

Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program
Division of Developmental and Behavioral Pediatrics
Cincinnati Children's Hospital Medical Center
University of Cincinnati Center for Excellence in Developmental Disabilities

Project Abstract

Disabled Parenting Project (DPP): Leveraging Research to Inform Social Policy

Diane Burns; Felicia Foci, MSOT, OTR/L; Emily Jones, MS, MEd, CCLS; Tiffany Moody;
Kara Ayers, PhD and Ilka Riddle, PhD

Project Summary

Background: Women with intellectual and developmental disabilities (IDD) encounter numerous barriers to healthcare services, including environmental, physical, informational, attitudinal and other barriers. As the number of women with IDD reaching reproductive age grows, healthcare systems and providers need to be prepared to provide quality care for these women. There is a paucity of resources for medical professionals and self-advocates on the topic of pregnancy and parenting with IDD. Resources for self-advocates are largely inaccessible and difficult to find.

Objectives: Our project sought to fill an educational gap by creating two evidence-based fact sheets to be utilized by self-advocates and OB/GYNs. The Disabled Parenting Project (DPP) SEBM team selected Robyn Powell, JD, PhD, research associate at Brandeis University and attorney at law as our Policy Partner. With her research expertise on the needs and experiences of parents with disabilities and their children, the intersection of disability law and the child welfare system, and access to perinatal care for disabled women and associated child outcomes, Robyn Powell provided valuable input on important topics to address with the fact sheets and avenues for dissemination.

Methods: For this project, we followed the evidence-based decision making (EBDM) model. Our clinical question was as follows: "Among healthcare providers and women with developmental disabilities, does providing information about pregnancy (including needed resources and adaptations), compared to standard practice, improve outcomes during the prenatal, delivery and postnatal periods?" In order to create two fact sheets with similar but distinct information, two literature searches were completed. The first literature review addressed medical outcomes and information that would be beneficial for healthcare providers. The second literature review, geared towards self-advocates, guided our search for community-based resources. Key themes from the literature reviews and community resources were summarized into fact sheets.

Results: We developed two informational factsheets, one for healthcare providers titled "Providing Prenatal Care for Women with Developmental Disabilities" and one for women with disabilities called "So You Are Going to Have a Baby: A Guide for Women with Disabilities". Once drafted, the fact sheets were edited for readability, accessibility, and practicality. We solicited feedback from several content experts, including physicians, self-advocates and mothers with IDD.

Next Steps: Our final step will be to disseminate our factsheets primarily online via the DPP website, shared interested groups, topic experts, and social media platforms.