



Addressing Current Gaps in the Provision of Prenatal Testing to Improve Patient Support and Present Disabilities More Equitably

Center for Dignity in Healthcare for People with Disabilities

Stephanie Meredith, MA, University of Kentucky's Human Development Institute

Scotti Brackett, Down Syndrome Diagnosis Network

Nikki Watson

Dr. Marsha Michie, Case Western Reserve University School of Medicine



Gap Analysis Description

In 2020, prenatal and disability subject matter experts from the academic, medical, advocacy, and disability fields assessed 76 documents that addressed prenatal diagnosis and disability via a 4-step process:

1. Identification of the current state
2. Identification of the ideal future state
3. Finding gaps
4. Identifying potential ways to close gaps

Themes synthesized across 6 domains:

- funding
- policy/legislation
- research/data
- clinician related
- patient related
- issues caused by stigma and ableism

Gaps Identified for Medical Professionals

- Lack of required training pertaining to individuals with disabilities or how to deliver pre- or post-natal diagnoses to parents
- Lack of consistent guidance about the provision of patient education about prenatally detected genetic conditions
- Ableism in policies and practice reflecting bias, stigma, and discrimination toward people with disabilities

Potential Solutions

1. Improved healthcare professional training and accountability to include the social and civil rights context of disability with equitable representation by people with disabilities and best practices for delivering a diagnosis.
2. Better patient experiences through the provision of balanced, accurate, and up-to-date information about genetic conditions; pre-and post-test counseling; and information about local and national advocacy organizations.
3. Create, enforce, and fund policy and guidelines such as Down Syndrome Information Acts and ensure that guidelines from professional medical and genetics societies address patient and provider education needs about conditions and involve people with disabilities as diverse stakeholders.
4. Robust data collection and related research, including investigating the impact of medical outreach on healthcare providers and evaluating the quantity and quality of information patients received.

Gaps Identified for Patients

- Subpar information about genetic conditions and genetic testing
- Negative experiences with prenatal screening
- Lack of compassion
- Patients reported negative experiences:
 - when negative language was used in presenting prenatal screening results
 - when receiving medical information but no information about social supports or life outcomes.