

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

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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.

When it comes to pregnancy and parenting, women with IDD have the same needs as other women, including being treated with dignity and respect.

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. Our project sought to fill an educational gap.

Objectives

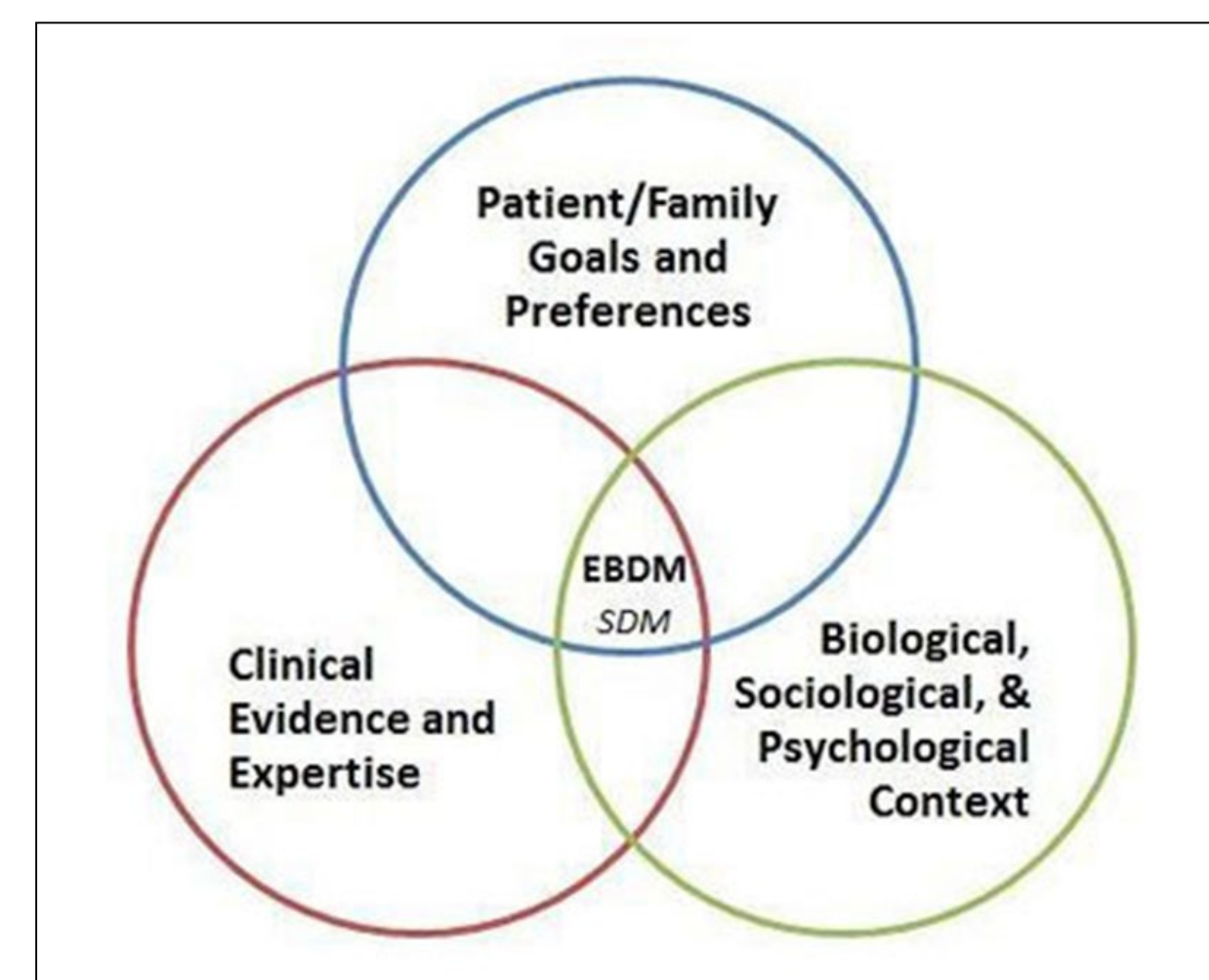
Our aim was to create two evidence-based fact sheets to be utilized by 1) OB/GYNs and 2) pregnant women with intellectual and developmental disabilities.

Policy Partner: We partnered with Robyn Powell, JD, PhD, research associate at Brandeis University and attorney at law. 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 our fact sheets and avenues for dissemination.



Methods

For this project, we followed the evidence-based decision making (EBDM) model.



Clinical Question

- P (Population/Problem): Among healthcare providers and women with developmental disabilities
- I (Intervention): Does providing information about pregnancy (including needed resources and adaptations)
- C (Comparison): Compared to standard practice
- O (Outcome): Improve outcomes
- T (Time): During the prenatal, delivery and postnatal periods?

Provider Education

Target Population: OB-GYNs, primary care physicians and nurses or nurse educators who care for or may care for women with IDD.

Project Steps:

- A review of 38 peer-reviewed journal articles was completed
- Key themes/important highlights were summarized into a provider fact sheet
- Edits were made based on feedback provided by content experts, including a developmental pediatrician, parents with IDD, and a board-certified maternal-fetal medicine physician

Parent Education

Target Population: Women with IDD who are pregnant or who are thinking about becoming pregnant

Project Steps:

- A review of 18 peer-reviewed journal articles was completed
- The literature review guided a secondary search for community-based resources
- Key themes were summarized into a fact sheet for women with IDD
- Edits were made based on feedback from self-advocates and mothers with IDD.

Results

We developed two (2) informational factsheets, one for healthcare providers and one for women with disabilities:

Provider Factsheet

“Providing Prenatal Care for Women with Developmental Disabilities”



Parent Factsheet

“So You Are Going to Have a Baby: A Guide for Women with Disabilities”



To access Fact Sheets, scan this QR code:

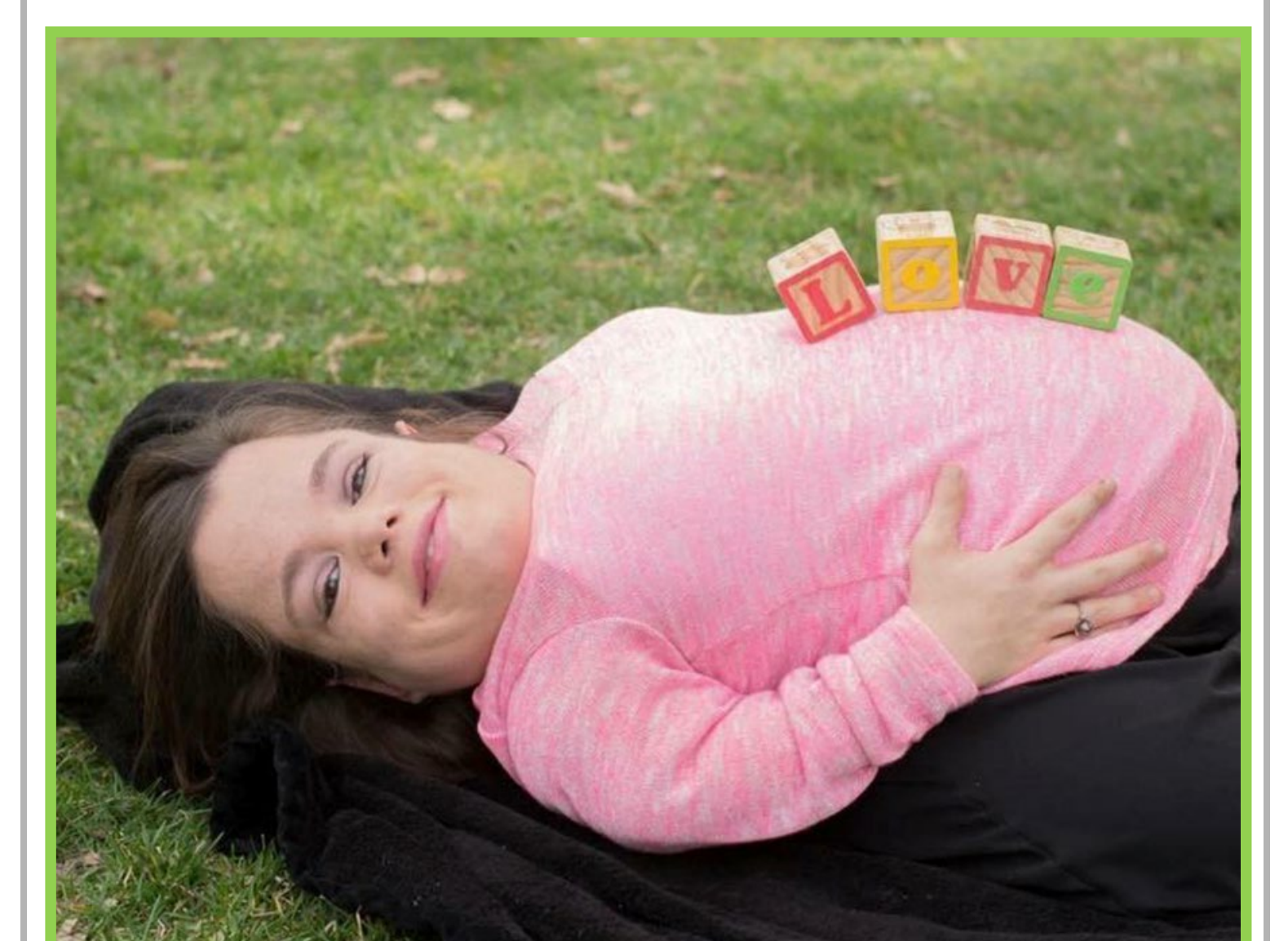


Next Steps

Dissemination

Conducted primarily online through:

- The Disabled Parenting Project website
- Shared interest groups (e.g. the Down Syndrome Association, Planned Parenthood, etc.)
- Topic experts (maternal-fetal providers, developmental pediatricians)
- Social media platforms for women with developmental disabilities



Resources

Select Scholarly Articles:

- Smeltzer, S. C. & Sharts-Hopko, N. C. (2005). A provider's guide for the care of women with physical disabilities and chronic health conditions. CDC.
- Stockburger, S. & Omar, H. A. (2015). Women with disabilities: reproductive care and women's health. Pediatrics Faculty Publications, 8(4), 429-447.
- Greenwood, N. W., & Wilkinson, J. (2013). Sexual and reproductive health care for women with intellectual disabilities. International Journal of Family Medicine, 2013, 1-8.
- Parish, S. L. et al (2015). Pregnancy outcomes among U.S. women with intellectual and developmental disabilities. American Journal on Intellectual and Developmental Disabilities, 120(5), 433-443.
- Darney, Blair G., Frances M. Biel, Brian P. Quigley, Aaron B. Caughey, Willi Horner-Johnson (2016). Primary Cesarean Delivery Patterns among Women with Physical, Sensory, or Intellectual Disabilities. Women's Health Issues 27-3 (2017) 336-344.

Select Community Resources:

- Being a Healthy Adult: How to Advocate for Your Health and Health Care:
<http://rwjms.rutgers.edu/boggscenter/products/documents/TransitiontoAdultHealthcare-EN-complete.pdf>
- Transition to Adulthood: A Health Care Guide for Youth and Families:
<http://rwjms.rutgers.edu/boggscenter/products/documents/TransitiontoAdultHealthcare-EN-complete.pdf>
- Take Charge! A Reproductive Health Guide For Women with Disabilities:
<https://www.accessliving.org/index.php?download=1410gacfi270>

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