# The National Research Center for Parents with Disabilities: Overview

November 2021

## Introduction

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Although society has become increasingly accepting of parents with disabilities, there's still work to be done. The effects of eugenics, systemic racism, and other social ills continue to strip disabled parents of their social support networks, civil rights, and human dignity. To eliminate these prejudices and work toward a more equitable future for parents with disabilities, the **National Research Center for Parents with Disabilities**, or Parenting Center, conducts research and provides training to improve the lives of these parents and their families—especially parents of color. Led by principal investigators Drs. Monika Mitra (Brandeis University) and Linda Long-Bellil (University of Massachusetts Chan Medical School), the Parenting Center is housed at the Lurie Institute for Disability Policy at Brandeis University.

To ensure that our research reflects the needs of the community we serve, we've created a National Advisory Board of racially and ethnically diverse parents with a range of disabilities. We also collaborate with partners from universities across the United States, including the University of Michigan, Arizona State University, Rochester Institute of Technology, the University of Massachusetts, Gallaudet University, and the University of Cincinnati.

The Parenting Center has three goals:

1. Use population research and state policy analysis to address gaps in knowledge about the experiences, difficulties, and needs of parents with disabilities and their families, especially parents of color and their families;



National Research Center for Parents with Disabilities

Centro Nacional de Investigación para Padres con Discapacidades



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- 2. research supports for parents with various disabilities and their families by developing, adapting, testing, and expanding intervention programs; and
- 3. translate our research findings for policymakers, self-advocates, service providers, and the general public. Our knowledge-translation efforts include a website with comprehensive information about parents with disabilities, webinars featuring experts on parenthood and disability, summaries of our research findings, and plain-language writing.

## **Research Projects**

To meet these goals, we will conduct six wide-reaching research projects that include quantitative and qualitative analysis, education and training about parents with disabilities, and intervention programs for service providers.

**Project 1a · Project Director: Dr. Monika Mitra, Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University** We will analyze largescale national data sets to learn about the needs and experiences of parents with disabilities, especially parents of color and their families. Policymakers and service providers can in turn use these data to improve policies and programs geared toward parents with disabilities.

**Project 1b** • **Project Director: Dr. Robyn Powell, Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University:** For Project 1b, we will analyze laws that allow courts in the fifty states and the District of Columbia to use disability as grounds for terminating parental rights. We will also hold interviews with parent attorneys to understand the effect of these laws on parents with disabilities, as well as the influence of racial and ethnic prejudice on judges' rulings.

**Project 2a · Project Director: Dr. Joanne Nicholson, Institute for Behavioral Health, Heller School for Social Policy and Management, Brandeis University:** We will adapt the ParentingWell intervention, a routine approach to adult behavioral healthcare that centers parenting experiences and considerations, for racially and ethnically diverse parents with psychiatric disabilities.

**Project 2b** · **Project Director: Dr. Kara Ayers, University of Cincinnati:** We will develop and test the feasibility and acceptability of Empowered Disabled Parenting, a peer support program for parents with intellectual disabilities that helps them navigate service systems.

**Project 2c** • **Project Director: Dr. Michael McKee, University of Michigan:** We will also develop and test the feasibility and acceptability of Deaf Empowered Parenting, a peer support program for Deaf parents that helps them navigate service systems.

**Project 2d** · **Project Director: Dr. Elizabeth Lightfoot, Arizona State University** We will create and test a program that will teach child welfare workers about the needs of parents with disabilities to improve these workers' approaches to disabled parents and their families.

### **Dissemination Plan**

We will also work with our national partners—including the AUCD, ARC, National Disability Rights Network, American Council of the Blind, American Foundation for the Blind, Mental Health America, Autistic Self Advocacy Network, the Child Welfare League of America, Autism Women & Nonbinary Network, and the Psychiatric Rehabilitation Association—to develop workshops, webinars, plainlanguage summaries, policy briefs, information sheets, and other resources to share our research findings and teach policymakers, service providers, self-advocates, attorneys, and other researchers about the needs and experiences of parents with disabilities. We will also partner with our International Consortium of Research on Parents & Parenting with Disabilities to share ideas and lessons learned, so that we can expand our global reach.



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Activities/ Products	Parents & grandparents with disabilities & their families	Advocates	Child-welfare workers & social workers	Attorneys & judges	Medical & behavioral health professionals	Policymakers	Researchers
Bilingual PEP Center websites							
Social media							
Webinars on supporting parents with disabilities (Continuing- education/accredited whenever relevant; topics identified by National Advisory Board)							
Webinar featuring International Consortium of Researchers on Parents & Parenting with Disabilities					$\bigcirc$		
Peer-reviewed journal articles & conference presentations							
Community blog							Š
State of the Science conference (virtual)	Ø						
Searchable database of resources, including local Protection & Advocacy Organizations							4

**Target Audience** 

	Parents & grandparents with disabilities & their families	Advocates	Child-welfare workers & social workers	Attorneys & judges	Medical & behavioral health professionals	Policymakers	Researchers
Data dashboard, enabling users to easily find links to relevant state and national data points pertaining to the prevalence and life circumstances of disabled parents							
Policy dashboard providing a snapshot of the parental rights laws in all fifty states and Washington D.C.							
ParentingWell resources, adapted for diverse and marginalized parents							
Resources from Disabled Empowered Parenting and Deaf Empowered Parenting Interventions							
Intervention resources for child welfare professionals							
Training suite for legal professionals							
How-to videos, parenting tips, forums							
Policy and research briefs, white papers, state policy analyses, plain language article summaries, other policy and advocacy materials and tools							5 of 8

### **Accessible Version of Dissemination Plan**

Our selected dissemination activities include the following activities and products:

Bilingual PEP Center websites, which have a target audience of parents and family members; advocates; child-welfare workers and social workers; attorneys and judges; medical and behavioral health professionals; policymakers; and researchers.

Social media, which have a target audience of parents and family members; advocates; child-welfare workers and social workers; attorneys and judges; medical and behavioral health professionals; policymakers; and researchers.

Webinars on supporting parents with disabilities (Continuing-education/accredited whenever relevant; topics identified by National Advisory Board), which have a target audience of parents and family members; advocates; child-welfare workers and social workers; attorneys and judges; medical and behavioral health professionals; and researchers.

Webinar featuring International Consortium of Researcher on Parents & Parenting with Disabilities, which has a target audience of parents and family members; advocates; child-welfare workers and social workers; attorneys and judges; medical and behavioral health professionals; policymakers; and researchers.

Peer-reviewed journal articles and conference presentations, which have a target audience of advocates; medical and behavioral health professionals; policymakers; and researchers.

Community blog, which has a target audience of parents and family members; advocates; child-welfare workers and social workers; medical and behavioral health professionals; and researchers.

State of the Science conference (virtual), which has a target audience of parents and family members; advocates; child-welfare workers and social workers; attorneys and judges; medical and behavioral health professionals; policymakers; and researchers.

Searchable database of resources, including local Protection & Advocacy Organizations, which has a target audience of parents and family members as well as advocates. Data dashboard, enabling users to easily find links to relevant state and national data points pertaining to the prevalence and life circumstances of disabled parents (Research Project 1a), which has a target audience of advocates; policymakers; and researchers.

Policy dashboard providing a snapshot of the parental rights laws in all fifty states and Washington D.C. (Research Project 1b), which has a target audience of parents and family members; advocates; and policymakers.

ParentingWell resources, adapted for diverse and marginalized parents (Research Project 2a), which have a target audience of parents and family members; advocates; child-welfare workers and social workers; medical and behavioral health professionals; policymakers; and researchers.

Resources from Disabled Empowered Parenting and Deaf Empowered Parenting Interventions (Research Projects 2b and 2c), which have a target audience of parents and family members; advocates; and child-welfare workers and social workers.

Intervention resources for child welfare professionals (Research Project 2d), which have a target audience of child-welfare workers and social workers.

Training suite for legal professional, which has a target audience of parents and family members; advocates; child-welfare workers and social workers; and attorneys and judges.

How-to videos, parenting tips, forums, which have a target audience of parents and family members as well as advocates.

Policy and research briefs, white papers, state policy analyses, plain language article summaries, other policy and advocacy materials and tools, which have a target audience of parents and family members; advocates; child-welfare workers and social workers; attorneys and judges; medical and behavioral health professionals; and policymakers.

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