Texas Bleeding Disorders Advisory Council
Report to the Texas Legislature

As Required By
Senate Bill 156 by Senator Joan Huffman
82nd Legislature, Regular Session, 2011

Department of State Health Services
December 2014

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Executive Summary

Senate Bill (S.B.) 156, 82nd Legislature, Regular Session, 2011, amended Chapter 103A, Texas Health and Safety Code, to establish the Texas Bleeding Disorders Advisory Council (Council). Council members were appointed on December 1, 2011. The legislation can be found at www.dshs.state.tx.us/tbdac/docs/Senate-Bill-156.doc.

Sec. 103A.008 requires the Council to submit a report of its findings and recommendations to the Governor, the Lieutenant Governor, and the Speaker of the House of Representatives, no later than December 1 of each even-numbered year. Prior to submission, the report is required to be made public and subject to public review and comment before adoption by the Council. The report was posted at http://www.dshs.state.tx.us/tbdac/Texas-Bleeding-Disorders-Advisory-Council-(TBDAC).aspx and this report incorporates stakeholder comments.

Additionally, not later than six months after the date the Council's annual report is issued, the commissioner of health is required to report on efforts to implement the recommendations in the report. The commissioner's annual report must also be made available to the public and include any related state or national activities in which the Council participates.

The Council makes the following recommendations that support the significance and need for awareness on issues that affect the health and wellness of persons with hemophilia and other bleeding or clotting disorders. Additional detail on each recommendation begins on page seven.

- Revise Chapter 41, Texas Health and Safety Code to add insurance premium payment as a benefit of the Hemophilia Assistance Program (HAP).

- Provide information and resources about medical home to hemophilia treatment centers (HTC) and treating physicians to help ensure that all persons with hemophilia and other bleeding or clotting disorders receive medical care within a patient centered medical home.

- Provide resources to HTCs and treating providers to ensure that youth with hemophilia and other bleeding or clotting disorders have the necessary supports needed to successfully transition into adulthood.

- Promote best practices in the provider community by requiring health benefit plans to adopt standards of care based on the latest evidence-based clinical research on hemophilia and other bleeding or clotting disorders.

- Promote improvements in care and services to persons with hemophilia and other bleeding or clotting disorders by offering continuing education on hemophilia and other bleeding or clotting disorders for health care providers or linking to already established programs.

- Promote awareness about diagnosing and treating hemophilia and other bleeding or clotting disorders by identifying resources and disseminating information to individuals

with these disorders, people affected by these disorders, health care providers, and stakeholders, using all types of media.

- Promote networking opportunities for families and friends of individuals with hemophilia and other bleeding or clotting disorders.

Introduction

In accordance with the legislation, the duties of the Council are to conduct studies and advise the Department of State Health Services (DSHS), the Health and Human Services Commission HHSC), and the Texas Department of Insurance (TDI) on:

1. Public use data, outcome data, and other information submitted to or collected by the department under Chapter 108 or other law related to hemophilia or other bleeding or clotting disorders and the department's disclosure and dissemination of that information within and outside of the department; and
2. Other issues that affect the health and wellness of persons living with hemophilia or other bleeding or clotting disorders.

No later than December 1 of each even-numbered year, the Council is required to submit a report of its findings and recommendations to the Governor, the Lieutenant Governor, and the Speaker of the House of Representatives. The Council's report must be made public and is subject to public review and comment before adoption by the Council. Additionally, no later than six months after the date the Council's annual report is issued, the commissioner is required to report on efforts to implement the recommendations in the report. The commissioner's annual report must also be made public and include any related state or national activities in which the Council participates.

S.B. 156 was passed into law on June 17, 2011. Council members were appointed on December 1, 2011, and the group has met quarterly since their first meeting on January 27, 2012. The Council is composed of the DSHS commissioner and the commissioner of insurance, or their designees, serving as non-voting members. Ten voting members were jointly appointed by the DSHS commissioner and the commissioner of insurance. A list of the Council members is available in Appendix A.

The first *TBDAC Report to the 82nd Texas Legislature* was published December 2012. The *Overview of Efforts to Implement the Recommendations of the TBDAC* was published July 1, 2013.

The recommendations in this second report are based on discussions held during routine meetings in 2013 and 2014. The Council reviewed and studied the 2012 report and determined which data, recommendations, and rationales should be updated and included in the current report and created subcommittees to focus on three main areas of concern:

- HAP premium payment assistance;
- Medical Home and Transition Services; and
- Health and Wellness.

The report has been made public via the Council website at http://www.dshs.state.tx.us/tbdac/Texas-Bleeding-Disorders-Advisory-Council-(TBDAC).aspx, and incorporated stakeholder comments prior to adoption by the Council.

Background

The exact number of people living with hemophilia in the United States is not known. Currently, the number of people with hemophilia in the United States is estimated to be approximately 20,000, based on expected births and deaths since 1994.[1]

While hemophilia is rare, it has high treatment costs. In fact, the treatment of hemophilia ranks among the most expensive chronic diseases in the United States. New technology has led to remarkable advances in improving the safety of new blood products, but these technologies have come at ever-increasing costs. It is difficult to separate these cost increases from the overall cost increase in health care nationwide; however, research and development for many of these specialized products come with a huge price tag. Current factor concentrates are among the most costly therapies in the world, with a total annual cost per person ranging from $60,000 to $150,000.[2] However, with an adequate quantity of treatment products and proper care, people with hemophilia or other clotting and bleeding disorders can live perfectly healthy lives. Without treatment, most children with severe hemophilia will die young.[3]

An estimated 400,000 people worldwide are living with hemophilia and only 25 percent receive adequate treatment according to the World Federation of Hemophilia (WFH).[4] Nonetheless, the Healthy People 2020 Leading Health Indicators[5] place renewed emphasis on overcoming these challenges by advocating for early preventive care to decrease bleeding and lessen joint disease and disability.

Recommendations

The following recommendations are presented as options for the Legislature to consider in improving access to care for persons living with hemophilia, thrombophilia, and other bleeding or clotting disorders.

Recommendation #1: Revise Chapter 41, Health and Safety Code, to add insurance premium payment as a benefit of the HAP.

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[1] http://www.cdc.gov/ncbddd/hemophilia/data.html
[2] http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=34&contentid=24
[3] http://www.wfh.org/en/page.aspx?pid=642
[4] Ibid.
[5] http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=4

Rationale: The HAP provides blood factor replacement products to Texas residents who are age 21 or older with a diagnosis of hemophilia and incomes at or below 200 percent of the federal poverty level. Current funding provides up to $25,000 toward the cost of blood factor replacement products within a fiscal year to individuals with hemophilia as long as funds allotted for the program have not been exhausted for the fiscal year.

- $25,000 of factor will purchase, for individuals with severe hemophilia, approximately one to two months of blood factor replacement products under normal circumstances.
- The premium costs for private insurance will vary based on client income and the health benefit package. Federal subsidies are available to individuals with limited income.
- Allowing HAP to pay for insurance premiums would give the individual access to comprehensive health insurance coverage and would provide blood factor replacement products year-round while decreasing the individual's cost to the HAP. In turn, the HAP would be able to serve additional individuals. As a secondary benefit, an individual having full insurance coverage could lessen the financial impact of uncompensated care on health care institutions such as hospital emergency departments.

Recommendation #2: Provide information and resources about medical home to HTCs and treating physicians to help ensure that all persons with hemophilia and other bleeding or clotting disorders receive their medical care within a HTC and/or patient-centered medical home.

Rationale: According to the *Joint Principles of the Patient-Centered Medical Home* promulgated by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association, the patient-centered medical home is a health care setting that facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient's family.[6] Healthy People 2020[7] has established the goals of increasing the proportion of children with special health care needs who receive their care in family-centered, comprehensive, and coordinated systems and increasing the proportion that have access to a medical home. According to the *National Survey of Children with Special Health Care Needs 2009-2010*,[8] the outcome that children with special health care needs who receive coordinated, ongoing, comprehensive care within a medical home was achieved 43 percent of the time nationally and this standard was met for 40.1 percent of this population in Texas. The American Academy of Pediatrics Council on Children with Disabilities *Policy Statement on Care Coordination in the Medical Home* reports that research supports the benefit of professional care coordination in clinical and process improvements and

[6] American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, American Osteopathic Association, Joint Principles of the Patient-Centered Medical Home, Published on Patient Centered Primary Care Collaborative

[7] http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=9#403

[8] http://mchb.hrsa.gov/cshcn0910/core/pages/co6/s.html

in reducing health care costs and improving family satisfaction.[9] The policy recommends that primary care physicians caring for children with special health care needs facilitate access to community-based strategies through the use of medical home strategies and that those groups should "work cooperatively to develop effective care coordination models that take into consideration the continuum of health, education, and social services needed to improve the quality of care for children with special health care needs."[10] As a condition of their CDC grants, federally-funded HTCs are incorporating patient-centered medical home principles, but not all persons with hemophilia have access to an HTC.

- DSHS should invite participation in the Medical Home Workgroup and should provide ongoing technical assistance to providers interested in the medical home.
- Medical home resources and literature should be included on the following websites:
    - Texas Bleeding Disorders Advisory Council Home Page (http://www.dshs.state.tx.us/tbdac/Texas-Bleeding-Disorders-Advisory-Council-(TBDAC).aspx)
    - Hemophilia Assistance Program (http://www.dshs.state.tx.us/hemophilia/default.shtm)
    - Children with Special Health Care Needs Services Program Medical Home (http://www.dshs.state.tx.us/cshcn/medicalhome/default.shtm)

Recommendation #3: Provide resources to HTCs and treating providers to ensure that youth with hemophilia and other bleeding or clotting disorders have the necessary supports needed to successfully transition into adulthood.

Rationale: Most youth with chronic illnesses will survive into adulthood and, depending on the severity and specifics of their disability, should transition to an adult model of care.[11] Healthy People 2020[12] has established the objective to increase the proportion of youth with special health care needs whose health care providers have discussed transition from pediatric to adult care. According to the *National Survey of Children with Special Health Care Needs 2009-2010*,[13] the outcome that youth with special health care needs receive the services necessary to make the transition to adult health care was achieved 40 percent of the time nationally and in Texas this standard was met for 35.4 percent of this population. In 2002, the American Academy of Pediatrics, American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine published "*A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs*" which sets the goal of

[9] Council on Children with Disabilities, Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children with Special Health Care Needs, *Pediatrics* 2005; 116; 1238

[10] Ibid.

[11] American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group, Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. Pediatrics, 2011: 128; 132

[12] http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=9#403

[13] http://mchb.hrsa.gov/cshcn0910/core/pages/co6/s.html

transition to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. According to this policy, the central rationale for health care transition planning for young people with special health care needs is to achieve this goal by ensuring that adults receive primary medical care from those trained to provide it.[14]

- DSHS should invite participation in the Texas Title V Transition Workgroup and should provide ongoing technical assistance to those providers interested in health care transition.
- Transition resources and literature should be included on the following websites:
    - Texas Bleeding Disorders Advisory Council Home Page(http://www.dshs.state.tx.us/tbdac/Texas-Bleeding-Disorders-Advisory-Council-(TBDAC).aspx)
    - Hemophilia Assistance Program (http://www.dshs.state.tx.us/hemophilia/default.shtm)
    - Children with Special Health Care Needs Services Program Transition Services (http://www.dshs.state.tx.us/cshcn/Transition-Resources.aspx.)

Recommendation #4: Promote best practices in the provider community treating individuals with hemophilia and other bleeding or clotting disorders by requiring health benefit plans to adopt standards of care based on the latest evidence-based clinical research on hemophilia and other bleeding or clotting disorders.

Rationale: The Institute of Medicine defines evidence-based practice as the integration of best research evidence with clinical expertise and patient values. General practice providers that treat individuals with hemophilia that are not specialists (hematologists) may not be familiar with the latest evidence-based treatment recommendations and standards of care. The Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Federation (NHF) established the standards of service guidelines. This group is composed of the leading experts on bleeding disorders in the United States, including physicians, researchers, and other health care providers. Taken together, MASAC's recommendations represent the medical standards of care for the treatment of bleeding disorders throughout the United States, and are equally respected around the world. MASAC can be accessed at: https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC, and NHF at: http://www.hemophilia.org/.

Health maintenance organizations (HMOs) are regulated by TDI. Texas Administrative Code, Title 28, Part 1, Subchapter T**,** §11.1902(2)(B)(iv), requires HMOs to have a quality improvement program work plan that includes "…practice guidelines that (I) are approved by participating physicians and individual providers; (II) are communicated to physicians and individual providers; and (III) include preventive health services."

[14] American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine, a Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs, *Pediatrics* 2002; 110; 1304

- DSHS should promote the use of the latest evidence-based treatment recommendations and standards of care by posting links on the Council and HAP websites.
- TDI should require health benefit plans to adhere to the standards of care for the treatment of hemophilia and other bleeding and clotting disorders.

Recommendation #5: Promote improvements in care and services to persons with hemophilia and other bleeding or clotting disorders by offering continuing education on these disorders for health care providers or linking to already-established programs.

Rationale: Physicians and providers are required to complete a certain number of continuing education hours for licensure renewal. The number of hours will vary depending on the board certification and specialty practice area. Texas Health Steps (THSteps), an online provider education program, offers modules on a variety of topics. Presently there is not a module on hemophilia. THSteps online provider education program is free, and continuing education is provided for nurses, physicians, and social workers.

- DSHS should create an online training module related to hemophilia and other bleeding or clotting disorders to enhance patient care by increasing the knowledge and skill of providers who are unfamiliar with treatment guidelines. The course will serve as a foundation to build additional skills through continuing education and clinical practice.
- In addition, the course should include links to the THSteps Medical Home module and the Transition Module, which would support the family-centered approach to assess, diagnosis, treat, and manage individuals with these disorders.
- The course should also include links to the National Hemophilia Federation (NHF) at http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=84&contentid=68, to the Hemophilia Federation of America (HFA) at http://www.hemophiliafed.org/, to the World Hemophilia Federation (WHF) at http://www.wfh.org/en/page.aspx?pid=492, and to other resources as appropriate.

Recommendation #6: Promote awareness about diagnosing and treating hemophilia and other bleeding or clotting disorders by identifying resources and disseminating information to individuals with these disorders, people affected by these disorders, health care providers, and stakeholders using all types of media.

Rationale: Healthy People 2020's[15] Health Communication and Health Information Technology goal is to "use health communication strategies and health information technology to improve population health outcomes and health care quality, and to achieve health equity." Effective use of communication and technology by health care and public health professionals can bring about an age of patient- and public-centered health information and services. By strategically combining health information technology tools and effective health communication processes, there is the potential to:

- Improve health care quality and safety;
- Increase the efficiency of health care and public health service delivery;

[15] http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=9#403

- Improve the public health information infrastructure;
- Support care in the community and at home;
- Facilitate clinical and consumer decision-making; and
- Build health skills and knowledge.

There are many avenues for consideration when disseminating information to individuals with hemophilia and other bleeding or clotting disorders as well as stakeholders.

- Print media: DSHS should support the creation of an article on these disorders posted on the Council and HAP websites as well as post a link to the professional journal in which it is published. Provider sector may be reached through articles on hemophilia for publication and distribution through professional associations, either by posting on their website or including in a print newsletter. Examples of professional associations include the Texas Medical Association, the Texas Academy of Medical Osteopathy, the Texas Pediatric Society, the American College of Physicians-Texas Chapter, and the Texas Nurses Association.

- The latest engineering tools: DSHS should post information on engineering tools that support the care and treatment of these disorders on the Council and HAP websites. Providers would benefit from decision support tools using informatics and social media. Many providers presently access mobile devices as they are making rounds or treating patients in their offices.

- Social media: DSHS should support the use of social media to disseminate information about health information and services for providers that treat hemophilia and bleeding or clotting disorders for individuals diagnosed, and for family members that care for individuals with these disorders. Facebook and Twitter are current high-volume venues for dissemination of information on a variety of topics.

- Web-based tools: DSHS should include a link to the CDC website on the Council and HAP websites as well as other web addresses associated with the hemophilia and bleeding or clotting disorders community.

Recommendation #7: Promote networking opportunities for families and friends of individuals with hemophilia and bleeding or clotting disorders.

Rationale: The Children with Special Health Care Needs Services (CSHCN) Program supports the principle that children should live in families in their communities. One way to accomplish this is to provide family support services, such as respite care. There are also advantages for families that have a support network such as partnering with the state Family Voices.

- DSHS should include networking opportunities on the Council website at http://www.dshs.state.tx.us/tbdac/Texas-Bleeding-Disorders-Advisory-Council-(TBDAC).aspx,on the HAP website at http://www.dshs.state.tx.us/hemophilia/default.shtm; and on other appropriate websites.

- Chapter networks can be found on the following links: http://texcen.org; http://lonestarhemophilia.org and http://hemoelp.org.

Conclusion

Hemophilia and other bleeding or clotting disorders can have severe health, social and economic impact on individuals and families affected by these disorders. This report by the Texas Bleeding Disorders Advisory Council is intended to highlight some of the significant issues and raise awareness about the impact of these disorders. The Council makes the recommendations above for consideration by the commissioner of health, the commissioner of insurance, and members of the state legislature.

Appendix A: Texas Bleeding Disorders Advisory Council Members

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Voting members:

- A physician licensed to practice medicine in the state of Texas who treats individuals with hemophilia or other bleeding or clotting disorders;
- A licensed nurse who treats individuals with hemophilia or other bleeding or clotting disorders;
- A social worker who treats individuals with hemophilia or other bleeding or clotting disorders;
- A representative from a hemophilia treatment center in this state, that is federally funded;
- A representative of a health insurer or other health benefit plan that holds a certificate of authority by TDI;
- A representative of a volunteer or nonprofit health organization that serves Texas residents with hemophilia or other bleeding or clotting disorders;
- A person who has hemophilia or a caregiver of a person with hemophilia;
- A person who has a bleeding disorder other than hemophilia or a caregiver of a person who has a bleeding disorder other than hemophilia;
- A person who has a clotting disorder or caregiver of a person with a clotting disorder; and
- A pharmacist licensed in the state, with hemophilia therapy experience, who at the time of appointment represents a pharmacy provider that is not a specialty pharmacy provider participating in the Drug Pricing Program.

Non-voting members:

- DSHS representative
- TDI representative