

Title: Identifying the impact of ableism on maternal health outcomes among Medicaid-enrolled women with IDD
Protocol Number: 2404010507
Sponsor: National Institute of Child Health and Human Development (NICHD)
Investigator: Lindsay Shea, MS, DrPH, Associate Professor AJ
Drexel Autism Institute
3020 Market Street, Suite 560
Philadelphia PA, 19104
poddstudy@drexel.edu

GENERAL INFORMATION

Topic: The purpose of this research is to survey and interview providers about perinatal care delivery to patients with I/DD.

Voluntary: Your participation in this research study is voluntary and you may withdraw at any time. You may skip any question that you do not wish to answer or that makes you uncomfortable in any way. At the end of the survey, we will ask to retain your email for payment purposes. This is optional. Participating in the study will not affect your employment.

Confidentiality: Your responses will be confidential (not released to employers, insurers, patients, or anyone other than research staff of this study). To keep your information confidential, your survey will be labeled with a code rather than your name or other details that could identify you. Your name and contact information will be stored in secure limited access network, with access restricted to authorized study personnel only. While we plan to publish findings from this study, we won't include any personal information that could let others know who you are. Your survey responses may be combined with existing administrative health care data maintained by Medicaid programs for research purposes. Any information that could directly identify you will be removed before analysis and dissemination. Limited information from your survey may continue to be used after the study is over, for other research, education, or other activities but this would never include your identifiable information.

Benefit and Rights: Research can lead to new discoveries and may potentially benefit from the use of the data or discoveries. You will not have rights to these discoveries or any proceeds from them. Answering our survey won't benefit you directly. We hope what we learn will help other people in the future.

Data Sharing: Your identifiable private information may be stripped of identifiers and used for future research studies or distributed to another researcher for future research studies without additional informed consent.

Consent/Assent to Collect for Unspecified Future Research: This project involves the option to allow the study team to keep your data for use in future research. I understand that it is my choice whether to allow future use of my data. I understand that if my ability to consent or assent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study. **By completing the survey, you are indicating your consent to participate in the study.**

Compensation: To thank you for taking part in our study, we'll send you a \$200 gift card after you take the survey.

Contact Information: If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, please contact the research team using the email address on the front page of this form. This research is being overseen by an Institutional Review Board ("IRB"). An IRB is a group of people who perform independent review of research studies. You may talk to them at (267) 359- 2471 or HRPP@drexel.edu if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.