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MCH Innovations Database Practice Summary & Implementation Guidance

Expanded eligibility for WV CYSHCN through enhanced screening

The West Virginia CSHCN Screener uses the CSHCN Screener© and questions from the National Survey of Children’s Health as a framework to implement a flexible definition of children with special health care needs to broaden the scope of children who are identified and to inform care coordination services across systems of care.



Location

Charleston, WV



Topic Area

Health
Screening/Promotion;
Service
Coordination/Integration



Setting

Community; Clinical



Population Focus

CYSHCN



NPM

NPM 11: Medical Home;
NPM 12: Transition; NPM
15: Adequate Insurance



Date Added

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Section 1: Practice Summary

PRACTICE DESCRIPTION

Children and youth with special health care needs (CYSHCN) are defined as “those who have or are at increased 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.”¹ The West Virginia (WV) Children with Special Health Care Needs (CSHCN) Program’s diagnosis-based eligibility criteria were limited in scope and inconsistent with this consequence-based definition of CYSHCN. The WV CSHCN Program sought to develop new, more inclusive eligibility criteria that would allow the program to provide services to a greater number and broader range of CYSHCN. The WV CSHCN Program Screener calculates a child’s program eligibility status and intensity level using the child’s CYSHCN status, presence of a physical special health care need, acuity of functional limitations, service utilization, risk-based categorical eligibility criteria, and financial eligibility, as needed if Title V funding for medically necessary medical foods are required. The program has adopted a methodology including the five question CSHCN Screener[®], additional questions from the National Survey of Children’s Health regarding functional limitations and service utilization, and program-specific eligibility criteria to determine a child’s eligibility status. First, children are identified by risk-based categorical eligibility (e.g., children in foster care, children diagnosed with neonatal abstinence syndrome). Then, the child’s special health care needs status is determined by the CSHCN Screener[®]. The CSHCN Screener[®] is a quick five question survey administered to parents/caregivers to identify if a child has a special health care need. Next, questions adapted from the National Survey of Children’s Health assess specific functional limitations and service utilization. Finally, financial eligibility for Title V funding for medically necessary medical foods is determined.

CORE COMPONENTS & PRACTICE ACTIVITIES

The WV CSHCN Program developed and implemented the WV CSHCN Program Screener to increase the number and scope of CYSHCN served by the program. The WV CSHCN Program Screener was developed by combining the five-question CSHCN Screener[®], additional questions from the National Survey of Children’s Health regarding functional limitations and service utilization, and program specific eligibility criteria to determine an applicant child’s eligibility status. The core components of this program include training interviewers and Registered Nurse reviewers, engaging

¹ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A new definition of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):137-40. doi: 10.1542/peds.102.1.137. PMID: 9714637.

² Bethell, C. D., Read, D., Stein, R. E., Blumberg, S. J., Wells, N., & Newacheck, P. W. (2002). Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics*, 2, 38-48.



CYSHCN and their families, confirming responses via a medical record review, documenting the of review findings, and monitoring for quality assurance.

Core Components & Practice Activities		
Core Component	Activities	Operational Details
Training	Training interviewers and Registered Nurse reviewers	Ensures all involved staff are knowledgeable and complete the WV CSHCN Program Screener process accurately and consistently
Family Engagement	Interview CYSHCN and their family to complete the WV CSHCN Program Screener	Engages the CYSHCN and their family and obtains their perspective on the CYSHCN’s health status and needs
Medical Review	Registered Nurse reviews WV CSHCN Program Screener responses and available medical records	Assesses the CYSHCN’s health status and needs,
Documentation	Registered Nurse documents review findings on WV CSHCN Program Screener Supplement	Provides a concise medical summary for the CSHCN Program care coordination team
Quality Assurance	Epidemiologist and Nursing Director review WV CSHCN Program Screener results, as needed	Promptly addresses staff concerns while completing the WV CSHCN Program Screener process. This contributes to ongoing quality assurance monitoring and identifies training needs as they arise.



HEALTH EQUITY

The population of the WV is largely homogenously White, with only 6.5% of the population identifying as non-White.³ That is not to suggest that racial inequities do not occur in WV, just to state that inequities in WV are typically addressed through the lens of poverty.

The CSHCN Program aims to promote equity in every aspect of its programming, starting at intake with the WV CSHCN Program Screener. The primary goal of the CSHCN Program is to promote health care access through care coordinating a complex system for CYSHCN. The WV CSHCN Program Screener identifies the CYSHCN's health care needs, unmet medical and mental/behavioral health needs, and health education needs of the CYSHCN and their family/caregiver. The WV CSHCN Program Screener also addresses adequacy of health insurance, food insecurity, and financial need when determining financial eligibility for Title V funding for medically necessary medical foods. Coverage of medical foods also address economic stability by relieving the financial burden for families with CYSHCN who require costly medical foods.

The WV CSHCN Program Screener can identify unmet medical and mental/behavioral health needs. The cause of those needs, be it financial burden, provider availability, transportation, will be addressed by the program's care coordination efforts upon enrollment. According to the Census Bureau, 15.6% of people in WV live in poverty, one of the highest rates in the country. WV is the second most rural state in the nation. Most of the state's population is connected by winding secondary roads with little to no access to public transportation. Most medical specialists in the state are located in and around the three tertiary care centers, leaving small rural towns with little access to required medical care. Care coordination can help address these issues by linking CYSHCN and their families with community resources.

Children who are in foster care face a variety of hardships and trauma that define them as CYSHCN. Furthermore, they can change placements frequently causing a loss of social support and a sense of community. Foster children often come from disenfranchised backgrounds. The WV CSHCN Program Screener identifies these children, provides a comprehensive view of their medical and mental/behavioral health needs, and informs care coordination efforts to bridge the unmet needs and link to community resources. This record will follow the foster child through their entire duration in foster care and will be retained should they reenter care. In addition, there are many children being cared for by aging grandparents and great-grandparents that face similar hardships to children in foster care. This aging population may have their own health concerns to manage in addition to those of the children in their care.

EVIDENCE OF EFFECTIVENESS

All children who apply for or are referred to the WV CSHCN Program will have a WV CSHCN Program Screener completed. Parents and caregivers of CYSHCN can apply directly to the program or can be referred from a variety of sources, including foster care and the Medicaid Managed Care

³ U.S. Census Bureau, Population Estimates Program (PEP), July 1, 2019



Organizations (MCOs). The WV CSHCN Program Screener questions will be completed via phone with the CYSHCN and their primary caregiver by a representative from the MCO making the referral, WV HealthCheck (WV's EPSDT Program) foster care liaisons, or the WV CSHCN Program eligibility specialists. Results will be input into the WV CSHCN Program's data system. Subsequently, a registered nurse reviewer will confirm the responses with the available medical documentation. Discrepancies between the caregiver's response and the medical documentation will be noted. If the child requires medical foods, a financial eligibility determination will be completed by the registered nurse reviewer. The WV CSHCN Program Screener and the financial eligibility determination calculate the child's program eligibility.

Upon enrollment to the program, the WV CSHCN Program care coordination team registered nurse will enter all the child's diagnoses into the program's data system. If necessary, diagnosis data will be requested from Medicaid for Medicaid-enrolled children to ensure comprehensive diagnosis records. The current enrollment and diagnosis data will then be compared to the pre-intervention data to determine the outcome measures listed below.

In order to gauge the effectiveness of this expanded eligibility, the CSHCN Program will use programmatic enrollment data to report on the following outcomes upon completion of the evaluation:

- Number of children enrolled in the CSHCN Program
- Percent of children with a mental/behavioral health diagnosis enrolled in the CSHCN Program
- Percent of children without a diagnosis from the previous eligible diagnosis list enrolled in the CSHCN Program
- Percent of infants with NAS enrolled in the CSHCN Program
- Percent of foster children enrolled in CSHCN

Section 2: Implementation Guidance

STAKEHOLDER EMPOWERMENT & COLLABORATION

Stakeholder Empowerment and Collaboration		
Stakeholder	How are they involved in decision-making throughout practice processes?	Does this stakeholder have lived experience/come from a community impacted by the practice?



CSHCN Program Manager, Nursing Director, Social Work Director, and Epidemiologist	During the development of the tool, the CSHCN Program piloted the WV CSHCN Program Screener with program staff (registered nurses and social workers). The staff were eager to provide feedback on both the questionnaire and the process. This feedback loop continues now.	No
CSHCN Program staff	The CSHCN's Medical Advisory Board endorsed the WV CSHCN Program Screener.	Yes
CSHCN Medical Advisory Board	The CSHCN's Medical Advisory Board endorsed the WV CSHCN Program Screener.	No
Parent Advisors	Parents of CYSHCN assisted to CSHCN Program Manager, Nursing Director, Social Work Director, and Epidemiologist in the initial research and development of the tool. These parent advisors were especially helpful in offering the parent perspective on how the WV CSHCN Program Screener questions may be perceived by the families which helped inform training needs.	Yes
CYSHCN and their families	Families and CYSHCN are engaged in the implementation of the WV CSHCN Program Screener by completing the screener. Discrepancies in the family's response and the registered nurses medical record review can identify issues with question clarity and identify opportunities for training and quality improvement.	Yes



REPLICATION

The WV CSHCN Screener was developed to easily adapt to new settings and priority populations. Automatic eligibility questions are included to incorporate priority populations that may not be found eligible based on the child's medical needs. Often these priority populations are included due to their increased risk of developing a special health care need. One of these priority populations include foster children. The American Academy of Pediatrics considers children in foster care children with special health care needs due to the trauma they experience which can be compounded by removal from their home.⁴ As such, children in foster care are automatically eligible for services by the CSHCN Program. However, when first developing the WV CSHCN Screener, the CSHCN Program failed to consider ongoing eligibility for children who are adopted from foster care. Despite achieving permanency, these children should still receive support from the CSHCN Program despite not qualifying conventionally due to their medical needs. Furthermore, the CSHCN Program did not want to impede adoptions by withdrawing services. An automatic Tier 1 category was added to the WV CSHCN Screener for children who receive Title IV-E adoption assistance.

As the growing burden of children diagnosed with Neonatal Abstinence Syndrome (NAS) or Intrauterine Drug Exposure (IUSE) in West Virginia became apparent, the CSHCN Program was tasked with providing ongoing monitoring and care coordination for these children and families. Initially, it was thought these children would be found eligible due to their medical needs or by proxy of being in foster care. However, it was identified that children diagnosed with NAS or IUSE largely present as healthy after recovering from their acute symptoms at birth and their needs are not captured by the WV CSHCN Screener. The CSHCN Program identified the need for ongoing monitoring of this population as they age and potentially develop special health care needs and made all children with a diagnosis of NAS or IUSE as automatically eligible to receive services.

In order to streamline referrals from the Medicaid Managed Care Organizations (MCOs), the CSHCN Program modified its intake protocol to allow for the MCOs to complete the WV CSHCN Screener with members to submit with the referral packet. The MCOs received training to appropriately complete the screener with the client and family.

The goal of the WV CSHCN Screener is to gain both the parent's perspective of the child's health care needs and the clinical reality. However, foster parents often have not had the child in their care for more than a few days before completing the WV CSHCN Screener. The CSHCN Program RNs rely more heavily on medical records to complete and confirm the WV CSHCN Screener for foster children to ensure a comprehensive assessment of the child.

⁴ COUNCIL ON FOSTER CARE; ADOPTION, AND KINSHIP CARE; COMMITTEE ON ADOLESCENCE, and COUNCIL ON EARLY CHILDHOOD. Health Care Issues for Children and Adolescents in Foster Care and Kinship Care. *Pediatrics*. 2015 Oct;136(4):e1131-40. doi: 10.1542/peds.2015-2655. PMID: 26416941.



INTERNAL CAPACITY

Fortunately, the expanded eligibility and screening process is completed with existing CSHCN Program and partner personnel. Development of the WV CSHCN Screener and process required CSHCN Program Administration, CSHCN Program staff, and the CSHCN Program Medical Advisory Board. Implementation of the process required CSHCN Program Administration, CSHCN Program Registered Nurses, CSHCN Program Eligibility Specialists, HealthCheck Program Specialists, and MCO staff. The CSHCN Program's Nursing Director liaised with the MCOs to improve the WV CSHCN Screener referral process.

This initiative would not have been successful without support from OMCFH Leadership to coordinate efforts between the CSHCN and HealthCheck Programs and to facilitate cooperation with the MCOs. Additionally, the CSHCN Program already employed a team of registered nurses with strong clinic judgement and experience with children with special health care needs. This process would not be a success without their expertise.

Currently this practice is being completed via fillable PDF forms, a Microsoft Access database, and a separate system that houses medical records. All communication is being done by email. While not necessary, the process could be streamlined by using an internal system with all required forms and communication built in.

PRACTICE TIMELINE

The practice timeline will be specific to the existing structure of the entity looking to replicate the process. For more information on this practice's timeline and specific practice activities, please contact Saylem DePasquale at saylem.m.depasquale@wv.gov.

PRACTICE COST

The practice cost will be specific to the existing structure of the entity looking to replicate the process. For more information on this practice's timeline and specific practice activities, please contact Saylem DePasquale at saylem.m.depasquale@wv.gov.

LESSONS LEARNED

The WV CSHCN Program will engage all stakeholders to identify where the WV CSHCN Program Screener process can be strengthened and made more efficient. Quality assurance monitoring, including review of WV CSHCN Program Screener results by the WV CSHCN Program's Nursing Director and the OMCFH Medical Director, will identify training needs and process improvements. The CSHCN Program Epidemiologist will be performing data surveillance and analysis to determine



anomalies in WV CSHCN Program Screener results and the child's eligibility and diagnoses. To date conversation with individuals completing the WV CSHCN Program Screener questions with CSHCN and their caregivers has identified a need for staff training with regard to caregiver understanding and response to some of the questions on the WV CSHCN Program Screener. Data surveillance has identified opportunities for training for the registered nurse reviewers on functional limitations as they relate to a child's physical special health care needs

NEXT STEPS

The WV CSHCN Program will continue to use this practice as its eligibility standard, but does not have any plans to expand this practice. Continuous quality improvement efforts will inform any necessary change and additional priority populations will be addressed as the need arises.

RESOURCES PROVIDED

- [West Virginia CSHCN Screener](#)
- [West Virginia CSHCN Screener Nursing Notes](#)

