WISCONSIN

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)

population subgroup: children transitioning to adulthood

fact sheet compiled by Jena Wallander October 30, 2017

SUBGROUP PRIORITY INDICATOR: PERCENT OF CYSHCN WHO RECEIVED THE SERVICES NECESSARY TO MAKE TRANSITIONS TO ALL ASPECTS OF ADULT LIFE, INCLUDING ADULT HEALTH CARE, WORK, AND INDEPENDENCE

- US 40.0%
- Wisconsin 44.4%

Data source: National Survey of Children with Special Health Care Needs 2009-2010 (NS-CSHCN)

IN WISCONSIN, TRANSITION PLANNING MUST BE INCLUDED IN THE INDIVIDUAL EDUCATION PLAN STARTING AT AGE 14

WISCONSIN DEPARTMENT OF HEALTH MATERNAL AND CHILD HEALTH PROGRAM 2011-2015 PRIORITY AREA UPDATE (5 YEAR NEEDS ASSESSMENT)

MCH Priority Area 3: "increase the number of children and youth with special health care needs and their families who access necessary services and supports"

This priority area was identified by the WI MCH program through specific priority indicators identified via the National Survey of Children with Special Health Care Needs (NS-CSHCN) and through referral tracking by CYSCHN Regional centers and sub-contracted agencies.

The NS-CSHCN was a telephone survey last conducted 2009-2010. It is now integrated with the National Survey of Children's Health.

Wisconsin's performance on these priority indicators was slightly higher than or the same as the national percentages and beyond the subgroup priority indicator at left, included:

- % of CYSCHN whose families partner in decision making at all levels and are satisfied with the services they receive (*WI 74.4%; US 70.3%*)
- % of CYSCHN whose families report the community-based service systems are organized so they can use them easily (*WI* 64.6%; US 65.1%)
- % of parents of CYSHCN who report their doctors or other health care providers usually or always "help you feel like a partner in the child's care" (*WI 88.0%, US 87.0%*)
- %of referrals where the child or family did not have their needs met (*WI 31.5% in 2013, US unknown*)

It seems that the WI MCH Program did the best assessment it could with the most recent data available, though they did not do any state-wide surveying for the purposes of this assessment and more timely data may be helpful for program planning. As the NS-CSHCN becomes integrated with the National Survey of Children's Health, the data will be available yearly as of this year. The assessment process began in 2013 and involved stakeholder engagement, MCH program capacity, data synthesis, selection of priorities based on data and national performance measures, and strategic planning that is ongoing.

WI has a focus on systems-level comprehensive care, which is appropriate especially for assessing quality of transition planning for this population.

NATIONAL PERFORMANCE MEASURE 12:

PERCENT OF ADOLESCENTS WITH AND WITHOUT SPECIAL HEALTH CARE NEEDS WHO RECEIVED SERVICES NECESSARY TO TRANSITIONS TO ADULT HEALTH CARE

Data source: National Survey of Children with Special Health Care Needs 2009-2010 (NS-CSHCN) priority indicator data on pg. 1

STATE IDENTIFIED PERFORMANCE MEASURES:

ESM 12.1: CUMULATIVE NUMBER OF FAMILY MEMBERS TRAINED ON "WHAT'S AFTER HIGH SCHOOL" TRANSITION PLANNING

Significance: Training family members on "What's After High School" transition planning will increase the likelihood that adolescents with and without special health care needs receive the services necessary to transition to adult health care.

ESM 12.2: CUMULATIVE NUMBER OF TRANSITION QUALITY IMPROVEMENT QI GRANT PARTICIPANTS THAT HAVE A HEALTH CARE TRANSITION PROCESS MEASUREMENT TOOL TOTAL SCORE GREATER THAN OR EQUAL TO 70

Significance: Training medical practices on Got Transition concepts will increase the likelihood that adolescents within those practices receive the services needed to transition to adult health care. (overview pg. 3)

Data source (both): REDCap (Research Electronic Data Capture through University of Wisconsin); 2016 data unavailable

WISCONSIN STATE ACTION PLAN (2016 APPLICATION)

State Priority Needs for CYSHCN: "Healthcare Access and Quality"

Problem Statement: "Too few adolescents ages 12-17 receive the services and supports necessary to transition to adult health care."

Objectives:

- By 2020, work with partners to coordinate services with healthcare systems and between community partners
- By 2020, work with adult and pediatric medical providers to assure knowledge and awareness of transition
- By 2020, work with partners to increase the number of adult providers that serve YSHCN population and participate in transition planning
- By 2020, work with partners to assure family and teen knowledge and support regarding transition

Planning Activities:

- Investigate strategies included in transition intervention planning matrix and prioritized by stakeholders as June 2015 MCH Advisory Committee
- Select strategies to incorporate in 5 year work plan that includes process measures, specific time-framed activities, and responsible parties

Proposed Strategies:

- Align activities with the Wisconsin CYSHCN Medical Homes Systems Integration Grant
- Explore opportunities to collaborate with Medicaid/ACA initiatives to assure they are mindful of youth health transition provisions
- identify opportunities to encourage payers and health systems to support pediatric to adult transition coordination
- support the Wisconsin Youth Health Transition Initiative work in training and outreach using GoT Transition's Six Core Elements of Health Care Transition (pg. 3), including practice-based transition training and Quality Improvement pilot projects
- Strengthen collaboration across national, state, and local agencies through participation on GoT Transition Advisory Committee, the cross state agency Community of Practice on Transition (CoT) and county collaborations
- Support transition training for families and CYSHCN-serving partners at the community level
- Explore the development of a common statewide communication to all sixteen year olds and their families on key steps in transition to adulthood
- Support youth/family cross system coordination by providing information and referral to link individuals to existing supports and services related to transition

SIX CORE ELEMENTS OF HEALTH CARE TRANSITION 2.0

Developed in 2009

by AAP/AAFP/ACP Clinical Report on Transition to assess implementation of transitionplanning care and to assess dissemination of transition planning information to adolescents in a practice's network:

- Transition Policy
- Transition Tracking and Monitoring
- Transition Readiness
- Transition Planning
- Transfer of Care
- Transfer Completion

GoT Transition has subset goals with a transition scoring tool to assist health care providers in transition planning improvement. Each element is scored by a certain number of points. The highest number of points a practice or clinic could receive is 100. The provider should assess transition planning at the beginning of improvement and assess periodically throughout the improvement process.

Source: gottransition.org

CONCLUSION

As below half of the CYSCHN youth population in Wisconsin reported receiving services and counseling necessary for transitioning to adulthood in 2009-2010, it's appropriate that the state would be focused on increasing that percentage (goal is 48% by 2021 according to National Performance Measures website).

The strategies and planning activities outlined by the state (pg. 2) show that Wisconsin is committed to achieving it's goal in a way that is system-focused and comprehensive to CYSCHN needs. The 2011-2015 Priority Area update states: "Without a comprehensive, quality system of care, families will expend more personal resources on health care, work less, and experience a lower quality of life and adverse health outcomes over the life course of the family."

REFERENCES

- 5 Year Needs Assessment Summary (Rep.). (2016). Retrieved October 30, 2017, from https://www.dhs.wisconsin.gov/mch/blockgrant/5-year-needs-assessment-summary.pdf
- *Executive Summary* (Rep.). (2016). Retrieved October 30, 2017, from Wisconsin Department of Health Services website: https://www.dhs.wisconsin.gov/mch/blockgrant/executive-summary-title-v.pdf
- Children and Youth with Special Health Care Needs Program (CYSHCN). (2017, January 24). Retrieved October 30, 2017, from https://www.dhs.wisconsin.gov/cyshcn/index.htm
- GoT Transition. (2014). Six Core Elements of Health Care Transition 2.0 [Brochure]. Author. Retrieved October 30, 2017, from http://www.gottransition.org/resourceGet.cfm?id=234
- National Performance Measures. (2016). Retrieved October 30, 2017, from

https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerforma nceMeasures

- National Survey of Children with Special Health Care Needs. (2016). Retrieved October 30, 2017, from http://www.childhealthdata.org/learn/NS-CSHCN
- Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. (2011). *Pediatrics, 128*(1), 182-200. doi:10.1542/peds.2011-0969
- Wisconsin Maternal and Child Health Program: 2011-2015 Priority Area Update (Rep.). (2015). Retrieved from https://www.dhs.wisconsin.gov/publications/p01005.pdf
- Wisconsin Stare Action Plan Table (Rep.). (2016). Retrieved October 30, 2017, from Wisconsin Department of Health Services website: https://mchb.tvisdata.hrsa.gov/uploadedfiles/2016/submittedFiles/state Actionplan/WI_stateActionplan_printversion.pdf
- University of Wisconsin-Madison, Waisman Center. (2017). Finding Your Way: A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities [Brochure]. Author. Retrieved from

http://www.waisman.wisc.edu/cedd/pdfs/products/community/FYW_e.p df