

REPORT TO THE OLMSTEAD SUBCABINET

HEALTHCARE AND HEALTHY LIVING 2J.1

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Olmstead Final Report on HC 2J.1

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Action item HC 2J.1: By December 31, 2014 50% of Minnesota's transition age youth with disabilities will receive the services necessary to make transitions to adult health care. Biannually thereafter, there will be a 5% increase in the proportion of transition age youth with disabilities who receive the services necessary to make transitions to adult health care.

Brief description: Increase number of children with special health needs receiving the services necessary to make transitions to adult health care.

Refer to Action # 2I Benchmark Report Oct. 8, 2014 for background information.

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.

Benchmark #1

Monitor the data for changes in the number of youth with special health needs who receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work and independence. Explore new data that would indicate that children and youth with special health needs are receiving the necessary services. (Additional information was submitted on the measurable goal worksheet.)

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 47% of Minnesota youth with special health needs receive the services necessary to make appropriate transitions to adult health care, work and independence.

Collection of data for the National Survey of Children's Health (NSCH) used to alternate with collection for the National Survey of Children with Special Health Care Needs so that new data are available every 2 years for one or other of the surveys and every 4 years for a particular survey. The 2011/12 NSCH was released in early 2013. The next fielding of these surveys are pending results from the current review and revision process, but it is projected that data collection will commence in 2015.

<http://childhealthdata.org/learn/faq#again>

Benchmark #2

Develop an online Transition in Health Care toolkit for primary care providers and clinic care coordinators across Minnesota so that they discuss and plan with youth and their families for the changing health care needs as the youth transition to adult health care.

Family Voices of Minnesota transition project was funded by Minnesota Department of Health Children and Youth with Special Health Needs program. The timeline on the grant with Family Voices of Minnesota was extended to June 30, 2015 to accommodate presenting results and products at the next Health Care Home learning days in May 2015. There are currently four medical clinics that have tested the tools. There will be approximately 500 attendees at the learning days from all areas of Minnesota. Currently the tool kit is available through the National website Got Transition <http://www.gottransition.org> and Family Voices of MN <http://www.familyvoicesofminnesota.org>. It is important that families know about the resources and tools so they can request their primary care provider to use them. The tool kit is adaptable for use at each clinic. Evidence of this impact will be measured through the ongoing monitoring of the NSCH Survey and through anecdotal stories from families and providers. A family from CentraCare in St. Cloud reported a positive experience using the toolkit when their daughter transitioned to adult medicine. The family met with the pediatrician and the adult primary care physician at a joint clinic visit and a care plan was developed and transitioned with the youth. The parent said the tools were very helpful.

Benchmark #3

Promote implementation of the transitions in health care online toolkit through the Children and Youth with Special Health Needs website and through intra and interagency connections.

Benchmark #1 explains that the tool kit has been developed and is being used at four clinics as part of the transitions in health care project with FVM. Health Partners has committed to spread the transition tools throughout their health system. The toolkit will be spread throughout health care homes beginning in May, 2015. The tool kit will remain on the Got Transition website and on the Family Voices of MN website. It will be spread through the interagency partners in benchmark #4.

Benchmark #4

Partner with the Minnesota Department of Education, Vocational Rehabilitation and the Department of Human Services to develop and implement a cross agency focus so that youth with special health needs receive the services necessary to make transitions to all adult systems including adult health care.

Currently all four departments are working together on a quality improvement project titled "students transition to adult system appropriately." Two school districts have been identified to help discuss and plan for the spread of this QI interagency project. Northern Lights in Duluth is one chosen area. Duluth Essentia Medical Clinic is one of the four clinics in the transition project with Family Voices of MN mentioned above. The other district is Independent School District 916. Health Partners has clinics in

this locality of the metro. The first meeting of the cohort is planned for March 2015. The state partners have been reviewing literature and best practices. The project will develop protocol for child-to-adult handoff including health transition. The agencies will develop a baseline for proficiency in interagency coordination and look at ways to assess improvement. The project will look at the percentage of professionals demonstrating proficiency in transition from child to the adult system. Historically, different agencies begin transition planning at different ages. There currently is not consistency about when to plan or deliver services. In 2015 the cohort will develop consistent ways to identify young adults who are transitioned appropriately to adult services. Modules on interagency partnerships will be created with a plan to spread throughout Minnesota in 2016. An evaluation process will be included.

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- By December 31, 2014, 50% of Minnesota's transition age youth with disabilities will receive the services necessary to make transitions to adult health care. Biannually thereafter, there will be a 5% increase in the proportion of transition age youth with disabilities who receive the services necessary to make transitions to adult health care.

BASELINE: There are 76,735 children aged 12-17 in Minnesota with special health needs. Of those youth, 36,065 or 47.1% receive the services necessary to make transitions to adult health care.

MEASURABLE GOAL:

- By December 31, 2014, the number of Minnesota's transition age youth with disabilities who receive the services necessary to make transitions to adult health care will increase to 38,368 (50%).
- By December 30, 2016, the number of Minnesota's transition age youth with disabilities who receive the services necessary to make transitions to adult health care will increase to 42,204 (55%).
- By December 30, 2018, the number of Minnesota's transition age youth with disabilities who receive the services necessary to make transitions to adult health care will increase to by 46,041 (60%).

NOTES:

According to the 2012 Minnesota County Health Tables there are 715,660 youth between ages 10-19. There are approximately 397,588 children between ages 12-17.

According to the National Survey of Children with Special Health Care Needs 19.3% of children ages 12-17 have a special health care need. That means there are approximately 76,735 children and youth with special health needs ages 12 – 17. Currently 36,065 or 47.1% of families report that they receive the services necessary to make transitions to adult health care. Nationally the percentage is only 40.0%

The goal to increase by 5% is based on work being done through the Transitions in Health Care grant and historical trends. The Transitions project is working with four health care homes throughout Minnesota to enhance transitioning to adult health care. The numbers transitioning should continue to rise with spread throughout other medical clinics. However, 2013 Minnesota birth rates dropped to their lowest levels in 20 years. If this continues the number of children with special health needs will likely decrease.

At this time the only source of statewide data is the National Survey of Children with Special Health Needs (SLAITS) which is done every three years. The last data collection was from 2009-2010 and released in 2013. In the future, the National Survey for Children's Health and the National Survey for Children with Special Health Care Needs are being combined into a single survey, to be conducted annually. State-level estimates will be available bi-annually. Work is underway to revise, standardize, and pretest the instrument. The next full survey will be fielded in summer– fall 2016. Public data is planned to be released (late) spring 2017.