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A COMPREHENSIVE POLICY ANALYSIS TO ADDRESS THE PUBLIC HEALTH DILEMMA OF SYSTEMIC  
ABLEISM AND PATIENT DISTRESS FOLLOWING PRENATAL SCREENING FOR DISABILITIES

by

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A Dissertation Submitted to the School of Public Health of Georgia State University in Partial

Fulfillment of the Requirements for the Degree:

DOCTOR OF PUBLIC HEALTH

ATLANTA, GEORGIA 30303

## Approval Page

A Comprehensive Policy Analysis to Address the Public Health Dilemma of Systemic Ableism and  
Patient Distress Following Prenatal Screening for Disabilities

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Proposed final defense date: March 7, 2024

## Author's Statement Page

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Stephanie Hall Meredith

A handwritten signature in cursive script that reads "Stephanie Meredith".

Signature of Author

## Dedication and Acknowledgment

This dissertation is dedicated foremost to my husband and children. My husband, Justin Meredith, supported me throughout this journey with words of encouragement, financial support, and help with kids. I love him, and he's my person. I am deeply grateful to my daughter, Lily, who supported me all along by bringing me food, encouraging me to have fun, being understanding about having a busy mom, and even helping clean up transcriptions of interviews. Many thanks to my daughter, Kate, for her unwavering support and encouragement and for her help with holding down the fort at home and to Andy Meredith, my son with Down syndrome who forever changed how I view the world in the best ways and who makes me laugh and inspires me with his confidence. They are my inspiration and joy.

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without Nancy Iannone, Harold Kleinert, and Madeleine Will. Thanks also to Andy Imparato and Daniel Crimmins for the AUCD Leadership Seminar that inspired me to return to school.

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## Abstract

**Background:** For nearly twenty years, research studies have demonstrated that the majority of pregnant patients do not receive the information and support they need when learning about a potential disability diagnosis (Meredith et al., 2023; Nelson Goff et al., 2013; Skotko, 2005).

These negative experiences and lack of information can lead to lasting emotional harm for the pregnant patient and negatively impact patient/provider relationships (May et al., 2020).

Therefore, the purpose of this policy analysis is to identify potential policy solutions that can address this problem.

**Methods:** Using the Bardach Model for Policy Analysis, I applied the eightfold path which includes 1. defining the problem; 2. assembling evidence; 3. constructing the alternatives; 4. selecting the criteria; 5. projecting the outcomes; 6. confronting the trade-offs; 7. deciding; 8. and telling the story. In completing Step 2, “Assembling Evidence,” I conducted a targeted literature review and qualitative interviews with 10 different interdisciplinary and bipartisan policy experts using the responsive interview approach, then I applied the Framework Method to analyze interview data.

**Results:** The literature and interviews suggest that federal policy initiatives are unlikely to pass given the current political climate but can be effective at bringing skeptical stakeholders to the table. The most cost effective and promising solutions involve 1. applying for research funding to improve outcomes for people with disabilities as a health disparities population at the first point on the life course and 2. advocating directly to medical and genetics organizations to be

more inclusive of the disability community in their health equity initiatives and the development of guidelines, medical training, and organizational practices.

**Conclusion:** Fundamentally, the disability bias conveyed during prenatal screening conversations that causes negative experiences for pregnant patients is rooted in systemic ableism. Therefore, the literature and interviewees in this policy analysis pointed to medical and genetics organizations as the linchpins for establishing standards in the field of obstetrics to address the harms to both people with disabilities and their parents caused by ableism, and federal research grants hold significant promise in facilitating collaborative work between medical organizations and the disability advocacy community.



## Table of Contents

<b>Approval Page</b> .....	<b>2</b>
<b>Author’s Statement Page</b> .....	<b>3</b>
<b>Dedication and Acknowledgment</b> .....	<b>4</b>
<b>Abstract</b> .....	<b>6</b>
<b>List of Abbreviations:</b> .....	<b>11</b>
<b>List of Tables</b> .....	<b>12</b>
<b>Chapter 1: Introduction and Statement of Purpose</b> .....	<b>13</b>
<b>1.1. Problem Statement: Step 1</b> .....	<b>13</b>
<b>1.2. History of the Problem</b> .....	<b>17</b>
1.2.a. Patient experiences .....	17
1.2.b. Systemic Bias .....	18
1.2.c. Current Problem .....	24
<b>1.3. Purpose and Significance of Analysis</b> .....	<b>26</b>
<b>1.4. Reflexivity Statement</b> .....	<b>30</b>
<b>Chapter 2: Literature Review</b> .....	<b>34</b>
<b>2.1 Federal Policy</b> .....	<b>36</b>
2.1.a. Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCAA) .....	36
<b>2.2 Organizational Policies About Prenatal Testing and Disabilities</b> .....	<b>49</b>
2.2.a. Organizational Prenatal Testing Policies .....	49
2.2.b. Organizational Disability Health Equity Efforts.....	51
<b>2.3. Current Proposed Policy Solutions</b> .....	<b>53</b>
2.3.a. Fund the Kennedy-Brownback Act/PPDCAA .....	54
2.3.b. Fund disability cultural competency training for clinicians. ....	55
2.3.c. Incentivize disability equity in the creation of guidelines.....	55
2.3.d. Create sustainable patient education funding models.....	56
<b>2.4. Models:</b> .....	<b>57</b>
2.4.a. PCORI: Grant funding model .....	57
2.4.b. Folic Acid .....	59
<b>2.5. Limitations</b> .....	<b>62</b>
<b>Chapter 3: Methods</b> .....	<b>63</b>
<b>3.1. Introduction</b> .....	<b>63</b>
<b>3.2. Methodological Perspective</b> .....	<b>63</b>
<b>3.3. Research Design</b> .....	<b>65</b>
3.3.a.Rationale .....	65
3.3.b Description of Methods .....	67
<b>3.4 Data Collection</b> .....	<b>75</b>
3.4.a. Interview guide.....	75

3.4.b. Participant Selection .....	76
3.4.c. Procedures and setting .....	77
<b>3.5. Data Analysis.....</b>	<b>77</b>
<b>3.6. Ethical Considerations .....</b>	<b>80</b>
<b>3.7. Validity and Reliability .....</b>	<b>80</b>
<b>Chapter 4: Results.....</b>	<b>82</b>
<b>4.1. Assemble Some Evidence—Interviews: Step 2 .....</b>	<b>82</b>
4.1.a. Participant Characteristics .....	82
4.1.b. Themes and Subthemes .....	82
<b>4.1.c. Indexing and applying the analytical framework .....</b>	<b>90</b>
<b>4.1.d. Charting the data into the framework matrix .....</b>	<b>91</b>
<b>4.2. Construct the Alternatives: Step 3 .....</b>	<b>91</b>
4.2.a. Mapping and interpretation .....	91
4.2.b Alternatives .....	98
<b>4.3. Select the Criteria: Step 4.....</b>	<b>103</b>
<b>4.4. Project the Outcomes: Step 5.....</b>	<b>106</b>
4.4.a. Alternative 1: No action. ....	106
4.4.b. Alternative 2: Fund the Prenatally and Postnatally Diagnosed Conditions Awareness Act. ....	110
4.4.c. Alternative 3: ACOG, SMFM, and genetic organizations include people with disabilities in health equity measures, the development of guidelines and clinical practices, and the training of residents and fellows on how to sensitively discuss disabilities training. ....	111
4.4.d. Alternative 4: Federal funding agencies, including NIH and CDC, which are now funding health equity initiatives that include people with disabilities as a health disparities population, can prioritize funding toward research and resource dissemination to improve prenatal diagnosis experiences as the first point on the life course.....	114
4.4.e. Alternative 5: Congressional funding used as a reward or penalty for medical organizations and providers to address disabilities more equitably.....	116
4.4.f. Policy Analysis Criteria Matrix .....	117
4.4.g. Break-even estimates .....	119
<b>4.5. Confront the Trade-offs: Step 6 .....</b>	<b>121</b>
<b>4.5.a. Policy Analysis Trade-Off Matrix .....</b>	<b>121</b>
<b>Chapter 5: Conclusions.....</b>	<b>125</b>
<b>5.1. Deciding: Step 7.....</b>	<b>125</b>
<b>5.2. Limitations and Future Research.....</b>	<b>133</b>
<b>5.3. Conclusion .....</b>	<b>134</b>
<b>References.....</b>	<b>137</b>
<b>Appendix 1: Potential Interviewees: .....</b>	<b>160</b>
<b>Appendix 2: Interview guide .....</b>	<b>161</b>
<b>Appendix 3: Potential Legislative Champions .....</b>	<b>162</b>
<b>Appendix 4: Index.....</b>	<b>167</b>

***Appendix 5: Analytical Memo ..... 168***  
***Appendix 6: Telling Your Story: Step 8 ..... 186***

## List of Abbreviations:

DSIA: Down Syndrome Information Act

DS: Down syndrome

cfDNA: Cell-free DNA

NIPS: Non-invasive prenatal screening or NIPT: Non-invasive prenatal testing

PPDCAA: Prenatally and Postnatally Diagnosed Conditions Awareness Act

SB: Spina Bifida

## List of Tables

Table 1: Bardach Model Step Directory: 67

Table 2: Assembling Evidence Methods: 73

Table 3: Participant Selection Characteristics: 76

Table 4: Major Inductive Themes: 83

Table 5: Policy Analysis Criteria Matrix: 118

Table 6: Policy Analysis Trade-Off Matrix: 122

## Chapter 1: Introduction and Statement of Purpose

### 1.1. Problem Statement: Step 1

A majority of pregnant patients in the US undergo blood tests such as maternal serum screening and cell-free DNA (cfDNA) screening to detect if their fetus has increased chances for disabilities such as Down syndrome (DS). Indeed, maternal serum screening for disabilities was being utilized by about 72% of the 4 million pregnant patients in the US by 2013 (Palomaki et al., 2013), and the commercialization of these screening tests has grown since more accurate cell-free DNA screening tests were introduced to the market in 2011-2012. Indeed, among parents of children with DS born between 2016-2021, about 71% reported undergoing cfDNA screening, and 26% reported serum screening (Meredith et al., 2023). This screening is broadly offered through coverage from private insurers, as well as public funds and public health departments, as demonstrated by the coverage of cell-free DNA (cfDNA) by the Louisiana Department of Health (Newsroom, 2019) and the California Prenatal Screening Program as part of the California Department of Public Health (California Department of Public Health, 2023).

Prenatal screening tests, such as traditional maternal serum screening (like the “quad screen”) and ultrasounds have been used for decades to detect whether a fetus has increased chances for various conditions such as DS and Spina Bifida (SB) (Parens & Asch, 2000), and more recent cell-free DNA tests were introduced over ten years ago and have greater sensitivity and specificity than traditional maternal serum screening at detecting aneuploidies such as DS and Trisomy 13 and 18, as well as sex chromosome conditions. However, false positives and false negatives can still occur; therefore, they are still considered screening tests and not diagnostic (Society of Maternal Fetal Medicine, n.d.). On the other hand, amniocentesis (available since

the 1960's) and chorionic villus sampling (CVS) (available since the 1980's) are considered diagnostic because they can provide results that are nearly 100% certainty for the broadest range of conditions (Parens & Asch, 2000). Consequently, the American College of Medical Genetic and Genomics and the Society of Maternal Fetal Medicine do not recommend providing information about disabilities or making irreversible pregnancy decisions such as termination until after confirmation with a diagnostic test (American College of Obstetricians and Gynecologists' Committee on Practice Bulletins—Obstetrics et al., 2020; Society of Maternal Fetal Medicine, n.d.). However, this policy can be challenging when addressing the needs of expectant parents who choose to prepare for the birth of a baby with Down syndrome because even though 97% of parents of children with DS reported undergoing prenatal screening in a recent study, only 37% went on for confirmatory diagnostic testing (Meredith et al., 2023). Moreover, 86% indicated that the most important stage for receiving information about DS was after prenatal screening (Meredith et al., 2023). Therefore, based on these patient preferences, when referring to a prenatal "*diagnosis experience*" throughout this policy analysis, I am referring to the first point on the diagnostic journey when a pregnant patient learns about the potential disability of a fetus, whether following confirmatory diagnostic testing (an amniocentesis or chorionic villus sampling) or following prenatal screening that provides a high probability score.

Optional prenatal screening continues to offer patients increasingly more genetic information about their pregnancy, should they wish to pursue it. This information can be used for a range of reasons such as preparing for the birth of a baby with a disability, making pregnancy management decisions (termination, adoption, or continuing the pregnancy), and

pursuing more aggressive prenatal care such as increased non-stress tests and detailed ultrasounds. While genetic information can help some patients to feel empowered, it can influence others to feel distressed. While patients certainly experience significant unavoidable stress if they find out their baby has a life-threatening condition, most parents of children with non-life threatening conditions report that a major source of that distress is the way the diagnosis is delivered (Nelson Goff et al., 2013). Indeed, research shows that the way the diagnosis is delivered can cause distress for many expectant parents learning about a diagnosis of Down syndrome (May et al., 2020).

Skotko et al. outlined research-based recommendations for how best to deliver a diagnosis of Down syndrome in 2009, including the following (Skotko et al., 2009). While these recommendations focus on Down syndrome, parents of children with other prenatally diagnosed conditions, such as Spina Bifida, have expressed similar preferences (Meredith, Brackett, et al., 2022; Payne, 2013). Moreover, the recommendations have also been modified with input from representatives of the National Society of Genetic Counselors to include cell-free DNA and additional conditions (Meredith, 2016).

1. Clearly outline the differences between prenatal screening and diagnostic tests. Importantly, patients need to understand that screening tests (including cfDNA) indicate a patient's chances for having a baby with various genetic conditions.
2. If a pregnant patient wants to undergo testing, ask her about why having a diagnosis prior to birth would be important to her. This question prenatally can help better guide any future conversations about a test result and to avoid repeated questions about termination after a patient has expressed a preference.



3. When possible, deliver the results in person or at a pre-established time by phone. Determine a standard way of handling all results and tell patients about that up front so that they do not get the impression that an appointment or phone call is only scheduled if results indicate a diagnosis.
4. Personally deliver the diagnosis as soon as possible following definitive prenatal testing. Use commonly understandable terms and convey information in a patient's native language when translation is available.
5. Each condition detected with prenatal testing has different outcomes, and each expectant parent reacts differently based on his or her background and experience, life circumstances, and perceptions about parenting. Assess the emotional reactions of the expectant parents and validate these feelings. Use active listening and empathetic responses to offer support (Sheets, Crissman, et al., 2011).
6. If a condition does not cause premature death, use neutral language such as, "The results indicate..." and not begin with, "I'm sorry," or "Unfortunately, I have some bad news..."
7. Provide accurate and up-to-date information about the genetic condition and contact information for local support organizations.

Because these recommendations are not being implemented by many/most clinical practices, below is the problem statement as outlined in Step 1 of the Bardach Framework method:

*As prenatal screening expands, too **many expectant parents** experience emotional harm because they are not provided balanced, accurate, and up-to-date information about genetic*

*conditions, and they experience clinical bias that perpetuates discrimination against people with disabilities.*

## 1.2. History of the Problem

### 1.2.a. Patient experiences

Multiple research studies have found that the information needs of a majority of pregnant women were not met by clinicians delivering a prenatal diagnosis of Down syndrome even after nearly two decades of available recommendations and resources (Meredith et al., 2023; Nelson Goff et al., 2013; Skotko, 2005). Research similarly shows that parents of children with Trisomy 18, SB and hydrocephalus, and congenital heart defects have similarly indicated that they often do not receive sufficient information about those conditions following screening results. (Carlsson et al., 2016; Chaplin et al., 2005; Walker et al., 2008). DS is the chromosomal condition most commonly diagnosed during pregnancy; therefore, research about prenatal experiences is most prolific for this population. Therefore, DS can serve as a litmus test and model for other disabilities detected prenatally. One research study found that women were three times more likely to describe the way their positive results from prenatal screening or diagnosis are delivered as a negative experience than as a positive experience (Nelson Goff et al., 2013). Notably, these study participants did not indicate that the diagnosis itself was their reason for the negative experience but rather “the reasons for the negative perceptions included: the medical professionals’ insistence on terminating the pregnancies, the perpetuation of negative stereotypes of individuals with DS, the lack of information about DS provided by the medical professionals, and the perceived lack of compassion exhibited by the medical professionals” (Nelson Goff et al., 2013, p. 453). Recent research further indicates that

a diagnosis experience can cause lasting emotional harm when the diagnosis experience is perceived as negative, and negative diagnosis experiences are largely caused by a perceived lack of compassion, pressure to terminate the pregnancy, pessimistic expectations about outcomes for their child and family, and the provision of limited or no additional resources or support systems (May et al., 2020).

### 1.2.b. Systemic Bias

Ableism is discrimination against people with disabilities, and systemic ableism is discrimination against people with disabilities built into structures such as health care or education (Lagu et al., 2022). Systemic ableism and bias against people with disabilities can be projected in various aspects of prenatal screening. As described in more detail below, these include: 1. the administration of prenatal screening through a biased social context where screening itself suggests a condition is negative in a society where people with disabilities regularly experience discrimination (Parens & Asch, 2000); 2. the bias conveyed in the marketing and administration of screening to produce “healthy babies” (Estreich, 2019) 3. the absence of people with disabilities—as those with lived experience—in the development of medical guidelines and medical training (Meredith, Brackett, et al., 2022), and 4. biases in the justifications for funding for prenatal screening (National Council on Disability, 2019a).

#### *1.2.b.(1). Prenatal Screening Within the Context of Social Bias Against People with Disabilities*

Notably, the development of prenatal testing and screening emerged in a society during the 1960’s when people with disabilities were subject to substantial discrimination and continued remnants of eugenics policies: broad institutionalization through the 1970’s; continued forced sterilization; before the enactment of Section 504 in 1973; before the passage

of the Individuals with Disabilities Education Act in 1975; and before the passage of the Americans with Disabilities Act in 1990 (Nielsen, 2012). In Parens and Asch's 2000 seminal work, *Prenatal Testing and Disability Rights*—the outcome of a two-year Hastings Center project—they explain that the disability rights critique of prenatal testing posits that prenatal testing is often based on misinformation about what it means to live with disability, particularly in a society rife with discrimination against people with disabilities, and that the selective abortion of people with disabilities expresses a harmful attitude about disabilities given the discriminatory environment in which prenatal screening and reproductive options are offered (Parens & Asch, 2000). In the book and Hastings Center reports, Parens and Asch describe Allen Buchanan's "expressivist argument" that "prenatal tests to select against disabling traits express a hurtful attitude about and send a hurtful message to people who live with those same traits" (Parens & Asch, 1999, p. 13). Indeed, research confirms that the majority of clinicians convey implicit, and in some cases, explicit bias against disabilities in those prenatal conversations (Meredith et al., 2023), and some tend to focus on "empirically inaccurate and gloomy predictions" that unfairly catastrophize disability (Knight & Miller, 2021a, p. 98). The "expressivist critique" of prenatal screening is defined as "the social phenomenon of prenatal testing [that] has unfolded against a backdrop of the medicalization of pregnancy and of disabilities, and this context of medicalization enables the social phenomenon to convey a discernable negative message about disabilities (Kaposy, 2022, p. 59).

#### *1.2.b.(2). Eugenic Marketing and Administration of Prenatal Screening*

Bioethicist George Estreich argues that the marketing messaging about prenatal screening reinforces biased perceptions about disabilities (Estreich, 2019). Prenatal screening

laboratories have frequently used marketing language express the view that prenatal screening offers “peace of mind.” Yet, prenatal screening does not inherently offer “peace of mind.” Those who undergo prenatal screening and find out their baby likely has a genetic condition often report that the delivery of the news is distressing either because of their concern for their child or because of the negative way in which the information is presented. Those who find out their baby likely doesn’t have a prenatally diagnosed condition may experience “peace of mind,” but that reaction often reflects deeply embedded ableist perceptions about life with disability. In *Fables and Futures*, Estreich asserts that the original marketing of these tests employed images to sell the healthy and prosperous ideal family (Estreich, 2019). As Estreich explains, “This is why the pictures of ideal families are important: set beside them, disability is not merely an abstract risk, a percentage, but a risk *to* something, to the combination of ideal children, motherhood, and family, to the vision of a good life” (Estreich, 2019, p. 121). Harkening back to eugenic ideals of fitter families in the early twentieth century, these images conjure the deeply ableist idea that families are better, happier, and more successful without people with disabilities.

During the eugenics era, scientists and other prominent members of society argued that society could genetically weed out those deemed as “undesirable” through better breeding and instituted programs such as discriminatory immigration policies and forced sterilization of those deemed mentally unfit (Lombardo, 2010; Rutherford, 2023). However, these eugenic ideals were widely discredited as racist, ableist, and abhorrent as they were used as inspiration by Hitler in his quest to cultivate a “superior race” during World War II by eliminating all those he deemed as unfit (Rutherford, 2023). Fundamentally, eugenics was developed by predominantly white, wealthy men in positions of power who were incorrectly attributing the bulk of societal

problems to genetic causes and applying their own biased perceptions of ideal and undesirable to the broader population (Rutherford, 2023). Yet, disability rights advocates and quality of life research studies of people with disabilities and their families demonstrate that people with disabilities, like Down syndrome, are largely happy with their lives (Skotko et al., 2011b, 2011a).

Scholars like Rosemarie Garland-Thomson, Gareth Thomas, and Tom Shakespeare—who all explicitly support a patient’s right to choose whether or not to continue a pregnancy—contend that cfDNA screening itself can be viewed as a form of “contemporary eugenics” (Garland-Thomson & Larson, 2023; T. W. Shakespeare, 2011; Thomas & Rothman, 2016). They argue that even though force is not involved through policies, social pressure to undergo prenatal screening and social biases against people with disabilities are so dominant that individual reproductive choices are unduly influenced and can collectively amount to eugenic outcomes (Garland-Thomson & Larson, 2023; T. W. Shakespeare, 2011; Thomas & Rothman, 2016).

### *1.2.b.(3). Lack of Disability Representation in Obstetric and Genetic Guidelines, Education, and Training*

A lack of representation of people with disabilities in the training of clinicians and the guideline development for genetics and medical organizations compounds the problems above. Indeed, only about half of U.S. medical schools report having any type of disability awareness program as part of their curriculum (Keller, 2022). Moreover, education that does cover disability in medical schools tends to focus on the medical model of disability, where disability is viewed as a problem to be fixed, rather than also incorporating the social model of disability that defines the challenges associated with disability as largely constructed by societal barriers or the identity model of disability that defines disability as a meaningful cultural identity (Keller,

2022). Examples of disability cultural competency training include the Brighter Tomorrow program through the University of Kentucky (Jackson et al., 2020) and the Competencies for Disability in Health Care Education, which were developed and vetted by an inclusive committee led by Susan Havercamp and are currently being shared with medical schools and continuing education programs: [https://nisonger.osu.edu/wp-content/uploads/2019/08/post-consensus-Core-Competencies-on-Disability\\_8.5.19.pdf](https://nisonger.osu.edu/wp-content/uploads/2019/08/post-consensus-Core-Competencies-on-Disability_8.5.19.pdf). Interdisciplinary advocates have called for improved training in cultural competency about disability in genetic and obstetric education and the inclusion of people with disabilities in the development of that training in order to avoid the perpetuation of default societal biases against a historically marginalized population (Meredith, Brackett, et al., 2022). Disabled bioethicists and scholars specifically argue for the training of obstetricians and genetic counselors to intentionally include disabled leaders with lived experience, to focus on the counter-narratives of people with disabilities, and to facilitate anti-ableist training where professionals, according to Dietz and Reynolds, are “committed not just to informedness, but also to the idea that genetic counselors and their clients should acknowledge and combat how dominant epistemic frameworks shaping healthcare decision-making can perpetuate ableism” (Dietz & Reynolds, 2021, p. 1; Garland-Thomson & Larson, 2023; T. Shakespeare & Hull, 2018; Stramondo, 2020).

Further, people with disabilities have largely been excluded from the development of obstetric guidelines related to prenatal screening—a practice that implicitly reflects perspectives on quality of life for people with disabilities such that inclusion of people with disabilities is not perceived as critical. The American College of Medical Genetics and Genomics, the American College of Obstetricians and Gynecologists, the Society for Maternal Fetal

Medicine (SMFM), and the National Society of Genetic Counselors (NSGC) all offer guidelines on the administration of prenatal screening and testing. However, the only guidelines that specifically document receiving input from the disability community as a stakeholder population are the “Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the NSGC.” Therefore, interdisciplinary advocates have expressed the view that people with disabilities and their families need to be included as stakeholders in the development of guidelines to avoid the projection of bias against disabilities (Meredith, Brackett, et al., 2022).

#### *1.2.b.(4). Biases in Funding Justifications for Prenatal Screening*

A final and fundamentally unethical bias in prenatal screening is the justification sometimes used for screening as a public health benefit, which rarely calculates the education of patients and providers as a cost of screening which is not negligible. These justifications are most egregious when they rely on an equation that factors in the population-wide cost of the tests weighed against termination rates and the lifetime costs of people with different genetic conditions. One highly cited publication analyzing the cost-effectiveness of Non-Invasive Prenatal Testing (NIPT) included a calculation of the lifetime cost of a person with a genetic condition that did not factor in the contributions made by those individuals, implicitly assuming that the healthcare costs they documented were not offset by either community contributions or economic contributions through paid work (Benn et al., 2015). Moreover, the calculation presumed a termination rate of 87%, which is both inaccurate and based on the current social climate where prenatal screening results are delivered with a bias against disability (Benn et al., 2015). The most recent termination rate estimate only among those who undergo diagnostic



testing is 67% (Natoli et al., 2012), and the overall reduction rate for the total number of babies with Down syndrome born each year is estimated at 30% (de Graaf et al., 2015). The study authors acknowledge that “decreasing termination rates was associated with a reduction in NIPT value” (Benn et al., 2015). Moreover, the cost calculations did not include any costs for an education and support infrastructure for patients and providers to address inherent societal biases about disabilities that typically color those prenatal screening conversations. Indeed, this particular omission is a regular problem with most cost effectiveness studies (National Council on Disability, 2019a). Therefore, cost-effectiveness justifications such as this one inherently rely upon bias against disabilities. The National Council on Disability (NCD) released a report in 2019 arguing that the use of measures like Quality-Adjusted Life Years by health economists inherently devalues the lives of people with disabilities by subjectively assigning scores to rate the severity of conditions in determining quality of life (National Council on Disability, 2019b). To create a more ethical prenatal screening model based on benefits for patients and the disability community, justifications must rely instead upon better mental and physical health outcomes for patients and/or their offspring with disabilities. For this result to be achieved, an education, training, and support structure must also be factored into the equation. However, NCD also presents a compelling argument that the entire enterprise of using this kind a cost-benefit analysis that quantifies the lives of people at all is ethically problematic (National Council on Disability, 2019b).

### 1.2.c. Current Problem

A research study of 242 women who received prenatal screening results for Down syndrome between 2016-2021 found that only 29% of respondents from that study reported

receiving any information about supports and services, and only 22% reported receiving any information about national advocacy organizations (Meredith et al., 2023). Meanwhile, 64% of respondents received information about medical issues (Meredith et al., 2023). This is particularly problematic given that supports and social services are so instrumental in addressing social determinants of health for people with disabilities (Kennedy & Wood, 2020). Moreover, this information gap exemplifies the privileging of the medical model over the social model of disability where the medicalized assessment is valued more highly than the biomedical and social variables that give people with disabilities more control over their life choices and support from a social justice perspective (Knight & Miller, 2021a; Rubeis & Steger, 2019).

Furthermore, 61.3% of respondents indicated that their obstetric medical providers projected implicit bias about disabilities in prenatal conversations by saying, “I’m sorry” and conveying the information as bad news. Carroll, Schwartz, and Vellody explain that when clinicians use value-laden words like “burden” or “retarded” to describe disabilities or deliver news using presumptive language such as “I have bad news to share,” they convey unconscious bias (Carroll et al., 2018; Schwartz & Vellody, 2016). Knight and Miller assert that the incongruence between the negative disability bias conveyed by some medical professionals and most parents’ more positive descriptions of their lived experience raising children with disabilities like Down syndrome leads skeptics to assert that parents “sugarcoat” their experiences as an adaptive behavior. This dismissal of the lived experiences of parents and people with disabilities is described as “testimonial injustice” where the testimony of those with lived experience as parents is not perceived as credible (Knight & Miller, 2021a, p. 104; Reed &

Meredith, 2020) and can lead to this bias in prenatal screening discussions about disability because the perspectives of those with lived experience are excluded.

Despite significant work done by interdisciplinary teams of committed professionals (including myself) to create and disseminate patient education materials, engage in research on patient diagnosis experiences, offer presentations at conferences, publish articles drawing attention to their issues, and more, ***most patients are still experiencing bias and not receiving the information they need to understand genetic conditions***. Because these efforts are largely being done in pockets by committed professionals without federal funding or policy requirements to prompt systemic change, the purpose of this policy analysis is to examine the problem in depth and determine what policy initiatives might be able to offer systemic solutions.

### 1.3. Purpose and Significance of Analysis

While many good-faith efforts have been implemented to improve prenatal screening experiences, research has shown that the impact of these interventions has been limited in improving patient experiences. Most patients in these studies have reported that their clinicians conveyed implicit bias against people with disabilities, and most patients also reported that they were not receiving accurate, up-to-date, and balanced information when receiving prenatal diagnostic results or screening results suggesting a diagnosis of Down syndrome. The level of distress this situation induces for patients and the societal impact on bias against the disability community constitutes a genetic information public health crisis for the following reasons:

1. Negative prenatal screening experiences and outcomes have been found to occur throughout the US, and negative experiences are particularly damaging for people with

intersectional marginalized identities such as disability and race or low socioeconomic status (Chung et al., 2023; Krell et al., 2023; Meredith & Wright, 2023).

2. Prenatal screening is the first point on the life course that has long-term impacts on patient and provider trust. Because this population already has a higher incidence of medical complications and lower life expectancy, trust between patients and providers from the first point on the life course onward is essential to improving those health outcomes, particularly for Hispanic parents of children with DS (Chung et al., 2023).
3. People with disabilities comprise a population that desperately needs to be connected with services and supports immediately, given inequities in social determinants of health in which people with disabilities are more likely to experience poverty, unemployment, and other forms of discrimination (Iezzoni et al., 2021; Kennedy & Wood, 2020).
4. People with disabilities describe discrimination based on perceptions about genetic screening in the US (Parens & Asch, 2000; Piepmeier et al., 2021).
5. Public health entities are involved in the funding and administration of prenatal screening programs, and substantial research suggests that patients do not receive adequate counseling about the testing or the conditions for which they are being tested and experience negative outcomes accordingly. Consequently, the provision of education, clinical training, and services are essential for justifying a public health benefit for prenatal screening given the current negative impact on patients (May et al., 2020; Nelson Goff et al., 2013; Skotko, 2005).

Therefore, the purpose of this policy analysis is to examine what policy solutions could systemically improve the experiences of pregnant patients learning about a possible diagnosis

and reduce disability bias among obstetric and genetic professionals. This policy analysis will focus on federal legislation and guidance, given that federal policies and organizational guidelines have the greatest capacity for systemic change that will impact the most clinicians and patients uniformly across the US. While many promising state-level solutions have been implemented, including over twenty state Down Syndrome/Genetic Conditions Information Acts (Center for Dignity in Healthcare for People with Disabilities, 2021), those are outside the scope of this analysis given their inconsistency in content/quality and in facilitating systemic change from state-to-state. Moreover, those state-level solutions have had limited effectiveness within the states themselves at improving diagnosis experiences (Lehman et al., 2021).

Using the Bardach Model for Policy Analysis, I will apply the eightfold path that includes: 1. defining the problem; 2. assembling evidence; 3. constructing the alternatives; 4. selecting the criteria; 5. projecting the outcomes; 6. confronting the trade-offs; 7. deciding; 8. and telling the story. A similar application of the Bardach method was used in health policy for the disability community in the “Policy analysis on power standing systems” by LaBerge, and Detterbeck in Preventative Medicine Reports (Masselink et al., 2021), which considered three viable options to address the lack of Medicare coverage for power standing systems on power wheelchairs and then evaluated these options against five criteria determined by using the Bardach framework. Correspondingly, Engelman et. al (2019) outline the practical, feasible, and powerful value of using the Bardach model to turn clinical ideas into action through health policy analysis.

The model enables me to address the complexity of a multidimensional problem that has already had much work done to address some of the issues with patient experiences. However, the stages of assembling evidence and constructing alternatives allow me to consult with

experts and review the literature to determine why the problem continues to persist and what alternative strategies could be used to address it.

The Bardach model further elaborates that the problem should be quantifiable. For this purpose, we rely on research demonstrating that over 60% of patients are not receiving adequate information about Down syndrome from their clinicians, and about 61% of pregnant patients experience disability bias in those conversations (Meredith et al., 2023). Moreover, we can quantify how many pregnancies are diagnosed with disabilities per year and the costs of providing adequate education and support for those expectant parents. This gives us a measure to determine whether policy interventions are achieving their goals by evaluating whether a higher percentage of patients indicate that they received resources and received unbiased counseling after an intervention has been implemented. These numbers can further be used in future cost analysis estimates.

Rhetoric on this issue, which often can be partisan or ideological (Bardach & Patashnik, 2020), revolves around abortion and selective termination for people with disabilities. Because the problem is entangled with this highly volatile issue rhetoric, movement forward to address challenges with prenatal screening has historically been stagnated in the political quagmire of abortion in our divided political system. However, by defining the problem as emotional harm as demonstrated in the research by May and Hennessy (May et al., 2020), and setting evaluation criteria that can be agreed upon by both pro-choice and pro-life advocates—patient education and ameliorating bias against people with disabilities—the issue rhetoric can be assuaged for a majority of political players. The possibility of cross-cutting cooperation on this issue has been demonstrated by the passage of the bi-partisan Kennedy-Brownback Act, the passage of pro-

information state laws, and criteria agreed upon by bi-partisan, interdisciplinary leaders at the Prenatal Disability Education Summit (M. W. Leach, 2016; Meredith, 2022).

#### 1.4. Reflexivity Statement

*Being the mother of a young adult with Down syndrome has profoundly shaped my identity as a disability rights advocate and as an academic. During the past two decades of experience with my son and the broader disability advocacy community, I have learned that the lives of people with disabilities are much more multi-dimensional, multi-layered, marginalized, and meaningful than the public often realizes. In my position as a mother and disability rights advocate, I'm immersed in the world of disability rights and disability, so I see the world through that lens—which could be perceived as a bias. However, I would posit that because we live in a society in which people with disabilities have experienced historic discrimination and stigma, the public typically has a bias against disability, including medical professionals. Therefore, the perspective of someone within the community is likely more balanced with real-life experience ... as we would expect from those with first-hand experience from different races, ethnicities, and socioeconomic backgrounds.*

*I had a positive diagnosis experience when I was 23 years old and learned about my son's diagnosis hours after he was born. The pediatrician neutrally explained the characteristics of Down syndrome, and the next day a parent support staff member at the Newborn Intensive Care Unit brought us a book about Down syndrome and showed us a photo of her son on a bike. This was a normalizing moment for us as first-time parents, and she connected us with supports and services right away. I was surprised when research showed this was not the experience for most new parents (Skotko, 2005) Therefore, I am motivated by empathy for these other new and*

*expectant parents to improve their diagnosis experiences so that they get the support and resources I received. I'm also deeply grateful for the medical providers who supported me, and I feel compassion for medical professionals who feel uncomfortable when delivering unexpected news. I want to provide them with the tools and resources they need to navigate that process as sensitively as possible.*

*As I conduct research about the families of people with disabilities, my first-hand experience parenting a person with a disability, advocating for disability rights, and supporting new and expectant parents for the past 20 years can be beneficial in knowing what research questions to frame about quality of life, diagnosis experiences, and supports and services. In addition, I have a unique advantage when seeking community-based participatory research partners and when interpreting data to discern how responses correspond to patterns of experiences and themes I've observed over the years while supporting hundreds of families. However, my experience can be a disadvantage among medical professionals who may perceive me as a biased advocate because I am genuinely skeptical of a strictly medical approach to disability. I do believe we must acknowledge any medical issues associated with disabilities and address them, but I also believe that presenting disability in a social context is essential for a more complete picture to meet the needs of patients and present disability with equity.*

*Because of my personal morality and my ideals as a feminist and disability rights advocate, my beliefs about abortion are complicated and don't fit a traditional framework. Fundamentally, I feel empathy for all parties involved. I believe pregnant patients should have equitable access to prenatal screening technologies they want to utilize, and I did utilize prenatal screening for preparation in subsequent pregnancies. I also believe pregnant patients should*



*receive the full spectrum of support and resources to cope with those results. My primary concern is ensuring that patients have access to the support, resources, and healthcare they need so that they are not alone and so that disabilities are presented equitably. I feel profound empathy for them as someone who has gone through that experience myself. I have also personally witnessed and experienced discrimination in health care, systemic ableism, and low societal expectations for my son, and I worry that the information provided to pregnant patients may be tainted by those same biases so that the reproductive decisions they make are based on outdated perceptions of a historically marginalized population. I also feel it is not my place to make pregnancy decisions for other people; my primary goal is to give them the resources they need to understand disabilities and feel empowered to make decisions that reflect their own values. In many ways, the fragile internal compromises I've made about abortion put me in a unique position to understand the doctors whose priority is to serve patients, the feminist advocates who fear encroachment on women's rights, and the disability rights advocates whose main priority is to ensure pregnant women receive accurate, up-to-date, and balanced information about genetic conditions.*

*Toward that end, I have been involved in many efforts over the past two decades to address the lack of balanced, accurate, and up-to-date information provided about genetic conditions and the clinical bias that perpetuates discrimination against people with disabilities as an author of patient education materials, a conference presenter, an educator, and a researcher. Indeed, many people who are disability rights advocates have lived experience as individuals and family members and can contribute perspectives about life with disabilities that are essential to prenatal screening conversations, and no one approaches this issue objectively.*

*Therefore, all interested parties need to share their unique perspectives and be aware of potential bias whether they be disability rights advocates, medical professionals, scientists, or policy makers. See Appendix 1.*

## Chapter 2: Literature Review

As described in the detailed discussion of the problem in Chapter 1, disability rights advocates have raised concerns for nearly four decades about the potential discriminatory impacts of prenatal screening on people with disabilities (Parens & Asch, 2000); the negative prenatal experiences of patients and the lack of provision of information about the conditions (May et al., 2020; Nelson Goff et al., 2013; Skotko, 2005); the lack of a properly trained medical and genetics workforce to discuss disabilities (Dietz & Reynolds, 2021; Keller, 2022); and the inequity between the funding of testing and the educational infrastructure to support patients following testing (Estreich, 2019). Correspondingly, dedicated advocates and professionals have developed programs and resources to address those concerns as also discussed in Chapter 1. However, recent research shows that these initiatives have not sufficiently or systemically addressed ableism or improved patient experiences given that the majority of parents in recent research indicated that they experienced bias and did not receive the information they needed to understand Down syndrome (Meredith et al., 2023). Because research shows that training interventions like “Brighter Tomorrows” are effective at improving the knowledge and empathy of medical students when discussing a diagnosis of Down syndrome (Jackson et al., 2020), and resources like the Lettercase “Understanding a Down Syndrome Diagnosis” booklet are identified as meeting the needs of expectant parents in focus groups (Levis et al., 2012), these instruments developed collaboratively by medical, genetics, and advocacy experts to improve patient diagnosis experiences and provider competency have demonstrated effectiveness. However, these validated resources have been grossly underutilized for the past 15 years despite being featured in published literature, disseminated in print and email through grant

initiatives, being featured on state department of public health and medical/genetics organization websites, distributed at conferences, and distributed through grassroots efforts with advocacy organizations. Therefore, the failure to enact systemic change appears to be primarily due to ineffective or non-existent organizational and public policies to facilitate and require dissemination and clinical training (Knight & Miller, 2021a). *Indeed, patients report that the majority of clinicians are conveying bias and not providing them with supports and service information about the condition in language they can understand (Meredith et al., 2023)*

In the following literature section, I will review the federal and organizational policies currently in place to address the problem as outlined in Step 2 of the Bardach Policy Analysis Model so that we can subsequently examine outcomes in the policy analysis if we continue without change and the potential outcomes if we pursue different policy paths (Bardach & Patashnik, 2020).

*State laws are the not the focus of this analysis. These issues are important, but this analysis is staying laser focused on the problem identified: the provision of condition-specific information and disability bias in prenatal diagnosis conversations. The focus is on the provision of information and training to support families whatever their decision across an ever-changing landscape of abortion rights. For the broadest systemic change, the emphasis of this analysis centers on federal not state policies. Moreover, even though about half the states have passed their own versions of Down Syndrome and Genetic Conditions Awareness Acts to fill this gap, research suggests that these laws have minimal impact toward improving patient diagnosis experiences and the provision of accurate, balanced, and up-to-date information about genetic conditions (Lehman et al., 2021).*

## 2.1 Federal Policy

### 2.1.a. Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCAA)

As disability right advocates raised concerns about discrimination against people with disabilities in prenatal screening in the late 1990's, and Dr. Brian Skotko provided research to codify the negative prenatal experiences of parents receiving a Down syndrome diagnosis in 2005, the disability community started demanding policy intervention to systemically address these issues. The first draft of the Prenatally and Postnatally Diagnosed Conditions Awareness Act was introduced in 2007 by Senators Ted Kennedy and Sam Brownback to require that clinicians provide information about “the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes” (*Text of S. 1810 (110th)*, 2007). The bill was sponsored by pro-choice and disability rights advocate, Sen. Ted Kennedy (D-MA), and pro-life advocate, Sen. Sam Brownback (R-KS), to signal bipartisan support (M. W. Leach, 2016). Disability rights advocates knew that the bill needed to be a bipartisan measure that brought together legislators from both sides of the aisle with a focus on disability rights instead of becoming mired in highly contentious abortion rights territory, and hearings featured the findings of Dr. Skotko do highlight the need for accurate, up-to-date, and balanced information about conditions for new and expectant parents. Indeed, both pro-life and pro-choice disability rights advocates unified to create a “pro-information movement” that focused on giving prospective parents “more balanced, up-to-date information and literature about the lived experience of conditions like Down syndrome, so that pregnant women have a fuller and more nuanced idea of what it might mean to give birth to and raise a child with a genetic impairment” (Knight & Miller, 2021a, p. 90). The original version of the bill

required the provision of this information and also a funding provision of \$5 million for each of 5 years (M. W. Leach, 2016).

These demands reached a climax when the American College of Obstetricians and Gynecologists released Practice Bulletins 77 and 88 in 2007, which recommended that all women, regardless of age, be offered prenatal screening for aneuploidy (an abnormality in the number of chromosomes, such as Trisomy 18 and Trisomy 21 or Down syndrome) (“ACOG Practice Bulletin No. 77,” 2007; “ACOG Practice Bulletin No. 88,” 2007). Prior to 2007, ACOG only recommended that women over 35 or considered “high risk” be tested. However, research data found that the calculus used by parents to determine whether or not to undergo screening could be applied to pregnant patients of all ages (Kuppermann & Norton, 2005). Moreover, the accuracy of the screening for Down syndrome was progressing so that the reduced false positives and negatives made screening a more appealing option. The revised recommendations caused alarm for the disability community given the negative diagnosis experiences of many parents that had yet to be addressed. They feared for both the exponential increase in negative prenatal diagnosis experiences as well as the potential eradication of the disability population based on the provision of biased and out-of-date information and counseling. Notably, for some pro-life disability rights advocates the motivation was to “save babies,” but among the most vocal disability rights advocates like Adrienne Asch and Allison Piepmeier, who were equally vocal pro-choice advocates, the objective was to ensure that clinicians did not unduly influence reproductive decision-making—leading to de facto eugenics—by perpetuating discriminatory anti-disability bias in their prenatal care (Parens & Asch, 1999; Piepmeier et al., 2021). The solution both sides could rally behind—to promote disability rights without infringing on

reproductive rights—was that patients and providers needed support and accurate, up-to-date, and balanced information about disabilities.

With this increased and unified advocacy momentum, Congress passed the **Prenatally and Postnatally Diagnosed Conditions Awareness Act** in October 2008 to support new and expectant parents learning about their child’s disability diagnosis. Policymakers passed this act in response to research and testimony recognizing that people with disabilities are a historically stigmatized population and that parents need accurate, up-to-date, and balanced information to truly understand these conditions. However, compromises were made to ensure the passage of the legislation, and “these compromises stripped the mandatory language from the bill and instead merely authorized the Secretary of Health & Human Services (HHS) to provide grants for the development of patient education resources (Pub. L. No. 110-374, 2008) (M. W. Leach, 2016, p. 85). Yet, Congress never appropriated the planned \$25 million to fulfill the promise of supporting these families to fully understand these conditions and the supports, services, and opportunities available to children and families receiving diagnoses. (M. W. Leach, 2016)

#### *Barriers:*

The first and most basic reason why this policy intervention didn’t accomplish its purpose was that it was never funded. But why would a bill that passed with overwhelming support lack sufficient commitment for funding?

#### *2.1.b. Political Wrangling Over Reproductive Rights*

One theory is that Democratic legislators lost their motivation once the disability advocacy focus shifted to reproductive justice disputes upon celebration of the PPDCAA from pro-life advocates and reflexive criticism from pro-choice advocates. Initially, the law was lauded

as a bipartisan victory that could signal a truce in the culture wars by prioritizing a common interest in supporting pregnant women learning about disabilities and providing an opportunity for “customary adversaries to collaborate on other policies that manage to preserve choice and at the same time promote open-minded and nondiscriminatory perspectives on life with disability (p. 8) (Dresser, 2009, p. 8). However, almost immediately after the bill was passed, pro-life advocates employed rhetoric about saving babies with Down syndrome with articles like the one in the Baptist Press indicating that, “Pro-life advocates hope Brownback’s measure will reduce the abortion rate for children diagnosed with Down syndrome and other conditions” (Wood, 2008). Indeed, the provision of accurate, up-to-date, and balanced information about disabilities—in contrast with counseling and information biased against disabilities—may well create an environment where patients are more likely to make the choice to raise a child with a disability based on their own values when weighing current and unbiased information. However, the unified purpose of the legislation was to better meet patient needs by providing accurate and balanced information about genetic conditions. In fact, the same article quotes David Tolleson, the Executive Director of the National Down Syndrome Congress as saying, “As far as the termination rate, we never know what goes into a woman’s decision related to that ... What we do know by studies is that doctors traditionally do a poor job delivering a diagnosis. Our point of view is mothers need to have all the information so that whatever decision they make will be an informed decision and not the doctor’s prejudices” (Wood, 2008, para. 13).

Yet, funding was not appropriated for the PPDCAA and consequently did not accomplish the creation of an educational infrastructure to support new and expectant parents. Subsequently, disillusioned advocates began advocating for the passage of state Down



syndrome Information Acts patterned after the PPDCAA in 2012 starting in Massachusetts to address the continued negative diagnosis experiences. Their objectives ranged from seeking state appropriations to using mandatory “shall” language that required doctors to disseminate information.

Reflexively, pro-choice advocates and medical professionals criticized state and federal Down Syndrome Information Acts, arguing they sought to indirectly limit patient autonomy by requiring that clinicians provide positive information about disabilities rather than using non-directive language, which is held up as the ideal standard of practice for patient counseling (Caplan, 2015; Giric, 2016). However, these criticisms were not particularly convincing given that research and disability rights advocates confirm that prenatal counseling about disabilities tends to be negatively biased as a baseline, so the requirement for balancing information can more effectively be argued to achieve neutrality (Meredith, Brackett, et al., 2022). Moreover, nowhere in the federal “Prenatally and Postnatally Diagnosed Awareness Act” (or in the corresponding state Down Syndrome Information acts) does the legislative statute say that “positive” information be given but rather “information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes” (*Text of S. 1810 (110th)*, 2007). The reflexive response appeared to be substantively in reaction to media headlines from pro-life advocates about the laws rather than the actual text of the laws themselves, as well as concerns about mounting conscience clauses requiring ultrasounds and information about abortion to be provided to patients prior to electing termination. In *Framing Disability*, however, Emens argues that the PPDCAA was not the same as conscience clauses because the primary purpose was not to influence reproductive

decision-making but rather to influence perception of disability (Emens, 2012). Emens proposes that a possible solution could be to provide the information to all prospective parents following screening but before they receive screening results so that parents receiving screen “positives” would not be directly targeted (Emens, 2012). Interdisciplinary experts also recommend avoiding positive or negative bias by developing information about disabilities that is created collaboratively with input from medical providers and disability advocacy organizations, such as the Lettercase materials (Knight & Miller, 2021a; Meredith, Brackett, et al., 2022)

Nevertheless, the concerns of pro-choice advocates about the ultimate intention of the laws for some political actors have been validated over the past 15 years by statutes passed in certain states. Down syndrome reason-based abortion bans have been enacted in states including Arkansas, Arizona, Indiana, Kentucky, Missouri, Ohio, North Dakota, South Dakota, and Utah (Crary & Samuels, 2021; Mizner, 2020; Roesner et al., 2022). Additionally, the Down Syndrome Information Acts in states such as Louisiana, Indiana, and Texas prohibited the mention of termination in materials provided by the state (M. W. Leach, 2016). The combination of reason-based abortion bans and restrictions on language about reproductive options in educational materials between 2008-2022 did validate the concerns of ethicists as the policies created an atmosphere where patients could be reticent to discuss the option of abortion of the fetus with DS with a medical provider because the abortion would be illegal if the provider knew DS was the reason. Interestingly, these new language provisions were largely driven by pro-life advocates such as the Bioethics Defense Fund in Louisiana, Texas Alliance for Life, Indiana Right to Life, and pro-life legislators rather than disability rights advocates (M. W. Leach, 2016). In fact, disability rights advocates spoke out against what they perceived as the politicization of a

disability rights agenda when the law restricting language was passed in Louisiana (Iannone, 2014), and Texas had two competing Down Syndrome Information Act bills—one written by the Texas Down syndrome organizations without restrictive language about termination and one written by pro-life legislators that included the language restriction. However, even amidst all the political strife, an overlapping concern of both pro-life and pro-choice advocates remains the common goal to support new and expectant parents and people with disabilities (Meredith, 2022); therefore, laws could conceivably remain bipartisan and non-coercive if the target remains focused on disability rights and the provision of accurate, up-to-date, and balanced information—objectives that Democrats and Republicans agreed upon in the PPDCAA.

The media responses and the wrangling over different state laws attached controversial partisan labels to what had been a bipartisan compromise to support new and expectant parents and the broader disability community. These partisan labels could be one reason why legislators were reluctant to fully embrace the funding of the law. In fact, the pro-life Charlotte Lozier Institute indicated that the Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008 could be a helpful tool for “providing patients with information about outcomes for people with the diagnosed condition and contact information regarding support services including peer support” but claims the law was not funded because the “legislation failed to exclude abortion referral” (Donavan, 2023, para. 60). However, this reasoning does not withstand scrutiny, given that an administration can still govern the rules for how HHS administers the funding, and no resource currently recommended by any state actually provides an abortion referral (Center for Dignity in Healthcare for People with Disabilities, 2021). In addition, this assessment does not hold true for the time when the law

was passed and when appropriations would have been expected because Democrats controlled both the House and Senate during the 110<sup>th</sup> and 111<sup>th</sup> United States Congress between January 2007 to January 2011 (*Ballotpedia*, n.d.). No public explanation has been provided for the lack of appropriations by the Democrat-controlled Congress, particularly when “A joint response issued by the Disability Rights Education and Defense Fund, Generations Ahead, National Women’s Health Network, Reproductive Health Technologies Project, and World Institute on Disability called the law “a positive step toward providing better information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with a disability” (Disability Rights Education and Defense Fund et al., 2008, para. 1).

Consequently, overcoming this hurdle could involve a bipartisan commitment to disability rights and patient support over posturing about pro-life/pro-choice stances and a media campaign focusing on the disability rights angle of the bill and the poor experiences of patients—fundamentally creating a more compelling story to generate broad support than the reproductive rights angle that is so often the contentious center of discourse on this topic. Strong support from both the disability advocacy and medical communities for the appropriations could also present a compelling case for neutrality. However, given the 2022 *Dobbs v. Jackson Women's Health Organization* decision reversing the *Roe v. Wade* decision and leaving reproductive legislation up to the states, the rancor over abortion politics is unlikely to abate to allow for the prioritization of disability rights for this issue. Moreover, given Republican efforts such as requiring pregnant patients to obtain ultrasounds or read materials about abortion procedures before terminating a pregnancy under the guise of informed decision-making, even the most neutrally intended efforts originating from the advocacy community to

influence the provision of prenatal information is likely to be suspect as a perceived biased source and attempt to coerce pregnant patients. Yet, these kinds of “forced” and partisan counseling statutes meant to cause mandatory friction that discourages abortion are quite different from the more neutral information statutes like the PPDCA which were prompted by bipartisan concerns about negative disability bias (Emens, 2012).

### 2.1.c. Loss of Leadership

Perhaps the death of Senator Ted Kennedy in 2009 as the champion of the bill in the controlling party was the most significant reason why the appropriations did not proceed. (*U.S. Senate: Edward M. (Ted) Kennedy: A Featured Biography*, n.d.) The original bill had been named the Kennedy-Brownback bill as it was introduced by Senator Edward M. “Ted” Kennedy, a pro-choice and pro-disability Democrat, and Senator Sam Brownback, a pro-life Republican (Disability Rights Education and Defense Fund et al., 2008). Senator Kennedy had been urged to support the law by his sister Eunice Kennedy Shriver, founder of Special Olympics and long-time disability rights advocate (McNamara, 2018). With Senator Kennedy’s death in 2009 while the Democrats controlled Congress and Sam Brownback’s transition out of the Senate in 2011, perhaps the appropriations simply never materialized without the champions of the bill to advocate for it.

Overcoming this hurdle would involve recruiting strong advocates from both parties in both chambers of Congress who can squarely focus on disability rights without becoming mired in the abortion debate surrounding this issue. Potential allies could include the following based on their expressed commitment to disability rights and ability to reach across the aisle. See Appendix 3: Potential Legislative Champions.

### 2.1.d. Lack of Cohesive Advocacy

*Researcher Note: I am the author of “Understanding a Down Syndrome Diagnosis” and am therefore an active and subjective participant in the events described below.*

After ACOG released their practice guidelines in 2007 recommending that all women be offered prenatal screening for chromosomal aneuploidies, including Down syndrome, the Down

syndrome community and advocacy organizations were concerned given the negative diagnosis experiences reported by parents and the potential decrease of the population. Consequently, Madeleine Will, Dr. Richard Ferrante, and Janice Edwards organized a Down Syndrome Consensus Group meeting including representatives of the National Down Syndrome Society (NDSS), National Down Syndrome Congress (NDSC), American College of Obstetricians and Gynecologists (ACOG), American College of Medical Genetics (ACMG), and National Society of Genetic Counselors (NSGC) on November 16 and 17, 2008, in Columbia, South Carolina with the purpose of fostering understanding between the groups, elucidating misperceptions, and identifying areas of consensus and possible collaborations (Edwards & Ferrante, 2009). Areas of consensus focused on the need for public education about the lives of Down syndrome; the need for up-to-date disability education for medical providers; and accurate and balanced information about Down syndrome and prenatal screening for patients (Edwards & Ferrante, 2009). Specifically, an area of collaboration identified was the development of a “gold standard” of information to be given parents about Down syndrome when receiving a potential diagnosis and a training manual for parent support for providers. Subsequently, the consensus group was presented “Understanding a Down Syndrome Diagnosis” to review after the booklet had been selected as the gold standard by the national Down syndrome organizations as part of the First Call grant funded by the Joseph P. Kennedy, Jr. Foundation, and the booklet was subsequently edited by representatives selected by each organization that participated in the Down Syndrome Consensus Group (M. Leach, 2021). Notably, the final document included extensive feedback and input from all organization representatives, and one area of compromise between the organizations was to add sections on both termination and adoption for parents who might

choose not to parent (*The Down Syndrome Community's Abortion Rift* | Matthew Hennessey, 2012a). (*I served as the author and editor incorporating this feedback.*)

The organizations were tentatively unified in their approach and advocacy until cell-free DNA was released in 2011, but there remained tension about the termination compromise and who should own the booklet (*The Down Syndrome Community's Abortion Rift* | Matthew Hennessey, 2012b). (*My husband and I owned the copyright at the time and founded a non-profit to house the booklet: Lettercase.*) Yet, research funded by the Center for Disease Control and Prevention confirmed that the booklet's "clinical information about DS, information about families with a child with DS, the degree of medical complications, resources for parents", and "photographs of children with DS engaging in everyday activities" matched the needs identified by expectant parents and people planning to become pregnant who participated in focus groups (Levis et al., 2012, p. 9). However, the release of cell-free DNA in 2011 and the promise of an earlier and more accurate screening options prompted significant concern among some disability advocates that termination rates would rise, particularly in a climate where screening conversations were largely biased against people with disabilities (May et al., 2020; Szabo, 2013). Consequently, the National Down Syndrome Congress ultimately pulled out of the consensus group and removed their support from the booklet to join the recently formed Global Down Syndrome Foundation and released a separate booklet that did not mention termination (M. Leach, 2014). The reasoning at the time was that people with Down syndrome found the mention of termination offensive; however, neither of the Down syndrome advocacy organizations selected a person with Down syndrome to participate as a representative in the



Down Syndrome Consensus Group to provide input. NDSC and Global continue to support use of the separate booklet; NDSS supports both resources.

Separately, the copyright for “Understanding a Down Syndrome Diagnosis” was donated to the Joseph P. Kennedy, Jr. Foundation with the administration being run by the University of Kentucky’s University Center for Excellence in Developmental Disabilities, the Human Development Institute (HDI) (*AUCD - “Understanding a Down Syndrome Diagnosis” Booklet Available Through Kennedy Foundation and Kentucky’s Human Development Institute, 2012*). HDI created the Lettercase National Center for Prenatal and Postnatal Resources as a program at the university and is responsible for printing and disseminating the booklet as well as providing medical outreach training. In addition, the Down Syndrome Consensus Group transformed into the Genetic Conditions Consensus Group, and the medical and genetics organizations continued collaborating with the Lettercase National Center for Prenatal and Postnatal Resources in the creation of resources about Jacobsen syndrome, Prader-Willi syndrome, Turner syndrome, Klinefelter syndrome, and Spina Bifida (*Lettercase – The National Center for Prenatal and Postnatal Resources, n.d.*). Interestingly, the Genetic Conditions Consensus Group agreed in 2017 to change the termination section in “Understanding a Down Syndrome Diagnosis” to a general “Pregnancy Loss” section to also account for those who lose their pregnancies due to miscarriage, so termination is no longer specifically mentioned, but the recommended external resource cited in the booklet supports patients who lose a pregnancy for a range of reasons including miscarriage and termination (Meredith, 2017).

These divisions within the Down syndrome advocacy community, the complication of the abortion debates, and the lack of cohesive or cross-disability advocacy efforts on this topic

have also likely been factors in not sufficiently convincing legislators to prioritize funding for this issue. Therefore, one strategy to overcome this barrier could be addressed through a broad-based disability coalition to advocate for the funding of prenatal disability education with a focus on the distress and bias families are currently experiencing. Moreover, perhaps the broader coalition could support an understanding that there is no need to agree on one universal solution for patient education and provider training but rather to have HHS funding available for multiple competitive awards presenting a range of possible solutions that can be evaluated by advocates and experts in the field on their individual merits.

## 2.2 Organizational Policies About Prenatal Testing and Disabilities

### 2.2.a. Organizational Prenatal Testing Policies

The American College of Medical Genetics and Genomics (ACMG), the American College of Obstetricians and Gynecologists (ACOG), the Society for Maternal Fetal Medicine (SMFM), and the National Society of Genetic Counselors (NSGC) all offer guidelines on how to administer prenatal screening and testing. However, the NSGC “Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome” are the only guidelines that specifically document receiving input from the disability community (Sheets, Crissman, et al., 2011). The authors of the recommendations included genetic counselors who were actively involved in the DS community, one parent of a child with DS, and a member of the NDSC board, and they published research the same year alongside leaders of national DS advocacy organizations to outline what information is most important to parents and providers at the moment of diagnosis (Sheets, Best, et al., 2011). This research meaningfully informed the guidelines, and, consequently, they are the only guidelines to specifically offer recommendations for how to

sensitively discuss a diagnosis, provide an overview of medical and social outcomes, and offer recommendations of resources about Down syndrome. In contrast, the other guidelines drafted exclusively by medical providers and scientists focus almost exclusively on prenatal screening technology and some medical outcomes.

People with disabilities have recently been federally recognized as a health disparity population that has been historically marginalized (*NIH Designates People with Disabilities as a Population with Health Disparities, 2023*); and *Health in All* policies outline that health equity measures need to include people from health disparity populations when determining policies about those populations (Rudolph et al., 2012). In addition, the GRADE “Guidance on how to assess and address health equity within the evidence to decision process,” cited as a framework by ACMG in their most recent guidelines, indicates that “It is extremely important to collect input from key stakeholders from disadvantaged populations in considering acceptability since assumptions by panel members may be biased by their personal experience” (Pottie et al., 2017, para. 28). In the case of prenatal screening, this requirement can be complicated by the fact that the prenatal screening patient is the pregnant person and not directly a person with a disability. However, this recognition calls for the inclusion of representatives from key affected populations in the drafting of medical and genetics guidelines about prenatal screening:

1. Patients who continue a pregnancy following a diagnosis. These parents have reported distress following negative diagnosis experiences (May et al., 2020), and, particularly in the case of people with multiple marginalized identities, the experience may cause lasting mistrust of doctors among parents caring for medically vulnerable children (Chung et al., 2023; Krell et al., 2023).

2. Patients who terminate a pregnancy following a diagnosis. These patients are also particularly vulnerable given the ever-shifting landscape of reproductive rights in the US (Meredith, Ayers, et al., 2022).
3. People with disabilities. Prenatal screening can frame societal and medical perceptions about people with disabilities as a broad population; prenatal screening has the potential to impact the size of the population of people with disabilities; and clinical behavior following prenatal screening can impact the health of babies born with disabilities. Moreover, people with disabilities also get pregnant, and those with heritable conditions such as Down syndrome, Deafness, and achondroplasia are more likely to pass those conditions to their children. Therefore, this is also a key population to be consulted when drafting guidelines.

#### 2.2.b. Organizational Disability Health Equity Efforts

The ACOG website section on “Diversity, Equity, and Inclusive Excellence at ACOG” makes no mention of ableism as a concept, and disability is not addressed in the Collective Action Plan or the Diversity, Equity, and Inclusion (DEI) curriculum roadmap (*Diversity, Equity, and Inclusive Excellence at ACOG, 2024*). Moreover, no policy or committee opinion specifically addresses disability as a topic (*Equity-Focused Clinical Guidance and Policies, 2024*). Among the 13 total documents on the DEI section of the ACOG website—8 clinical guidelines, 4 policy statements, and one resource, disability is mentioned 5 times. However, the mentions are extremely brief: two times in a list of intersectional identities, one time in a list of identities that experience discrimination, and one time regarding the need of captioning in telehealth for health equity for Deaf patients (ACOG Committee on Ethics, 2017; *Equity-Focused Clinical*

*Guidance and Policies*, 2024). Moreover, even though the recently released “Permanent Contraception: Ethical Issues and Considerations” encourages clinicians to preserve reproductive autonomy for patients with limited cognition as much as possible, it still fails to identify the historic context of eugenics that informs this recommendation even though the same document does successfully provide the context for discrimination experienced by other marginalized populations—including the forced sterilization of incarcerated people (“Permanent Contraception,” 2024).

In the ACOG professional training materials, none of the webinars address disability specifically (*Education and Training*, 2024). Yet, the Council on Resident Education in Obstetrics and Gynecology (**CREOG**) Health Equity Curriculum does include disability in slide decks discussing the history of health equity, social determinants of health, health disparities, and bias. Unfortunately, examples are not provided for how to address those disparities and what the manifestations of bias look like in obstetric care (*Health Equity*, n.d.). Additionally, no person on the current DEI committee states that they have a disability or represent the disability perspective (ACOG, 2024), and the ACOG DEI staff and Chair did not respond to my email requests asking: “Do you know if ACOG’s DEI committee by any chance has a representative from the disability community, and do you know if any clinical guidance or policy/position statements specifically cover bias experienced by people with disabilities?” [personal correspondence] Finally, there are no sessions addressing disability as a minority underserved population on the upcoming 2024 ACOG Annual Meeting schedule while there are three sessions on racial health equity, one session on Asian American and Pacific Islander health equity, one session on transgender care, one session addressing inequities due to

socioeconomic status, and a keynote speaker addressing LGBTQ social justice issues (*ACOG Annual Clinical & Scientific Meeting, 2024*). The Society for Maternal Fetal Medicine similarly lacks disability representation or areas of focus in their health equity initiatives highlighted on the website and did not include ableism or disability bias as an area of focus at their 2024 annual meeting (SMFM, 2024a, 2024b).

In contrast, the National Society of Genetic Counselors does feature a position statement on disability on the Justice, Equity, Diversity and Inclusion (J.E.D.I.) section of their website and also featured parents and individuals with disabilities (Chromosome 18, skeletal dysplasia, and Down syndrome) at their 2023 Annual Meeting (*Disability, n.d.; NSGC > POLICY > Position Statements, n.d.; National Society of Genetic Counselors, 2024*). Additionally, the American College of Medical Genetics and Genomics is featuring a session on “[The Genetics of Disability Rights & Ethics - A DEI Committee Sponsored Session](#)” at their 2024 Annual Clinical Genetics Meeting and includes professionals with disabilities as part of their Diversity, Equity, and Inclusion committee (ACMG, n.d.; *ACMG Committee, 2024*).

### 2.3. Current Proposed Policy Solutions

The primary texts offering practical solutions to patient and disability population harms caused by prenatal screening include: 1. the National Council on Disability (NCD) Report, “Prenatal Testing and the Rush to Perfection” (National Council on Disability, 2019a); 2. the Prenatal Disability Education Summit Report representing the convening of leaders from medical, genetic, bioethics, and advocacy leaders nationwide in May 2022 (Meredith, 2022); 3. the collaborative journal article by Meredith et al. as a product of the Administration on Community Living funded Center for Dignity in Healthcare for People with Disabilities,

“Recommendations to improve the patient experience and avoid bias when prenatal screening/testing” (Meredith, Brackett, et al., 2022); and 4. the book, “Prenatal genetic testing, abortion, and disability justice” by Amber Knight and Joshua Miller (Knight & Miller, 2021a). The proposed nationwide policy and organization solutions have been identified in one or all of those publications as strategies to improve patient diagnosis experiences and, correspondingly, the provision of information about prenatally diagnosed conditions and avoiding negative disability bias.

### 2.3.a. Fund the Kennedy-Brownback Act/PPDCAA

The NCD report, the Prenatal Disability Education Summit Report, the Meredith et al. article, and the Knight and Miller book all recommend the full funding of the PPDCAA (Knight & Miller, 2023; Meredith, 2022; Meredith, Brackett, et al., 2022; National Council on Disability, 2019a).

Miller and Knight write:

*“In order to standardize medical practice across states and uphold the integrity of information related to prenatal testing for the sake of women’s autonomy, we recommend that the federal government adequately fund the Kennedy-Brownback Act. This funding will enable the Department of Health to collect and disseminate accurate, up-to-date, comprehensive information about test results and the range of outcomes associated with the diagnosed condition. Additional information should include patient support networks, including information about how expectant parents of fetuses diagnosed with DS can connect with other parents who have had the same experience through First Call programs. In turn, medical providers should then be required to make this information accessible to patients via written materials” (Knight & Miller, 2021a, p. 111).*

### 2.3.b. Fund disability cultural competency training for clinicians.

All texts recommend incentivizing “the development of educational units on disability experience and exposure” in genetic and obstetric education (National Council on Disability, 2019a). The reasoning described by Knight and Miller outlines the following (Knight & Miller, 2021b):

*To begin, the current education system is not producing physicians with the requisite disability cultural competencies, so structural reform in the medical education system is warranted. According to survey data, medical professionals have reported feeling unprepared to treat patients with disabilities or patients pregnant with disabled fetuses in a manner informed by the lived experience of disability and its cultural components (Santoro et al., 2017). Studies have also shown that nearly a third of genetic counselors have been dissatisfied with the disability training they obtained in their graduate programs (Sanborn & Patterson, 2014).*

Therefore Knight and Miller recommend that medical schools include disability training in their standard curricula as a possible solution (Knight & Miller, 2021a).

### 2.3.c. Incentivize disability equity in the creation of guidelines.

The NCD report, the Prenatal Summit report, and the Center for Dignity recommendations all recommend incentivizing disability equity and representation in the creation of obstetric and genetic organizational guidelines to better meet patient education needs.

*The development of prenatal guidelines, recommendations, and practice bulletins should include representation from leaders in the disability community as stakeholders to achieve health equity. Leadership in the disability community available to consult*



*include: CDHPD, National Organization for Rare Disorders (NORD), Association of University Centers on Disability, American Academy of Developmental Medicine & Dentistry (AADMD), Genetic Alliance, NIH condition groups, Self-Advocates Becoming Empowered (SABE), or condition-specific advocacy groups if guidelines are specific (Meredith, Brackett, et al., 2022, p. 5).*

Disability Prenatal Education Summit participants identified the following as top priorities for evaluating disability education and representation in organization policies/guidelines:

- 1. We need increased disability representation that is meaningful and effective. Inclusion must be real – not tokenism. Effective representation at the outset of the process will lead to better questions and solutions.*
- 2. Difficulty of collaboration among organizations. Need to increase communication among professional organization and patient advocacy groups in guideline development to ensure guidelines are developed to meet needs of community being served – not just certain interests such as the laboratories offering the testing. (Meredith, 2022, p. 18)*

#### 2.3.d. Create sustainable patient education funding models

Recommendations for sustainable patient education funding models about prenatally diagnosed conditions largely revolved around creating sustainable funding mechanisms such as an excise tax on testing labs or a parity requirement for insurance companies that pay for prenatal screening to correspondingly pay for patient education and counseling. Then, those funds would be used for the perpetual funding of educational and support initiatives for patients or an organization that provides an educational infrastructure.

1. Prenatal Disability Education Summit participants discussed the creation of an organization to provide sustainable federal grant funding for prenatal patient education and provider training efforts derived from an excise tax on prenatal screening tests. This structure would be like the funding of the Patient-Centered Outcomes Research Institute (PCORI), derived from an excise tax on Affordable Care Act health insurance policies. See more below.
2. In a 2022 collected volume, *Born Well: Prenatal Genetics and the Future of Having Children*, Summit participant Mark W. Leach proposes a parity requirement for insurance companies that pay for prenatal screening to correspondingly pay for patient education and counseling.  
  
*Instead of funding just the testing to prevent lives with a genetic condition, funding should be provided, and only provided, when the patient has access to proper genetic counseling and accurate, balanced, up-to-date written resources about the condition with contact information for area support organizations. If this funding change were to happen, then prenatal genetic testing could be said to not be in pursuit or based on eugenics, but instead be based on maternal and child health (M. Leach, 2021, p. 44)*

## 2.4. Models:

### 2.4.a. PCORI: Grant funding model

PCORI was created as part of the Patient Protection and Affordable Care Act of 2010 and is funded through the Patient-Centered Outcomes Research Trust Fund (PCOR Trust Fund.

“Under the 2019 amendment to the authorizing law, the PCOR Trust Fund receives income from two funding streams: statutory appropriations from the general fund of the Treasury and a fee

assessed on private insurance and self-insured health plans (the PCOR Trust Fund Fee) ... PCORI receives 80 percent of the monies collected by the PCOR Trust Fund to support its research and programmatic funding and operations. The Department of Health and Human Services (HHS) receives the other 20 percent of Trust Fund monies to support dissemination and research capacity-building efforts (the majority of HHS's share goes to the Agency for Healthcare Research and Quality)" (PCORI, 2014, para. 1). Basically, the PCOR Trust Fund Fee has amounted to between \$1.00-\$2.79 charged per ACA health insurance policy since 2012 and has generated an amount ranging from \$275,500,000 in FY 2020 to \$399 million in FY 2029 (IRS, 2023).

If the PCORI model were replicated to provide funding for a patient and provider education infrastructure about prenatally diagnosed conditions supported by an excise tax on prenatal screening at \$2 per test, this model would generate \$6 million per year based on the estimated 3 million women per year who undergo prenatal screening. With tests costing between \$695-\$1,349 (Kliff & Bhatia, 2022), this amounts to .3%-.1% of the cost of the test. Moreover, this model would place the cost of the public health responsibility squarely on the industry creating the public health problem. Importantly, prenatal screening places a significant financial and human resources burden on advocacy organizations, who are left to provide support for patients who have undergone prenatal screening and have increased education and support needs. However, the prenatal screening industry—composed of competitive for-profit companies receiving significant financial profits from prenatal screening tests—has failed to provide information and support for expectant parents by offering a standardized and sustainable educational infrastructure. Moreover, commercial funding may create ethically problematic conflicts of interest for patient advocacy groups, who would prefer to be perceived

as patient- and family-centered sources of information. Financial power imbalances and a desire to remain independent make it challenging for PAGs to negotiate with testing laboratories for financial support to respond to the growing demands on advocacy groups caused by “cfDNA screening” (Meredith et al., 2016; Skotko et al., 2019). A PCORI model would democratize this process by requiring commercial labs to provide funding for education, and a neutral entity would be able to disseminate the funds to eliminate the power imbalance.

#### 2.4.b. Folic Acid

A model for increasing awareness about an issue impacting people with disabilities in the prenatal period could be the folic acid campaign run between mid 1990s-early 2000s. This campaign consisted of a National Folic Acid Clearinghouse (operated by CDC)—similar to the clearinghouse proposed in the PPDCAA—as well as a Public Awareness campaign with media ads and printed posters and support; a working coalition of the Spina Bifida Association, national medical organizations, the March of Dimes, maternal and Hispanic health organizations, and applicable US agencies; and federal funding for program evaluation (CDC, USDA) (CDC, 2000). The campaign significantly increased awareness of the need for women to take the recommended amount of folic acid during pregnancy through public service announcements, leaflets, and information kits. “[The] Folic Acid Campaign launched in 1999 in collaboration with the Centers for Disease Control and Prevention (CDC), the American College of Obstetricians, the American Academy of Pediatrics, and the Spina Bifida Association of America. Providing education for women, health care providers and the public to urge compliance with folic acid consumption guidelines for reducing risk of NTDs was the main focus of the campaign” (Walani & Biermann, 2017, p. 4). Ultimately, this collaborative campaign

demonstrated substantial societal change by increasing awareness of the importance of folic acid consumption before and during pregnancy where only 4% of women reported knowing that folic acid can prevent birth defects in 1995 as compared to 24% of women in 2004 (Walani & Biermann, 2017).

One major component was the March of Dimes Think Ahead campaign in 1995, “designed to promote folic acid awareness through multiple channels (e.g., professional and public education, media campaigns, advertisements), and its efforts were supplemented by state initiatives designed to promote awareness and consumption of foods containing or fortified with folic acid” (Ahluwalia & Daniel, 2001, para. 14). In addition, the National Council on Folic Acid (NCFA) was established in 1997 to provide support for patients in child-bearing years and health professionals by working in partnership with local and state coalitions as led by professional associations, maternal and child health advocacy groups, and community-based health organizations with experience in education and folic acid awareness campaigns (Ahluwalia & Daniel, 2001). Following this campaign, “The March of Dimes reported that folic acid awareness increased from 52% in 1995 to 66% in 1997 to 68% in 1998 and to 75% in 2000 -- an overall increase of 44%. At the same time, consumption of vitamins containing folic acid increased from 28% in 1995 to 34% in 2000, a 22% increase” (Ahluwalia & Daniel, 2001, para. 15). These interdisciplinary collaborative efforts reflect the broad and focused support needed for prenatal education efforts to be successful.

Strategies found to be successful to increase folate awareness were a paid media campaign targeting prospective Hispanic parents through Spanish-language media and a community education campaign conducted in 2002 (Flores et al., 2007); the provision of printed

educational material for patients of child-bearing age (Watson et al., 1999); and a comprehensive, long-term and ongoing health promotion campaign with specific instructions on how to engage the media (Watson et al., 1999).

## 2.5. Limitations

Some limitations of the above analysis, and this general field of study, include a lack of research and data collection. Indeed, there is a dearth of research about the impact of diagnosis experiences on people with prenatally diagnosed conditions beyond Down syndrome. However, anecdotal media and social media reports highlight similarly negative experiences that reflect the Down syndrome research (Kliff & Bhatia, 2022). In addition, many of the studies lack of information about the impact of these negative diagnosis experiences on people from diverse racial backgrounds given the overexpression of White respondents in research (Meredith et al., 2023; Skotko, 2005). However, recent PCORI-funded projects by Skotko and Meredith are exploring the impacts of health disparities on Black and Hispanic parents of children with DS and parent informational preferences at the moment of diagnosis (Krell et al., 2023). Furthermore, there is an overall lack of data collected about the impact of training programs to reduce ableism.

## Chapter 3: Methods

### 3.1. Introduction

The purpose of this analysis is to apply principles of policy research to examine federal and organizational policies aimed at supporting new and expectant parents and providers discussing prenatal screening results; to assess these policies based on current evidence and expert opinions; and to provide policy proposals to address identified gaps and encourage systemic change. This dissertation aims to elucidate the following research questions as they relate to improving patient diagnosis experiences and addressing disability bias in obstetrics/gynecology:

1. What federal and organizational policies can be implemented, expanded, or funded to *improve patient prenatal screening experiences in terms of the provision of information about social outcomes and supports and services?*
2. What federal and organizational policies can be implemented, expanded, or funded to *address disability bias in genetics/obstetrics?*

The answers to these questions can offer alternatives and solid recommendations for policies that improve prenatal screening experiences for patients, as well as provide guidance to policymakers, public health practitioners, and medical professionals on the implementation of policies to address disability bias in obstetrics and genetics.

### 3.2. Methodological Perspective

This policy analysis relied on the philosophy of *interpretive constructionism* to determine how individuals and groups actively interpret their experiences and realities while constructing the world and being constructed by the world (Koch, 1995). This strategy was vital given that



this policy analysis required consulting with political experts and patient advocates with a range of perspectives that needed to be interpreted and then constructed—by both the participants and me as the researcher—into potential policy solutions. Interpretive constructivism includes elements of Heidegger’s interpretive phenomenology (with its focus on the value of different individual experiences and perceptions of reality, including the researcher) within the constructivist paradigm (with its emphasis on the value of determining themes and patterns in social research through data analysis) (Burns et al., 2022). Interpretive constructivism weaves these approaches to provide a more comprehensive view of the research topic (Burns et al., 2022; Y. Lincoln et al., 2018). Therefore, interpretive constructivism allows me to adapt the methods and theoretical frameworks to address this specific research question and context.

Advantages of interpretive constructivism for this analysis include the following:

1. The emphasis on researcher positionality is central to acknowledging existing biases. Heidegger shares that an unbiased perspective is not truly a realistic expectation for any researcher given that all individuals invariably bring personal histories and biases that can subjectively influence their position and framing of a subject (Burns et al., 2022). This philosophy is central in this policy analysis since I have been involved as a researcher, creator, and advocate for the past 15 years and offer both an informed and subjective perspective, and I am relying upon research participants to also contribute their very different perspectives based on deep personal histories.
2. Interpretive constructivism is a combination of interpretivist, constructivist, and participatory phenomenology. Lincoln and Guba posit that constructivist and participatory phenomenological models can take a step beyond interpretation and

understanding toward social action to attract champions for equity and justice (Charmaz et al., 2018). This social action is the ultimate objective of this policy analysis that results in concrete recommendations.

### 3.3. Research Design

#### 3.3.a. Rationale

##### *3.3.a.(1) Policy Analysis*

Eugene Bardach's (2020) Eightfold Path model of policy analysis was relevant for the analysis because it allowed for an examination of key factors in broadly complex systems to construct practical and actionable solutions and evaluate the pros and cons of the alternatives presented (Masselink et al., 2021). This has been exemplified in disability policy through Masselink et al.'s policy analysis on how to expand wheelchair coverage options through Medicare. This method allowed for the examination of a complex problem in the disability community, which involved public and private insurers, and the construction of possible policy alternatives to address the problem as determined by an interdisciplinary team consisting of non-profit leaders, medical professionals, and legal experts (Masselink et al., 2021). Similarly, prenatal screening involves broadly complex systems in healthcare between public and private insurers, curricula and guidelines determined by national medical and genetics organizations, and existing state and federal policies. Additionally, the proposed policy solutions included an interdisciplinary team of patient advocacy groups, medical and genetics professionals, and policy experts. Moreover, the Bardach Model assumes the exercise of considerable judgment by the analyst as a non-neutral instrument, which allows for an analyst with substantial experience to make informed determinations about the nature of the problem and the feasibility of

solutions and to tell the story (Bardach & Patashnik, 2020). This was a particular strength given my 20 years of experience as a leader in the field and personal experience as the parent of a person with Down syndrome.

### *3.3.a. (2). Responsive Interviewing Rationale*

Semi-structured interviews provided flexibility while ensuring that key topics were covered, allowing for in-depth exploration of key informants' recommendations for policy solutions to improve prenatal screening experiences and promote equity. In another policy analysis using the Bardach method, Owen described choosing the Rubin and Rubin responsive interviewing technique as a compass and not as a guide because of the flexibility of the process in determining the unique perspective of the interviewee (Owen, 2014). According to the interpretive constructionist researcher, the goal of an interview is to find out how people perceive an issue (Owen, 2014). Given that we were seeking the input of interdisciplinary experts on their perspectives about policy, we did not anticipate determining a definitive truth. Instead, we were seeking practical policy solutions that weighed the potential strengths and benefits of various alternatives as informed by the key informants (Bardach & Patashnik, 2020). The conversational approach of responsive interviewing and the prioritization of social partnerships were a benefit given the existing relationship I already had as a researcher with many of the subjects as colleagues in the field.

### *3.3.a.(3). Framework Method Rationale*

The Framework Method is commonly used for the analysis of qualitative data in multi-disciplinary health research and policy analysis. (Gale et al., 2013). I employed the Framework Method, developed by Ritchie and Spencer (1994), to systematically analyze the qualitative data

collected during the semi-structured interviews. The Framework Method was particularly helpful for organizing and analyzing the interviews, allowing for the development of summaries, clear themes, and patterns (Ritchie & Spencer, 2002). The Framework Method allowed for a combination of the inductive and deductive approaches to qualitative research where I could deductively begin with categories derived from the fundamental research questions and the Bardach Model as a theoretical framework to establish the categories for data coding and to guide the organization and interpretation of the data based on established criteria (Ritchie & Spencer, 2002). Correspondingly, I determined global themes and emergent themes within categories using inductive data coding. This method uses a systemic and flexible approach to construct a framework matrix from the input provided by the interviewees (Gale et al., 2013), which supports the categorization of possible solutions to be used in the policy analysis for constructing and weighing alternatives.

### 3.3.b Description of Methods

#### 3.4.b.(1). Policy Analysis Methods

Table 1 below, and the following outline of the Bardach model for policy analysis, shows how the model was applied for this dissertation.

*Table 1: Bardach Model Step Directory*

Bardach Steps	Chapter	Page Number
Step 1: Defining the Problem	Chapter 1: Introduction and Statement of Purpose	13
Step 2: Assemble Some Evidence: <i>Literature Review of Policy</i>	Chapter 2: Literature Review	34
Step 2: Assemble Some Evidence: <i>Interviews</i>	4.1. Assemble Some Evidence— Interviews: Step 2	82

Step 3: Construct the Alternatives	4.2. Construct the Alternatives: Step 3	91
Step 4: Select the Criteria	4.3. Select the Criteria: Step 4	103
Step 5: Project the Outcomes	4.4. Project the Outcomes: Step 5	106
Step 6: Confront the Trade-offs	4.5. Confront the Trade-offs: Step 6	121
Step 7: Decide!	5.1. Deciding: Step 7	125
Step 8: Tell Your Story	Appendix 6: Telling Your Story: Step 8	186

**1. Defining the Problem**

The “problem” as defined by the Bardach model is positioned by thinking in terms of deficit and excess. Therefore, I defined the problem in Chapter 1 in terms of excess in stating:

*As prenatal screening expands, too **many expectant parents** experience emotional harm because they are not provided balanced, accurate, and up-to-date information about genetic conditions, and they experience clinical bias that perpetuates discrimination against people with disabilities.*

Additionally, I specified the conditions that cause the problems and corresponding evaluative criteria as 1. the lack of provision of balanced, accurate, and up-to-date information provided about genetic conditions and 2. bias against people with disabilities. Bardach explains that the evaluative criteria must be defined to determine whether policy interventions are achieving their goals. For more details about the

context of the problem and an iterative discussion as described in the Bardach framework, see Chapter 1: Introduction and Statement of Purpose.

## **2. Assemble Some Evidence**

The Bardach model does not require an exhaustive search of all data related to a topic, as would normally be expected in a comprehensive literature review. Rather, an efficient approach to data collection is suggested so that the policy analyst can find information that can be transformed into evidence to assess the problem, find similar policies, and identify promising solutions (Bardach & Patashnik, 2020).

### ***Literature Review***

The Literature Review featured in Chapter 2: Literature Review focuses on the policy interventions for this issue since the articulation of the problem and surrounding context are discussed in Chapter 1: Introduction and Statement of Purpose. The Literature Review was performed by searching the PubMed and Google Scholar databases for the following specific keywords: “Prenatally and Postnatally Diagnosed Conditions Awareness Act;” “Kennedy-Brownback Act;” and “prenatal diagnosis” AND “disability rights critique” OR “disability bias.”

The Bardach model further explains that certain information sources provide more highly valued evidence, particularly existing policy analyses by advocacy organizations and surveys of best practices (Bardach & Patashnik, 2020). Therefore, key sources of information about prenatal screening, disability, and public policy included the following: *Genetic Testing and the Rush to Perfection* by the National Council on Disability; *Prenatal Genetic Testing, Abortion, and Disability Justice* by Amber Knight and

Joshua Miller; Prenatal Laws: Down Syndrome Information Acts by The Center for Dignity in Healthcare for People with Disabilities (CDHPD); *Prenatal Disability Education Summit Report* by Stephanie Meredith et al.; and *Recommendations to Improve the Patient Experience and Avoid Bias When Prenatal Screening/Testing* by Stephanie Meredith et al.

### ***Policy Interviews***

A second form of evidence assembled was interviews with noted experts and policy leaders in the field. Because this method involved interviewing key informants, I used Rubin and Rubin's "responsive interviewing" as a model to pose iterative questions and probes as I engaged in semi-structured interviews with participants (Rubin & Rubin, 2005). Specific details about policy interview methods, including participant selection, data collection, and data analysis—aligned with the traditional five-chapter dissertation structure—are described in the next section of this proposal.

### **3. Constructing the Alternatives**

The next step recommended by Bardach involved constructing alternatives that started comprehensive and ended focused. These needed to be actionable and feasible alternatives that were relevant to resources and that modeled the system in which the problem was located (Bardach & Patashnik, 2020). I completed this step by proposing and describing five alternatives or possible policy solutions informed by the framework matrix from the key informant interviews and policy recommendations found in the literature.

#### **4. Selecting the Criteria**

The subsequent step defined by Bardach involved selecting criteria to measure the alternatives against each other including measurable and quantifiable, efficacy/effectiveness/usefulness, equity, efficiency, cost, administrative robustness, political sustainability, sustainability, fairness, freedom (free markets, economic freedom, reproductive freedom), legality, political acceptability, and robustness and improvability. I assigned the weight for the criteria based on what was identified as important by the key informants, by experts in the literature, and based on my experience as a professional in the field.

#### **5. Project the Outcomes**

The next step of the Bardach model involved putting the five alternatives into an outcome matrix to assess the criteria for each alternative and to compare them against each other. Fundamentally, this step involved projecting all the outcomes for each alternative that I or other interested parties might reasonably care about (Bardach & Patashnik, 2020, p. 49). The base case involved doing nothing and continuing with a minimal privately funded educational infrastructure to support patients and providers. Additionally, I determined the break-even estimate by estimating the percentage of reduction in inadequate information about disabilities and disability bias that would be worth the expenditure given the variables that could influence the perceived cost and value of an intervention.



## **6. Confronting the Trade-offs**

Determining policy “trade-offs” involved comparing the costs and benefits and positives and negatives of the projected outcomes for each of the five alternatives (Step 3) after projecting the outcomes (Step 5) (Bardach & Patashnik, 2020). Subsequently, this step required revisiting the break-even analysis to determine whether each alternative provided a quantifiable return on investment or was even feasible. This was done by determining the number of pregnant patients who would benefit from each projected outcome at the first point on the life course. Other criteria to examine would be the total annual costs and expenditure of time as constructed in a matrix and considering the likelihood of success for each alternative.

## **7. Deciding**

After examining the outcomes and confronting the trade-offs, the next step was to decide on the recommended solution or solutions. Bardach indicates that at least one of the alternatives should be selected or more than one, if possible, based on an iterative process of examining the projected outcomes for each alternative and the most politically feasible and sustainable options (Bardach & Patashnik, 2020). Arguments to defend the decision included the rational analytical model, representative examples and counter examples; analogies; arguments by authority with informed and impartial triangulated sources; and arguments about causes and leverage that could be used to motivate the adoption of the selected alternatives (Bardach & Patashnik, 2020).

## 8. Telling the Story

Because my intent with this policy analysis was to prompt policy change to address the issue, I created a collaborative advocacy letter to encourage professional obstetric and genetic organizations to adopt organizational health equity measures for people with disabilities. Moreover, I created an email introducing the letter to the advocacy organizations to encourage them to support the letter, which includes my personal story as parent who received a diagnosis and the stories of other parents cited in my research who have experienced bias during prenatal testing conversations as well as a broader advocacy strategy and logical explanation for how the strategy can be implemented successfully. The purpose of the email is to explain why the medical organization actions to improve health equity toward people with disabilities are vital using the pathos (emotional plea argument) of traditional rhetoric. I also provided a comprehensive list and advocacy plan to apply the lever for change.

### *3.3.b.(2). Policy Interview Methods*

This section outlines the study design using the Framework Method and Responsive Interviewing. In this section, I provide a comprehensive overview of how Responsive Interviewing and the Framework Method were applied in the dissertation study as part of the “Assembling Evidence” step of the Bardach Model. Table 2 shows the different methods used for policy interviews.

*Table 2: Assembling Evidence Methods*

	Method	Procedure
Interviewing	Responsive Interviewing	Data Collection
Qualitative Data Analysis	Framework Method	Data Analysis

I conducted semi-structured interviews with 10 policy and organizational experts from various relevant disciplines and political persuasions. Interviewees were selected using purposive sampling with maximum variability to identify different perspectives and commonalities between them in policy solutions. I posed iterative questions and follow ups as I engaged in semi-structured interviews with participants (Rubin & Rubin, 2005).

The Framework Method will be employed for the systematic analysis of qualitative data by “sifting, charting and sorting material according to key issues and themes” (Ritchie & Spencer, 2002, p. 177). This method consists of the following steps:

1. **Familiarization:** Familiarization involves immersion in the data such as audio recordings and transcripts while taking notes on key ideas and recurring themes (Ritchie & Spencer, 2002).
2. **Identifying a thematic framework:** Initial codes are organized into a thematic framework, including major themes and subthemes relevant to the research questions. This thematic framework is determined by themes in the literature, emergent themes raised by research participants, and analytical themes that arise when coding (Ritchie & Spencer, 2002).
3. **Indexing:** In this stage, all the data in the dataset is indexed according to the thematic framework using a numerical system, which is documented in the margins of the interview text and which links back to the index (p. 182) (Ritchie & Spencer, 2002).
4. **Charting:** Data is systematically organized into charts or matrices, with rows and columns representing participants and themes and subthemes. Charting relies on the

summary of data rather than copying and pasting text; however, the original text from the transcript should be referenced with page numbers (Ritchie & Spencer, 2002).

5. **Mapping and interpretation:** In the final stage, patterns and relationships within the data are identified and interpreted, leading to the definition of concepts, the mapping of the range and nature of phenomena, the creation of typologies, the discovery of associations, and the development of explanations and strategies (Ritchie & Spencer, 2002).

### 3.4 Data Collection

#### 3.4.a. Interview guide.

An interview guide was developed and utilized to gather the information used to complete the proposed policy analysis, including the development of alternatives and criteria, the projection of outcomes, the confrontation of tradeoffs, and the selection of a politically feasible solution.

Questions included policy and organizational questions such as:

1. Recent research we conducted also found that most expectant parents described that their obstetricians conveyed implicit or explicit bias against people with disabilities when receiving prenatal screening results suggesting a possible diagnosis of a genetic condition.
  - a. What policy solutions do you think could help address that bias?
  - b. What national medical or advocacy organizational solutions do you think could help address that issue?

### 3.4.b. Participant Selection

The participants for this study were selected using purposive sampling. This method was chosen to ensure that individuals with the most relevant experiences and insights related to prenatal disability education policy are included in the study, as well as those with the highest capacity to influence prenatal disability education. Interviews were conducted with 10 of the following key experts to gather input from a range of thought leaders in the field, including representatives from the disability community (Down syndrome and Spina bifida), medical and genetics organizations, and the federal government.

*Table 3: Participant Selection Characteristics*

Position	Organization	Expertise	Party Affiliation	Race	Sex	Disability Connection
Prenatal Disability Policy Expert		Legal; disability issues; lived experience	Democrat	W	M	Self
Prenatal Disability Policy Expert		Lobbying; disability issues; lived experience or parent	Republican	W	F	Parent
Staffer	US Senate	Disability Issues	Republican	W	F	N/A
Staffer	US Senate	Disability Issues	Democrat	W	M	Parent
Staffer	US Senate	Disability Issues	N/A	W	F	Sibling
Staffer	US House	Disability Issues	Republican	W	M	Parent
Executive Director	Black Down Syndrome Association	Disability Advocacy	N/A	B	F	Parent
Policy Director	National Down Syndrome Congress	Disability Advocacy	N/A	W	F	Parent
Policy Director	Spina Bifida Association	Disability Advocacy	N/A	W	F	Parent
Policy Director	National Society of Genetic Counselors	Medical/Genetics	N/A	W	M	N/A

### 3.4.c. Procedures and setting

I conducted interviews with participants across the country in a private setting via Zoom to encourage convenient, open, and honest discussion. The range for interviews was 30-67 minutes with the average interview lasting 52 minutes. Each interview was recorded via Zoom with the participant's consent and later transcribed verbatim by scrupulously comparing the transcription feature in Zoom against the audio recording. Field notes were also taken during and after the interviews to capture contextual information.

### 3.5. Data Analysis

Inductive coding was used to assemble themes and subthemes identified by the interviewees to allow for the discovery of new insights and criteria as well as deductive coding within the categories of the Bardach model. (Ritchie & Spencer, 2002). The process involved recording and transcribing the interviews, listening to the interviews again, constructing an analytical memo, and performing open coding of the transcripts. Next, I developed a working analytical framework in the analytical memo and then coded the data to enter the data in a framework matrix to be used in interpreting the data, constructing alternatives, selecting criteria, projecting the outcomes, confronting the trade-offs, and deciding on a solution as outlined in the Bardach Model.

Below is a description of Ritchie and Spencer's steps for the Framework Method as I applied them:

1. **Familiarization:** I recorded the 10 semi-structured interviews via Zoom and generated a transcript with closed captioning. I then immersed myself in the data by listening to the audio recording to meticulously verify and edit the transcript. Then, I reread the interviews while taking notes on key ideas and recurrent themes.
2. **Identifying a thematic framework:** In this stage, I created themes and subthemes based on themes identified in literature, emergent themes in the interviews, and recurrent themes in the interviews in response to the following research questions:
  - *What federal and organizational policies can be implemented, expanded, or funded to improve patient prenatal screening experiences in terms of the provision of information about social outcomes, supports and services?*
  - *What federal and organizational policies can be implemented, expanded, or funded to address disability bias in genetics/obstetrics?*

Specifically, I looked for themes and subthemes applicable to the steps outlined in the Bardach model, particularly potential alternatives, criteria for determining the effectiveness of different alternatives, and projections for outcomes and trade-offs for different alternatives. I also looked for emergent themes about the effect of party politics on policy approaches to addressing inequities toward people with disabilities in prenatal screening and care. Subsequently, I created an alpha-numeric system to categorize each theme and sub-theme to be assigned during indexing.

3. **Indexing and applying the analytical framework:** I indexed the data by assigning numbered themes and sub-themes to the passages from the interviews. I printed all the interviews and wrote my indexed content into the margins. In addition, I iteratively

revised the themes and sub-themes as needed to inductively reflect the content of the qualitative data.

4. **Charting the data into the framework matrix:** I systematically organized the indexed qualitative data from the interviews into charts or matrices, with rows representing themes and subthemes and columns representing participants. I also cited the original transcript using page numbers and bolded pages in red where I highlighted key quotes.
5. **Mapping and interpretation:** In the final stage, I identified and interpreted patterns and relationships within the data to define concepts that might be used for selecting alternatives and selecting criteria for policy solutions; create typologies and determine how different types of participants might have characteristics that influence their selection of alternatives for policy solutions; map the range and nature of phenomena, including attitudes and political nuances that might influence outcomes for different policy solutions; discover associations and how the implicit and explicit characteristics of different types of participants might influence their perception of trade-offs for the different alternatives; and develop explanations and strategies to address peoples' attitudes, experiences, and behavior when discussing projected outcomes and trade-offs for the Bardach Model.

These were presented as *Results* for presenting alternatives and selecting criteria in the Bardach Model as well as projecting outcomes and considering trade-offs.



### 3.6. Ethical Considerations

This research adhered to ethical guidelines, including informed consent, confidentiality, and participant anonymity where requested. Ethical approval was obtained from the Georgia State University Institutional Review Board (IRB Number: H24198).

### 3.7. Validity and Reliability

To enhance the rigor and trustworthiness of the data collection and analysis, I utilized recommended practices as outlined in Lincoln and Guba's "four criteria of trustworthiness" for a range of qualitative paradigms in *Naturalistic Inquiry*—namely credibility, transferability, dependability, and confirmability (Y. S. Lincoln & Guba, 1985).

1. To establish **credibility** and confirm the validity of the research findings, I outlined the credentials of all participants, gave participants the opportunity to review and validate findings to allow for member checking, outlined my own prolonged engagement in the field in a positionality statement, and used multiple sources to triangulate the data (Y. S. Lincoln & Guba, 1985).
2. **Transferability** (the ability to replicate the context) was achieved by providing rich descriptions of the research context, participants, and methods in an analytical memo (Y. S. Lincoln & Guba, 1985).
3. Likewise, the analytical memo included detailed documentation about the research process and decisions to establish **dependability** based on the stability and consistency of the research findings over time and with different researchers (Y. S. Lincoln & Guba, 1985).

4. Finally, **confirmability** or the degree to which the research findings are shaped by the participants and the context rather than my biases and values were validated through peer debriefing with my dissertation chair; the use of quotations and thick descriptions in the text to highlight key points and allow readers to confirm the validity of the findings; and a transparent audit trail and documentation for how codes and themes were determined in a codebook that documents each theme and sub-theme to be assigned during indexing (Y. S. Lincoln & Guba, 1985). Moreover, I shared my reflexivity statement and acknowledged my own biases throughout the analysis as not only a researcher but an active participant in the field.

The qualitative data analysis approach practically maintained rigor during the qualitative process as outlined by Johnny Saldaña, and informed by Lincoln and Guba, through systematic coding with an audit trail (using the indexing and framework matrix of the Framework Method) (Y. S. Lincoln & Guba, 1985; Saldaña, 2021). I created well-defined code categories and themes documented in a codebook and implemented constant comparative analysis by iteratively evaluating the themes. Furthermore, I created transparent documentation of coding, themes, and interpretation in an analytical memo; engaged in peer debriefing with Dr. Vinoski-Thomas; reached data saturation by interviewing a representative sample of participants; and clearly reported of results (Saldaña, 2021).

## Chapter 4: Results

*While literature is typically not presented in the Results section, the Bardach model requires a triangulation of evidence from both the interviews and literature from Step 2 when selecting criteria, projecting the outcomes, and confronting the trade-offs to make the most informed policy decisions. Therefore, data from the literature and interview results necessarily weave together to generate the most informed policy analysis in this Results section.*

### 4.1. Assemble Some Evidence—Interviews: Step 2

#### 4.1.a. Participant Characteristics

The interviews included ten experts who were either medical organization leaders, community leaders, federal policy experts, or representatives of national advocacy organizations. Of the ten participants, three were current Senate staff, one was a former House of Representatives Chief of Staff and disability community leader, one was a policy expert from a national genetics organization, three were national disability advocacy leaders, and two were leaders in the disability community. 40% were Male, and 60% were female, and 90% were White and 10% were Black/African American. All participants had some level of higher education with representation across the US. Additionally, one participant identified as a person with a disability, seven identified as immediate family members of a person with a disability (six parents and one sibling), and two did not have an immediate personal connection to the disability community.

See Table 3: Participant Selection Characteristics.

#### 4.1.b. Themes and Subthemes

Seven major themes were inductively derived from the interviews—and subsequently triangulated with the literature review to place the data in the context of existing literature. The major themes primarily articulate the problems that need to be solved and why the issue is important.

*Table 4: Major Inductive Themes*

Theme	Subthemes	Percent Respondents
1. First point on the life course		60%
2. People with disabilities as minority population		10% (100% including subthemes)
	a. Bias against PWD	100%
	b. Exacerbated intersectional bias	30%
3. Parent emotional harm		50%
4. Lack of services and support		60%
5. Lack of funding		40%
6. Med orgs/doctors devalue disability		60%
7. Bad diagnosis experiences		30%

**Theme 1: The first point on life course is critical for health equity for people with disabilities and caregivers (access to supports and services).**

Six participants described the moment a patient received prenatal screening results as a critical first point on the life course related to access to supports and services, which are also essential social determinants of health for people with disabilities. Participants indicated that the information provided during this first moment of learning about a potential disability would ideally help to establish trust with providers, empower them with information to make decisions about treatment, and improve access to supports and services that can address social determinants of health like financial stability and social infrastructure. However, failure to meet these needs at the moment of diagnosis erodes patient trust in their providers, weakens their

ability to make treatment decisions, causes emotional harm, and hinders access to social services and supports.

*“Pro-information gives both camps a really compelling reason to advocate for more information..., and everyone who has to go through the decision-making progress will feel more empowered with that decision, and that ripples throughout the child's life, their whole life, because parents who are forced into one way or the other have all this trauma. They feel like they are not in control of this life. And that comes across in the way that they parent and usually not in good ways... And with Spina Bifida, prenatal testing and diagnosis is more important than a lot of different disabilities diagnosed early because there are options for you to do earlier that may reduce disability and improve quality of life. So, parents have to know all this information, and it's not the ideal situation to give them all of this information along with a side of trauma and being just completely terrified because then you can't make good treatment decisions.”*

*—Colleen Payne, Staff at the Spina Bifida Association and Mother of a Person with Spina Bifida (speaking in personal capacity)*

*“So, I come to this work with that perspective and understanding the prenatal diagnosis experience via my parents and how that shaped their pregnancy and then the birth of my sister and services and supports thereafter.”*

*—Senate Staff 1*

*And then, them not feeling like they got the support and things that they needed ... They were told they were sorry, and this is not going to be a good thing for you and your family, and just kind of deal. And so they come with lots of questions, lots of worry, lots of anxiety. And we do our best to, one, welcome them but then, two, reassure them that ‘hey you're not alone in this’ and this is not at all a bad thing and trying to guide them to and give them the resources they need so they can make just more informed decisions.”*

*—Crystal Lotterberry, Director of the national Black Down Syndrome Association, Mother of Person with Down Syndrome*

**Theme 2: Recognize people with disabilities are a minority population subject to discrimination.**

***Subtheme 2.1: Strong bias against people with disabilities is conveyed by providers during prenatal screening.*** Every participant interviewed indicated that providers often convey

bias about people with disabilities during prenatal screening experiences which challenges the morality and ethics of the entire enterprise. Parent participants described experiences ranging from implicit bias where doctors automatically framed disability as bad news and said, “I’m sorry” to explicit bias where parents were advised about institutionalization, where terminations were scheduled before patients were offered the procedure or provided consent, and where patients received materials using offensive racist and ableist terms such as “Mongoloid” in 2005.

*And so because [Down syndrome is] scary to [the doctor] [They’re] automatically biased and think it’s bad. So then when [they] deliver news to parents, [they’re] like, “oh, sorry, sucks for you” as opposed to just “okay.” I don't know that's so simplistic, right? —Crystal Lotterberry*

*“I’m focused on getting better information to parents. I’m not focused on trying to prevent them from doing something with that information. But the fact that they’re not getting good information to me is a failure of the system. And it’s a challenge to the morality and ethics of the system.*

*We have this powerful scientific technology that we’re deploying without being really thoughtful about how we’re deploying it. And that’s the part that feels immoral because it reinforces bias. Some would say it creates bias.” —Andy Imparato, Former Chief of Staff for Democratic Senator, Former President of the American Association of People with Disabilities, Former Director of the Association of University Centers on Disability, Executive Director at Disability Rights California, and person who identifies as having a person with a disability (speaking in personal capacity)*

**Subtheme 2.2: Inequities can be exacerbated by race, ethnicity, and other intersectional identities.** 30% of participants further expressed that inequities can be exponentially influenced by other identities like race, ethnicity, socioeconomic status, and other intersectional identities.

*“I think there is definitely still lots of work to do, especially in the Black and Brown communities. Just as an organizational leader, we meet so many families who are just being diagnosed, they're joining the group, and they're like, ‘Oh, I didn't even know there were Black people with Down syndrome.’ Okay, well, we're here.” —Crystal Lotterberry*

**Theme 3: Parents of children with disabilities are experiencing emotional harm during prenatal screening.**

The theme that parents of children with disabilities are experiencing emotional harm during prenatal screening was indicated by 50% of the participants.

*“Many people who had a very bad experience, it stays with them for the rest of their lives. You never, never forget it, and it's not like you never think about it again after the child is home, and you're going about your lives. No, it's always there, that memory. Because it's something so important in life. And to get a false perspective is just shattering.” —Madeleine Will, Former Policy Director of the National Down Syndrome Congress, Former Directors of OSERS, Organizer of Down Syndrome Consensus Group, and Mother of a person with Down syndrome (speaking in personal capacity)*

1. *“Everyone’s diagnosis story, especially if it’s negative like so many of ours, those are permanent wounds. I will never get back my daughter’s birthday—how it should have been a happy day, and it was the worst day of my life.” —Heather Sachs, National Down Syndrome Congress Policy Director, Mother of a Person with Down Syndrome) (speaking in personal capacity)*

*“I do remember every nurse and doctor who encountered me that day looking at me like with tears in their eyes and with fear and telling me they were so sorry. I was like, ‘oh crap, this must be bad.’ That is what that conveyed to me. If they are upset about this, I don’t know anything about it, but if they’re upset about it, it must be really, really bad. And then just the fear of the unknown and so the more information you get upfront about what this is and what supports and services there are for it the more you know but if you are having to navigate this in the dark, knowing nothing except what’s swirling around in your head, that’s traumatic.” —Colleen Payne*

Indeed, every advocacy leader interviewed who was a mother described emotional harm from the way in which the diagnosis was delivered and used emotive terms such as “shattering,”

“never, never forget,” “permanent wounds,” and “traumatic.” This was true for both Spina Bifida and Down syndrome.

**Theme 4: Parents of children with disabilities not receiving critical information about social outcomes, support, and services during prenatal screening.**

Six participants expressed the view that parents are not provided critical information they need about services and supports during the diagnosis experience which limits their ability to make treatment decisions, make social connections within the disability community, address social determinants of health, and get the help they need.

*“Oh, and in addition to ‘I’m sorry,’ I was not given any information about local Down syndrome organizations or the national organizations. So, after we took our baby home, and after I was able to get myself together, and luckily, I have a very research and business-oriented husband, he started doing some research, and he connected us with [our local Down syndrome group]. So that’s how I became active in the local organization, meeting people, and joined a mom’s group for babies around the same age and started to hear that everyone had a similar diagnosis story, and it didn’t matter what hospital we delivered in, it didn’t matter if it was a prenatal or postnatal diagnosis.”*

*—Heather Sachs*

*And I also think just a lack of options about something and feeling forced into one road or the other is it can lead to trauma for parents. —Colleen Payne*

*The next step after the study that was funded by the Kennedy Foundation which is very interesting because one of the findings was that when parents received this news, there were lots of failings. They didn’t like what they were told, how they were told, they didn’t get the supports they needed.*

*—Madeleine Will*

**Theme 5: Lack of funding for work to address problems with diagnosis experiences.**

The theme about the lack of funding was indicated by 40% of the participants interviewed, including lack of funding for the development of educational resources for providers, the lack of funding for the dissemination of patient and provider education resources about disabilities,



and the lack of funding for advocacy organizations to dedicate human resources to the increased needs of prenatally diagnosed patients.

*I think practitioners are not educating practitioners on developmental disabilities in general, let alone you know, Down syndrome or other genetic conditions at that prenatal stage. And I think that there are resources that have been developed for families that are excellent, but families don't know how to access them, and our families don't know that those resources exist or where to go. They don't know that there are family to family health information centers ... It is a dissemination problem in many ways. —Senate Staff 1*

**Theme 6: Professional medical organizations need to value disability perspective and people with disabilities.**

60% of participants said that professional medical organizations like ACOG need to better demonstrate that they value the disability perspective and people with disabilities.

*It's always the central problem in disability world. ... How is the person valued? —Madeleine Will*

*When are we going to learn our lesson that if we just rely on our medical scientific training and we don't take the time to get to know people as people and respect and value people as people, then we're never going to be good scientists? —Andy Imparato*

*“The biggest thing in getting over the initial hurdle is that ACOG ought to recognize a disability group internally and show that ACOG, as an organization, cares about people with disabilities and families with children with disabilities.” —David Hoppe, Former Chief of Staff for Republican Members of the House and Senate and Father of a Person with Down Syndrome (speaking in personal capacity)*

**Theme 7: Much work has been done, but bad diagnosis experiences are still the norm.**

40% of the participants indicated that even though much work has been done to improve diagnosis experiences through state and federal legislation, collaborative

meetings with leaders of advocacy and medical organizations, research, professional publications, and the development of patient and provider education materials, bad diagnosis experiences are still the norm and need to be addressed as a problem. All the respondents expressing these concerns were also parents.

*“So, when my daughter was born, I had an awful, awful diagnosis experience that I’ve testified before the [state] legislature about. I was given, at a major hospital in a metropolitan area, resources that were so outdated that they actually still used the word Mongoloid in them. And was just basically every way that it could be handled badly. They told me the news when my husband was out of the room, and they sent in a junior social worker who looked like she was about 20 years old who was crying when she gave me the diagnosis. As I said, we got information about, ‘You’ve had a Mongoloid, now what?’ I was also told by the nurses there that there was a farm ... where the owners have adopted some kids with Down syndrome, and if we didn’t want to keep the baby then you know that might be an option. This was in 2005.”*

—Heather Sachs

*If we could get the medical groups to adopt this as something they do regularly at their conferences, it would help what is found to be still clearly a lack of knowledge about many families who find out they might have a child with a disability. That’s how [to improve] the percentage numbers of people who are handled very badly just because everything is seen in the negative.*

*We ought to be able to overcome that. We certainly haven’t done that.*

—David Hoppe

Additionally, three inductively derived categories aligned with the research questions (1.

*What federal and organizational policies can be implemented, expanded, or funded to improve patient prenatal screening experiences in terms of the provision of information about social*

*outcomes, supports and services? 2.What federal and organizational policies can be*

*implemented, expanded, or funded to address disability bias in genetics/obstetrics?). The*

categories included **Medical Organization Actions**, **Disability Advocacy Actions**, and **Policy**

**Actions**. The Medical Organization Action themes revolved around what organizations such as

ACOG and SMFM could do to improve diagnosis experiences and reduce bias against disabilities;

the Advocacy Organization Action Items focused on advocacy initiatives that disability organizations could engage in to improve prenatal experiences for families; and the Policy Actions focus specifically on what federal government actions at the congressional or agency level can prompt improved diagnosis experiences. Three medical organization action themes were identified, seven disability advocacy action themes, and ten policy action themes.

Further, seven deductive categories were derived from the Bardach model for policy analysis, including funding options, measures of effectiveness, perceived costs, challenges/barriers, benefits, positives, and negatives. 78 themes and additional subthemes were inductively identified for each of these categories. Separately, four political themes and additional subthemes were found to inform more nuanced approaches for navigating policy issues, specifically political motivations and strategies for approaching policy solutions. Moreover, the values and most effective solutions that were summarily identified by each participant were used to inform the top policy alternatives and criteria for determining the effectiveness of different alternatives discussed below.

See Appendix 5: Analytical Memo.

#### 4.1.c. Indexing and applying the analytical framework

While indexing the data by assigning themes and sub-themes with alpha-numeric codes to the passages from the interviews, the themes and sub-themes were iteratively revised to reflect the content of the qualitative data. For example, eight political themes were originally identified; however, four of the themes—“Laws Don’t work at changing behavior,” “Prenatal screening and information about disabilities gets mired in reproductive rights debates,” “Down Syndrome Information Acts have limited effectiveness,” and “Dysfunction in the disability

community” — were so prevalently identified as political barriers that they were merged into the deductively defined “Challenges” category from the Bardach model. The remaining political themes focused on political motivations and strategies. Moreover, potential solutions/alternatives were divided into policy strategies, medical organization strategies, and advocacy organization strategies to define which entities more clearly would be responsible for executing those alternatives. The benefit was that solutions introduced, which did not emerge as top alternatives/solutions, could be used as strategy levers to encourage the adoption of the final recommendation. For example, one participant identified that a strategy for advocacy organizations could be contacting federal agencies to encourage the inclusion of prenatal screening issues as a priority for health disparities funding initiatives. Thus, the advocacy strategy could be used as a lever to encourage the policy solution.

#### 4.1.d. Charting the data into the framework matrix

The framework index features data from the interviews sorted into a table matrix with rows representing themes and subthemes and columns representing participants. Each cell of the table includes page numbers from the original transcript where the representative statements could be found, and the page numbers with powerful quotes pertaining to each theme were bolded in red.

See Appendix 4: Index.

### 4.2. Construct the Alternatives: Step 3

#### 4.2.a. Mapping and interpretation

##### *4.2.a.(1) Concepts for Selecting Alternatives*

The concepts used for selecting alternatives revolved around three major concepts based on which entity would be executing the actions: 1. national medical and genetics professional organizations, 2. national disability advocacy organizations, or 3. federal agency or congressional policy actions. While there are many activities national disability advocacy organizations can do to support new and expectant parents—develop resources, collaborate with medical organizations, and advocate to medical organizations, legislators, and agencies—they are fundamentally dependent on medical organizations to influence the broad population of clinicians delivering diagnoses. Therefore, any meaningful alternative must involve an action executed by health professionals and national medical and genetics organizations who have the greatest influence on the clinical practice through guidelines and practice bulletins (ACOG, 2019).

Research about patient experiences and the effectiveness of state laws, as well as the insight from our interviewees, corroborated that actions by advocacy organizations and departments of public health have little to no impact on the way clinicians deliver diagnoses (Lehman et al., 2021; Meredith et al., 2023). Clinicians rarely proactively look to advocacy organizations or departments of public health for what resources to provide, and the clinicians who do are already biased to use those resources. Primarily, obstetricians and other medical professionals rely on practice guidance from the protocols and checklists issued by their professional organizations, training during residency or through continuing medical education, and professional protocols and guidelines that appear in electronic clinical support systems such as Up-to-Date and Dynamed (ACOG, 2019; Sanford et al., 2021).

*I think that, in terms of provider education. In my mind, it's more effective when it's organizational versus the government. I think organizations, particularly in this space where it's so innovative and fast moving. I think the organizations flex much quicker than the government can. —John Richardson, NSGC Policy Director*

Consequently, any meaningful attempt to influence clinical behavior must involve the professional organizations that issue those guidelines for clinical practice and the training requirements. Further, there were a plethora of advocacy and policy strategies suggested by the interviewees to prompt medical organizations to create guidelines and training that are more equitable to people with disabilities, such as direct advocacy from patient advocacy organizations to the medical organizations, grant and reimbursement incentives, and federal funding restrictions.

#### *4.2.a.(2) Characteristics of participants*

The characteristics of the interviewees did manifest in some of the preferences they expressed for alternatives and their criteria for policy solutions. For example, organizational representatives were more likely to promote solutions that benefitted their organization members such as the National Society of Genetic Counselors Policy Director advocating for expanded insurance coverage for genetic counselors and the National Down Syndrome Congress Policy Director advocating for increased funding to advocacy organizations. Therefore, it was important to examine whether their inherently subjective recommendations were supported by other respondents or the literature. For instance, even though NCD's "Prenatal Testing and Rush to Perfection," the 2022 Prenatal Disability Education Summit, the Meredith et al. "Recommendations to improve the patient experience and avoid bias when prenatal screening/testing", and Knight and Miller's "Prenatal Genetic Screening, Epistemic Justice, and

Reproductive Autonomy further corroborate the value of expanding insurance coverage for genetic counseling, only one other interviewee also shared that recommendation as a solution. While this suggestion did not rise to the top among solutions recommended by the most participants, this does not necessarily indicate that the proposal is not promising but could suggest a need for NSGC to engage in greater advocacy with the disability community to promote the Access to Genetic Counselor Services Act about the potential for genetic counselors to aid in addressing the inequities experienced by patients during prenatal screening.

In addition, family members were more likely to understand the discrimination experienced by people with disabilities and their families in clinical care. Even though all the participants identified this clinical bias against people with disabilities as a problem, family members used stronger, more emotionally evocative language, and they were more willing to suggest alternatives that would be either a policy reward or penalty for how medical organizations and clinicians treat individual patients.

#### *4.2.a.(3) Attitudes and Political Nuances for Policy Solutions*

To get a better understanding of the attitudes and policy nuances for this issue, particularly potential partisan differences, the interviewees included three Republican policy experts and three Democrat policy experts. During the interviews, Democrats were less likely to be prescriptive about patient/provider relationships and expressed significant reticence for any measures—including funding initiatives—that could be perceived as dictating what providers should do, particularly following the Dobbs Supreme Court decision. One policy concern repeated by Democrats was the ability of one Senator to thwart balanced approaches by

preventing legislation from proceeding or watering it down with amendments such as Senator Tuberville's blocking of military confirmations over paid leave and cost reimbursements for service members who travel to get an abortion. Overall, Democrats opposed any policy solutions that could be perceived as pro-life or prescriptive about patient/provider relationships. The more convincing approaches for Democrats tended to revolve around establishing health equity measures to benefit people with disabilities and their families and addressing bias against people with disabilities.

On the other hand, the Republican participants were likely to be pro-life and select more authoritarian policy approaches such as statutes requiring the provision of accurate, balanced, and up-to-date information for patients learning about disabilities and federal funding regulations for medical organizations. However, all the Republicans indicated that these authoritative measures were the least likely to pass and would encounter significant opposition. The two Republican participants firmly entrenched in the disability community correspondingly emphasized the importance of a moderate, centrist approach to maintain bipartisan support and support from the medical community. Both Democrats and Republicans, emphasized the importance of congressional champions if any legislative action needs to move forward and emphasized that change is slow on this issue.

Interestingly, federal funding requirements were mentioned by both Republicans and Democrats as possible alternatives. In addition, a broad spectrum of participants agreed that medical providers are a product of an ableist society and that they are not singularly the source of the problem. Andy Imparato stated, "I think we need to recognize what we're up against. You know the ableism that exists in society at large. And then the medical profession has grown up



over generations. And it's not something that can easily be legislated away. So, I don't think there's a simple or linear policy solution.” However, some participants indicated that because of the level of intellectual achievement required to be a scientist or doctor, they can sometimes be even more resistant to change and have an even greater negative view of intellectual disability than the general population. Therefore, all participants agreed that alternatives aligned with the credibility of their own medical organizations carry the greatest weight for medical providers over actions by advocacy organizations and federal policy.

#### *4.2.a.(4) Associations and Perceptions of Trade-Offs*

All participants collectively expressed concern about and agreed upon the emotional harm to families caused by negative diagnosis experiences and the value of people with disabilities as a population that should be included as a health disparity population in broader health equity initiatives. However, 70% of the interviewees across parties expressed doubt that federal policy can change attitudes and bias while all agreed on the importance of ACOG and other professional medical and genetics organizations improving disability health equity with better training and collaboration between the medical and genetics organizations and disability community. Although most participants agreed that cost was an important factor to consider, they were divided on whether the cost would be perceived as low or high. This makes the construction of a break-even estimate in the Projected Outcomes particularly important so that leaders can make informed decisions about the cost of preventing emotional harm for pregnant patients and bias against people with disabilities.

#### *4.2.a.(5) Explanations and Strategies*

Due to the dysfunction of the federal government described by interviewees, the rancor over reproductive rights, the inability of the laws to change attitudes, and the absence of a sufficient number of legislative champions, federal policies requiring legislative action are not likely to pass or even be brought to a vote. Therefore, I dismissed legislative alternatives such as the Insurance Parity Bill already proposed to the House of Representatives or a statute requiring the provision of information suggested by a few interviewees. The Insurance Parity Bill requires that any insurer providing prenatal screening must also provide educational information about the conditions. This bill is beneficial in being bipartisan with Rep. Marc Molinaro (R-NY) and Rep. Nikki Budzinski (D-IL) as legislative champions. However, it not currently written with enough specificity about what constitutes information that benefits new and expectant parents, and it has the same problem as the PPDCAA where no funds are currently appropriated. A separate statute requiring the provision of accurate, up-to-date, and balanced information would also need appropriations, the quality of resources would be variable, and the proposed law is likely to be perceived by progressives as pro-life in the post-Dobbs era—making it unlikely to pass.

The participants offered differing opinions on the policy carrots and sticks that would motivate national medical and genetics organizations to better engage the disability community and offer better training for clinicians about disabilities. Some proposed carrots included funding incentives and collaborative grants (which could be possible with the new health disparities population designation of people with disabilities) while others proposed sticks such as statutes and funding requirements. Sometimes these advocacy and political actions do not need to be the alternatives per se but can be used as levers to promote the truly intended

alternatives such as prompting medical organizations to improve their collaboration with the disability community. Indeed, proposing legislation can still bring people to the table and be used as a lever even if it never passes.

*“It's wonderful when we pass the Kennedy-Brownback Bill. But we're not always going to be able to pass every piece of legislation that's proposed. But don't ignore the good that comes from just the introduction of it and the discussion of it across the communities. And then they table it. It doesn't matter. People were talking about it, there were some good things, and it emphasizes this idea that you're alluding to that these individuals have to be treated equitably and their families too. And when we're pointing out occasions when that's not happening, it takes a while, but it changes opinion over time.” —Madeleine Will*

Even though no congressional action is likely, the threat can be used to generate action and media attention to be used as motivators.

#### 4.2.b Alternatives

Fundamentally, the most promising alternatives that drew consensus from the highest percentage of interviewees and scholarship revolve around actions by medical organizations to address bias and federal agency funding to address a range of issues. Based on the alternatives identified in the literature and the alternatives identified as the most promising by the interviewees, the following alternatives will be compared in the Bardach policy analysis:

##### 1. **Alternative 1: No action.**

With research showing that emotional and informational harm continues to occur for 61-70% of patients learning about a prenatal diagnosis of Down syndrome (Meredith et al., 2023) after over two decades of the issue being identified as a problem (Parens & Asch, 1999; Skotko, 2005), we can anticipate that these outcomes will not improve without an

intervention measure such as a national organization or federal policy action.

**2. Alternative 2: Fund the Prenatally and Postnatally Diagnosed Conditions Awareness Act.**

Funding PPDCAA is repeatedly cited as a potential solution for the provision of accurate, up-to-date, and balanced information by experts in the field, including from NCD's "Prenatal Testing and Rush to Perfection," the 2022 Prenatal Disability Education Summit, the Meredith et al. "Recommendations to improve the patient experience and avoid bias when prenatal screening/testing", and Knight and Miller's "Prenatal Genetic Screening, Epistemic Justice, and Reproductive Autonomy." In addition, the law has already been passed and only requires right-sized funding to be enacted.

*In order to standardize medical practice across states and uphold the integrity of information related to prenatal testing for the sake of women's autonomy, we recommend that the federal government adequately fund the Kennedy-Brownback Act. This funding will enable the Department of Health to collect and disseminate accurate, up-to-date, comprehensive information about test results and the range of outcomes associated with the diagnosed condition. Additional information should include patient support networks, including information about how expectant parents of fetuses diagnosed with DS can connect with other parents who have had the same experience through First Call programs. In turn, medical providers should then be required to make this information accessible to patients via written materials (Knight & Miller, 2021a).*

**3. Alternative 3: ACOG, SMFM, and genetic organizations include people with disabilities in health equity measures, the development of**

**guidelines and clinical practices, and the training of residents and fellows on how to sensitively discuss disabilities.**

All the interviewees agreed that professional organizations like ACOG need to prioritize people with disabilities as a health equity population and provide better training for practicing clinicians and students, and this solution is further corroborated by NCD's "Prenatal Testing and Rush to Perfection," the 2022 Prenatal Disability Education Summit, the Meredith et al. "Recommendations to improve the patient experience and avoid bias when prenatal screening/testing", and Knight and Miller's "Prenatal Genetic Screening, Epistemic Justice, and Reproductive Autonomy."

***Organizational Inclusion:** So, I think that would be a real collaboration among the advocacy groups. The medical community that specializes in those different conditions and then the medical organizations like the ACOG and genetic societies and that sort of thing. We really need a lot more collaboration than we have right now. That's the only way to make everybody happy but also to get everybody's buy-in and to get the best product. You have to have all of those perspectives on board.*  
—Colleen Payne

***Better Training:** I think better training of doctors because oftentimes you never know how long it's been since a person's been a medical school or what beliefs they may have about Down syndrome, if anything, right? And they may have never actually seen a person with Down syndrome in practice or in anything. So just to have better knowledge of what's currently going on, and maybe what's in your medical books is not truly an accurate depiction of what real life is with a person with Down syndrome.* —Crystal Lotterberry

***Disability Representation:** And so every single thing they do including their health guidelines for the care of people with Spina Bifida always include adults, and usually include parents and of course medical providers and others, but the people with a*

*disability have to be front and center giving their input.*  
—Colleen Payne

**4. Alternative 4: Federal funding agencies, including NIH and CDC, which are now funding health equity initiatives that include people with disabilities as a health disparities population, prioritize funding toward research, career development, and resource dissemination to improve prenatal diagnosis experiences as the first point on the life course.**

People with disabilities were only recently designated as a health disparities population by NIH in September 2023 with access to funding for research and dissemination initiatives to benefit minority underserved populations who experience discrimination in healthcare (*NIH Designates People with Disabilities as a Population with Health Disparities, 2023*).

80% of interviewees agreed that this could be an important federal agency action that could improve diagnosis experiences among patients and reduce bias against disabilities among clinicians. Specifically, they indicated that the funds could be used for the following: research about diagnosis experiences and the competency of clinicians in discussing disabilities; grants to diversify the medical workforce to include more people with disabilities in leadership positions; grants to medical organizations for improved training and resource development; funding for patient education resource development that includes the social model of disability, dissemination, and implementation; grants for

collaborative meetings between the medical organizations and the disability community to develop interdisciplinary guidelines; funding for advocacy organizations to host First Call programs that support patients contacting them after receiving prenatal screening results; and funding to update resources about disabilities on federal websites.

*Especially these days we're doing a lot of studies on the health disparities, whether it's rural or race, and we could put in individuals with disabilities in that grouping too so we're making sure that they are getting the attention they need and deserve.*

—Senate Staff 2

*I feel like having strings attached to funding is a good way to try to drive behavior change. So, if there's federal funding going into certain types of education, making sure that some of that funding is supporting this kind of education [lack of information provided to pregnant patients about disabilities]. There's funding going into research. Maybe take some percentage of it to make sure that this kind of information is disseminated along with the fruits of the medical research. —Andy Imparato*

**5. Alternative 5: Congressional funding used as a reward or penalty for medical organizations and providers to address disabilities more equitably.**

60% of participants proposed that federal funding driven by Congress could be used as a reward or penalty for medical organizations to include people with disabilities in health equity measures and to improve clinical counseling about disabilities. 30% proposed the restriction of funds if organizations do not comply with requirements to include people with disabilities in health equity measures. This intervention was proposed by participants with demographic identities as **policy leaders** who were also

either family members or a self-identified PWD across political affiliations:

2 Democrats and 1 Republican.

*One of the things you could do is say that no federal funds will go to any group that does not include training on people with disabilities. You know, the [medical organizations] I'm sure get a lot of federal funds doing different things. Well, if they aren't willing to teach about how to deal with and work with people with disabilities, why should they be getting federal government funds? Why should I give them my taxes? And that's one way to do is not to start a new program with extra money, but to say, you aren't going to get any of the money you're getting right now unless you include people with disabilities. Figure it out, boys. I'll guarantee you they'll figure it out in less than 6 months.*  
—David Hoppe

30% of the participants recommended incentives for providers to discuss disabilities more equitably during prenatal screening—such as tax incentives or higher reimbursement rates for clinicians who obtain disability certifications. This intervention was proposed by participants with demographic identities as **advocacy leaders** and parents across political affiliations: one Democrat, one Republican, and one undefined.

*Maybe there's some type of financial incentive. Or some other incentive that can be found through a simple certification ... Here we have a green certified business if they do certain things to protect the environment. So maybe there's some type of certification that they can hang their hat on as a way to show that they're a better practice than one that doesn't have a certification ... or maybe some sort of tax incentive. I mean, money talks, right? —Heather Sachs*

#### 4.3. Select the Criteria: Step 4

The most important criteria identified by the participants were whether the solutions were **politically feasible** (90%) and whether the solutions promoted **equity** for people with



disabilities (90%). Most participants agreed that any federal policy initiative involving Congress—ranging from bipartisan initiatives like funding PPDCAA to more partisan statutes requiring the provision of information during prenatal screening— would be either the most difficult to enact or impossible. Indeed, even Senate Staff who are personally and professionally sympathetic to this issue, indicated significant reluctance to prescribe any component of the patient and obstetrician relationship, particularly in the post Dobbs era of rancor over reproductive rights (Meredith, Ayers, et al., 2022). Further, a Senate staffer indicated, “So I think it's politically very challenging to maneuver. I think it was politically challenging to maneuver 12-13 years ago when Kennedy Brownback was passed, but if we were to do something similar or right-size that in funding, it would continue to be challenging.” Even Republican counterparts in the Senate and the House who were more willing to pursue prescriptive statutes and funding acknowledged that those measures would be difficult and face significant opposition. Moreover, when identifying challenges, 70% of the participants indicated that laws do not change behavior, 60% identified the politics of abortion as a significant barrier when addressing inequities in prenatal screening, and 30% said the federal government was fundamentally broken for this issue. Therefore, the vast majority of participants said that advocacy directly to the medical organizations and federal agencies would be most politically feasible for finding solutions, particularly since the recent designation of people with disabilities as a health disparities population by NIH (*NIH Designates People with Disabilities as a Population with Health Disparities*, 2023).

Because 90% of the participants expressed the view that health providers convey bias against people with disabilities during prenatal screening, health equity toward people with

disabilities was also a top priority for 90% of the interviewees. Specifically, they defined health equity as including people with disabilities in medical organizations, avoiding bias during prenatal screening conversations, and providing accurate, balanced, and up-to-date resources about disabilities to new and expectant parents, as well as available supports and services. Participants indicated that the best measures of the effectiveness in achieving equity and improving patient experiences would be to assess patient experiences, provider perceptions of competence in discussing disabilities, and the engagement of the medical organizations with the disability community in the development of prenatal screening guidelines.

Additionally, **cost** was identified by 70% of the participants as an important criterion to measure—both financial cost and time cost. However, participants were divided between whether they perceived the financial costs as low or high. Because funding for these types of initiatives have typically been calculated in annual grant dollars, that metric will be used as the criteria in this policy analysis matrix. The time cost specifically related to the time spent by clinicians and medical organizations to implement training and health equity initiatives for people with disabilities.

Therefore, the criteria to be evaluated in the matrix will be the following:

- Promotes equity for PWD/Possible number of patients experiencing emotional harm (Y/N)
- Improves provision of resources to address health disparities (Y/N)/Possible number of patients to benefit
- Reduces bias among clinicians (Y/N)/Possible number of clinicians with improved competence

- The time cost of an organization to include people with disabilities in the development of guidelines and training
- The time cost of training per resident or practicing clinician
- The total dollars spent on the program annually
- Politically feasible (Y/N)

#### 4.4. Project the Outcomes: Step 5

##### 4.4.a. Alternative 1: No action.

Even though there is no financial cost associated with this alternative, there are substantial consequences and costs in the emotional harm and mental anguish experienced by patients who have a negative diagnosis experience, the lack of supports and services provided to the parents of medically-vulnerable children, the harm to patient/provider relationships, the impact of the emotional harm on parenting, and the ultimate impact on the health and treatment of people with disabilities. While one can argue that receiving positive prenatal screening results alone can cause parents distress, the research and the participants in this study repeatedly demonstrate that the way in which those results are delivered by health professionals can profoundly exacerbate or ameliorate those impacts (May et al., 2020; Meredith et al., 2023; Nelson Goff et al., 2013). Andy Imperato explains, “There's a cost associated with bias and discrimination. That affects the parents, affects the child as the child grows up, affects the family as a whole. And those costs are often not considered when we do cost benefit analysis. So basically, if you're going to evaluate the cost of a solution, I would encourage you to also evaluate the cost of doing nothing.”

The baseline for what is currently occurring is that no action or intervention will be implemented, so at least 61% of patients will continue to experience bias and subsequent emotional harm when receiving a diagnosis based on the experiences of parents with Down syndrome (Meredith et al., 2023). While there is no quantitative data about the bias and emotional distress experienced by the parents of children with other conditions, the qualitative literature shows that parents of children with Spina Bifida, Klinefelter syndrome, achondroplasia, and Turner syndrome experience similar harms (Bourke et al., 2014; Hill et al., 2003; Payne, 2013; Starke et al., 2002). Additionally, quantitative research by Iezzoni et al. shows that 82.4% of clinicians reported that disabled people have a worse quality of life than non-disabled people (Iezzoni et al., 2021). Therefore, 61% would be a conservative estimate of patients who experience bias and subsequent emotional harm from a negative diagnosis experience.

Both the literature and our interviewees indicated that the cost of these negative diagnosis experiences impacts the mental and emotional health of the parent, patient/provider relationships, and the individual with disabilities.

***Negative Diagnosis Impact on Parenting and Individual with Disabilities:***  
*Traumatized parents parent differently than parents who are not traumatized and so I think my impression, my experience that I've had is parents who have less trauma or have dealt with their trauma raise more independent self-determined people than the parents who are scared and pessimistic about their child's life. So, in my opinion, it's better for people with disabilities in general if we deal with this prenatal diagnosis, cause that's the start of the parenting. And I think if we want to raise independent self-determined adults, it starts with the diagnosis. —Colleen Payne*

***Negative Diagnosis Impact on Patient/Provider Relationships:*** *I also think it trickles down to if you realize that the provider who gave you the diagnosis was wrong, that may be the first time that you really think about how*

*providers don't always know what they're talking about. I had blind trust in the medical community before this. If a doctor said it, I believed it. I think this really harms the trust between parents and providers and then those people with disabilities and their providers because they're learning what they know from their parents. There's a lack of trust there because, "Remember that time you told me that my child would be a vegetable. Look at her now, she's amazing. You didn't know what you're talking about." And it feeds into later on, "Well, the urologist said that we need to start cathing, but I don't think that we do. Parents know better than the doctors anyway." It just starts this adversarial relationship that's unhealthy both mentally and especially physically ...*

*You have to have a good trusting relationship with those providers to give the child the best outcome, and so this botching of the diagnosis sabotages that future relationship. —Colleen Payne*

Both the adversarial relationship with medical providers and the lack of provision of resources about supports can potentially impact the long-term health of people with disabilities that can increase societal cost for healthcare (May et al., 2020; Meredith et al., 2023). Research quantitatively shows that 70% of pregnant patients did not receive accurate, up-to-date, and balanced information about Down syndrome in language they can understand (Meredith et al., 2023), and 71% did not receive information about supports and services. Given similar qualitative findings for Klinefelter syndrome, Turner syndrome, achondroplasia, and Spina Bifida, that same metric is applied to people with the range of prenatally detectable conditions for this policy analysis.

The current number of the impacted population is relatively small compared with the larger population of about 3.7 million pregnancies per year (*FastStats*, 2023). About 120,000 babies are estimated to be born with birth defects each year (CDC, 2023a), and the prenatal screening panel is constantly expanding to include additional conditions; however, for the purposes of this assessment, we will conservatively evaluate numbers for the most common

conditions currently included in prenatal screening technology where most people born with the condition live to adulthood: Down syndrome, Spina Bifida, Turner syndrome, Klinefelter syndrome, XYY, and achondroplasia. The total for those populations amounts to 13,445 babies born with the prenatally detectable conditions outlined below. If 61% experience bias and subsequent emotional harm, that amounts to 8,202 babies. If 71% do not know about resources for supports and services, that amounts to 9,546 babies.

- Down syndrome: 6,000 (CDC, 2023b)
- Spina Bifida: 1,500 (CDC, 2020)
- Turner syndrome: ~925 given that 1:2000 females are born with Turner syndrome (37000000/2/2000) (*Turner Syndrome - Symptoms, Causes, Treatment* / *NORD*, n.d.).
- Klinefelter syndrome (XXY): 3,000 (Samango-Sprouse & National Organization for Rare Disorders (NORD), 2020)
- XYY: ~1,850 given that 1:1000 males are born with XYY (3600000/2/1000) (MedlinePlus [Internet], 2022).
- Achondroplasia: 170 given that 4.6/100,000 are born with achondroplasia ((3600000/100,000)\*4.6) (Foreman et al., 2020)

Finally, disability rights advocates have long asserted that the information conveyed during prenatal screening experiences likely raises termination rates because parents are left to make pregnancy decisions in a setting that is often clouded by negative bias and without sufficient information to understand the condition (Piepmeier et al., 2021). This perspective was further confirmed by the participants in this study. While we do not calculate his

variable into the matrix, this can be a substantial concern if parents are making reproductive decisions that are based more on bias and lack of information rather than choices that reflect their own values based on accurate, up-to-date, and balanced information delivered without coercion or influence.

*I wasn't given any information other than, "Your child has 90% chance of having Down syndrome and do you want to?" And I stopped her before she said what I assumed would be, "Do you wanna have a conversation about alternative options?" But because I had Google, I was able you know to get the information that I needed and find the national organizations that supported prenatal diagnoses such as DSDN and a couple of other organizations where I got information from. —Crystal Lotterberry*

*The uninformed choice is more likely to be terminating because there's fear in just inaccurate information there. Most of these terminations are due to fear and love. Parents love their babies. They don't want them to suffer, and it certainly sounds like they're gonna suffer from the person who told them about this and so they are willing to take on this grief for the rest of their lives so that their child does not have to when that may not be the case at all.*

*—Colleen Payne*

#### 4.4.b. Alternative 2: Fund the Prenatally and Postnatally Diagnosed Conditions Awareness Act.

The PPDCAA originally proposed the appropriation of 5 million per year for five years for the HHS Secretary, acting through the Director of the National Institutes of Health, the Director of the Centers for Disease Control and Prevention, or the Administrator of the Health Resources and Services Administration, to “authorize and oversee certain activities, including the awarding of grants, contracts or cooperative agreements to eligible entities” to build a library of resources about prenatally and postnatally diagnosed conditions (M. W. Leach, 2016; *Text of S. 1810 (110th)*, 2007) With \$25 million, this alternative would provide ample funding for resource development and dissemination dedicated to this issue and could improve the provision of resources to address health disparities.

However, notably the PPDCA does not address training medical professionals or impacting medical guidelines, so its impact on the biases of clinicians would likely be minimal, particularly with the insight from most interviewees that non-mandatory public policy rarely changes attitudes or biases. Additionally, if the materials developed are not recommended by the national medical and genetics organizations, then the dissemination, implementation, and adoption are likely to be limited.

Moreover, given the insight from the participants about the dysfunction in the federal government, the reticence to propose or pass any bills related to reproductive health, and the lack of legislative champions, any alternatives that require congressional actions—including right-sizing funding— are not politically feasible. Further, participants reported that the dysfunction of advocacy orgs competing over dollars and influence make both advocacy and the execution of passing legislation on this issue challenging.

4.4.c. Alternative 3: ACOG, SMFM, and genetic organizations include people with disabilities in health equity measures, the development of guidelines and clinical practices, and the training of residents and fellows on how to sensitively discuss disabilities training.

The inclusion of people with disabilities by the national obstetrics and genetics organizations was agreed upon by all participants as an effective intervention and would be relatively inexpensive in cost and time. Several models are available to use for time and cost estimates.

The Prenatal Disability Education Summit hosted by the National Center for Prenatal and Postnatal Resources in 2022 and funded by the Joseph P. Kennedy, Jr. Foundation and other sponsors cost approximately \$30,000, and it took one 8-hour day of community conversations to determine an action plan to improve diagnosis experiences for families (Meredith, 2022). David Hoppe also suggested two days of meetings, which would amount to 16 hours. Other



options for gathering input from the disability community are giving speaker slots or covering meeting participation at existing guideline development meetings to about three disability rights advocates, which costs about \$3,000 maximum per person for per diem costs and reimbursement at \$150/hour for 8 hours. Therefore, the financial estimate to be more inclusive of people with disabilities at organizational planning and education meetings would be about \$39,000 and 16 hours of organizational time each year, so the conservative estimate for the policy analysis will be \$50,000 and 20 organizational hours for the inclusion of people with disabilities at organizational planning and education meetings.

In addition, ACOG has models of equity-focused clinical guidance and policies with racial health equity, and CREOG has a Health Equity Curriculum. Amending these guidelines to be more inclusive of people with disabilities and an ethical and moral disability framework would likely be similar to the cost of updating the Brighter Tomorrows curriculum, which cost about \$20,000. Given the level of coordination involved and compensation of additional consultants, the cost estimate for creating a more inclusive training curriculum would be about \$50,000—bringing the total organizational costs up to \$100,000 when adding the inclusion of people with disabilities at meetings previously estimated at \$50,000. Additionally, the amount of time for individual clinicians to undergo disability health equity training would be approximately 2 hours, which would be the amount of time required to complete the Brighter Tomorrows training on how to deliver a diagnosis and understand the history of disability rights. The training has demonstrated effectiveness in significantly improving provider competence in delivering prenatal screening results and discussing disabilities more knowledgeably and equitably (Campbell et al., 2009; Jackson et al., 2020; Kleinert et al., 2009).

Because this alternative would be shared by the major professional organizations for obstetricians and genetic counselors, these solutions would have the greatest likelihood for adoption and would promote improved competence, improved equity toward people with disabilities, and the increased provision of resources for patients learning about disabilities. However, external funding would be necessary to make this option politically feasible and influence clinical behavior because the likelihood of the medical professional organizations spending \$100,000 is extremely unlikely—even with the proposed benefits. Any solution involving the medical and genetics professionals’ organizations would need to be paired with a funding alternative for the development and dissemination of resources, resident and clinical training, guideline development, and collaborative meetings.

Other challenges associated with this alternative largely stem from the reticence of clinicians to change practice, concerns about time and financial cost, and deeply embedded societal ableism exacerbated by exceptionally high value placed upon intelligence and health among medical professionals. However, these professional medical and genetics organizations are likely to be very responsive to public pressure—as demonstrated by their response to public pressure about racial health equity. Some strengths to this approach are that the advocacy would likely be successful even if minimal from at least 20 advocates collaboratively contacting the organizations through peer-reviewed publication commentaries, advocacy letters, emails, calls, and social media campaigns. These advocacy campaigns would be most effective if led by a broader disability advocacy organization with support from condition-specific groups. The most effective approach would be a health equity focus using data from Meredith et al. and Iezzoni et al. (2021; 2023) to support the claims. Additional important partners would be

organizations such as the Disabled Parenting Project which supports pregnant patients with disabilities who have experienced discrimination in gynecological/obstetric care. Another key benefit would be improving their experiences with obstetric care.

*So, the struggle with professional organizations is they need to feel some pressure to move some way because they typically are—and you know this so well because you've spent 20 years doing this—they're conservative, and they're slow to change, and they need a reason to actually change standards and guidelines. So, they need external push to do that. If a bunch of disabled people come to them and tell them that, that's a pretty good motivation. Like you said, it's hierarchically. It's probably the strongest. The family members are probably the next strongest, but there needs to be some organization and push in that area. —Senate Staff 3*

4.4.d. Alternative 4: Federal funding agencies, including NIH and CDC, which are now funding health equity initiatives that include people with disabilities as a health disparities population, can prioritize funding toward research and resource dissemination to improve prenatal diagnosis experiences as the first point on the life course.

*I think your strategy around either writing for an R1, which is great. And in some cases, the R26 would be a good target as well. Or you might look at something from **NIDILRR** or from OSERS possibly in terms of training materials. So, I think that's partly where you can find those types of things. And particularly if you can do it in partnership with some of these professional organizations, that's where there's a way to talk about the creation of those resources. —Senate Staff 3*

Because people with disabilities were recently designated a health disparities population in September 2023 with funding already allocated to address health discrimination issues faced by people with disabilities, the discrimination faced by people with disabilities and their families during prenatal screening at the first point on the life course could be a focus of the agencies like NIH distributing these grants. For example, two R1 research grants at 2.5 million over 5 years and three R25 dissemination grants at 310,000 over 5 years would amount to a total of \$1.2 million per year and could fund the development and dissemination of resources, resident and clinical training, guideline development, and collaborative meetings. These grants can be

used as positive motivation to bring both disability and medical organizations to the table to work together because organizations are most likely to obtain funding from these federal agencies if they are working collaboratively and engaging in community-based participatory research. The involvement of researchers and academics could also bridge the political gap between advocacy organizations and professional medical and genetics societies.

*I think that you probably have a better chance of being more effective at an agency level. Even with changes in administration I think that there are still a lot of policy impacts that an agency can make with the authorities that they already have ...*

*I think that there is public or political pressure that can be placed on these organizations to do that. I do not think that they would feel that necessarily unless there is a grant program that they are receiving from the federal government to do certain activities where they would be required to include people with lived experience. If they are self-generating these standards on their own, they are not beholden to anyone but the community calling them out for not including people with disabilities. —Senate Staff 1*

One of the challenges identified by the interviewees is that sometimes different minoritized populations can get competitive over what initiatives to prioritize and perceive competition over claiming pieces of a pie. Therefore, one advocacy strategy is collaboratively working together among various advocacy groups that represent minority-underserved population to advocate to Congress for an increase the amount of funding allocated for all groups. This will also benefit people with intersectional identities. Agencies can also make decisions and can be targets of advocacy by patient advocacy groups who may want increased prioritization on issues across the lifespan, including prenatal screening. This option is less costly than PPDCAA and can provide funding for resources and dissemination, clinical training, and research that demonstrates the effectiveness of different approaches for improving prenatal diagnosis experiences and the competence of clinicians delivering diagnoses.

4.4.e. Alternative 5: Congressional funding used as a reward or penalty for medical organizations and providers to address disabilities more equitably.

60% of participants proposed the use of congressional federal funding (as compared to agency funding) to motivate medical organizations to improve diagnosis experiences as well as be inclusive of people with disabilities and avoid bias. 30% wanted to restrict federal funds from being disseminated to medical organizations that discriminate against people with disabilities by not including them in equity measures like collaborative guideline development. The demographics of those who proposed funding restrictions were largely policy leaders who were also family members or people with disabilities (2 Democrat and 1 Republican). On the other hand, the other 30% proposed incentives or special tax benefits for medical organizations who were inclusive of people with disabilities and clinicians who sensitively counseled patients learning about prenatally screened disabilities or who obtained certifications on how to discuss disabilities. Those who made this suggestion were all advocacy leaders who were also parents (1 Republican, 1 Democrat, and 1 Undefined).

Both funding restrictions and incentives are clearly opposite ends of the spectrum in cost in that the restriction of federal funding costs \$0 while incentives provided at just \$150/hour for an estimated 2 hours of training and 1 hours of patient counseling for 33,624 ACOG Fellows nationwide would be about 15.1 million per year, plus the potential costs of administering a program like this which could be considerable (Rayburn et al., 2012). Given the congressional political limitations already mentioned, neither of these options is politically feasible. Funding restrictions would face stiff opposition from the medical community, and funding incentives would be too costly. However, with legislative champions who understand the true vision of uniting all parties to work together toward solutions rather than accomplishing the passage of

legislation, the bipartisan and zero cost nature of funding restrictions could be a powerful lever to bring medical professionals to the table and convince them of the seriousness of the issue.

*And that was really what opened the door to the OB/GYNs agreeing to sit down with us because we had tried for about 2 years before that to get them to meet with us to no avail. They would answer the phone calls, but it was clearly not something they had any interest in doing. But once we got a Brownback-Kennedy bill passed, they suddenly realized that maybe this was something they had to talk to us about. And that was part of getting the first meeting held at the University of South Carolina. —David Hoppe*

#### 4.4.f. Policy Analysis Criteria Matrix

Table 5: Policy Analysis Criteria Matrix compares the different alternatives identified in Step 5 in a matrix with the criteria identified in Step 4 to clearly weigh the pros and cons of each proposed solution.

Table 5: Policy Analysis Criteria Matrix

	Equity for PWD	Improves provision of resources to address health disparities	Improved competence of clinicians delivering a screening results	Time Cost: Org Inclusion of PWD	Time Cost: Training per resident	Total dollars spent on program annually	Political Feasible (Y/N)
No action	N	N	N	0	0	0	Y
Kennedy-Brownback Funding	N	Y	N	0	0	\$5 million	N
Med Org Disability Health Equity Inclusion and Training	Y	Y	Y	20 hours	2 hours	\$100,000	Y
Agencies Including Prenatal Disability Population in Health Equity	Y	Y	Y	20 hours	2 hours	\$1.2 million	Y
Federal funding used as incentive or penalty for medical organizations	Y	Y	Y	20 hours	3 hours	0-\$15.1 million	N

#### 4.4.g. Break-even estimates

Various interests between families, society, professionals, disability advocacy groups determine the cost value of investing in a solution to improve prenatal screening and diagnosis experiences and avoiding emotional harm. For families and society, the priorities in determining the cost would be emotional harm, distress, and mental anguish for the pregnant patient and family. The other cost to consider would be the family's reduced access to supports and services that can address social determinants of health and health ramifications for families who receive poor medical advice about issues as vital as prenatal surgical repair in children with Spina Bifida. For society, a consideration would be increased medical costs for patients who do not trust clinicians or make poorly advised medical decisions. For medical providers, potential costs to consider would be the risk of lawsuit for medical malpractice because of negligence caused by a breach of duty, particularly where Down Syndrome Information Acts have established a statute that clinicians "shall " provide information in 11 states and where states allow claims for emotional distress or mental anguish (Center for Dignity in Healthcare for People with Disabilities, 2021; Iannone, 2015). According to John Richardson, another risk to consider for clinicians would be lower patient satisfaction scores that can impact Medicare reimbursement rates. A lawsuit grounded in the Americans with Disabilities Act could also be a cost concern for professional medical societies who do not include people with disabilities in their health equity measures, which could be argued as a civil rights violation.

David Hoppe indicated that a 2.5% improvement in diagnosis experiences each year—or 25% reduction in negative diagnosis experiences over 10 years—would demonstrate acceptable progress as a worthwhile investment of funding. This number also hearkens back to the



successful measure of improvement for the Spina Bifida folic acid campaign, which amounted to 2% improvement each year for 10 years where a public awareness campaign led to a 20% increase over ten years in the number of women who reported knowing that folic acid can prevent birth defects (Walani & Biermann, 2017). Therefore, the number of people calculated for acceptable improvement each year for harm-reduction and resource provision during prenatal screening—based on the occurrence of prenatally detectable conditions (with life expectancies into adulthood) and 2.5% improvement each year—would be an annual incremental improvement of 336 individuals per year over a 10-year period or 18,480 total over 10 years.

*Well, the once again the benefits are an improvement, and we won't have 60% of the people saying they basically were treated in a negative manner when they got their test results back. That number will go down. Ultimately you would hope it would go to 0, but it's unlikely you'll ever be that successful. Having said that, you do something, and you're able to prove in 10 years from now that number is 35% [instead of 60%], I think that's been or maybe not all the progress you want, but demonstrable progress, and that's the sort of thing you want to look at it is setting goals for making sure that people are treated well and don't feel like their doctor is telling him the world's going to end tomorrow because they are going to have a baby with Down syndrome. —  
David Hoppe*

#### 4.5. Confront the Trade-offs: Step 6

The Trade-Off step of the Bardach Policy Analysis Model requires examining and comparing the quantifiable returns between the different proposed alternatives.

##### 4.5.a. Policy Analysis Trade-Off Matrix

The Table 6: Policy Analysis Trade-Off Matrix provides a visual representation of the comparisons between the different alternatives and the estimated number of people impacted.

Table 6: Policy Analysis Trade-Off Matrix

	Promotes equity for PWD (# of patients harmed/yr)	Improves provision of resources to address health disparities (# of additional patients receiving resources/yr)	Improved competence of clinicians delivering screening results (# of clinicians with improved competence/yr)	Time Cost: Org Inclusion of PWD	Time Cost: Training per resident and counseling	Total dollars spent on program annually	Politically Feasible (Y/N)
No action	N (8,202)	N (0)	N (0)	0	0	0	Y
Kennedy-Brownback Funding	Unknown	Y (336)	N (0)	0	0	\$5 million	N
Med Org Disability Health Equity Inclusion and Training	Y (unknown)	Y (unknown)	Y (unknown)	20 hours	2 hours	\$100,000	Y
Agencies Including Prenatal Disability Population in Health Equity	Y (336 fewer people/year)	Y (336 more people per year)	Y (1,681 more clinicians per year)	20 hours	2 hours	\$1.2 million	Y
Federal funding used as incentive or penalty for medical organizations	Y (336 fewer people/year)	Y (336 more people per year)	Y (1,681 more clinicians per year)	20 hours	3.5 hours	0-\$15.1 million	N

Because the participants defined political feasibility as the most important criteria for alternatives, we can immediately dismiss “Funding the PCAA” and “Congressional funding used

as a reward or penalty for medical organizations and providers to more equitably address disabilities” as politically infeasible given the current dysfunction in the federal legislature and the profoundly sensitive politics following the Dobbs decision. These are also the options with the highest potential financial costs, which further makes them more politically untenable. However, those proposals can still be used as political levers to prompt movement on other alternatives.

In addition, because the participants likewise determined equity toward people with disabilities to be the other highest priority, “No action” is also not an acceptable alternative. Indeed, both the literature and interviewees demonstrate that the current delivery of information to pregnant patients learning about disabilities is both emotionally harmful to patients and biased against people with disabilities.

The most politically feasible options that would also promote equity for people with disabilities, improve the provision of resources for expectant parents, and improve the competence of clinicians delivering a diagnosis would be the alternatives: “ACOG, SMFM, and genetic organizations include people with disabilities in health equity measures, the development of guidelines and clinical practices, and the training of residents and fellows on how to sensitively discuss disabilities training” combined with “Federal funding agencies, including NIH and CDC, which are now funding health equity initiatives that include people with disabilities as a health disparities population, can prioritize funding toward research and resource dissemination to improve prenatal diagnosis experiences as the first point on the life course.” The first alternative where the medical organizations include people with disabilities in health equity measures is essential for any initiative to work because the medical practice

guidelines are the authoritative source where clinicians seek guidance on how to deliver a diagnosis and what resources to provide. Professional medical and genetics societies are also the entities that primarily influence the curriculum taught to students in training and the information included in electronic clinical support systems. This alternative is essential for the adoption of improved practices and training. However, this alternative lacks the necessary funds to accomplish the development and dissemination of resources, the development of training, the hosting of collaborative meetings, and the drafting of guidelines.

The alternative involving the health disparities grants lacks the authoritative influence of the national medical organizations; however, it provides the most quantifiable benefits for the highest number of people at the lowest cost. As estimated, this alternative could decrease negatively biased diagnosis experiences by 2.5% each year (25% over 10 years) and increase the number of parents receiving information about supports and services by the same amount, so 336 parents of children with disabilities would benefit each year. The cost of grants to accomplish this task each year would be an estimated \$1.2 million, which amounts to \$3,571 per person. Additionally, a conservatively estimated 5% of obstetric medical providers (1,681) could improve their competence in discussing disabilities each year amounting to an improvement of 50% over 10 years. Indeed, the Brighter Tomorrows learning modules significantly improved the competence of medical residents who utilized that tool in a study of effectiveness (Jackson et al., 2020). Therefore, this solution could further benefit an estimated 1,681 clinicians per year and decrease their anxiety during prenatal screening conversations and improve their competence and knowledge of disability (Campbell et al., 2009; Jackson et al., 2020; Kleinert et al., 2009).

## Chapter 5: Conclusions

### 5.1. Deciding: Step 7

Ultimately, the most promising alternatives identified by the literature and study participants are a combination of the medical organization actions to improve health equity for people with disabilities and health disparity funding from federal agencies to address discrimination during prenatal diagnosis experiences. This recommendation also most closely aligns with the approach of the successful 1999 Folic Acid campaign which involved a collaborative approach with the CDC, ACOG, AAP, and SBA and funds allocated through federal agencies to accomplish that purpose through research and dissemination grants (Walani & Biermann, 2017). These two alternatives are the most politically feasible with the greatest potential for adoption by clinicians, as well as funding for resource development and dissemination, clinical training, and collaborative guidelines development. Moreover, the funding would lead to a 2.5% improvement each year for patient and a 5% improvement for clinicians so that 336 parents of children with disabilities would benefit each year, which amounts to \$3,869 per pregnant patient (\$1.3 million/336), as well as benefitting 1,681 medical providers through training efforts.

For medical organizations to fully embrace people with disabilities in health equity measures, we would expect that they would develop better organizational practices toward people with disabilities, develop better organizational disability standards/guidelines, and develop better medical education/clinical training about disability. Some better organizational practices suggested by participants include collaborating with and including people with disabilities—and other disciplines such as genetic counseling—on guideline development,

conferences, and research as also recommended in the “Recommendations to improve the patient experience and avoid bias when prenatal screening/testing” (Meredith, Brackett, et al., 2022). Another improved organizational practices would be to build the medical workforce development of people with disabilities so that ACOG is receiving input from experts within who have lived experience with disability. Additional organizational practices to improve health equity for people with disabilities would be to collaboratively establish a moral and ethical framework for addressing disability and to determine strategies for disseminating patient education resources about disabilities to providers and funding mechanisms.

Interviewees stated that medical organizations can further work toward developing better organizational disability standards/guidelines by offering timely referrals to specialists like genetic counselors and tertiary care centers, providing information about advocacy organizations, providing guidance to clinicians on how to avoid disability bias, and providing information about supports and services and the social model of disability. All of these suggestions are further corroborated in NCD’s “Genetic Testing and the Rush to Perfection” and “Recommendations to improve the patient experience and avoid bias when prenatal screening/testing” (Meredith, Brackett, et al., 2022; National Council on Disability, 2019a).

Finally, participants offered that organizations could develop better medical education/clinical training about disability by incorporating the value of people with disabilities as a historically marginalized population and providing the context of disability rights—particularly when inequities have specifically been fostered by that field and expressing cultural humility regarding disability and recognizing bias. All of these concepts are further reinforced by the Health in All Policies public health framework (Rudolph et al., 2012). Some resources to help

in the administration of training would be CREOG, DEI programs in hospital systems and ACOG, and genetic counselors who can offer training to clinicians in practice.

To support this effort, health disparity funding from federal agencies can provide the research, education, and dissemination grants to undergird these health equity initiatives by medical organizations, as well as the advocacy organizations and researchers working toward improving diagnosis experiences for families. Grants can be used to research diagnosis experiences and the knowledge and competence of clinicians in discussing disabilities; diversify the workforce; build disability cultural competence in clinicians through training that can be administered by medical schools and the national accreditation body (Liaison Committee on Medical Education), and technical assistance; develop and disseminate resources for families that include the social model of disability; form an interdisciplinary coalition that can develop guidelines, make dissemination and implementation plans, and develop resources; and provide First Call technical assistance for advocacy organizations. These funds could meaningfully support organizations that serve families and providers while also assessing the efficacy of these interventions.

We further discovered levers that can be utilized to motivate medical organizations and the federal agencies. While the two alternatives identified carry significant potential to improve diagnosis experiences for pregnant patients and reduce bias against people with disabilities in those conversations even by the most conservative estimates, the participants and literature identified the following political levers as essential for motivating all the actors to move forward:



1. ACOG and other medical and genetics organizations need to become more inclusive of disability in health equity measures, including guideline development, training, and advocacy efforts.

a. Levers: National disability organizations can advocate directly to ACOG and other medical and genetics organizations. Congressional policy expert participants said that 20 contacts generally raise the priority level of an issue for an organization, and there is also a model based on the successful advocacy efforts to raise the COVID-19 vaccine prioritization level of people with disabilities based on health equity arguments and patient harm in a number of states (Meredith, 2021)

i. Organizational letters; open letters

Write a collaborative letter to ACOG and other professional medical organizations as needed from national disability advocacy organizations, condition-specific organizations, genetic counselor organizations, prominent bioethicists and disability scholars in the field, and disability social justice activists advocating for medical organization practices that are more equitable toward people with disabilities, including in the administration of prenatal screening, disability representation in the workforce and organizational conferences, professional training, and the development of practice guidelines. *Our organization also used this approach in addressing prenatal screening program concerns with the California Department of Public Health, and we were successful in having the modify their website and provide training to reflect those concerns.*

Share stories in the letter to also frame prenatal screening issues in the context of emotional harm to parents caused by bias against people with disabilities and as the source of health disparities for people with disabilities based on the lack of provision of resources, supports, and services that help families and individuals address social determinants of health. See Appendix 6: Telling Your Story: Step 8.

ii. Carrots:

Carrots are positive motivation to encourage ACOG and other medical and genetics organizations to include people with disabilities at the table. The motivation can range from collaboration on funding initiatives to mutual support for strengthening the workforce to include genetic counselors who are trained to provide more comprehensive information about disabilities during the diagnosis experience.

1. Agency Funding: Advocacy organizations, researchers, and disability-informed bioethicists can solicit medical organizations to be grant partners in initiatives to fund meetings, collaborative guideline development, workforce development, and training programs. Agencies can issue requests for proposals that prioritize community-based participatory research and projects that include people with disabilities who have lived experience and their families.

2. Legislation: Advocates can join the National Society of Genetic Counselors in advocating for reimbursements for genetic counseling services such as H.R.3876 - Access to Genetic Counselor Services Act of 2023 so that clinicians have more support in the workforce when discussing disabilities (Rep. Smith, 2023).

iii. Sticks:

While sticks are risky in that they can jeopardize relationships, the interviewees and literature indicate that the following options can be effective to force ACOG to include people with disabilities at the table if carrots do not provide sufficient motivation:

1. From Congress: Threaten the restriction of funding if ACOG and other medical and genetics organizations do not include people with disabilities as a health equity population. For this to be effective, the disability community needs legislative champions who are willing to move forward on this initiative and stay on message about health equity for people with disabilities—not pro-life or pro-choice—while also understanding that the bill can be successful in bringing organizations together even if it never passes or gets brought to the floor.
2. From advocates: Work with organizations like the National Council on Disability and American Association of Developmental

Medicine and Dentistry to invite ACOG and other medical and genetics organization representatives to attend conferences and summits to answer questions about health equity for people with disabilities during prenatal screening as was done with the American Medical Association and American Dental Association (*NCD Announces Discussions on Disability Health Issues and Public Comment Opportunity at Upcoming Meeting, 2023*).

3. From advocates: Advocates can also engage in a grassroots initiatives with local disability advocacy organizations to encourage patients who have negative diagnosis experiences to reflect those experiences accurately in their patient satisfaction scores because patient satisfaction scores help determine Medicare reimbursement rates. If medical professionals and organizations recognize that advocacy organizations understand this point, that can be a bargaining chip for advocacy organizations to encourage medical organizations to be more inclusive of people with disabilities to improve prenatal diagnosis experiences for patients.

4. From advocates: Media blitz

If the letter is ineffective at prompting a response, engage in a media campaign sharing patient stories of emotional trauma during diagnosis experiences. Remain laser-focused on health

inequities and bias against people with disabilities without being forced into the abortion debate. Social media is, however, a riskier approach because it can easily skew the messaging and generate online backlash.

2. Funding agencies—prioritize funding for health disparities starting at prenatal screening.

a. Levers

- i. Letters: Similarly, advocates can write a collaborative letters to leaders at federal funding agencies from national disability advocacy organizations, condition-specific organizations, genetic counselor organizations, prominent bioethicists and disability scholars in the field, and disability social justice activists advocating for medical organization practices that are more equitable toward people with disabilities, including in the administration of prenatal screening. Priorities would include disability representation in the obstetric and genetics workforce and organizational conferences, professional training that values people with disabilities and social justice, and the development of more equitable practice guidelines. Share stories in the letter to also frame prenatal screening issues in the context of emotional harm to parents caused by bias against people with disabilities and as the source of health disparities for people with disabilities based on the lack of provision of resources, supports, and services that help families and individuals address social determinants of health.

- ii. Personal advocacy: Advocates can also personally meet with agency representatives at NIH, CDC, ACL, the Office of Special Education and Rehabilitative Services, The National Institute on Disability, Independent Living, and Rehabilitation Research, and other agencies with the funding authority to prioritize this issue.
- iii. Work through organizations like the National Council on Disability, the American Association of Health and Disability, and the American Association of Developmental Medicine and Dentistry which are located and working in Washington DC, and in the medical community on disability issues to raise the profile of addressing health equity for people with disabilities in prenatal screening at the agency level. This goal can be accomplished during their regular organizational meetings and forums, publications, and private meetings with agency leaders (Meredith & Weiss, 2023).

## 5.2. Limitations and Future Research

A major limitation is that people in decision-making and leadership positions tended to be White; therefore, a majority of the interviewees were White. This is both a limitation of this project and a systemic limitation. Fortunately, the Black Down Syndrome Association was founded in the past two years, thereby increasing leadership among Black parents of children with Down syndrome. An additional limitation for this study was the lack of representation of policy leaders who have lived experience individually or as family members with sex chromosome conditions, achondroplasia, or other prenatally diagnosed conditions. This study

demonstrated an overexpression of representation for Down syndrome given the personal connections of the researcher; however, DS occurs more frequently, and DS and Spina Bifida have been prenatally detectable longer than the other conditions. Another limitation was the lack of representation by members of the Disability Caucus in the House of Representatives. I reached out to several members in leadership positions, but they were either non-responsive or unable to meet. I contacted staff members for four members of the House of Representatives involved in the Down syndrome and Disability Caucus; however, three did not respond to three requests for appointments, and one responded that she was unable to meet. Part of the challenge was the dysfunction of Congress, and part was the reluctance to meet with someone who is not from their own district. To accommodate for this limitation, I interviewed David Hoppe, the father of a person with Down syndrome who also served as Chief of Staff for the Speaker of the House to provide the Representative perspective.

### 5.3. Conclusion

#### *Reflexivity Statement*

*This policy analysis did not lead to the results I anticipated even after working on this issue for over 15 years. I anticipated that the participants would conclude that we needed to fund the PPDCAA or implement an excise tax on prenatal screening to fund an educational infrastructure, but what I found was much more illuminating than I expected. As I was interviewing the participants, their suggestions seemed disjointed, but as I began to assign codes and overlay them, I found recurring messages that the linchpin was motivating the medical organizations, specifically ACOG, to be more inclusive of people with disabilities. This ranges from the development of their guidelines to the diversification of their workforce and the*

*implementation of their training, etc. For so many across the political spectrum, this issue is reduced to a popular volley in abortion wars, but for families, it is our first moment where disability is framed for us, the first glimpse of our child, the first interaction with how the world sees them, and the first birthday. Unfortunately for too many of us, the shock of that moment is influenced by a deep societal bias that everyone carries that is then magnified and distorted further by the biases of the person we trust most in the room. Many of us have no interest in influencing the reproductive choices of others—even though we have a nagging suspicion that the bias we experienced may have unduly influenced other—but most of us are deeply and profoundly interested in reducing the emotional harm other parents of children with disabilities endure, we are deeply and profoundly interested in the subsequent health and emotional impacts on people with disabilities, and mostly we are deeply and profoundly interested in ensuring that people with disabilities are valued by a medical establishment that has historically discriminated against them from the era of Eugenics, forced sterilization, and beyond.*

*We're no longer in a world where medical providers need to tell us what to do. We just need the information and support in making the decision that's right for us, and people will do that. People will make the decision that's right for them. I don't think we have to worry about what that decision is.*

*—Colleen Payne*

*What I also realized is that the skills developed in the past 10 years in the fight by disability rights advocates to save Medicaid in 2016-2017 and to raise concerns about health inequities for people with disabilities during COVID—specifically my own experience in crafting a book of Georgia Medicaid stories to influence policymakers, my own work with Heidi Moore to raise the vaccine prioritization of people with disabilities in Georgia during COVID, and my later*



*extrapolation of those lessons learned to successfully advocate for the California Prenatal Screening Program to modify their approach toward people with disabilities—have given us the skills to tackle this issue as the participants suggested in the interviews. Even if Congress is not the best vehicle for us to use right now, we as the broader disability community—and I as a professional and advocate—have the skills and influence now to approach the medical and genetics organizations and federal agencies directly to advocate for change and make a strong case for the allocation of research dollars.*

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## Appendix 1: Potential Interviewees:

- 1. Andrew Imparato: Former Chief of Staff for Democratic Senator, Former President of the American Association of People with Disabilities, Former Director of the Association of University Centers on Disability, Executive Director at Disability Rights California, and person who identifies as having a person with a disability (speaking in personal capacity)**
- 2. Madeleine Will: Former Policy Director of the National Down Syndrome Congress, Former Directors of OSERS, Organizer of Down Syndrome Consensus Group, and Mother of a person with Down syndrome (speaking in personal capacity)**
- 3. David Hoppe: Former Chief of Staff for Republican Members of the House and Senate and Father of a Person with Down Syndrome (speaking in personal capacity)**
- 4. Senate Staff 1 (speaking in personal capacity)**
- 5. Senate Staff 3 (Democrat) (speaking in personal capacity)**
- 6. Heather Sachs: National Down Syndrome Congress Policy Director, Mother of a Person with Down Syndrome) (speaking in personal capacity)**
- 7. Colleen Payne: Staff at the Spina Bifida Association and Mother of a Person with Spina Bifida (speaking in personal capacity)**
- 8. Senate Staff 2 (Republican) (speaking in personal capacity)**
- 9. Crystal Lotterberry (Director of the national Black Down Syndrome Association, Mother of Person with Down Syndrome)**
- 10. John Richardson (NSGC Policy Director) ([jrichardson@nsgc.org](mailto:jrichardson@nsgc.org))**

## Appendix 2: Interview guide

1. Recent research we conducted found that most expectant parents are not receiving accurate, balanced, and up-to-date information from obstetricians when receiving prenatal screening results suggesting a possible diagnosis of a genetic condition.
  - a. What policy solutions do you think could help address that information gap?
  - b. What national or medical organizational solutions do you think could help address that information gap?
2. Recent research we conducted also found that most expectant parents described that their obstetricians conveyed implicit or explicit bias against disabilities when receiving prenatal screening results suggesting a possible diagnosis of a genetic condition?
  - a. What policy solutions do you think could help address that bias?
  - b. What organizational solutions do you think could help address that issue?
3. What criteria would we use to determine whether these federal or organizational policies have been effective?
4. Are the policy solutions we discussed politically feasible, cost efficient, sustainable, equitable or fair? Do you have any concerns or feel more hopeful about certain solutions?
5. What could be the potential costs and benefits of the solutions we discussed?
6. What would be the positives and negatives of the solutions we discussed?
7. What solution do you think would be most effective?

### Appendix 3: Potential Legislative Champions

This chart is based on information listed about legislators in billtrack50.com. Legislators determined to offer broad disability support were identified if they sponsored three or more pieces of legislation related to disability rights and belonged to the Down syndrome or Disability caucus. Crossing party lines was determined if Democrats co-sponsored the Charlotte Woodward Organ Transplant Discrimination Prevention Act authored by a Republican or if Republicans supported disability health legislation authored by Democrats.

Name	House /Senate	Party	State	Disability Connection	Crosses Party Lines	Introduces legislation
Bob Casey	S	D	PA	Broad disability support and introduced REAAADI for Disasters Act Real Emergency Access for Aging and Disability Inclusion for Disasters Act and RISE Act Respond, Innovate, Succeed, and Empower Act		Y
Tammy Duckworth	S	D	IL	Introduced reproductive healthcare bill for PWD and Air Carrier Access Amendments Act of 2023		Y
Patty Murray	S	D	WA	Introduced reproductive healthcare bill for PWD		Y
Maggie Hassan	S	D	NH	Parent of a child with cerebral palsy and wrote letter of support for childcare access for parents of children with disabilities		Y

Chris Van Hollen	S	D	MD	Broad disability support and introduced IDEA Full Funding Act and Keep Our PACT Act Keep Our Promise to America's Children and Teachers Act		Y
Michael Bennet	S	D	CO	Broad disability support and introduced Latonya Reeves Freedom Act of 2023		Y
John Fetterman	S	D	PA	Broad disability support		
Kirsten Gillibrand	S	D	NY	Broad disability support		
Tim Kaine	S	D	VA	Broad disability support		
Christopher Murphy	S	D	CT	Broad disability support and introduced Keeping All Students Safe Act		Y
Chris Coons	S	D	DE	Introduced bipartisan legislation for student loan forgiveness of PWD		Y
Robert Menendez	S	D	NJ	Introduced bipartisan International Children with Disabilities Protection Act in US Congress		Y
Jon Tester	S	D	MT	Introduced Major Richard Star Act		
Bill Cassidy	S	R	LA	Support of Social Security legislation for PWD		Y
Rob Portman	S	R	OH	Bipartisan legislation for student loan forgiveness of PWD		
Mike Braun	S	R	IN	Bipartisan legislation for student loan forgiveness of PWD		
Jerry Moran	S	R	KS	Introduced International Children		Y

				with Disabilities Protection Act in US Congress		
Angus King	S	I	ME	Bipartisan legislation for student loan forgiveness of PWD		
Brian Fitzpatrick	H	R	PA	Disability Caucus Co-Chair	Y	Y
Cathy McMorris-Rodgers	H	R	WA	Parent of a child with DS and broad support of disability legislation	Y	
Marc Molinaro	H	R	NY	Broad disability support and co-sponsoring legislation.		
Kat Cammack	H	R	FL	Introduced Charlotte Woodward Organ Transplant Discrimination Prevention Act		
Pete Sessions	H	R	TX	Broad disability support.		
Glenn Thompson	H	R	PA	Broad disability support.		
Bryan Steil	H	R	WI	Broad disability support.		
Christopher Smith	H	R	NJ	Broad disability support.		
John Rutherford	H	R	FL	Broad disability support.		
Doug Lamborn	H	R	CO	Moderate disability support.		
Andrew Garbarino	H	R	NY	Broad disability support.		
Garland "Doug" Barr	H	R	KY	Moderate disability support.		
Stephanie Bice	H	R	OK	Broad disability support.		
Darrell Issa	H	R	CA	Moderate disability support.		
Mariannette Miller-Meeks	H	R	IA	Broad disability support.		
Pete Stauber	H	R	MN	Broad disability support.	Y	

Debbie Dingell	H	D	MI	Disability Caucus Co-Chair and introduced Charlotte Woodward Organ Transplant Discrimination Prevention Act		Y
Ayanna Pressley	H	D	MA	Introduced reproductive healthcare bill for PWD and disability justice amendments		Y
Cori Bush	H	D	MO	Introduced reproductive healthcare bill for PWD		Y
Seth Moulton	H	D	MA	Broad disability support.		Y
Eleanor Norton	H	D	DC	Broad disability support.		
David Trone	H	D	MD	Broad disability support.		
Darren Soto	H	D	FL	Moderate disability support.		
Adam Smith	H	D	WA	Broad disability support.		
Mark Pocan	H	D	WI	Broad disability support.		
Jamie Raskin	H	D	MD	Broad disability support.		
C.A. Ruppertsberger	H	D	MD	Broad disability support.		
James McGovern	H	D	MA	Broad disability support.		
Zoe Lofgren	H	D	CA	Broad disability support.		
Ted Lieu	H	D	CA	Broad disability support.		
Josh Gottheimer	H	D	NJ	Broad disability support.		
Lloyd Doggett	H	D	TX	Moderate disability support.		Y
Rosa DeLauro	H	D	CT	Moderate disability support.		

Diana DeGette	H	D	CO	Broad disability support.		
Steve Cohen	H	D	TN	Broad disability support and introduced Latonya Reeves Freedom Act of 2023	Y	Y
Tony Cardenas	H	D	CA	Broad disability support.		
Salud Carbajal	H	D	CA	Broad disability support.		
Julia Brownley	H	D	CA	Broad disability support.		
Jared Huffman	H	D	CA	Broad disability support.		Y
Angela Craig	H	D	MN	Broad disability support.	Y	
Jason Crow	H	D	CO	Broad disability support.	Y	
Donald Davis	H	D	NC	Broad disability support.	Y	
Marie Gluesenkamp Perez	H	D	WA	Broad disability support.	Y	
Ann Kuster	H	D	NH	Broad disability support.	Y	
Dina Titus	H	D	NV	Introduced Air Carrier Access Amendments Act of 2023		Y
Suzanne Lee	H	D	NV	Introduced Keep Our PACT Act Keep Our Promise to America's Children and Teachers Act		Y
Lisa Rochester	H	D	DE	Broad disability support.	Y	
Rebecca Sherrill	H	D	NJ	Broad disability support.	Y	
Paul Tonko	H	D	NY	Broad disability support.	Y	
Debbie Wasserman Schultz	H	D	FL	Broad disability support.	Y	

Appendix 4: Index  
See Attachment.



## Appendix 5: Analytical Memo

Stephanie Meredith: December 1, 2023

### **Background:**

#### ***Research Questions***

3. What federal and organizational policies can be implemented, expanded, or funded to improve patient prenatal screening experiences?
4. What federal and organizational policies can be implemented, expanded, or funded to address disability bias in genetics/obstetrics?

#### ***Positionality on Methods and Sampling:***

##### Participant Recruitment

Because of my deep connections in the genetics and disability communities, I was able to send email invitations to schedule interviews with colleagues who are policy representatives for national disability and genetics organizations, disability policy experts, and I was able to use snowball sampling to schedule a meeting with Republican Senate staff. Originally, the plan was to interview one Republican House member involved in disability issues and one Democrat House member involved in disability issues. However, I was unable to schedule meetings with House of Representative staff because I was not in the district of the ideal interviewees and did not receive responses back from them even after multiple solicitations. One declined to be interviewed due to time constraints. This is part of the challenge that will be addressed in the policy analysis: the lack of federal policy leadership on this issue and broken federal system. However, I was able to interview the Chief of Staff for a former Speaker of the House of Representatives to get a broad overview of that demographic.

##### Participant Demographics

Ten experts who were either a medical organization leader, community leader, federal policy expert, or representative of a national advocacy organization participated in the interviews. Of the ten participants, 3 were current Senate staff, 1 was a former House Chief of Staff and disability community leader, 1 was a policy expert from a national genetics organization, 3 were national disability advocacy leaders, and 2 were leaders in the disability community. 50% were in the 50-64-year age group, and 10% were African American. 40% were Male, and 60% were female. All participants had some level of higher education with representation across the US. Additionally, 1 identified as a person with a disability 7 identified as immediate family members of a person with a disability, and 2 did not have an immediate personal connection to the disability community.

##### Interview Structure

There were 10 semi-structured interviews conducted over Zoom with the recordings stored on the GSU Dropbox data storage system. The consent form was read to the participants at the beginning of each interview. Additionally, I took observational notes in a notebook during the interview documenting the behavior of participants.

### Data Cleaning

For the semi-structured interview transcripts, we used the closed caption feature on Zoom to create an initial draft of the transcripts and then listened to the audio to correct any mistakes and to eliminate duplicate and extraneous words. We also double checked the meaning of words that were difficult to understand and combined all quotes from one person that were separated with time stamps. After cleaning the data and listening to the audio a second time, I created a list of seven major inductively determined themes, which were also informed by the literature scan to place the data in the context of existing literature. Additionally, I utilized deductive categories that align with the research questions, including Medical Organization Actions, Disability Advocacy Actions, Policy Actions; and Bardach's model for policy analysis, including funding options, measures of effectiveness, cost, challenges/barriers, benefits, positives, and negatives. I inductively determined themes and subthemes for each of these categories using grounded theory. Further, I separately catalogued the political themes and subthemes to inform more nuanced approaches. Moreover, I separately pulled out the values and most effective solutions identified by each participant.

The semi-structured interview added up to 116 transcription pages. The data analysis process began by inductively creating themes and subthemes in each cluster category, which had been deductively pre-determined. 78 total intermediate axial themes were identified in the following categories:

- Major Themes: 7
- Medical Organization Action Themes: 3
- Disability Organization Action Themes: 7
- Policy Action Themes: 10
- Funding Options: 4
- Effectiveness: 11
- Cost: 5
- Challenges/Barriers: 14
- Benefits: 9
- Positives: 3
- Negatives: 1
- Political: 4 (There were originally 8, but 4 were subsequently reassigned as Challenge codes.)

Subsequently, as outlined in the Framework policy analysis model, I assigned letters/numbers to each theme/subtheme (1.a., 1.b., 1.b.i, etc.) and categorized each statement in the transcript

with the assigned number/letter/roman numeral written in the margin. Additionally, I highlighted particularly powerful quotes. The only data not coded was background data used to inform the demographics and consent dialogue. Next, I iteratively revised the themes and merged codes. The final step in the data analysis was to create a framework index where data from the interviews was sorted and tabulated in a table matrix with rows representing themes and subthemes and columns representing participants. I also cited the original transcript using page numbers, and the page numbers with powerful quotes pertaining to each theme were bolded in red.

### Challenges

Because of my personal and professional working relationships with many of the participants, I was able to receive much more candid responses; however, the collegial relationship also resulted in some deep dive conversations that veered significantly from the original interview questions. However, I believe the richness of the content was worth the trade-off. In addition, some of the questions seemed long at the end, particularly when discussing the list of values, so I found it helpful to post the last 5 questions in the chat.

### Trustworthiness and Rigor

To affirm the rigor and trustworthiness of the data collection and analysis, I utilized recommended practices as outlined in Lincoln and Guba's "four criteria of trustworthiness" — namely credibility, transferability, dependability, and confirmability.

1. To establish **credibility** and confirm the validity of the research findings, I outlined the credentials of all participants, gave participants the opportunity to review and validate findings to allow for member checking, outlined my own prolonged engagement in the field in a positionality statement, and used multiple sources to triangulate the data (Y. S. Lincoln & Guba, 1985).
2. **Transferability** (the ability to replicate the context) was achieved by providing rich descriptions of the research context, participants, and methods in an analytical memo (Y. S. Lincoln & Guba, 1985). Likewise, the analytical memo included detailed documentation about the research process and decisions to establish **dependability** based on the stability and consistency of the research findings over time and with different researchers (Y. S. Lincoln & Guba, 1985).
  1. Finally, **confirmability** or the degree to which the research findings are shaped by the participants and the context rather than my biases and values were validated through peer debriefing with my dissertation committee that included experts in the field; the use of quotations and thick descriptions in the text to highlight key points and allow readers to confirm the validity of the findings; and a transparent audit trail and documentation for how codes and themes were determined in a codebook that documents each theme and sub-theme to be assigned during indexing (Y. S. Lincoln & Guba, 1985). Moreover, I shared my reflexivity statement and acknowledged my own biases throughout the analysis as not only a researcher but an active participant in the field.

Summarily, the analysis of the qualitative data practically maintained rigor during the qualitative process as outlined by Johnny Saldaña, and informed by Lincoln and Guba, through

systematic coding with an audit trail (using the indexing and framework matrix of the Framework Method) with well-defined code categories and themes documented in a codebook; constant comparative analysis by iteratively evaluating the themes; transparent documentation of coding, themes, and interpretation in an analytical memo; peer debriefing with external reviewers; data saturation by interviewing a representative sample of participants; and clear reporting of results (Saldaña, 2021).

### ***Reflexivity Statement***

Being the mother of a young adult with Down syndrome has profoundly shaped my identity as a disability rights advocate and as an academic. During the past two decades of experience with my son and the broader disability advocacy community, I have learned that the lives of people with disabilities are much more multi-dimensional, multi-layered, marginalized, and meaningful than the public often realizes. In my position as a mother and disability rights advocate, I'm immersed in the world of disability rights and disability, so I see the world through that lens—which could be perceived as a bias. However, I would posit that because we live in a society in which people with disabilities have experienced historic discrimination and stigma, the public typically has a bias against disability, including medical professionals. Therefore, the perspective of someone within the community is likely more balanced with real-life experience ... as we would expect from those with first-hand experience from different races, ethnicities, and socioeconomic backgrounds.

I had a positive diagnosis experience when I was 23 years old and learned about my son's diagnosis hours after he was born. The pediatrician neutrally explained the characteristics of Down syndrome, and the next day a parent support staff member at the Newborn Intensive Care Unit brought us a book about Down syndrome and showed us a photo of her son on a bike. This was a normalizing moment for us as first-time parents, and she connected us with supports and services right away. I was surprised when research showed this was not the experience for most new parents.(Skotko, 2005) Therefore, I am motivated by empathy for these other new and expectant parents to improve their diagnosis experiences so that they get the support and resources I received. I'm also deeply grateful for the medical providers who supported me, and I feel compassion for medical professionals who feel uncomfortable when delivering unexpected news. I want to provide them with the tools and resources they need to navigate that process as sensitively as possible.

As I conduct research about the families of people with disabilities, my first-hand experience parenting a person with a disability, advocating for disability rights, and supporting new and expectant parents for the past 20 years can be beneficial in knowing what research questions to frame about quality of life, diagnosis experiences, and supports and services. In addition, I have a unique advantage when seeking community-based participatory research partners and when interpreting data to discern how responses correspond to patterns of experiences and themes I've observed over the years while supporting hundreds of families. However, my experience can be a disadvantage among medical professionals who may perceive me as a biased advocate because I am genuinely skeptical of a strictly medical approach disability. I do believe we must acknowledge any medical issues associated with disabilities and address them, but I also believe that presenting disability in a social context is essential for a more complete picture to meet the needs of patients and present disability with equity.

Because of my personal morality and my ideals as a feminist and disability rights advocate, my beliefs about abortion are complicated and don't fit a traditional framework. Fundamentally, I feel empathy for all parties involved. I believe pregnant patients should have equitable access to prenatal screening technologies they want to utilize, and I did utilize prenatal screening for preparation in subsequent pregnancies. I also believe pregnant patients should receive the full spectrum of support and resources to cope with those results. My primary concern is ensuring that patients have access to the support, resources, and healthcare they need so that they are not alone and so that disabilities are presented equitably. I feel profound empathy for them as someone who has gone through that experience myself. I have also personally witnessed and experienced discrimination in health care, systemic ableism, and low societal expectations for my son, and I worry that the information provided to pregnant patients may be tainted by those same biases so that the reproductive decisions they make are based on outdated perceptions of a historically marginalized population. I also feel it is not my place to make pregnancy decisions for other people; my primary goal is to give them the resources they need to understand disabilities and feel empowered to make decisions that reflect their own values. In many ways, the fragile internal compromises I've made about abortion put me in a unique position to understand the doctors whose priority is to serve patients, the feminist advocates who fear encroachment on women's rights, and the disability rights advocates whose main priority is to ensure pregnant women receive accurate, up-to-date, and balanced information about genetic conditions.

Toward that end, I have been involved in many efforts over the past two decades to address the lack of balanced, accurate, and up-to-date information provided about genetic conditions and the clinical bias that perpetuates discrimination against people with disabilities as an author of patient education materials, a conference presenter, an educator, and a researcher. Indeed, many people who are disability rights advocates have lived experience as individuals and family members and can contribute perspectives about life with disabilities that are essential to prenatal screening conversations, and no one approaches this issue objectively. Therefore, all interested parties need to share their unique perspectives and be aware of potential bias whether they be disability rights advocates, medical professionals, scientists, or policy makers.

### ***Background***

Further, I have personally witnessed and been involved in the advocacy fractures that can happen surrounding this issue when national disability organizations disagree about how to approach the abortion issue, who should lead the advocacy efforts, and what solutions are most appropriate. The dysfunction in the Down syndrome community and lack of cohesive approach makes it easier for medical and genetics organizations to absolve responsibility by pointing to the absence of clear messaging.

### ***Study Information:***

Submission Type: Exempt Protocol Category 2

IRB Number: H24198

Reference Number: 377031

## **Initial Codes Identified:**

### **1. *Major inductively derived themes:***

- a. First point on life course critical for health equity for people with disabilities and caregivers (access to supports and services)
- b. Recognize people with disabilities are a minority population subject to discrimination.
  - i. Strong bias against people with disabilities conveyed by providers at diagnosis.
  - ii. Inequities exacerbated by race, ethnicity, and other intersectional identities.
- c. Parents of children with disabilities are experiencing emotional harm.
- d. Parents of children with disabilities not receiving critical information about social outcomes, support, and services.
- e. Lack of funding for work to address problems with diagnosis experiences.
- f. Professional medical orgs need to value disability perspective and people with disabilities.
- g. Much work has been done, but bad diagnosis experiences are still the norm.

## **All other themes derived deductively and inductively based on the categories of the research questions and the Bardach Model:**

### **2. *Medical Organization Actions:***

- a. Develop better organizational practices toward people with disabilities.
  - i. Collaborate with and include people with disabilities, including guideline development, and conferences.
  - ii. Workforce development of people with disabilities. Protected class.
  - iii. Feature genetic counselors at conferences.
  - iv. Need ethical and moral framework for addressing disability.
  - v. Determine strategies for disseminating patient education resources about disabilities to providers.
- b. Develop better organizational disability standards/guidelines.
  - i. Offer timely referrals to specialists like genetic counselors.
  - ii. Provide information about advocacy orgs.
  - iii. Develop consensus on how to deliver a diagnosis/screening results— informed by people with disabilities and their caregivers (related to 2.a.i)
  - iv. Convey how to avoid bias: Don't say sorry or assume bad news.
  - v. Provide information about supports and services and social model.
- c. Develop better medical education/clinical training about disability.
  - i. Value of people with disabilities
  - ii. Provide context of disability rights
  - iii. Cultural humility regarding disability and recognizing bias.
  - iv. Genetic counselors offer training to physicians in practice.
  - v. Hospital systems (DEI)

### **3. Disability Advocacy**

- a. Advocate directly to ACOG to improve guidelines, training, and organizational practices.
  - i. Find multiple internal champions.
  - ii. No financial requirements
  - iii. [Observation] Advocacy orgs don't know how and are concerned about push-back [Ethan Saylor example]
- b. Advocate directly to state and federal funding agencies for grant prioritization.
- c. Advocate directly to foundations.
- d. Use advocacy strategies.
  - i. Thalidomide example—20 people
  - ii. Address as moral and ethical issue.
  - iii. Address as health equity issue.
  - iv. Share stories.
  - v. Collect data on referrals and diagnosis experiences.
  - vi. Do it annually until change is achieved?
- e. [Observation] Grassroots advocacy to impact patient satisfaction scores.
- f. Publish interdisciplinary publication of guidelines for delivering diagnoses and textbook.
- g. Advocate for people with disabilities to be included in any federal legislative or agency initiative involving health disparities.

### **4. Policy Actions:**

- a. Make federal or state funding to organizations dependent on measures.
  - i. Mandatory disability training (medical schools and CMEs)
  - ii. Provision of education information about disabilities
  - iii. Including people with disabilities in guideline development
  - iv. Significant opposition would emerge.
  - v. [Observation] Could be used as a “stick” threat to bring people to the table and get media attention.
- b. Insurance parity bill
  - i. Not currently well written
  - ii. Bipartisan
  - iii. Equity issue: only private insurers
  - iv. No appropriation
  - v. Potential for labs to dominate information provided.
  - vi. lag in time.
- c. Financial incentives for certification on disability sensitivity for practices and organizations
  - i. Money challenge
  - ii. Appropriations opposition
  - iii. Possible through agencies
- d. Funding for National First Call (combine with j)

- e. Policies to broadly support people with disabilities.
- f. Statute requiring the provision of information [stick]
  - i. [Observation] Pro-life label would lead to opposition.
  - ii. [Observation] Information widely variable in quality between states.
- g. Congress can change bills that are derogatory or discriminatory to people with disabilities.
- h. Expand coverage for genetic counseling (Medicare)
- i. Reimburse clinicians for following certain guidelines [carrot]
- j. Use health disparities population funding designation to improve diagnosis experiences by giving grants to do the following.
  - i. researching experiences
  - ii. diversifying workforce
  - iii. grants to medical org to build disability cultural competence in clinicians through training and technical assistance [carrot]
- k. Funding resources for families that include social model of disability.
- l. Fund an interdisciplinary coalition that can develop guidelines, make dissemination and implementation plans, and develop resources.

**5. Funding Options:**

- a. Get funding through research grants (minority underserved population) from NIH.
- b. Get dissemination funding through CDC.
- c. OSERS and NIDDLR for training grants
- d. Funding to local orgs, ARC, DD council, P&A, UCEDDs (ACL)

**6. Effective:**

- a. When doctors do it right as part of culture
- b. Referrals to specialists
- c. Distribution of educational materials
- d. Tracking medical choices of parents (termination, surgery—prenatal or postnatal)
- e. Patient outreach to local orgs
- f. Studies of parent experiences
- g. Studies of provider knowledge and competence
- h. Change in ACOG guidelines.
- i. Medical org engagement with disability community
- j. Evaluation of the adoption of standards at institution and community-level
- k. How is curriculum embedded in medical schools—how many?
- l. Peer assessment by genetic counselors

**7. Cost:**

- a. Substantial emotional harm and mental anguish for parents. Include mental health in cost/benefit analysis.
  - i. Emotional harm to parents impacts relationships with doctors.
  - ii. Emotional harm impacts parenting



- iii. Emotional harm impacts individuals with disabilities
- b. Exacerbated health disparities for people with disabilities.
- c. Financial cost of education and training—estimated as both low and high.
- d. High political cost for politicians criticized about reproductive rights stance.

### **8. Challenges/Barriers**

- a. Societal ableism problem
- b. Practical limitations of doctors (time, money)
- c. Doctors behind the times
- d. Arrogance of physicians.
- e. Scope of practice concerns
- f. Scientists can be hostile to the civil rights framing of disability.
- g. Advocacy organizations have limited funding and bandwidth to do work.
- h. Hard for people/professionals to keep up with innovation.
- i. Broken national government.

### **9. Benefits:**

- a. healthier, more independent, more self-sufficient, self-determined group of adults with disabilities
- b. empower parents to make the best decisions for their child.
- c. Stronger relationships between families and providers
- d. Improved competence of clinicians to deliver a diagnosis and discuss disability.
- e. Improve medical profession disability perception.
- f. Reduce emotional harm through information and support.
- g. Possible lower termination rates
- h. Reduced experiences of bias and better access to resources

### **10. Positives**

- a. Greater awareness of issue at many levels: Congressional and administrative level; Organizational level; provider level
- b. Bringing together political parties on disability issues (P.f.vii)
- c. Bringing together medical and disability communities (P.f.vii)

The political codes were not initially included among the themes and subthemes for the Framework analysis index but were being used to explore the political nuances.

#### **1. Political:**

- a. Politics: Laws don't work at changing behavior [Medical, Policy] Can provide incentives and punishments.
- b. Politics: Need policy champions who are willing to collaborate with disability community
  - i. Molinaro bill
  - ii. Be transparent with constant communication—develop trust.
  - iii. Disability rights has to be most central priority.

- c. Agencies
  - i. Politics: Do not tell agencies what to do [Dem]
  - ii. Politics: Working through agency can avoid legislative politics. [Advocacy]
  - iii. Changing leadership can impact sustainability.
- d. Medical Providers
  - i. Politics: Prescribing relationship between patient and healthcare providers [Dem]
  - ii. Politics: [Observation] Republicans more open to requirement for physicians and regulation. Democrats opposed.
  - iii. More pushback on political sticks than carrots from constituents. Observation: policymakers seem more willing to pursue sticks.
  - iv. Politics: Be specific and collaborative about policy to alleviate concerns about scope creep [Med policy]
  - v. Medical community and patients skeptical of parent organizations.
  - vi. Powerful pharmaceutical lobby to resist regulation.
- e. Reproductive Rights
  - i. Politics: Mired in pro-life/pro-choice. Pro-information. [Advocacy]
  - ii. Politics: Federal policy action more difficult post-Dobbs
  - iii. Politics: Pro-life Republicans need to support healthcare.
  - iv. Politics: For pro-life: less likely to terminate
  - v. Politics: For pro-choice: more resources to support people with disabilities across lifespan.
  - vi. Politics: Use their motivation to accomplish purpose. [Advocacy]
  - vii. Politics: State not federal when involving abortion. May be easier to start groundswell at state level.
  - viii. Politics: Abortion bans make it harder. [Advocacy]
- f. General Politics
  - i. Politics: Power of one senator/Amendment Demands [Dem]
  - ii. Politics: More difficult with partisan/tribal politics
  - iii. Politics: Hatred is more tolerated now. [Dem]
  - iv. Politics: Baby steps are important.
  - v. Politics: Be strategic in politics in what will move the needle. [Med policy]
  - vi. Missing the policy window.
  - vii. Policy can convey a message and facilitate collaboration even if never passed. Motivate people to come to the table.
  - viii. Need to be moderate/centrist to have support of medical community.
  - ix. Relieve anxiety of legislators
  - x. Uncover opposition.
  - xi. State laws.
  - xii. Federal law already exists.
- g. Politics: DS Info bills have limited effectiveness. [Advocacy]
  - i. No requirement
  - ii. No funding
  - iii. Language and approach difficult to address problem.

- iv. Competing advocacy voices.
- h. Disability “p” politics
  - i. Politics: Disability org silos. [observation]
  - ii. Politics: Competing disability orgs.
  - iii. Politics: Disability community has more critical legislative priorities. [Advocacy]

**Codes Merged and Added:**

1. **Major inductively derived themes: [Why the issue is important]**
  - a. First point on life course critical for health equity for people with disabilities and caregivers (access to supports and services) **and not just point of reproductive decision-making.**
  - b. Recognize people with disabilities are a minority population subject to discrimination.
    - i. Strong bias against people with disabilities conveyed by providers at diagnosis.
    - ii. Inequities exacerbated by race, ethnicity, and other intersectional identities.
  - c. Parents of children with disabilities are experiencing emotional harm.
  - d. Parents of children with disabilities not receiving critical information about social outcomes, support, and services.
  - e. Lack of funding for work to address problems with diagnosis experiences.
  - f. Professional medical orgs **and public health** need to value disability perspective **and civil rights and include** people with disabilities.
  - g. Much work has been done, but bad diagnosis experiences are still the norm.

**All other themes derived deductively and inductively based on the categories of the research questions and the Bardach Model:**

2. **Medical Organization Actions: [What national medical organizations like ACOG and SMFM can do to improve diagnosis experiences]**
  - a. Develop better organizational practices toward people with disabilities.
    - i. Collaborate with and include people with disabilities **and other disciplines**, including guideline development, conferences, and research: ***merged with original 2.a.iii to include genetic counselors and other disciplines and merged with original 2.b.iii since duplicative about collaborating on guidelines development.***
    - ii. Workforce development of people with disabilities. Protected class.
    - iii. Need ethical and moral framework for addressing disability.
    - iv. Determine strategies for disseminating patient education resources about disabilities to providers **and funding mechanisms.**
  - b. Develop better organizational disability standards/guidelines.
    - i. Offer timely referrals to specialists like genetic counselors and tertiary care centers.

- ii. Provide information about advocacy orgs.
- iii. Convey how to avoid bias: Don't say sorry or assume bad news.
- iv. Provide information about supports and services and social model.
- c. Develop better medical education/clinical training about disability.
  - i. Value of people with disabilities
  - ii. Provide context of disability rights
  - iii. Cultural humility regarding disability **and recognizing bias.**
  - iv. Genetic counselors offer training to physicians in practice.
  - v. Hospital systems (DEI)

### 3. Disability Advocacy

- a. Advocate directly to ACOG to improve guidelines, training, and organizational practices.
  - i. Find multiple internal champions  
*Related to 2.a.ii but distinct because 2.a.ii refers to medical organizations seeking disability advocacy workgroups and developing the workforce while 3.a.i refers to advocacy organizations developing internal champions at organizations. However, the strategies can be interrelated.*
  - ii. [Observation] No financial requirements
  - iii. [Observation] Advocacy orgs don't know how and are concerned about push-back [Ethan Saylor example]
- b. Advocate directly to state and federal funding agencies **for grant inclusion in health disparity initiatives.**  
*Merged with former 3.g: Advocate for people with disabilities to be included in any federal legislative or agency initiative involving health disparities.*
- c. Advocate directly to foundations.
- d. Use advocacy strategies.
  - i. Thalidomide example—20 people
  - ii. Address as moral and ethical issue.
  - iii. Address as health equity issue.
  - iv. Share stories.
  - v. Collect data on referrals and diagnosis experiences.
  - vi. Do it annually until change is achieved?
  - vii. **Added: Be pro-info, not pro-life**
- e. [Observation] Grassroots advocacy to impact patient satisfaction scores.
  - i. **Added: Can become just a checklist**
  - ii. **Added: Fraud is possible**
- f. Publish interdisciplinary publication of guidelines for delivering diagnoses and textbook.

### 4. Policy Actions:

- a. Make federal or state funding to organizations dependent on measures.
  - i. Mandatory disability training (medical schools and CMEs)
  - ii. Provision of **resources** about disabilities **at diagnosis**

- iii. Including people with disabilities in guideline development
- iv. Significant opposition would emerge.
- v. [Observation] Could be used as a “stick” threat to bring people to the table and get media attention.
- b. Insurance parity bill
  - i. Not currently well written
  - ii. Bipartisan
  - iii. Equity issue: only private insurers
  - iv. No appropriation
  - v. Potential for labs to dominate information provided.
  - vi. **Added: lag in time**
- c. Financial incentives for certification on disability sensitivity for practices and organizations
  - i. **Merged 4.c.i and 4.c.ii: Money and appropriations challenge.**
  - ii. Possible through agencies
- d. Policies to broadly support people with disabilities.
- e. Statute requiring the provision of information [stick]
  - i. [Observation] Pro-life label would lead to opposition.
  - ii. [Observation] Information widely variable in quality between states.
- f. Congress can change bills that are derogatory or discriminatory to people with disabilities.
- g. Expand coverage for genetic counseling (Medicare)
- h. Reimburse clinicians for following certain guidelines [carrot]
- i. Use health disparities population funding designation to improve diagnosis experiences by giving grants to do the following.
  - i. researching experiences
  - ii. diversifying workforce
  - iii. grants to medical org to build disability cultural competence in clinicians through training and technical assistance [carrot]
  - iv. Funding resources for families that include social model of disability.
  - v. Fund an interdisciplinary coalition that can develop guidelines, make dissemination and implementation plans, and develop resources.
  - vi. First Call technical assistance grant

**Merged former 4.d. Funding for National First Call**
- j. Update federal resources.

#### 5. **Funding Options:**

- a. Get funding through research grants (minority underserved population) from NIH.
- b. Get dissemination funding through CDC.
- c. OSERS and NIDDLR for training grants
- d. Funding to local orgs, ARC, DD council, P&A, UCEDDs (ACL)

#### 6. **Effective:**

- a. When doctors do it right as part of culture
- b. Referrals to specialists
- c. Distribution of educational materials
- d. Tracking medical choices of parents (termination, surgery—prenatal or postnatal)
- e. Patient outreach to local orgs
- f. Studies of parent experiences
- g. Studies of provider knowledge and competence
- h. Change in ACOG guidelines.
- i. Medical org engagement with disability community
- j. Evaluation of the adoption of standards at institution and community-level
- k. How is curriculum embedded in medical schools—how many?
- l. Peer assessment by genetic counselors

### **7. Cost:**

- a. Substantial emotional harm and mental anguish for parents. Include mental health in cost/benefit analysis.
  - i. Emotional harm to parents impacts relationships with doctors.
  - ii. Emotional harm impacts parenting
  - iii. Emotional harm impacts individuals with disabilities
- b. Exacerbated health disparities for people with disabilities.
- c. Financial cost of education and training—estimated as both low and high.
- d. High political cost for politicians criticized about reproductive rights stance.
- e. **Added: Time cost for clinical training**

### **8. Challenges/Barriers**

- a. Societal ableism problem
- b. Practical limitations of doctors (time, money)
- c. Doctors behind the times **on disability rights**
- d. Arrogance of physicians.
- e. Scope of practice concerns
- f. Scientists can be hostile to the civil rights framing of disability.
- g. Advocacy organizations have limited funding and bandwidth to do work.
- h. Hard for people/professionals to keep up with innovation **in genetics and disability.**
- i. Broken national government.
- j. Change is slow.
- k. **Abortion politics**  
*Merged from former P.e policy code.*
- l. **Politics: Laws don't work at changing behavior [Medical, Policy] Can provide incentives and punishments.**  
*Merged from former P.a policy code.*
- m. Limited effectiveness of DS bills  
*Merged from former P.g policy code.*
- n. **Dysfunction of disability orgs**

*Merged from former P.h policy code.*

**9. Benefits:**

- a. healthier, more independent, more self-sufficient, self-determined group of adults with disabilities
- b. empower parents to make the best decisions for their child **through better resources and information.**  
*Removed reference to resources from 9.f and 9.h to clarify.*
- c. Stronger relationships between families and providers
- d. Improved competence of clinicians to deliver a diagnosis and discuss disability.
- e. Improve medical profession disability perception.
- f. Reduce emotional harm to patients.
- g. Possible lower termination rates
- h. Reduced experiences of bias **to be more equitable and fairer to people with disabilities**
- i. **Added: Genetic counselors can help**

**10. Positives**

- a. Greater awareness of issue at many levels: Congressional and administrative level; Organizational level; provider level
- b. Bringing together political parties on disability issues (P.f.vii)
- c. Bringing together medical and disability communities (P.f.vii)

**11. Added: Negatives**

- a. **Can't make informed treatment decisions.**

Note: Four of the policy codes were recoded as Challenges due to the persistent mention of them as barriers.

**Summaries:**

**Most Important Values:**

- Measurable and quantifiable
- Efficacy/effectiveness/usefulness
- Equity
- Efficiency
- Cost
- Administrative robustness
- Political sustainability
- Sustainability
- Fairness
- Freedom: free markets, economic freedom; reproductive freedom
- Legality

- Political acceptability
  - Robustness and improvability
1. MGM Values:
    - a. Politically feasible [Extrapolated]
    - b. Equity [Extrapolated]
    - c. Cost efficient [Extrapolated]
  2. CP Values:
    - a. Equity
    - b. Politically feasible
  3. HS Values:
    - a. Politically feasible [extrapolated]
    - b. Cost efficient
    - c. Equity
    - d. Sustainability
  4. CL Values:
    - a. Politically feasible
    - b. Sustainable
    - c. Equity
    - d. Cost efficient
  5. CR Values:
    - a. Politically Feasible
    - b. Equity
    - c. Cost efficient
  6. JR:
    - a. Politically feasible
    - b. Cost efficient
    - c. Fair
  7. SM:
    - a. Equity
    - b. Political feasibility
    - c. Cost efficient
    - d. Sustainability
  8. MW:
    - a. Politically feasible [extrapolated]
    - b. Equity [extrapolated]
  9. DH:
    - a. Equity
    - b. Cost efficient
  10. AI:
    - a. Equity
    - b. Ethical
    - c. Politically feasible



**Most effective solutions:**

1. MGM: Advocate directly to professional organizations.
2. CP: More collaboration between ACOG and disability orgs.
3. HS: Funding for national First Call Center/technical assistance center. Money given to medical orgs for training and assistance and certification for disability training.
4. CL: providing the additional training for the medical professionals or mandating the additional training. Collab between medical and advocacy (seat at table.)
5. CR: Be inclusive of people with disabilities in health disparity initiatives.
6. JR: Change ACOG guidelines and pass bill to reimburse GCs.
7. SM: Change medical guidelines and practices. Build a groundswell of support.
8. MW: Bring people to the table to collaborate on solutions.
9. DH: Motivate medical orgs to value and include people with disabilities.
10. AI: Including people with disabilities in professional orgs through workforce pipeline

**Observations:**

The sophistication of the advocacy experts in considering the multiple perspectives ranging from patient continuing a pregnancy, patients considering termination, providers, and policymakers reflected more nuance than the approach of representatives from medical organizations in this interview or published literature.

Advocacy experts often make the claim with anecdotal evidence that more information about disabilities makes it less likely that patient will terminate, but we have no way to verify if this claim is true. However, given the level of bias experienced by patients continuing a pregnancy and the fear and emotional harm caused by the lack of information about the disability or outdated information provided to them, the claim does not seem unfounded.

Improved societal acceptance of people with disabilities has been both policy-driven and socially driven; therefore, social and policy solutions will likely be the most likely effective approaches for improving diagnosis experiences.

Many participants reported that change is slow.

While the “health disparities,” “inclusion,” and “minority underserved population” approaches are helpful designations for people with disabilities, some participants warned against being associated with politically fraught Diversity, Equity, and Inclusion (DEI) initiatives.

There was general consensus that genetic counselors are better trained at delivering diagnosis.

One lever for doctors could be patient satisfaction scores, which are important for Medicare reimbursement (<https://www.cms.gov/medicare/quality/initiatives/hospital-quality-initiative/hcahps-patients-perspectives-care-survey> and

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9690600/>)

Examine models like Alzheimer’s research.

**Alternatives:**

Address both bias and need for resources:

Improve ACOG policies toward PWD

Funding dependency

Health disparities funding

Do not address bias:

Expand coverage for GCs

Statute requiring provision of information

Insurance parity bill

## Appendix 6: Telling Your Story: Step 8

### Advocacy Letter to ACOG

Dear Dr. Christopher Zahn, Ms. Nancy O’Reilly, Ms. Courtney Salley, Dr. Wanda Nicholson, and ACOG DEI Workgroup Members:

We are deeply grateful that over the past five years ACOG has taken vital steps toward addressing health inequities faced by historically marginalized populations. Notably, ACOG has issued a policy statement on the importance of addressing racism in obstetrics and gynecology with corresponding webinars, training modules, and conference presentations to improve practice. Similarly, ACOG has issued committee opinions, position, and policy statements, and learning modules to address health inequities experienced due to sexuality, gender identity, and socioeconomic status. These are important and valued actions as these populations have all faced significant health disparities in the field of obstetrics and gynecology, and we appreciate the work to improve outcomes and care. Unfortunately, a population visibly less represented in the health equity efforts at ACOG are people with disabilities who account for a quarter of the population and who were designated as a health disparity population by NIH in September 2023 (*NIH Designates People with Disabilities as a Population with Health Disparities, 2023*).

Indeed, an assessment of the of the ACOG website section on “Diversity, Equity, and Inclusive Excellence at ACOG,” demonstrated that the website makes no mention of ableism as a concept, and disability is not addressed in the Collective Action Plan or the Diversity, Equity, and Inclusion (DEI) curriculum roadmap (*Diversity, Equity, and Inclusive Excellence at ACOG, 2024*). Moreover, no policy statement or committee opinion specifically addresses disability as a topic (*Equity-Focused Clinical Guidance and Policies, 2024*). Disability is most often referenced in these documents as a related intersectional identity but not addressed specifically. Moreover, the recently released “Permanent Contraception: Ethical Issues and Considerations” has improved in encouraging clinicians to preserve reproductive autonomy for patients with limited cognition as much as possible but still fails to identify the historic context of eugenics that informs this recommendation even though the same document does successfully provide the context for discrimination experienced by other marginalized populations—including the forced sterilization of incarcerated people.

Additionally, in the training materials, none of the publicly available webinars address disability specifically (*Education and Training, 2024*). Notably, the Council on Resident Education in Obstetrics and Gynecology (**CREOG**) Health Equity Curriculum does include disability when discussing the history of health equity, social determinants of health, health disparities, and bias. However, examples are not provided for how to address those disparities and what the manifestations of bias look like in obstetric care (*Health Equity, n.d.*). Furthermore, no person on the current DEI committee identifies that they have a disability or represent the disability perspective (ACOG, 2024).

Finally, there are no sessions addressing disability as a minority underserved population on the upcoming 2024 ACOG Annual Meeting schedule while there are three sessions on racial health equity, one session on Asian American and Pacific Islander health equity, one session on transgender care, one session addressing inequities due to socioeconomic status, and a keynote speaker addressing LGBTQ social justice issues (*ACOG Annual Clinical & Scientific Meeting, 2024*).

The various health disparity populations currently included in ACOG's health equity efforts are critically important and have experienced historical discrimination by the obstetric field that vitally need to be addressed. We stand in solidarity with them and acknowledge the benefit for patients with disabilities who share those intersectional identities. Similarly, people with disabilities have collectively experienced historic harms given the era of eugenics and forced sterilization, the discrimination in access disabled patients continue to face, the current disparities in maternal mortality and morbidity for patients with disabilities and their infants, and the profound bias often conveyed about disabilities during prenatal screening (Gleason et al., 2021; Meredith et al., 2023; Mitra et al., 2015; Powell et al., 2021; Rutherford, 2023).

Patients with physical, intellectual, and sensory disabilities have a higher risk for pregnancy-related complications and severe maternal morbidities that most significantly contribute to maternal mortality, and maternal death (Gleason et al., 2021; Mitra et al., 2015). Major factors cited are disparities in access due to lack of healthcare; communication and physical barriers; the lack of recognition of patients with disabilities collectively as a high risk pregnancy population; and the lack of provider comfort in treating patients with disabilities, particularly as more individuals with disabilities are choosing to become pregnant (Gleason et al., 2021; Mitra et al., 2015). Correspondingly, patients with disabilities are more likely to experience preterm labor and give birth to low-birthweight infants. Research also demonstrates that 61% of patients who give birth to babies with Down syndrome describe their obstetricians as conveying bias against disabilities, and clinicians who conveyed bias were significantly less likely to provide more comprehensive health care during pregnancy (Meredith et al., 2023).

Studies of these disability health inequities in obstetric care overwhelmingly recommend better training and medical education for obstetricians to recognize people with disabilities as a health disparity population with higher risk for poor maternal and child health outcomes (Gleason et al., 2021; Mitra et al., 2015; Mwachofi, 2017). Researchers further emphasize the importance of developing policies and procedures about caring for parents with disabilities and providing cultural competency training to counter disability bias and improve clinicians' knowledge about disabilities (Meredith et al., 2023; Powell et al., 2021).

Given the past and current health inequities faced by people with disabilities in obstetric care, this is a population that deserves to be recognized by ACOG as a health disparity population and that needs acknowledgment, training, and protection like all other health disparity populations. ACOG has taken some steps for which we are grateful, but much more needs to be done to address the specific needs of the disability community.

Therefore, we make the following requests of ACOG to work toward greater equity toward people with disabilities and to address historic discrimination faced by people with disabilities in the field of obstetrics:

1. Collaborate with and include people with disabilities and their caregivers at ACOG conferences, in research initiatives, and in the development of guidelines that reference people with disabilities or genetic conditions. This would also include inviting professionals who self-identify as a people with disabilities to participate on ACOG's Health Equity Team.
2. Work alongside the disability community on grants as research and project partners to improve equity toward people with disabilities such as the Respectful Care module done in collaboration with the Maternal Health Learning and Innovation Center (MHLIC) of the University of North Carolina Chapel Hill (UNC Chapel Hill).
3. Improve student and clinical training to include people with disabilities and disability social justice advocates covering topics such as historic harms done to people with disabilities in the field of obstetrics and current harms; strategies for improving practice, fostering cultural humility about disabilities, and avoiding bias in prenatal screening and the healthcare of patients with disabilities; and education about the history of disability rights.
4. Invest in the obstetric workforce development of people with disabilities as a protected class under the Americans with Disabilities Act.
5. Develop an ethical and moral framework for addressing disability to be published as a committee opinion, position, or policy statement with input from leaders in the disability community.
6. Determine strategies for disseminating patient education resources about disabilities to providers and funding mechanisms for developing and disseminating accurate, balanced, and up-to-date information created with input by people with disabilities. Be sure these resources provide information about advocacy organizations and supports and services as critical resources to address social determinants of health, particularly at the first point on the life course.
7. Encourage providers to provide timely referrals to experts and to collaborate with other professionals such as genetic counselors to improve care delivery.

We do not assert that ACOG or obstetricians and gynecologists are exceptional or intentional in their lack of recognition of people with disabilities as an identity that experiences bias and discrimination. This is a systemic and societal problem that has only recently been recognized by NIH as a gaping hole. What we are asking is for ACOG to help us step across the chasm because your allyship is critical with obstetric care being a first point on the life course for many families of people with disabilities and a significant health disparity for patients with disabilities.

Please contact us about your plans to move forward and address these issues so that we can begin collaborating on solutions as soon as possible. Our primary hope and intention are to work together as partners. Indeed, researchers in the field have identified ACOG as the linchpin

for addressing these health disparities for people with disabilities in obstetric care. We look forward to hearing from you and working together in the near future.

Possible signers:

National Center for Prenatal and Postnatal Resources  
AAHD  
AADMD  
Disabled Parenting Project  
Case Western Reserve Bioethics  
Hastings Center  
Spina Bifida Association  
TSSUS  
AXYS  
NSGC  
Genetic Support Foundation  
National Society of Genetic Counselors  
11q Research and Resource  
Little People of America  
Joel Michael Reynolds  
Mark Leach  
Robert Dinerstein

Progressive steps:

Send letter to entire ACOG board.  
Email campaign.  
Social media and media campaign.  
Meet with legislators.  
Draft legislation.

Email:

After decades of documented discrimination against people with disabilities in the field of obstetrics and genetics, the time has come for us to engage in advocacy for change, and collectively we have the power to make a difference. Never before have we centered the argument on health equity for people with disabilities and their families, and never before have we approached ACOG to recognize people with disabilities as a minority population that experiences discrimination in healthcare—particularly when ACOG has a stated interest in promoting health equity. People with disabilities are notably excluded from the current health equity initiatives at ACOG even though women with disabilities experience higher rates of maternal morbidity and mortality, and 61% of parents of children with disabilities reported that their clinicians conveyed implicit bias against disabilities in prenatal screening conversations, with nearly 1 in 10 reporting blatantly discriminatory and incorrect descriptions of disabilities. Patients report poorer health outcomes and lack of access to supports and services that can

improve health; therefore, we need to advocate directly to ACOG today for people with disabilities to be included in their health equity initiatives, in their organizational leadership, and in their training. Please join us today in signing on to a collaborative letter and also contacting ACOG directly about your concerns.