REPORT TO THE OLMSTEAD SUBCABINET

HEALTHCARE AND HEALTHY LIVING 2I

AUTHORS:
MINNESOTA DEPARTMENT OF HEALTH

SUBMISSION DATE:
FEBRUARY 26, 2015

Summary Statement

This report provides a system analysis describing barriers that need resolution for transitioning youth with special health care needs to adult health care. It also includes a plan for addressing those barriers.

Background

As stated in Minnesota's Olmstead Plan, youth with special health care needs will receive the services necessary to make transitions to adult health care. As children with disabilities become young adults with disabilities, Minnesota must do a better system-wide job of helping youth with special health care needs receive the services necessary to make transitions to adult health care. With good transitions from youth to adult services, people receive ongoing access to coordinate care that can prevent institutionalization. According to the 2010 National Survey of Children with Special Health Care Needs, nationally only 40% of youth with special health care needs receive the services necessary to make transitions to adult health care. In Minnesota in 2010, 47.1% of youth made this transition59.

Action Item HC 2I

By September 30, 2014, complete a system analysis describing barriers that need resolution; develop a plan for addressing these barriers.

Deliverables Submitted by MDH

Below is an overview of the MDH deliverables completed and submitted to the OIO for HC 2I:

Deadline	Action	Item Submitted	Content	Date Submitted
9/30/14	Part 1: Complete a system analysis describing barriers that need resolution.	**Olmstead Benchmark Report** (which is the analysis)	The document outlines three barriers that need resolution.	10/8/14
	Part II: Develop a plan for addressing these barriers.	**Olmstead HC 2I Plan for Addressing Barriers**	Barriers, strategies, implementation mechanisms, target dates and responsible person.	Initial Plan: 1/23/15 Revised Plan: 2/20/15

The Olmstead Benchmark Report and the Olmstead HC 2I Plan for Addressing Barriers can be found on the following pages.

Olmstead Benchmark Report

October 8, 2014

Submitted by Barb Lundeen RN, PHN, MA Children and Youth with Special Health Needs

Action # 2I

Definitions:

Children and youth with special health needs (CYSHN) are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. (Maternal and Child Health Bureau).

Transition has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.

Background:

Health care transition planning for youth with disabilities, including those with chronic conditions, came to the forefront in 1989 when former Surgeon General Dr. C. Everett Koop convened a conference of family members and health professionals to focus on the health needs of youth as they transition from school to work and from home to independent living. In 2002 the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physician coauthored a consensus statement; "The goal of transition in health care for young adults with special health care needs is 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." This process can be challenging, particularly for CYSHN. Currently one of the six core objectives of the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) is that "all youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence."

All youth need to be connected to programs, services, activities, and supports that prepare them to manage their physical, mental and emotional well-being and develop life skills to make informed choices. This is especially true for youth with chronic health conditions. The benefits of purposeful transition care are that it provides youth with ongoing access to primary care and subspecialist care, promotes competence of disease management, fosters independence, social and emotional development through teaching self-advocacy and communication skills, and allows for a sense of security for support of long-term health care planning and life goals. The employment rate for youth with special health needs is historically below the national average

for youth and young adults of similar ages without disabilities. The ability to manage one's health is critical to going to school and transitioning into employment.

The information and quotes found in this report are from the following group meetings:

- Community Transition Interagency Committee in Grand Rapids on April 10, Carlton May 7, and Minneapolis on September 10, 2014
- "Let's Talk About Transition" ARC sponsored meeting for professionals and parents in St. Cloud September 18, 2014
- South west Maternal Child Health Meeting in Olivia on September 22, 2014
- Governor's Council on Developmental Disabilities on October 1, 2014
- Minnesota Transition Community of Practice on October 3, 2014
- Youth Board meeting on October 6, 2014
- Care Coordination-Mapping the Current State for CYSHN on October 8, 2014
- Transitions grant quarterly reports from Family Voices of Minnesota. Meeting of the clinics in the grant project on May 1, 2014

Gap

A. Intentional Health Care Planning for Transitioning of Care. Youth with special health needs are not all receiving needed preparation from their health care providers about transition from pediatric to adult health care. According to the National Survey of Children with Special Health Care Needs only 52% on Minnesota youth with special health needs receive the services necessary to make appropriate transitions to adult health care, work and independence.

The role of parents may change when their son or daughter transitions to adult medicine. They may not be involved in all decision making. Many parents voice frustration and fear with their children leaving their pediatric provider. "I beg my pediatric specialists not to let my 18 year old go" said one parent. "Transition to adult services: It is a disaster. Like being shoved off a cliff." Another parent said "My son has 13 specialists." Youth, too are concerned about leaving their pediatric provider and finding a new clinician. "I don't know how to find a doctor that gets me and my mental health" said one youth. One hundred percent of youth from the PACER Advisory Board (ages 14-18) said that no physician has talked to them about transition. All of the youth agreed that they are most concerned with dealing with the pharmacy and refilling medications.

The MDH CYSHN Transition in Health Care eighteen month grant with Family Voices of Minnesota began August 2013. Family Voices of Minnesota is working with four clinics (Health Care Homes) in both rural and metro areas of Minnesota to incorporate the following National Health Care Transition Center's six core elements:

1. Transition policy-develop a practice health care transition policy and share with providers, staff, youth and families

2. Transition age youth registry-identifying transitioning youth (current/future) and enroll in a transition registry
3. Transition preparation –Assess and track all readiness for adult health care activities with youth and families.
4. Transition planning – address all health care transition needs/gaps setting goals together with youth and family.
5. Transition and transfer of care-transfer from pediatric to adult care.
6. Transition completion – transition/transfer is declared complete.

Got Transition, a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health, released The Six Core Elements of Health Care Transition, which define the components of transition support and are based on the AAP transitions clinical report. Three tool packages are available for practices, including one focused on youth transitioning out of pediatric care. Each package, available in English and Spanish, includes sample tools, feedback surveys, and measurement tools that are customizable and available for download. "There are transition tools available but we need to get them to the right providers." Family Voices of Minnesota

Parents who are in the transition project through this grant voiced positive experiences. "The adult practitioner came to the pediatric clinic four times and worked with the pediatrician, care coordinator and my family before my daughter was transitioned to adult medicine." She continued to say that "the care plan also transferred to adult medicine." Another parent from CentraCare said "the transition process has gone so easy". Parents voiced appreciating the transition tools. One St. Cloud parent said "there were things on the check list I never would have thought of discussing with my child."

A deliverable of the grant is to develop strategies to address special needs of the patient population including racial and ethnic disparities. A care coordinator reported concern that there is "another layer of parents who have English as a second language." Hennepin County Medical Center's (HCMC) transition model has successfully addressed the needs of families from diverse and linguistic groups by using community health workers.

Strategy:

- Each of the clinics will be expected to test tools from Got Transition and develop strategies to engage youth with special health needs and their families in transition programs and policies that can be spread to other clinics in Minnesota in the future.
- A tool kit that physicians can utilize will be available by December of 2014.
- A transition session including the tool kit will be presented to health care homes at the May 2015 HCH/ State Innovation Model (SIM)Learning Collaborative in St. Cloud.
- HCMC will report to the Learning Collaborative on their success with community health workers.

- Develop educational information and resources particularly for multicultural families. Present to parents at charter school and evaluate impact by parent satisfaction.
- Education and outreach for youth, families, and other caring adults. Underscore the interdependence between health and wellness, and employment through education and outreach.
- Provide training for youth and families regarding transition to adult health care systems.

B. Local Public Health Partnerships

Local public health nurses are not typically involved with families who have transition age children. They are, though, and integral part of the health care system. Staff from CYSHN has talked to public health nurses in the NE and SW portions of Minnesota. Another meeting is set for Oct. 23 in Bemidji to educate nurses on transition in health care and also on Olmstead.

Strategy:

- Continue to encourage local partnerships by attending local maternal child health meetings throughout Minnesota.
- Present at local Community Transition Interagency Committees and the Transition Community of Practice on the role of public health in youth transitioning.
- Encourage transition discussions to begin by age twelve.

C. Access to continuous and uninterrupted health insurance coverage. Despite the intent behind the Social Security Systems' employment support provisions such as Ticket to Work, the potential of losing financial benefits, and most important, health insurance discourages youth with disabilities from seeking employment. Failure to connect to the workforce in early adulthood has been linked to lower earnings and lower levels of employment in later life. Perceptions of the system contribute to keeping health care transitions and post-school transitions separate. Work and health are inextricably linked.

Strategy:

- Professional development for health care professionals that incorporate employment transition related outcomes.
- Provide health-care providers and other youth service professional development opportunities to gain the knowledge, skills and abilities needed to guide through a coordinated self-determined, cross discipline transition planning process.

Olmstead HC 2I Plan for Addressing Barriers

Name: Barb Lundeen PHN MDH Children and Youth with Special Health Needs	**January 23, 2015**	
RESPONSIBILITY #1: Complete a system analysis describing barriers that need resolution: develop a plan for addressing these barriers		

Barrier from system analysis	**Strategies**	**Implementation mechanism**	**Target date**	**Responsible person**
A. Lack of intentional health care planning for transitioning of care It was found that providers are not discussing transfer of care to an adult provider Refer to final benchmark report dated Oct 8th, 2014	Each of the four clinics in the transitions in health care project with Family Voices of Minnesota (FVM) will test tools and develop strategies to engage youth and their families in transition programs and policies that can be spread to other clinics in Minnesota	As a MDH Grant recipient, Family Voices of MN will assist clinics to: • build strong teams of advocates for adopting a successful model of care for the transition of YSHCN • document strategies for working with adult partners • provide opportunities to meet adult physicians or become familiar with the physicians • Present their findings at the Health Care Home Learning Community. There will be 500 people attending the conference. • Develop a tool kit to be presented as part of learning days	June 30,2015 May 13, 2015 May 13, 2015	Children and Youth with Special Health Needs (CYSHN) section at MDH along with Family Voices of Minnesota (FVM)
	Develop educational information and resources particularly for multicultural families	• Address disparity issues and the success of utilizing community health workers will be presented • Develop education and outreach	June 30, 2015	Hennepin County Medical Center/FVM project

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		for youth, families, and other caring adults.		
	Provide training for professionals working with transition age youth across the system.	Present to parents at a charter school and evaluate the impact of parent satisfaction. A cohort from north western Minnesota and another from the metro will meet to discuss and develop strategies. Plan for and spread of the training	Dec. 30, 2015 Dec 30, 2015 Dec. 30, 2016	CYSHN staff CYSHN staff along with other state partners form DHS, MDE and DEED
B. Lack of Local Public health involvement in transition	Continue to encourage Local Public Health to establish partnerships with education, human services, pediatric/adult health care providers and other local community resources for persons with disabilities.	Attend MCH areas around the state and discuss transition services for youth with special health needs Participate in Transitions Community of Practice. Encourage the involvement of local public health agencies in local community transition interagency committees.	Ongoing	CYSHN staff
C. Youth and	Professional	Health care transitions will be	Dec. 30, 2016	CYSHN staff

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families often fear losing health insurance if they become employed	development for health care professionals that incorporate employment transition related outcomes	incorporated to the interagency cohort trainings		