



Brandeis

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

2020
Lurie Institute
for Disability Policy
ANNUAL REPORT

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.

The Lurie Institute was created by a generous gift from the Nancy Lurie Marks Family Foundation in 2007. Over the past fourteen 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.

LETTER FROM THE DIRECTOR

I am pleased to share this report highlighting the 2020 achievements of the Lurie Institute for Disability Policy.



The Lurie Institute for Disability Policy has always been committed to supporting the rights, well-being, and integration of people with disabilities. In a year like no other, we continued our mission of ensuring equity and inclusion for people with disabilities through our research, community engagement, and training projects. The events of 2020—the COVID-19 pandemic, George Floyd’s death and the subsequent groundswell of support for Black Lives Matter, the thirtieth anniversary of the Americans with Disabilities Act—have reminded us of public policy’s tangible effects. Our values must be put into practice, not relegated to theory: we intend our research to be used to inform policies that acknowledge the rights, dignity, and autonomy of people with disabilities, especially those who must also contend with racism, misogyny, and other forms of discrimination.

For instance, we worked with the Ford Foundation and the Sillerman Center for the Advancement of Philanthropy to publish “Civic Engagement and People with Disabilities: A Way Forward through Cross-Movement Building,” a report that highlights the difficulties people with disabilities encounter when trying to make change in their communities and ways that organizations can help address those roadblocks.

Although the pandemic prevented us from holding events in person, we continued to bring our research into the community with webinars and online forums through the Community Living Policy Center and National Research Center for Parents with Disabilities.

I invite you to enjoy this annual report. If you have questions, comments, or feedback, please don’t hesitate to get in touch.

MONIKA MITRA

Nancy Lurie Marks Associate Professor of
Disability Policy

Director, The Lurie Institute for Disability Policy

FACULTY & STAFF

MONIKA MITRA

Director

EUN HA NAMKUNG

Senior Research Associate

AMY ABUSHANAB

Assistant Director

ARI NE'EMAN

Visiting Scholar

ILHOM AKOBIRSHOEV

Research Scientist

WENDY PEVERILL-CONTI

Senior Department Coordinator

JOE CALDWELL

Senior Scientist

LAUREN SMITH

Research Associate

FINN GARDINER

Communications Specialist

ROBYN POWELL

Research Associate

MIRIAM HEYMAN

Senior Research Associate

SERAH NTHENGE

Postdoctoral Fellow

SANDY HO

Research Associate

ANNE VALENTINE

Research Associate

H. STEPHEN KAYE

Visiting Research Scientist

MARJI ERICKSON WARFIELD

Senior Scientist and Lecturer

FRANK LI

Research Associate

HUSSAINI ZANDAM

Postdoctoral Fellow

The background of the entire page is a deep blue color. It is decorated with a repeating pattern of stylized, concentric circles. Each circle is composed of many thin, parallel lines that radiate outwards from a central point, creating a sunburst or fan-like effect. These circles are arranged in a staggered, overlapping manner across the top and bottom portions of the page, leaving a white rectangular area in the center where the text is located.

RESEARCH

2020 RESEARCH

“For a kid who grew up around the time of the landmark passage of the ADA, I’m drawn to Lurie’s research work because stories and perspectives on disability are being told through research in ways that resonate with the disability community.”

—Sandy Ho, South Street Seminar

The Lurie Institute conducts wide-ranging research on topics affecting people with disabilities, their families, and their supporters, including health and healthcare, parenthood, civic engagement, opioid use, education, employment, and community living. Moreover, the Lurie Institute is home to two research centers, the National Research Center for Parents with Disabilities and the Community Living Policy Center.

The Lurie Institute manages more than \$2.7 million from federal, local, and philanthropic grants to support our work.

In 2020, Dr. Monika Mitra, the director of the Lurie Institute, was named co-editor in chief of the *Disability and Health Journal*. By leading the *Disability and Health Journal*, Dr. Mitra highlights significant findings in the field, features community-

NEWLY AWARDED RESEARCH PROJECTS



Piloting Data-Collection Strategies to Measure LTSS Needs and Service Use among Adults under Age 65 with Disabilities

PRINCIPAL INVESTIGATOR Dr. Joe Caldwell
FUNDER Long-Term Quality Alliance



Birth, Parenthood, and Health Behaviors of Fathers with Disabilities

PRINCIPAL INVESTIGATOR Dr. Monika Mitra
FUNDER HRSA



Service Provision to Parents with Disabilities in the Child-Welfare System

PRINCIPAL INVESTIGATOR Dr. Miriam Heyman
FUNDER Brandeis University Office of the Provost



Advanced Rehabilitation Research and Training Program on the Health and Functioning of People with Disabilities (Postdoctoral Fellowship)

PRINCIPAL INVESTIGATOR Dr. Monika Mitra
FUNDER National Institute on Disability, Independent Living, and Rehabilitation Research



Impact of COVID-19 on Medicaid Beneficiaries Receiving Home- and Community-Based Services

PRINCIPAL INVESTIGATOR Dr. Joe Caldwell
FUNDER The Commonwealth Fund

based and partnered research, and promotes junior investigators' research.

NEWLY AWARDED RESEARCH PROJECTS IN 2020

In 2020, Lurie Institute researchers received five new grants to explore new areas of disability research, including the effects on Medicaid recipients receiving home- and community-based services, data-collection strategies to understand how adults under sixty-five use long-term services and supports, and the experiences of fathers with disabilities.

CIVIC ENGAGEMENT

In May 2020, the Lurie Institute and the Sillerman Center for the Advancement of Philanthropy released "Civic Engagement and People with Disabilities: A Way Forward through Cross-Movement Building," written by Sandy Ho and Monika Mitra of the Lurie Institute and Susan Eaton of the Sillerman Center for the Advancement of Philanthropy.

"The visibility of openly disabled politicians has been powerful for me."

—Sandy Ho, "Disability Rights Are Civil Rights"

Funded by the Ford Foundation, this qualitative study surveyed people with disabilities across the United States about their efforts to make changes in their communities—and the systemic roadblocks they encountered. Although people with disabilities from a variety of backgrounds can be disengaged from civic participation, this disengagement is especially common among

people who experience multiple forms of discrimination, such as racism, misogyny, and classism. Philanthropic foundations can use the information in "Civic Engagement and People with Disabilities" to support civic-engagement organizations in creating accessible spaces for people with disabilities to organize across movements and influence public policy.

Following the release of the report, the Lurie Institute and the Center for American Progress cohosted "Disability Rights Are Civil Rights," a panel discussion featuring Rebecca Cokley, then-director of the Disability Justice Initiative of the Center for American Progress, Claribel Vidal of the Ford Foundation, and Sandy Ho of the Lurie Institute. In this webinar, the panelists highlighted ways that philanthropic foundations, advocacy groups, and individual activists can make civic engagement more accessible for people with disabilities of all racial, gender, cultural, class, and religious backgrounds.

"Philanthropic organizations need to integrate disability. People need to continue the learning and bridging that happen through relationships."

—Claribel Vidal, "Disability Rights Are Civil Rights"

For instance, philanthropic organizations, community organizers, and activists must acknowledge the role of racism in dividing the disability-rights movement. Philanthropic organizations can also build relationships with disability-rights groups to support them in their advocacy.

FACTS & FIGURES

Children of color with disabilities are less likely to have high-quality healthcare than white children with disabilities or nondisabled children of color—the effects of racism and ableism combined are greater than each would be alone.

These disparities persist even in states and metropolitan areas with the best healthcare systems in the country.

City, state, and federal public-health and social-service programs should place a priority on creating programs that address these disparities.

Akobirshoev, I., Mitra, M., Li, S.F., Dembo, R., Dooley, D., Mehta, A., & Batra, N. (2020). The compounding effect of race/ethnicity and disability status on children's health and health care by geography in the United States. Medical Care.

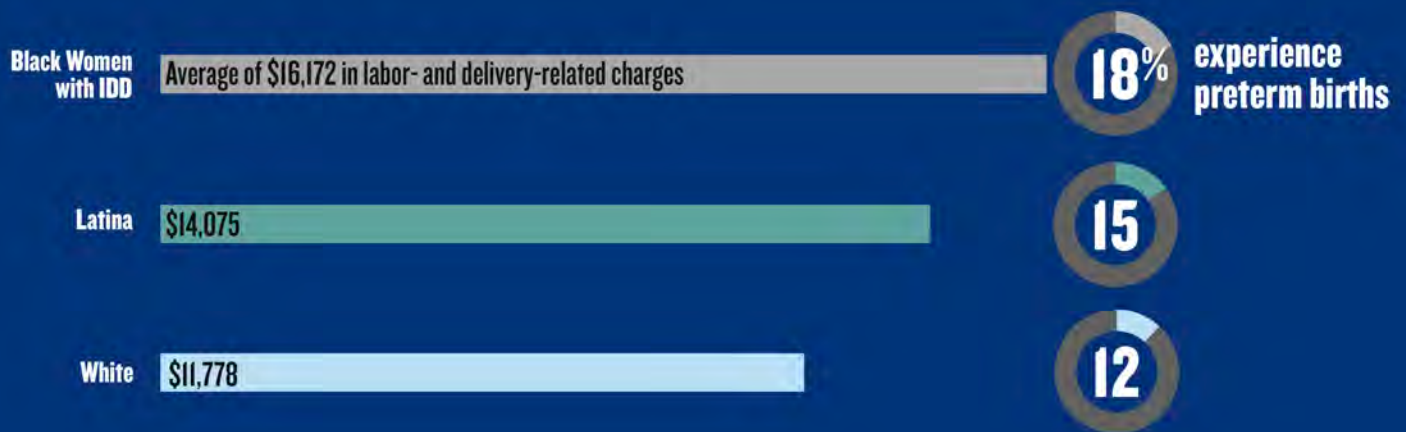


Pregnant women who are deaf or hard of hearing are at heightened risk of chronic conditions, pregnancy complications, and adverse birth outcomes.

Mitra, M., McKee, M.M., Akobirshoev, I., Valentine, A., Ritter, G., Zhang, J., McKee K., & Iezzoni, L.I. (2020). Pregnancy, birth, and infant outcomes among women who are deaf or hard of hearing. American Journal of Preventive Medicine.

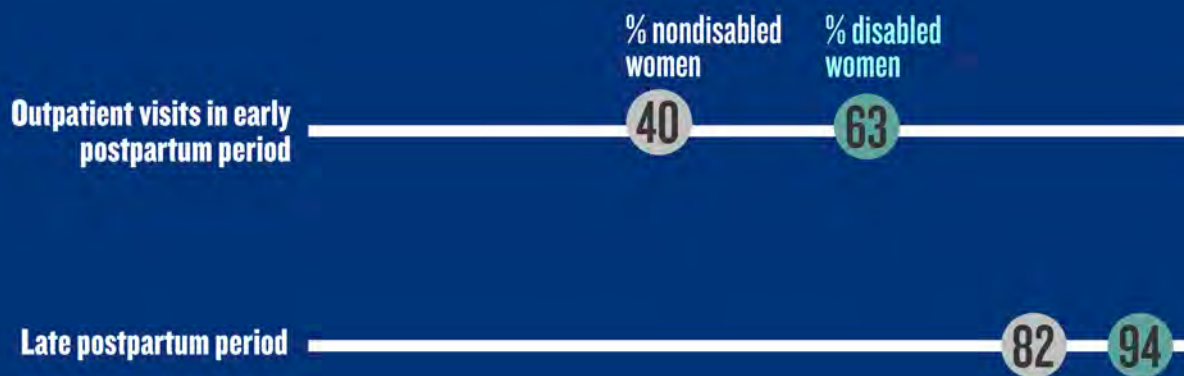
FACTS & FIGURES

Labor and delivery charges were higher for Black and Latina mothers than white mothers with intellectual and developmental disabilities, who were also at higher risk for birth complications than white mothers with IDD, including preterm births.



Akobirshoev, I., Mitra, M., Parish, S., Valentine, A., & Moore Simas, T. (2020). Racial and ethnic disparities in birth outcomes and labor and delivery charges among Massachusetts women with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 58(2), 126-138.

Women with intellectual and developmental disabilities were more likely to have other outpatient hospital visits than those without intellectual and developmental disabilities, both in the early and late postpartum periods.



Clements, K. M., Mitra, M., Zhang, J., & Parish, S.L. (2020) Postpartum health care among women with intellectual and developmental disabilities. *American Journal of Preventive Medicine*.

NATIONAL RESEARCH CENTER FOR PARENTS WITH DISABILITIES

“I think there’s been . . . a greater recognition of the capacity of individuals to live the whole human experience, including meeting folks and falling in love, and having relationships and having kids and all those things that many of us hold dear.”

—Mary Sowers, “Using Medicaid to Support Parents with Disabilities”

The National Research Center for Parents with Disabilities conducts research to understand the needs of parents with disabilities and their families, as well as prospective parents with disabilities. Our projects have included studies on the healthcare experiences of parents with disabilities; legislation protecting disabled parents from discrimination; racial and ethnic disparities; parents’ interactions with the child-welfare system; and support systems for parents with psychiatric disabilities and their families. Most recently, we’ve addressed the effects of COVID-19 on parents with disabilities through our webinars, blog posts, and social-media conversations.

IN A SURVEY OF

2,064
COURT CASES,



results showed that women were more likely to lose their parental rights if . . .



they had a history of drug or alcohol use



their income was below 200% of the federal poverty level



they were previously involved with the child-welfare system



experts testified against them in hearings



they received family-preservation or family-reunification services tailored to parents with disabilities

Powell, R., Parish, S.L., Mitra, M., Waterstone, M.E., & Fournier, S. (in press). Terminating the parental rights of mothers with disabilities: An empirical legal analysis. Missouri Law Review.

“People with disabilities are enjoying more opportunities than ever to live and work and participate in their communities, and that leads to people wanting to have relationships and form families, something that their nondisabled peers often do.”

—Robyn Powell, “Using Medicaid to Support Parents with Disabilities”

Our website, centerforparentswithdisabilities.org, provides resources for parents, professionals, and policymakers, including research summaries, reports, infographics, webinars, videos, workshops, and toolkits, most of which are available in English and Spanish. We also host a community blog for parents with disabilities to share their firsthand perspectives on parenthood, disability, civil rights, and community inclusion.

“How do a high-risk, almost deafblind mother and her potentially COVID-19–infected young daughter maintain social distance in a small one-bathroom bungalow?”

—Alicia Torres, “Life Is Not a Bowl of Cherries—It’s Empty,” National Research Center for Parents with Disabilities Community Blog



COMMUNITY LIVING POLICY CENTER

In *Olmstead v. L.C.*, the Supreme Court ruled that people with disabilities and older adults have the constitutional right to live in the community, but inconsistent enforcement has prevented many from enjoying that right. The Community Living Policy Center, or CLPC, researches home- and community-based services for people with disabilities in the United States, including housing, deinstitutionalization programs, and long-term services and supports such as personal-care attendants. Our research helps people with disabilities, as well as older adults, stay in their communities—and out of institutions, nursing homes, and other congregate settings. By understanding how existing services support people with disabilities, and how these services can improve, policymakers can use our research to develop programs and services that allow people with disabilities to be fully integrated members of their communities.

The current pandemic has underscored the need for home- and community-based services for people with disabilities and older adults—about 40 percent of all COVID-19 deaths in the United States have occurred in nursing homes and other long-term-care facilities. Over the past year, we've held webinars about the disproportionate impact COVID-19 has exerted on people with disabilities and older adults—and methods policymakers can use to address those inequities.

THE MONEY FOLLOWS THE PERSON PROGRAM

44 states and the District of Columbia participate in MFP



In top-performing MFP states, nursing-home residence rates went down more quickly than in other states

Top-performing states include Connecticut, Iowa, Louisiana, North Dakota, Ohio, and Washington



Sources: U.S. Department of Health & Human Services; Community Living Policy Center; National Health Policy Forum

Brandeis Lurie Institute for Disability Policy

CLPC

Upcoming Webinar

Using Medicaid to Support Parents with Disabilities

Friday, December 11, 2020
12:30pm - 2:00pm EST



Parenting is not considered an activity of daily living.

Government-funded home and community-based services, such as personal care attendant services, do not generally offer services to assist parents with disabilities with childrearing tasks.



CLPC
Community Living Policy Center



EDUCATION



EDUCATION

“Mentoring the next generation of disability leaders who will advance disability policy will ensure that the mission of the Lurie Institute will be realized for years to come.”

—Monika Mitra, South Street Seminar

The Lurie Institute is committed to supporting researchers who are dedicated to advancing the rights and opportunities of people with disabilities. Toward that end, we offer fellowships for undergraduates, doctoral students, and postdoctoral researchers; thesis supervision for graduate students; professional mentoring for students, established researchers, and recent graduates; and courses and seminars on disability justice, public health, and public policy.

POSTDOCTORAL FELLOWSHIPS

Intended for researchers who have recently completed a PhD in disability studies, sociology, public health, or related disciplines, the Lurie Institute’s Postdoctoral Fellowship offers valuable experience in research that improves the lives of people with disabilities and those who support them. Last year, the program received new

2020 GRADUATES

SASHA ALBERT · PhD

DISSERTATION “State-Level Policy and Abortion Clinics: Understanding How Clinics Adapt to Challenging and Changing Policy Environments”

ROBBIE DEMBO · PhD

DISSERTATION “Social Support and Health in Parents of Children with Developmental Disabilities: A Network-Oriented Approach”

ROBYN POWELL · PhD

DISSERTATION “The Intersection of the Americans with Disabilities Act and the Child Welfare System”

funding from the National Institute on Disability, Independent Living, and Rehabilitation Research.

In 2020, our postdoctoral fellows were Drs. **Eun Ha Namkung**, **Serah Nthenge**, and **Hussaini Zandam**.

SPOTLIGHT: POSTDOCTORAL RESEARCH

Sex Education and Contraception Use among Women with Cognitive Disabilities



Compared with nondisabled women, women with cognitive disabilities were less likely to receive comprehensive sex education before having sex for the first time.



Women with cognitive disabilities who were taught more sex-education topics were more likely to use contraception when they started having sex.

Namkung, E.H., Valentine, A., Warner, L., & Mitra, M. (2021) Contraceptive use at first sex among adolescent and young adult women with disabilities: The role of formal sex education. Contraception.

GRADUATE STUDENTS

Three Lurie-affiliated doctoral students successfully defended their dissertations in 2020: **Robyn Powell, Robbie Dembo, and Sasha Albert.** Dr. Albert is now a senior researcher at the Health Policy Commission, Dr. Dembo is a postdoctoral fellow at the University of Wisconsin–Madison, and Dr. Powell is a visiting faculty member at Stetson University Law School.

“If there is anything we know about challenging social issues, it is that we cannot solve them without peers and mentors. At the Lurie Institute, I found my match.”

—Kartik Trivedi, PhD candidate, South Street Seminar

Our current graduate students are **Natalie Chong, Emily Crandall, Gabby Katz, Kartik Trivedi, and Anne Valentine.**

The **Hon. Jonathan Brant Endowed Doctoral Scholarship**—named after Judge Jonathan Brant, a Brandeis alumnus and advocate for disability rights—provides financial and academic



GABBY KATZ
2020–21 BRANT FELLOW

support to Brandeis doctoral students specializing in disability policy. The 2020–21 Brant Fellow is **Gabby Katz.** Previous Brant Fellows include Drs. Robbie Dembo ’20 and Robyn Powell ’20.

“I’m currently working with the Lurie Institute in investigating ways to center the health and social services people receive in their home . . . We want to uncover processes that empower people to choose services that support their personal life goals.”

—Gabby Katz, PhD student and Brant Fellow, South Street Seminar

UNDERGRADUATES

Established in 2019, the Lurie Institute’s 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. Undergraduate fellows were invited to present at research conferences alongside Lurie researchers; for example, undergraduate fellows presented for the American Public Health Association, the South Street Seminar, and the New England Science Symposium. As of fall 2020, we have trained eighteen fellows.

The 2019–2020 undergraduate fellows were **Carmela Belizaire, Anna Davidge, Shoshi Finkel, Maddy Pliskin, Jack Rubinstein, and Regina Tham**, and the 2020–2021 undergraduate fellows are **Aishwarya Khanna, Luca Swinford, Michael Atkins, Sabrina Chow, Anna Cass, and Zoë Pringle**.

UNDERGRADUATE MENTORING

Mentors

Ilhom Akobirshoev
Joe Caldwell
Miriam Heyman
Frank Li
Rachel Sayko Adams
Lauren Smith

Students

Anna Cass
Michael Atkins
Luca Swinford
Sabrina Chow
Zoë Pringle
Aishwarya Khanna

“I have been provided with a research opportunity that I never thought would be possible at the undergraduate level—an opportunity to work with brilliant and caring people who are leading research regarding marginalized groups to advocate for social change.”

—Michael Atkins, Lurie Undergraduate Fellow, South Street Seminar

OTHER MENTORING

Monika Mitra

2020 Robert Wood Johnson Foundation
Mentor to Health Policy Research Scholars
Program

AcademyHealth 2020 Annual Research
Meeting Virtual Conference

The background of the entire page is a solid dark blue. Overlaid on this are several large, overlapping circles. Each circle is composed of numerous thin, parallel lines that radiate from its center, creating a sunburst or fan-like effect. The circles are arranged in a way that they partially overlap each other, with some appearing more prominent than others.

COMMUNITY ENGAGEMENT

EVENTS & WEBINARS

SELECTED LURIE INSTITUTE WEBINARS

Best Practices in the HCBS Settings Rule: Bringing HCBS to the Twenty-first Century

Presenters Ari Ne’eman, Samantha Crane,
and Alison Barkoff

Moderators Anne Womer and Joe Caldwell

Little People and Parenting

Presenters Laura Stout, Kelly Lee, and Francisca
Winston

Supporting the Lives of Children of Disabled Parents

Presenters Erin Andrews and Kara Ayers

Long-Term Services and Supports Coordinator: A Promising Practice to Advance Independent Living Philosophy and Recovery Principles within Integrated Care

Presenters Dennis Heaphy

Passing State Legislation to Protect the Rights of Parents with Disabilities

Presenters Robyn Powell, Kimberly Tissot, and
Sara Gelser

Disability Rights Are Civil Rights: A Conversation on Inclusive Democracy

Presenters

Rebecca Cokley and Claribel Vidal

Moderator Sandy Ho

Using Medicaid to Help Parents with Disabilities

Presenters Robyn Powell, Mary Sowers, and
Nikki Villavicencio

SELECTED PRESENTATIONS BY LURIE FACULTY AND STAFF

MONIKA MITRA

Disability-Related Disparities in Maternal Health in the United States

South Asia Centre for Disability Inclusive Development & Research, Indian Institute of Public Health, Hyderabad, India

Intersecting Research on Opioid Misuse, Addiction, and Disability Services

Institute on Disability, University of New Hampshire Disability Statistics Workshop

ILHOM AKOBIRSHOEV

Does Medical Home Reduce the Economic Burden Related to Care Coordination for Children with Special Health-Care Needs?

American Public Health Association

Emergency-Department Visits Involving Opioid Use Disorder and Associated Mortalities among Deaf or Hard-of-Hearing Adults in the US

Annual Disability Statistics Compendium

FINN GARDINER

Neurodiversity Rising: Eliminating Bias in Hiring

Neurodiversity in the Workplace

SANDY HO

ADA at 30: Building an Inclusive Progressive Movement

Center for American Progress Fund

EUN HA NAMKUNG

Birth Intention of US Fathers with Disabilities

American Public Health Association

SERAH NTHENGE

Perinatal Experiences of Childbearing Women with Physical Disabilities

AcademyHealth Annual Research Meeting

ROBYN POWELL

Family Law and the ADA: Treatment Plans, Reasonable Accommodations, and Resources

Office of Respondent Parents' Counsel's Carrie Ann Lucas Disability Advocacy Training

Supporting Disabled Parents and Their Families: Perspectives and

Recommendations from Parents, Attorneys, and Child-Welfare Professionals

PART

LAUREN SMITH

Clinician Experiences Managing Pregnancy Care of Women with Intellectual Disabilities

Navigating Caregiver Roles in Pregnancy Care

HUSSAINI ZANDAM

Prevalence of HIV among Women with Disabilities and Use of Modern Contraceptives in Sub-Saharan Africa

American Public Health Association

COMMUNITY PARTNERS & ADVISORY BOARDS

ORGANIZATIONS

ADvancing States
American Association
of People with
Disabilities
American Bar
Association
American Council of
the Blind
American Foundation
for the Blind
Arc of the United
States
Association of
University Centers on
Disabilities
Autism Women's and
Nonbinary Network
Autistic Self Advocacy
Network
Boston Center for
Independent Living
Centene Corporation

Child Welfare League
of America
Disability Policy
Consortium
Disability Rights
Education & Defense
Fund
Employment Options,
Inc.
Massachusetts
Behavioral Health
Partnership
Massachusetts
Department of
Mental Health
Massachusetts
Bureau of Substance
Addiction Services
MassHealth
Mental Health
America

National Association
of the Deaf
National Association
of Social Workers
National Disability
Rights Network
Psychiatric
Rehabilitation
Association
Topeka Independent
Living Resource
Center
Washington Division
of Behavioral Health
and Recovery
Washington Research
and Data Analysis
Washington State
Independent Living
Council

PEOPLE

Elizabeth Bostic
Lydia X.Z. Brown
Reid Caplan
Nikki Cherry
Henry Claypool
Kim Connor
Susan Connors
Jess Cuculick
Cheryl Cumings
Deborah Delman
Maryanne Frangule
Morénike Giwa-
Onaiwu
Jill Hatcher
Melinda Haus
Dennis Heaphy
Barbara Herbert
Kevin Irvine
Julie Kegley
Jeff Keilson

PEOPLE (CONTINUED)

Erin Krebs	Roslynn Rubin
Jennifer Lee	Mark Salzer
Linda Long-Bellil	Leo Sarkissian
Mike McKee	Nicole Lomerson
Spencer Milo	Shickling
Mike Oxford	Jennifer Senda
Susan Parish	Denise Simon
Julie Petty	Laura Stout
John Pirone	Susan Vaughan
John Piselli	Heather Watkins
Tammy Rayess	Anne Whitman
Lisa Razzano	
Roxanne Reddington	
Wilde	
Carmen Rosado	

ACKNOWLEDGMENTS

Report written and designed by Finn Gardiner, Lurie Institute Communications Specialist.

The Lurie Institute for Disability Policy receives financial support from the following organizations:

- The Nancy Lurie Marks Family Foundation
- Commonwealth Fund
- Health Resources and Services Administration
- Massachusetts Department of Public Health
- National Institute on Disability, Independent Living, and Rehabilitation Research
- National Institutes of Health

CONTACT US

LURIE INSTITUTE

lurie.brandeis.edu

facebook.com/LurieInstitute

twitter.com/LurieInstitute

NATIONAL RESEARCH CENTER FOR PARENTS WITH DISABILITIES

centerforparentswithdisabilities.org

facebook.com/nrcpd

twitter.com/NatRCPD

COMMUNITY LIVING POLICY CENTER

communitylivingpolicy.org

twitter.com/CLPolicy