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## **The Prenatally and Postnatally Diagnosed Conditions Awareness Act**

The Prenatally and Postnatally Diagnosed Conditions Awareness Act (S. 1810) is a positive step toward providing better information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with a disability. This information sheet highlights the Act's benefits and identifies some of the issues to monitor in its implementation.

With Democratic Senator Edward Kennedy as an original co-sponsor, the Act does not include anti-choice language nor restrict the ability to obtain an abortion, even though it was authored by Kansas Republican Senator Brownback, a staunch opponent of abortion. Both the Senate and House of Representatives passed S. 1810 and the President signed the bill into law on October 8, 2008.<sup>1</sup>

### **What the Act Will Do**

The Act will provide more comprehensive information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with Down syndrome or another condition. The Secretary of the Department of Health and Human Services is now authorized to:

- Collect and disseminate evidence-based information on Down syndrome and other conditions diagnosed either through prenatal genetic testing or screening or in the 12-month period beginning at birth.
- Establish a resource telephone hotline for new or expectant parents.
- Expand and further develop local and national networks for peer-support, outreach and information to parents.
- Establish awareness and education programs for health care providers who talk to parents about prenatal genetic testing.
- Set up a national registry or network of local registries of families interested in adopting newborns with Down syndrome and other conditions.

### **Preserving Reproductive Autonomy and Addressing Disability Community Concerns**

Disability advocacy groups and reproductive rights and justice organizations share an interest in pregnant women receiving unbiased, nondirective information about prenatal genetic conditions. The disability community has been concerned that pregnant women receive negatively biased information about what it means to have a child with a disability, shaped by negative societal attitudes toward disability. A lack of balanced information may contribute to the high rate of abortion upon a prenatal diagnosis of Down syndrome.

By providing more comprehensive information and resources, the Prenatally and Postnatally Diagnosed Conditions Awareness Act may effectively expand women's reproductive options. The information and support provided will allow a pregnant woman and her family to determine an outcome that fits within their personal, cultural, religious, and social context. Specifically, more comprehensive material about disability and an opportunity to speak to more people than one physician or genetic counselor will better prepare women and their families to make an independent decision that is right for them.

## **Implications for People with Disabilities and Society**

The disability community and society at large may benefit from the Act in several ways. Providing accurate, balanced information about both the positive and negative aspects of disability may expand people's views of disability and of the potential for people with disabilities to participate in and contribute to society. The Act may help parents and the public shift from viewing disability as simply a medical diagnosis and tragedy to a more enlarged view that encompasses the full potential of children with disabilities and the experience of parenting a child with a disability.

## **Implementation of the Act**

Disability rights organizations and reproductive rights and justice organizations can be instrumental in ensuring that the Act is implemented in a way that benefits all women. Some of the issues that must be considered are:

- Adequate funding must be allocated to properly implement the Act.
- As stipulated in the Act, disability advocacy groups should be actively involved in developing the supportive services in the Act. Information should include a broad disability perspective, covering many different disabilities and including the voices of adults with disabilities and parents of children with disabilities.
- Information and resources should take into account the broad range of reproductive options available to pregnant women and should not steer women to any particular decision.
- Resources and services must be available in a variety of formats to all women, including those from diverse cultural and linguistic backgrounds, those who do not have telephone or computer access, those who have disabilities, and those who cannot read written materials. Affected communities should be involved in preparing and distributing information and setting up networks.
- Information and support should be equally available to women who learn of a disability diagnosis at birth or through prenatal genetic testing, recognizing that not all women have access to prenatal testing, based on issues such as income, geography and language.
- Genetic counselors should be included in awareness and education programs for health care providers, even in states that do not require genetic counselors be licensed.
- Information and resources will need to be updated over time, and measures should be put in place to ensure continuing development and research.

With these issues considered, and with organizations from disability rights as well as reproductive rights and justice at the table, the Prenatally and Postnatally Diagnosed Awareness Act has the potential to benefit all of our communities.

***This information sheet is authored by Disability Rights Education and Defense Fund, Generations Ahead, National Women's Health Network, Reproductive Health Technologies Project, and World Institute on Disability.***

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<sup>1</sup> See Pub. L. No. 110-374 [2008].