

SENATE BILL REPORT

HB 2403

As of February 23, 2016

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: Passed House: 2/17/16, 97-1.

Committee Activity: Health Care: 2/23/16.

SENATE COMMITTEE ON HEALTH CARE

Staff: Kathleen Buchli (786-7488)

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

While every person with Down syndrome has different abilities, persons 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

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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 at the time of diagnosis. 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.

Committee/Commission/Task Force Created: No.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Staff Summary of Public Testimony: PRO: People with Down syndrome can do wonderful things in their lives. Everyone wants a healthy child and a diagnosis of Down syndrome can be frightening; this bill will help people faced with this diagnosis to understand Down syndrome and how loving the people with Down syndrome can be. In the past, providers of health care have not been able to provide information about Down syndrome to parents, or the information they provided encouraged parents to give up their children to RHCs or other living alternatives. Today, information on Down syndrome and services available to families can help expectant parents and keep families together. Information provided to parents today is not consistent and this will make sure that every parent is provided it. It gives parents the information they need. The future is bright for people with Down syndrome. People need to know that there are people living with Down syndrome who hold jobs, get married, have friendships, and build relationships. These resources will help parents understand the diagnosis of Down syndrome.

Persons Testifying: PRO: Rep. Kochmar, Prime Sponsor; Marsha Ford; Noah Seidel , Self-Advocates in Leadership; Becky Ronan, Down Syndrome Community; Susan Mountin, self; Rebecca Brandt, South Puget Sound Up with Down Syndrome; Eric Matthes, Self-Advocates in Leadership; Margaret-Lee Thompson; Marcia Cristal.

Persons Signed In To Testify But Not Testifying: No one.