

HOUSE BILL REPORT

HB 2403

As Reported by House Committee On:
Health Care & Wellness

Title: An act relating to Down syndrome resources.

Brief Description: Concerning Down syndrome resources.

Sponsors: Representatives Kochmar, Senn, Griffey, Appleton, Walsh, Wylie, Scott, Ryu, McCabe, Stambaugh, Short, Magendanz, Caldier, Hickel, Wilson, Zeiger, Muri, Kilduff and McBride.

Brief History:

Committee Activity:

Health Care & Wellness: 1/19/16, 1/29/16 [DP].

Brief Summary of Bill

- Directs the Department of Health to develop resources related to Down syndrome for expectant parents and parents who receive a positive diagnosis of Down syndrome.
- Directs specified health care providers and facilities to distribute the resources to expectant parents and parents who receive a positive diagnosis of Down syndrome.

HOUSE COMMITTEE ON HEALTH CARE & WELLNESS

Majority Report: Do pass. Signed by 12 members: Representatives Cody, Chair; Schmick, Ranking Minority Member; Caldier, Clibborn, DeBolt, Jinkins, Johnson, Moeller, Robinson, Short, Tharinger and Van De Wege.

Staff: Chris Blake (786-7392).

Background:

Down syndrome is a lifelong condition caused during cell division when the presence of an extra copy of chromosome 21 develops. According to the United States Centers for Disease Control and Prevention, approximately 6,000 babies are born in the United States each year

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with Down syndrome. It is the most common chromosomal condition diagnosed in the United States.

While every person with Down syndrome has different abilities, people with Down syndrome may have physical and intellectual challenges, such as hearing loss, obstructive sleep apnea, ear infections, eye diseases, or heart defects. Early treatment including speech therapy, physical therapy, occupational therapy, or educational therapy may help persons with Down syndrome improve their skills.

Down syndrome may be detected during pregnancy through either a screening test or a diagnostic test. The screening test involves a combination of a blood test and an ultrasound. Diagnostic tests are usually performed after a positive screening test and involves an examination of material from either the placenta, amniotic fluid, or the umbilical cord.

Summary of Bill:

The Department of Health (Department) must develop resources related to Down syndrome to be made available for distribution to expectant parents who receive a positive prenatal diagnosis of Down syndrome and parents who receive a postnatal diagnosis of Down syndrome. The resources must provide up-to-date, evidence-based, written information about Down syndrome and people with Down syndrome that has been reviewed by medical experts and Down syndrome associations. The resources must present contact information for support services, including information hotlines, clearinghouses, and national and local organizations. The resources must also be culturally and linguistically appropriate. The resources must address physical, developmental, educational, and psychosocial outcomes; life expectancy; clinical course; and intellectual and functional development and therapy options.

The Department must distribute the resources to specified health care providers and facilities to give to expecting parents and parents with a prenatal or postnatal diagnosis of Down syndrome. The health care providers and facilities include midwives, osteopathic physicians, osteopathic physician's assistants, physicians, physician assistants, nurses, genetic counselors, hospitals, and birthing centers.

Appropriation: None.

Fiscal Note: Available.

Effective Date: The bill takes effect 90 days after adjournment of the session in which the bill is passed.

Staff Summary of Public Testimony:

(In support) This bill will give parents resources at the time of learning that their child has a diagnosis of Down syndrome and will promote family discussions and additional research. This is a simple issue and a small expense.

Evidence-based research and information about Down syndrome needs to be distributed to families before they make a decision that they may regret. There is a 90 percent abortion rate when an expecting mother finds out she is carrying a child with a diagnosis of Down syndrome.

More is known today about Down syndrome and individuals with Down syndrome are now able to attend college, live independently, get married, and contribute to society. Many medical professionals still have outdated notions of what Down syndrome is and sometimes use negative phrases and communicate fear to parents about what Down syndrome really is. If this bill were to become law, every health care provider would have consistent, accurate medical information to give to parents.

This will give parents correct information and get children with Down syndrome on a positive track from an early age to have productive lives. When people are integrating into communities and they have correct information, that is when people thrive. Eight other states have passed similar legislation.

(Opposed) None.

Persons Testifying: Representative Kochmar, prime sponsor; Eric Matthes and Noah Seidel, Self Advocates in Leadership; Becky Ronan, Down Syndrome Community Board; Diana Stadden, The Arc of Washington State; and Brittany Stadden, People First.

Persons Signed In To Testify But Not Testifying: None.