amplifying the voices of disabled people and their experiences. With topics informed by our advisory committees and community surveys, our webinars hold a space for lived experiences, theory, and practice to intersect,

equipping practitioners, researchers, and the disability community with nuanced perspectives.

“I feel pride that I don't allow being Black or being deaf to make me feel lesser in any way because society questions that. It's part of who I am.”

— Earl Allen, *Black, Disabled, Deaf, & Proud*

“You feel in some ways very much alone and yet at the same time on display.”

— Patrick Cokley, *Disabled Parents in the NICU*

“I'm trying to raise my children to understand that disability is just another factor and another aspect of who people are. It's nothing to change or hide and it's nothing to be ashamed of.”

— Morénike Giwa-Onaiwu, *Black, Disabled, Deaf, & Proud*

“The need for accessible information materials about sexual and reproductive health and contraception methods is vitally important.”

— Anne Valentine, *Perinatal Health of Women with Intellectual and Developmental Disabilities*

“It's like we're slicing the bean [of housing resources] into ever smaller slices. And the whole problem is that one bean is not enough.”

— Mike Oxford, *Affordable, Accessible Housing and Community Living Policy*

## **Honors**

Members of the Lurie Institute for Disability Policy team received accolades for their scholarship and service.

### *Switzer Research Fellowship*

Racial and Ethnic Healthcare Disparities Associated with Multiple Chronic Conditions Among People with Intellectual and Developmental Disabilities in the United States

Hussaini Zandam

### *Early Career Award, APHA Law Section*

Robyn Powell

*Career Enhancement Student Scholarship Award, APHA Disability Section*  
Mike Vetter

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

“The relationship between unmet need for home and community-based services and health and community living outcomes”

Natalie Chong, Ilhom Akobirshoev, Joe Caldwell, Steve Kaye, & Monika Mitra

*Staff Service Award, Heller School for Social Policy and Management*  
Amy AbuShanab

## Education

The Lurie Institute draws from Heller’s core competencies—social-justice informed, intellectually rigorous public policy research and analysis—through collaborations across Heller’s programs, faculty and students. We offer undergraduate, doctoral and postdoctoral fellowships for junior researchers interested in advancing disability rights and social justice.

### **Undergraduate Fellowship**

Established in 2019, the Undergraduate Fellowship in Disability Policy offers Brandeis University undergraduate students the opportunity to develop research skills and expand their knowledge of disability policy through direct research training with established Lurie Institute investigators. The 2021–2022 fellows presented their research at the annual conference of the American Public Health Association (APHA) and the New England Science Symposium.

“The fellowship has made me more aware of health-related disparities facing people with disabilities and how research can highlight these disparities in intersectional ways. In my new job related to public health consulting, I will be bringing a deep understanding of how disabled people are uniquely facing health disparities.

— Allie Mundis

“Before the fellowship, I had never done research outside of the classroom at Brandeis. The fellowship gave me the opportunity to develop my quantitative research skills and made me realize that I would like research to be a part of my future career.”

— Zach Williams

### **Honorable Jonathan Brant 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 because of the opportunity to conduct research that is rooted in social justice and change but more importantly for the chance to get to know and to collaborate with other researchers working in disability. As a researcher with a disability who has faced numerous challenges in working towards my goal, being rewarded a fellowship that specifically supports scholars conducting research in disability rights gives me great comfort in knowing that this work is supported.”

— Jessica Chaikof

### **Postdoctoral Fellowship**

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 was established in 2015 with funding from National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

“The postdoctoral fellowship at Lurie allows me to explore new areas of research and creates ample opportunities to hear from colleagues with diverse expertise and experiences in researching disability policy.”

— Luanjiao (Aggie) Hu

## Acknowledgments

We would like to express our sincere gratitude to the members of our community advisory board for their guidance in shaping our research.

### **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



- Norma Moran
- Jennifer Senda
- Laura Stout
- Heather Watkins

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

- Sarah Arana
- Karen M. Duguid
- Timothy R. B. Johnson
- Kim Kelstone
- April Lyon
- Rosalyn Maben-Feaster
- Jamie L. Maes-Eishen
- Robert C. Nutt
- Adrianna Smart
- Joann (JoJo) Skowzgird Forbes
- Christa Williams
- Melissa Elmira Yingst

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

- Earl Allen
- Judith Brown
- Patrick Cokley
- Morénike Giwa-Onaiwu

- Keith Jones
- 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

### **Community Living Equity Center**

- Christine Liao
- German Parodi
- Janie Meijas
- LaWanda Cook

- Andy Arias
- Bernard Baker
- Melody Cooper
- Conchita Hernandez
- Legorreta Tyree Brown
- Jean-Luc Pierite
- Elaina Seep

### **Carrie Buck Distinguished Fellowship**

- Colleen Flanagan
- Morénike Giwa Onaiwu
- Monica Porter
- Heather Watkins

## Contact Information

### **Lurie Institute for Disability Policy**

- Web: [lurie.brandeis.edu](http://lurie.brandeis.edu)
- Twitter: [twitter.com/LurieInstitute](https://twitter.com/LurieInstitute)
- Facebook: [facebook.com/LurieInstitute](https://facebook.com/LurieInstitute)

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

- Web: [centerforparentswithdisabilities.com](http://centerforparentswithdisabilities.com)
- Twitter: [twitter.com/NatRCPD](https://twitter.com/NatRCPD)
- Facebook: [facebook.com/NRCPD](https://facebook.com/NRCPD)

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

- Web: [disabilityandpregnancy.org](http://disabilityandpregnancy.org)
- Twitter: [twitter.com/dis\\_pregnancy](https://twitter.com/dis_pregnancy)

## **Community Living Policy Center**

- Web: [communitylivingpolicy.org](http://communitylivingpolicy.org)
- Twitter: [twitter.com/CLPolicy](https://twitter.com/CLPolicy)

## **Community Living Equity Center**

- Coming soon: [communitylivingequity.org](http://communitylivingequity.org)
- Email: [CLEquity@brandeis.edu](mailto:CLEquity@brandeis.edu)