

# Recommendations for Stakeholders to Reduce Discrimination Against People with Disabilities in the Administration of Prenatal Screening/Testing



CENTER FOR  
DIGNITY IN  
HEALTHCARE FOR  
PEOPLE WITH  
DISABILITIES

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## Introduction

Prenatal testing is one of the most controversial and high-profile areas of concern for possible discrimination against people with disabilities because it involves the reproductive rights of pregnant patients. Therefore, many guidelines and protocols already exist from the major medical and genetics organizations.<sup>1,2</sup> However, research shows that there is a lack of consistency in the implementation of these guidelines and policies, particularly where those guidelines address how to deliver a diagnosis sensitively and what information about disabilities to provide patients.<sup>3-7</sup> Consequently, expectant parents continue to report negative and traumatic prenatal screening experiences caused by medical bias against people with disabilities in prenatal testing conversations and the inadequate provision of educational materials about disabilities.<sup>3,8</sup>

To better understand where inequities lie in the administration of prenatal testing, The Center for Dignity in Healthcare for People with Disabilities conducted a gap analysis.<sup>9</sup> A gap analysis is a tool that is used to help investigate and create a plan to fix a problem or issue, utilizing a 4-step process in which one identifies the current state of an issue, identifies the ideal future state, finds the gaps between the two and then creates a plan to close those gaps.

Gaps identified in the Gap Analysis for prenatal testing included:

1. A lack of policy and legislation to govern the regulation of prenatal screening technology and training of clinicians delivering a diagnosis
2. A lack of research and data about the impact of screening and life outcomes for people with disabilities
3. A lack of clinical training about disabilities and best practices when delivering a diagnosis
4. Negative patient diagnosis experiences and the inadequate provision of patient education information
5. Bias and stigma regarding disabilities when setting prenatal testing policies and delivering screening results
6. Lack of funding for an educational infrastructure to support patients.<sup>9</sup>

To address these gaps, all the important stakeholders need to be engaged to ensure that patient receive the support and information they need. Those stakeholders include: Disability Advocacy Organizations, Policy Leaders and Public Health Authorities, Federal Agencies, Individual Healthcare and Genetics Professionals, Healthcare and Genetics Organizations, Healthcare Educators, and Testing Laboratories. We have summarized the recommendations below for the different stakeholders to improve equity in prenatal screening.

# Recommendations for Disability Advocacy Organizations:

Disability advocacy organizations can be an important stakeholder in advocating for better policies and practices so that prenatal screening is more equitable in the presentation of people with disabilities by doing the following:

- Provide input as active stakeholders in the development of up-to-date and balanced resources about disabilities. Then, advocate for medical providers and prenatal testing labs to provide those up-to-date and balanced resources about disabilities at the moment of diagnosis, such as the resources from [lettercase.org](http://lettercase.org) and [healthychildren.org](http://healthychildren.org), which are included in most of the prenatal testing guidelines from medical and genetics organizations.<sup>1-10</sup>
- Advocate for medical providers to receive training on the sensitive delivery of a diagnosis, current information about disabilities, and disability studies concepts like ableism and disability bias.<sup>11,12</sup> Additionally, provide input on medical training curricula for medical providers as advocacy leaders and participate in training programs for medical students to expose them to the lived experience of individuals and families.<sup>13</sup>
- Advocate for leaders in the disability community to be meaningfully included in the development of any healthcare guidelines about prenatal testing and the determination of which conditions to test or screen for.
- Advocate for policies that promote equity in prenatal testing such as health insurance coverage of genetic counseling and funding the Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act at the federal level and implementing Down Syndrome/Genetic Conditions Information Acts at the state level, to make sure that expectant parents get the information they need.<sup>14,15</sup>
- Conduct quality public awareness campaigns about the lives of people with disabilities in different formats alongside the media and healthcare organizations.
- Participate in research about attitudes of healthcare providers about disabilities.<sup>16</sup>

# Recommendations for Policy Leaders, Federal Agencies, Public Health Authorities, and Research Funders:

Public policy leaders and public health authorities are also valued stakeholders as entities that can set and enforce policies and funding priorities to promote equity in prenatal testing by doing the following:

- Support policies, such as funding the Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act at the federal level and implementing Down Syndrome/Genetic Conditions Information Acts at the state level, to make sure that expectant parents get the information they need.<sup>14,17</sup>
- Pass laws that make sure financial ties between healthcare providers and commercial labs are ethical.
- Establish health insurance policies to cover genetic counseling.
- Actively regulate and monitor the marketing claims and practices of prenatal genetic testing companies to make sure they are not misleading and are reporting results accurately.
- Fund social science research about topics like healthcare providers attitudes about disability and strategies to improve training to counter implicit biases; the impact of the prenatal testing industry on genetic counseling and obstetrics; patient experiences with prenatal testing; and preferred supports and education tools following a prenatal diagnosis.
- Incentivize healthcare organizations to include leaders in the disability community, as a historically marginalized population, in policies and guidelines that impact them.

# Recommendations for Individual Healthcare and Genetics Professionals:

Healthcare and genetics professionals are absolutely key in shaping the prenatal testing experience and making sure that expectant parents get the information they need about a condition. Healthcare and genetics professionals can avoid discrimination toward people with disabilities, acknowledge available reproductive choices, and improve the patient experiences by doing the following:

- Most healthcare professional discuss the health issues linked to a prenatally diagnosed condition, and research shows families want that information. However, research shows that they also want information about life outcomes and treatments, as well as supports and services like early intervention programs, support groups, and/or local family contacts.<sup>10</sup>
- Provide expectant parents up-to-date and balanced resources about disabilities. Resources should include input from health and disability experts. Resources should also include photography and be easy to read like the resources at [lettercase.org](http://lettercase.org) and [healthchildren.org](http://healthchildren.org).<sup>18</sup>
- When delivering a prenatal diagnosis, offer support and show compassion. Avoid saying “I’m sorry” or assuming the diagnosis is bad news—unless the life of a child is at risk.<sup>19,20</sup>
- Provide pre-test and post-test counseling. Counseling is an essential part of any screening program. Use language patients can understand and clearly explain results.
- Offer referrals to specialists as needed and lead the team to meet the needs of the family.
- Seek training on the science of prenatal testing, how to share information about prenatal testing with expectant parents, and how to deliver a sensitive prenatal diagnosis.<sup>11,12,19</sup>
- Participate in research on the attitudes of healthcare providers about disabilities and methods to train healthcare providers about how to avoid disability bias.<sup>21</sup>

# Recommendations for Healthcare and Genetics Organizations:

Medical, genetics, and nursing associations establish the framework that health professionals follow when administering prenatal testing and communicating the results, and they can promote more equity in prenatal testing by doing the following:

- Include recommendations in their guidelines and other communication channels for health professionals to provide up-to-date and balanced resources about disabilities that include input from health and disability experts. Resources should also include photography and be easy to read.<sup>18</sup>
- Use ethical approaches to prenatal and carrier screening by including all stakeholders, including leaders in the disability community, when deciding which conditions to test or screen for and when creating guidelines. National health organizations should invite leaders from the disability community to participate in the process of developing guidelines that impact their population and include recommendations to share information about support groups and share disability resources.
- Invite disability advocacy leaders to participate in the development of any training materials about disabilities.
- Partner with national disability advocacy organizations to create and share public awareness campaigns in different formats with health professionals. The campaigns can showcase the lives of people with disabilities.
- Help implement state and federal policies to make sure that expectant parents get the information they need.<sup>14,15,17</sup>
- Participate in policy initiatives to make sure financial ties between healthcare providers and commercial labs are ethical.
- Monitor marketing claims from prenatal genetic testing labs and lab reports to make sure they are not misleading and advocate for accuracy in marketing and reporting.
- Advocate for health insurance policies to cover genetic counseling.
- Support research about how prenatal testing impacts the field of genetic counseling and obstetrics and take action to prevent any identified conflicts of interest.
- Support research on the attitudes of healthcare providers about disabilities and methods to train healthcare providers about how to avoid disability bias.<sup>13</sup>

# Recommendations for Healthcare Educators and Accreditation Boards:

Another important stakeholder is healthcare educators, including medical and advanced practice nursing program accreditation boards and licensing and certification organizations. Healthcare educators can promote greater equity in prenatal testing by doing the following:

- Work with disability advocacy leaders when making any training materials about disabilities.
- Offer training on how to deliver a sensitive prenatal diagnosis.<sup>11,19</sup>
- Provide clinicians with an education about the science of prenatal testing.
- Provide clinicians with training on how to share information about prenatal testing with expectant parents.
- Require training about disabilities and how to avoid disability bias in the training and continuing education of healthcare and genetics professionals.<sup>13</sup>

# Recommendations for Testing Laboratories:

Prenatal testing laboratories are in a unique stakeholder position because they receive significant profit from prenatal testing and have substantial capacity for dissemination between their relationships with medical providers and patients. Therefore, they can help promote equity in prenatal testing by doing the following:

- Provide healthcare professionals with up-to-date and balanced resources about disabilities to provide patients when delivering a screening results.<sup>10</sup>
- Support the dissemination of research that provides important data on recommendations for healthcare providers on how to deliver a diagnosis, expectant parent support and information needs when receiving prenatal screening results.

# Conclusion

We urge all stakeholders to address this health disparity and end discrimination against people with disabilities in prenatal testing. The Center for Dignity in Healthcare for Disabilities is available to serve as a resource and partner to help you and your colleagues implement these recommendations.

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