Vision Statement: All West Virginia children and youth with special health care needs will have access to comprehensive, coordinated services and supports in a patient/family-centered medical home.

Mission Statement: To ensure quality health care and related services for children and youth with special health care needs throughout the State of West Virginia.

Explanation of Terms:

Assessment: The review and examination of the client, his/her presenting condition and all aspects of his/her history to facilitate formulation of the client care plan.

Care coordination: Care coordination, an essential element of the pediatric medical home, is a service to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families.[1] Care coordination focuses on assuring that patients and families have access to needed care in a timely fashion, maximizing appropriate and efficient resource use while minimizing duplication of effort. Care coordination is multifaceted; it involves needs identification, assessment, prioritizing and monitoring.[2]

Care Coordinator: CSHCN Program staff that, on behalf of the medical home teams of CSHCN clients, facilitates the patient and family engagement necessary for coordinated, ongoing, comprehensive care.

Client Care Plan: A mutually agreed upon plan of goals and tasks developed to describe the services and resources required to meet the client's/family's needs identified through assessment, including time frames, specific action steps and responsible persons necessary to meet each identified need. The care plan comprehensively addresses and integrates the activities of all parties involved with service to the child/youth and family. The care plan should align the goals and objectives necessary to support and ensure medically necessary services are provided to the child/youth and family.

Clinical services: Services rendered by a board-certified or board-eligible doctor of medicine (M.D.) or doctor of osteopathy (D.O.) in CSHCN Program sponsored clinics. During these appointments, the physicians assess, evaluate and plan for initial or on-going care of the client. Each client is seen individually, a treatment plan is agreed upon, and responsibilities are defined. The goal of these clinic appointments is to progress the client to their maximal potential in maintaining optimal health status for each individual. The CSHCN Program staff attend these appointments to offer support to the clients, families and physicians.

CSHCN Screener©: A five item, parent-reported tool designed to reflect the federal Maternal and Child Health Bureau's consequences-based definition of children with special health care needs.

[1] Social Security Act §501(b)(3)
[2] Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children with Special Health Care Needs. *Pediatrics* 2005;116;1238. DOI: 10.1542/peds.2005-2070

Early Periodic Screening, Diagnosis and Treatment (EPSDT): Medicaid Program enacted in 1967 to ensure that Medicaid-eligible individuals under the age of 21 receive a comprehensive range of preventive and primary health services. This program provides periodic, comprehensive, preventive and primary health examinations, vision, dental and hearing assessments, immunizations and treatment follow-up of conditions found during the health examinations. EPSDT entitles enrolled infants, children and adolescents to any treatment or procedure that fits within any of the categories of Medicaid-covered services listed in Section 1905(a) of the Social Security Act if that treatment or service is necessary to "correct or ameliorate" defects, physical and mental illnesses or conditions.

Foster care: 24-hour substitute care for all children placed away from their parent(s) or guardian(s) and for whom the State IV-E agency has placement and care responsibility. This includes, but is not limited to, placements in foster family homes, foster homes of relatives, group homes, emergency shelters, residential facilities, child care institutions, and preadoptive homes. A child is in foster care in accordance with this definition regardless of whether the foster care facility is licensed and payments are made by the State, Tribal or local agency for the care of the child, whether adoption subsidy payments are being made prior to the finalization of an adoption or whether there is Federal matching of any payments that are made.[3]

Functional limitation: A functional limitation is a substantial impairment in an individual's ability to function in the condition, manner or duration of a required major life activity as related to his/her chronic physical special health care need. The term refers to inabilities to perform tasks or requirements necessitated by usual roles and normal daily activities, including the capacity for self-care and mobility.

Medical home: A medical home is both an approach to providing comprehensive primary care and a health care setting that facilitates partnerships between children and youth with special health care needs (CYSHCN), their families (as appropriate), personal physician(s) and, when appropriate, their communities. A medical home is ready and willing to provide well, acute and chronic care for all children and youth, including those affected by special health care needs or who hold other risks for compromised health and wellness.[4] The medical home is widely identified as the standard of care for CYSHCN.

Medically necessary: Health care specialty services or supplies needed to prevent, diagnose or treat an illness, injury, condition, disease or its symptoms and that meet nationally accepted standards and guidelines of medicine.

[3] 45 CFR 1355.20

[4] United States Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Envision 2020: *A 10-year Strategic Plan for the Division of Services for Children with Special Health Care Needs.* Rockville, MD: United States Department of Health and Human Services, 2011.

Medical nutrition food: A food which is formulated to be consumed or administered internally under the supervision of a physician and which is intended for the specific dietary management of a disease or condition for which distinctive nutritional requirements on the basis of recognized scientific principles are established by medical evaluation.[5] Generally, to be considered a medical nutrition food, a product must meet the following criteria: a) The product is a food for oral or tube feeding; b) The product is labeled for the dietary management of a medical disorder, disease or condition; and c) The product is distinguished from the broader category of foods for special dietary use and from foods that make health claims by the requirement that medical nutrition foods are to be used under medical supervision. The term "medical nutrition foods" does not pertain to all foods fed to sick patients. Medical nutrition foods are foods that are specially formulated and processed (as opposed to a naturally occurring foodstuff used in its natural state) for the patient who is seriously ill or who requires the product for a particular condition.[6,7]

Physical Special Health Care Need: A physical health care need denotes an organ dysfunction and/or a neuromotor or musculoskeletal chronic condition that must have lasted, or is certain to last, for at least one year and is not behavioral or emotional in origin.

Primary Care Provider: A physician (M.D. – Medical Doctor or D.O. – Doctor of Osteopathic Medicine), nurse practitioner, clinical nurse specialist or physician assistant, as allowed under state law, who provides, coordinates or helps a patient access a range of health care services.

Provider: A physician (M.D. – Medical Doctor or D.O. – Doctor of Osteopathic Medicine), health care professional or health care facility licensed, certified or accredited as required by state law.

Screening: A brief procedure designed to identify children who should receive more intensive diagnosis or assessment.

Specialist: A physician specialist focuses on a specific area of medicine or a group of patients to diagnose, manage, prevent or treat certain types of symptoms and conditions. A non-physician specialist is a provider who has more training in a specific area of health care.

Therapeutic Modality: An intervention or technology used to improve healing.

[5] Section 5(b) of the Orphan Drug Act (21 U.S.C. 360ee (b) (3)
[6] U.S. Food and Drug Administration, Compliance Program Guidance Manual, Chapter 21– Food Composition, Standards, Labeling and Economics.
[7] Frequently Asked Questions About Medical nutrition foods Federal Register, 60663,1996 FDA, Office of Nutritional Products May 2007.

Title IV-E: The federal foster care program that helps to provide safe and stable out-of-home care for children until said children are safely returned home, placed permanently with adoptive families or placed in other planned arrangements for permanency. The program is authorized by Title IV-E of the Social Security Act, as amended and implemented under the Code of Federal Regulations (CFR) at 45 CFR parts 1355, 1356, and 1357.

1.0 Purpose

The purpose of the Children with Special Health Care Needs (CSHCN) Program policy manual is to provide accurate and timely information relating to the standards and business conduct of the CSHCN Program. Most of the manual sections are of a permanent nature and remain accurate across time. When required, the manual is updated to reflect the most recent policy changes.

1.1 Intent

The policies set forth herein are regulations governing the provision of the West Virginia CSHCN Program. The manual serves as an operational reference for health care professionals, contracted agents, CSHCN Program employees, clients and their families. Health care professionals, contracted agents and CSHCN Program employees are expected to conform to the policies and processes contained in this manual and all future revisions. The CSHCN Program provides training to existing and new employees to assure program compliance. All CSHCN Program employees will receive West Virginia CSHCN Program updates relevant to any changes in policies and processes. This policy manual is not intended to be a set of clinical guidelines for the general population.

1.2 Introduction

The Maternal and Child Health Bureau (MCHB) is the federal administrative unit responsible for MCH Block Grants, along with other Title V programs. MCHB is a component of the Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (HHS). Title V Maternal and Child Health Block Grant enables states to maintain and strengthen their leadership in planning, promoting and coordinating health care services for mothers and children and for supporting health care services for those who do not have access to quality maternal and child health care. Each state has the authority to determine its population's needs, set priorities and allocate funds. In West Virginia, the Office of Maternal, Child and Family Health (OMCFH) housed within the Bureau for Public Health (BPH), Department of Health and Human Resource (DHHR), is the single state agency responsible for administering the Title V Maternal and Child Health Block Grant.

Managed by the Division of Infant, Child and Adolescent Health (ICAH) within the OMCFH, the West Virginia CSHCN Program maximizes both Title V and Medicaid/Title XIX funding to ensure specialty medical care, diagnosis, treatment and health care coordination for children with special health care needs and those who may be at risk of disabling conditions. The CSHCN Program promotes and facilitates an integrated system of services for children and youth with special health care needs (CYSHCN) through partnerships with other state level agencies, local health departments, local private and nonprofit agencies, West Virginia colleges and universities and in collaboration with tertiary care centers.

CSHCN Program staff:

1. support and oversee the care coordination function of CSHCN Program clients' medical homes;
2. in coordination with the medical home teams of CSHCN Program clients, develop and monitor treatment plans;
3. assist families with scheduling and transportation for medical care;
4. provide clinical services (as appropriate) to support access to medical specialty care; and
5. facilitate communication among medical home teams.

Title V funds are used as payer of last resort to offset the unmet needs of CYSHCN in the state. The West Virginia CSHCN Program is administered pursuant to Title V of the Social Security Act and West Virginia Code §49-4-1.

The West Virginia CSHCN Program is managed by the CSHCN Program Administrative Team, comprised of: the Program Manager, the Director of Nursing and the Director of Social Services. Under the direction of the CSHCN Program's Administrative Team, community-based care coordination teams (Registered Nurses, Social Workers and Office Assistants) implement the mission of the CSHCN Program. CSHCN Program staff can be contacted at 1-800-642-8522.

The West Virginia CSHCN Program is financed through multiple sources. Direct services are financed by the client's primary coverage source(s) which include Title XIX (Medicaid), Title XXI (CHIP) and private health insurance. The CSHCN Program is not an entitlement program and the extent of services provided is contingent upon available funds. To be eligible for CSHCN Program services, clients must meet specific criteria, as defined in the "Program Eligibility" section of this manual.

As defined by the MCHB, the goals related to providing comprehensive care to children, adolescents, and young adults with a chronic and debilitating health care need include:

- **Family Professional Partnerships:** Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
- **Medical Home:** CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.
- **Insurance and Financing:** Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.
- **Early and Continuous Screening and Referral:** Children are screened early and continuously for special health care needs.
- **Easy to Use Services and Supports:** Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.
- **Transition to Adulthood:** Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

- **Cultural Competence:** All CYSHCN and their families will receive care that is culturally and linguistically appropriate (attends to racial, ethnic, religious and language domains).

Specifically, the OMCFH has chosen three performance measures related to systems of care for CYSHCN as a result of the Title V Block Grant Transformation. The OMCFH will focus efforts and allocate funding to:

- Improve the proportion of CYSHCN who report they receive ongoing, comprehensive, coordinated care in the medical home
- Improve the proportion of YSHCN who report they receive the services necessary to make the transition to adult health care
- Decrease the unmet need for services for CYSHCN as a result of inadequate insurance

1.3 Target Population

In West Virginia, both OMCFH and Medicaid play key roles in improving access and health outcomes for children, youth and families. Coordination and partnerships between the two agencies are key to achieving this purpose. As an essential Medicaid partner, the CSHCN Program is charged with the identification of CYSHCN and production of a sustainable care model for CYSHCN to receive a patient/family-centered medical home approach to comprehensive, coordinated services and supports. The MCHB defines CYSHCN as "those who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." The West Virginia CSHCN Program will identify CYSHCN using this definition and those CYSHCN will receive tiered care coordination based on assessment of their function limitations and service utilization.

Due to the overwhelming number of factors that can contribute to one's likelihood of developing a special health care need, risk is difficult to systematically assess. As such, the CSHCN Program will, at minimum, provide periodic screening and monitoring to select at risk populations, including children in the custody of the state of West Virginia. For more detailed information see the "Program Eligibility" section.

1.4 Medical Nutrition Foods Service Authorizations, Reimbursement, Limitations and Exclusions

Authorization for medical nutrition foods services paid for with Title V funds will be accomplished in accordance with the following:

- The CYSHCN must be found medically and financially eligible for the CSHCN Program.

- A request for medical nutrition foods services to be paid with Title V funds must be reviewed for consistency with program guidelines and must conform to the stated goals and objectives on the Care Plan. CYSHCN and their families must adhere to their responsibilities as described in the Care Plan.
- Medical nutrition foods services must be approved by the Food and Drug Administration (FDA).
- The CSHCN Program is not an entitlement program and the extent of services provided is contingent upon available funds for the delivery of services.
- No services will be authorized for out-of-state providers if an equivalent service is available within the state of West Virginia.

Before Title V funds can be utilized for medical nutrition foods, financial eligibility must be determined.

1.5 Clinical Services Authorizations, Reimbursement, Limitations and Exclusions

Providers of services paid with Title V funds must be enrolled as Medicaid providers or a contracted agent of the CSHCN Program. Physicians providing clinical services must be West Virginia board-certified or board-eligible in their field of practice. All providers must maintain all applicable federal and state certifications or licenses. When legally required, health professionals must perform clinical services under a physician's written standing protocol. Additionally, in order to obtain reimbursement for clinical services, health care professionals other than contracted agents must:

- Sign a Provider Agreement with the CSHCN Program, and
- Must be deemed qualified to provide services to CYSHCN by the CSHCN Program Director of Nursing.

Payments to providers of services using Title V funds will be made using the current CSHCN Program standards and payment schedules as negotiated by the CSHCN Program's administration. A provider will accept the fees paid under this section as full payment for services rendered. The CSHCN Program is a secondary payer to all private and other public funded health programs. The CSHCN Program may pay for specialty services with Title V funds only after payment by all entitlement programs and by all other private and public funding resources, except where prohibited by federal law.

1.6 Suspected Abuse and Neglect Reporting Requirements

Any CSHCN Program staff or service provider who suspects an incidence of abuse or neglect is mandated by West Virginia State Codes §9-6-1, §9-6-9 and §49-6A-2 to report the incident to the local DHHR office in the county where the person who is allegedly abused lives. Reports of abuse and/or neglect may be made anonymously to the county DHHR office or by calling 1-800-352-6513, seven days a week, 24 hours a day. A Child Protective Services (CPS) or an Adult Protective Services (APS) worker may be assigned to investigate the suspected or alleged abuse.

1.7 Non-discrimination

No persons shall be discriminated against on the basis of race, sex, national origin, religion, age, sexual orientation, handicap or condition. All participants will have such rights as are available under any applicable federal state or local law prohibiting discrimination.

1.8 Health Insurance Portability and Accountability Act (HIPAA) Guidelines

The CSHCN Program is legally and ethically bound to maintain the confidentiality of all oral and written information obtained while determining eligibility and in the delivery of services. Staff members and/or collaborative partners with access to the client's records are required to observe confidentiality and professional ethics. The legal mandate for the protection of health information falls under the Health Insurance Portability and Accountability Act (HIPAA) of 1996.

1.9 Client Information

The client, parent, legal guardian or legal representative has the right to review and/or copy the client's record at any time. The client, parent, legal guardian or legal representative may not remove documents, but can ask that information be changed if it can be demonstrated that the information is incorrect. When reviewing the record, the client has the right to have an attorney or other representative of his/her choice present. A member of the CSHCN Program Administrative Team or their representative, must be present during review. To protect the privacy of CSHCN Program clients, this review must take place in a private area/room.

All requests for client record information must be directed to the CSHCN Program Eligibility Unit, including those requests received in the CSHCN Program field offices and by CSHCN Program clients, parents or legal guardians. The official state office record is used as the source for release of all client information. All requests must be made in writing and include a written release of information signed by the parent, legal guardian or client if 18 years of age or older. Only client information and clinic/medical reports generated by the CSHCN Program are released. Requests received for information in reports generated by other sources will be directed to the original source of the material.

Information which is never available for release to clients, parents, guardians, or other agencies includes:

- Adoption information
- Identity of person making protective service referral

If a client, parent or legal guardian requests to review the chart, a member of the CSHCN Administrative Team or their representative, must first review the chart and remove any of the information which falls under the categories listed above.

Any CSHCN Program representative discussing case files or divulging client information to unauthorized persons is subject to disciplinary action which could lead to suspension and/or termination. “Unauthorized person” is defined as any person not employed by the DHHR and/or persons not authorized to work with the client and/or those persons not permitted by the client/family/legal guardian to obtain information.

According to West Virginia State Law (West Virginia Code §48-9-601), each parent has full and equal access to a child’s medical records, absent a court order to the contrary. Neither parent may veto the access requested by the other parent. If necessary, either parent is required to authorize medical providers to release to the other parent copies of any and all information concerning medical care provided to either parent (this applies to divorced parents). The CSHCN Program staff must share information with both parents unless one parent provides a copy of a court order stating that the other parent cannot be given information.

If CSHCN Program staff is aware that the client’s parents were not married when the child was born, they cannot share information with a father until legal paternity is determined. Legal paternity is established by the father’s name on the birth certificate, a Declaration of Paternity Affidavit or a court order.

1.10 Reporting False Information

When a client/family reports different information than what is obtained through DHHR systems, the discrepancy is reported to the appropriate DHHR case worker or DHHR supervisor. Reports should only be made when information is confirmed and not based on rumor or information obtained from the community at large.

1.11 Requests for Medical Information

The CSHCN Program Application (CSHCN-1) contains a statement giving permission to request/release information concerning the client/family for the period of one year. An explanation of this agreement is given to the client/family at the time of initial contact by the CSHCN Program Eligibility Unit. On an annual basis the CSHCN Program care coordination teams request the client/parent or legal guardian sign the Consent for Release of Information (CSHCN-22) to give permission to request medical information from physician’s offices for annual eligibility determination.

1.12 Public Documents

Agency materials released as public documents including annual reports, program pamphlets, state program policy or fiscal reports are not considered confidential.

1.13 Employee Conflict of Interest

In compliance with the West Virginia Governmental Ethics Act, the DHHR Administrative Memorandum 2108 states:

> Employees are expected to avoid conflicts of interest between their personal life and their employment. Employees shall not provide services to or make decisions concerning eligibility for Agency programs for spouses, relatives, friends and neighbors, present or former co-workers.

Requests for specialty services and questions regarding eligibility in these potentially conflicting situations should be referred to supervisors for reassignment. Further, an employee's receipt of any benefit from the Agency must be based solely upon eligibility to receive those benefits.

1.14 Congressional or Legislative Inquiries

Congressional or Legislative inquiries must be sent to the CSHCN Program Director for submission to the Office of Legislative Services within 24 hours. The CSHCN Program representative receiving a telephone inquiry will explain to the caller that he/she will relay the request to the CSHCN Program Director for response. If the CSHCN Program Director is unavailable, the CSHCN Program representative will contact the supervisor available.

1.15 Information to Civic Organizations

The CSHCN Program does not provide client names or other identifying data elicited by civic or other organizations. The CSHCN Program care coordinators will inform the client/family of available programs, organizations and services and encourage them to make the contact if they are interested in participating.

1.16 Freedom of Information Act (FOIA)

Requests received under the Freedom of Information Act (FOIA) should be submitted in writing and specifically state the type of information being sought. Requests received by CSHCN Program staff members are immediately sent to the CSHCN Program Director, who will forward the requests to the OMCFH Director.

1.17 Subpoenas

Any DHHR-related subpoena must be served at One Davis Square, Charleston, WV 25301. If a subpoena is served to a CSHCN Program regional care coordinator, the care coordinator must refuse the subpoena with instructions to serve the subpoena at One Davis Square, Charleston, WV 25301. The care coordinator will immediately notify her/his immediate supervisor of the subpoena.

1.18 Appeals and Hearings

The purpose of the appeal process is to determine if the CSHCN Program followed policy accurately and consistently in making the determination of covered specialty services. It is not to determine medical necessity or request policy changes to include coverage of denied specialty services. Appeals should be submitted in writing to the CSHCN Program Director, who will apply DHHR Common Chapters Manual 900 – Program and Document Integrity.

2.0 Client Eligibility

This section gives criteria for program eligibility, when client eligibility begins and requirements for subsequent eligibility determination.

2.1 Age Eligibility

To be eligible for CSHCN Program care coordination and specialty services, individuals must be under 21 years of age.

2.2 Residency Eligibility

To receive tiered care coordination an individual must be a U.S. citizen and a resident of West Virginia. A child in the legal custody of the West Virginia DHHR may continue to receive CSHCN Program services should he/she be placed in another state.

2.3 Categorical Eligibility

Children who meet the following criteria are automatically or "categorically" eligible for CSHCN Program care coordination services:

- Receives 100% nutritional intake through the gastrointestinal tract via a tube, catheter or stoma that delivers sustenance distal to the oral cavity, as confirmed by the CSHCN Program's Eligibility Unit;
- Is a member of the Children with Disabilities Community Services Program (CDCSP);
- Is in foster care, as defined by 45 CFR 1355.20.
- Was in foster care, as defined by 45 CFR 1355.20 and now qualifies for federal Title IV-E adoption assistance.[8]
- Diagnosed with Neonatal Abstinence Syndrome (NAS; ICD-19 code: P96.1).[9]

2.4 CYSHCN Identification

The CSHCN Program identifies CYSHCN utilizing the Maternal and Child Health Bureau's consequence-based definition and CSHCN Screener©.

[8] The CSHCN Program (via the assigned CSHCN Care Coordinator and in collaboration with the child's adoptive parents and medical home team) will provide patient-centered, coordinated care and, as applicable, a Registered Dietician for the child's medical home team. As appropriate, the CSHCN Care Coordinator will facilitate application of Medicaid's Early Periodic Screening Diagnosis and Treatment (EPSDT) benefit for any medically necessary medical nutrition foods.
[9] These children will be automatically referred to the OMCFH by the West Virginia Birth Score Office.

2.5 CSHCN Program Eligibility

The eligibility process includes consideration of age, residency, categorical eligibility, financial eligibility, physical special healthcare need status, use of services and limits in ability to function due to the identified physical special healthcare need.

2.6 Tier Levels

After completion of the WV CSHCN Screener, a tier level is assigned to quantify and qualify the population and define care coordination activities and strategies. Tier level assignment is completed after review of physical special health care needs and moderate or severe functional limitations in two or more of the following areas:

a. Self-Care;
b. Understanding and using language;
c. Learning;
d. Mobility;
e. Self-Direction and capacity for independent living; and

Multiple needs for services (two or more) are identified:

a. Medical Specialty Care (does not include primary care services);
b. Early Intervention;
c. Special Education;
d. Mental Health;[10]
e. Family Support; and
f. Therapeutic Modalities.

Care Coordination Tier levels will range from Tier 1 – CSHCN identified; Tier 2 – CSHCN with a special physical health care need in addition to high service utilization and moderate to severe functional limitations; and Tier 3 – Tier 2 eligible clients who meet financial eligibility and require medical nutrition foods prescribed by a physician.

The initial determination date is the date the Eligibility Unit determines the applicant eligible for services. The applicant must have a written determination that they meet eligibility criteria. Initial eligibility is determined by the Eligibility Unit through completion of the CSHCN Screener© and review of medical reports which may include: medical history, diagnosis, mental status examination, labs and any other documentation deemed appropriate.

[10] The need for mental health care services must be related to the child's physical special health care need.

2.7 Financial Eligibility

Financial eligibility determination is necessary when Title V funds are used for medically necessary medical nutrition foods. All applicants who request payment for specialty services through the CSHCN Program are required to apply for Medicaid through their local Department of Health and Human Resources. The family's Modified Adjusted Gross Income (MAGI) may not exceed 200% of the Federal Poverty Level (FPL).

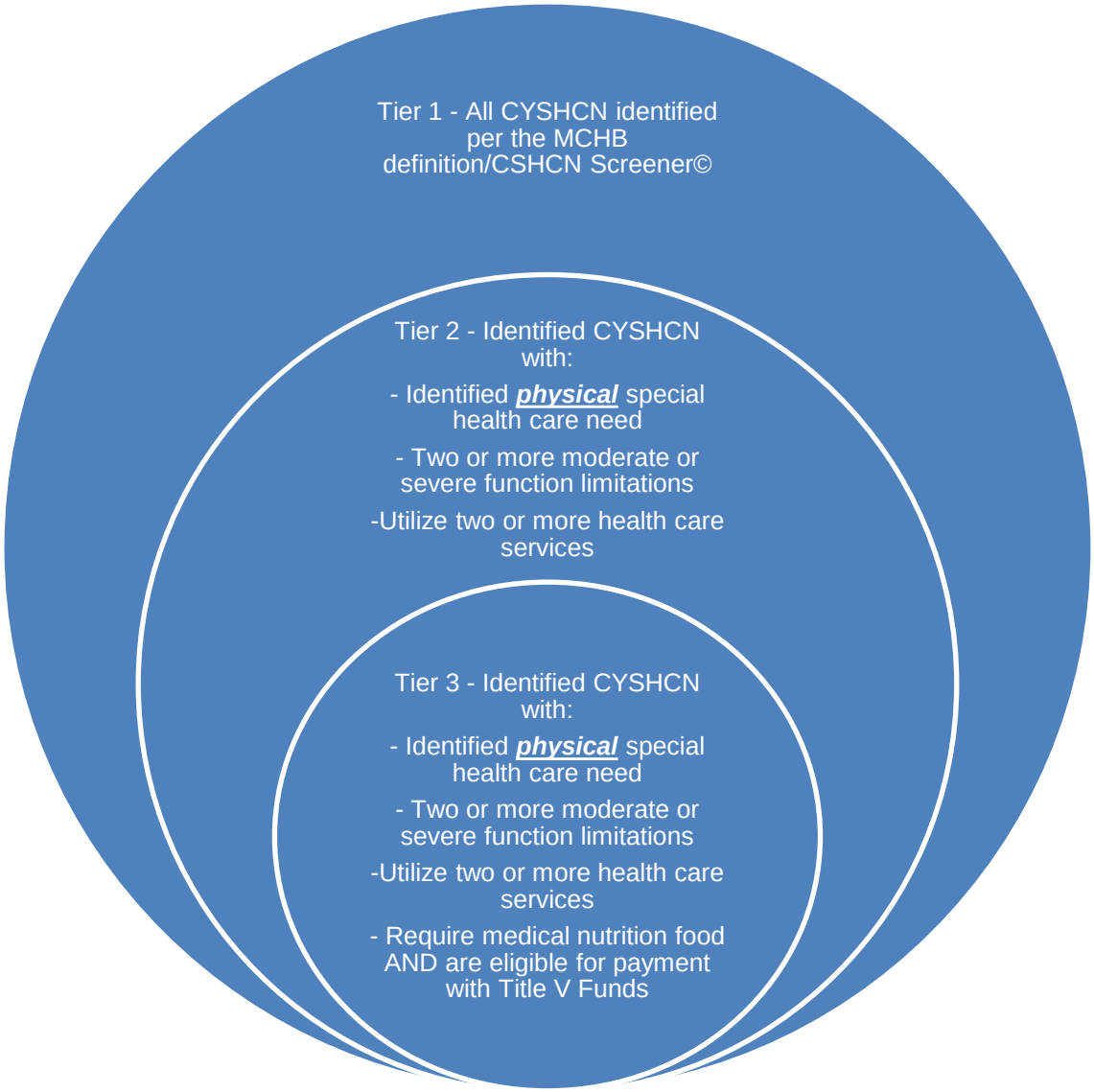
Financial eligibility must be established before Tier 3 medical nutrition foods are funded. Any request for medical nutrition foods paid with Title V funds must be reviewed and approved by the CSHCN Nursing Director (or designee) to ensure consistency with CSHCN Program guidelines. Use of Title V funds to pay for Tier 3 medical nutrition foods is contingent upon the availability of Title V funds. Tier 3 medical nutrition foods must be approved by the Food and Drug Administration (FDA).

All determinations to fund Tier 3 medical nutrition foods will be made in accordance with the CSHCN Program's Financial Eligibility Policy. Financial eligibility does not constitute entitlement to Title V funds through the CSHCN Program. Individuals qualifying for low-income Medicaid are not required to verify income through the CSHCN Program's financial eligibility process. Clients who receive Women, Infants and Children (WIC) benefits or are in the legal custody of the state of West Virginia will be considered financially eligible for the CSHCN Program.

2.8 Annual Eligibility

1. Medical – A client's medical eligibility will be determined annually, within 30 days (before or after) of the anniversary of the initial determination date. Medical eligibility will be facilitated via administration of the West Virginia CSHCN Screener. The client's case must be closed if annual medical eligibility is not determined.
2. Financial – If a client is receiving Tier 3 services paid from Title V funds, financial eligibility must be determined annually, within 30 days (before or after) of the anniversary of the client's initial determination date. If there is a change in family income, size or any area that could affect financial eligibility, eligibility will be re-determined at the time the information becomes known to the CSHCN Program care coordination team. The client's Title V funded Tier 3 services must be terminated if annual financial eligibility is not determined within the stated timeframe. If the annual financial eligibility is not completed through fault of the CSHCN Program, eligibility may be backdated for up to 90 days.

2.9 Summary of Eligibility Requirements



3.0 Delivery of Services

The MCH Block Grant mandates Title V agencies to assume a leadership role in assuring the development of community-based systems of services for CYSHCN and their families. The performance measures chosen by the OMCFH relevant to the CSHCN Program are discussed in Section 1. These performance measures address medical home, transition and adequacy of insurance. The CSHCN Program will align its service delivery system to perfect these measures.

Services provided by the CSHCN Program may include:

- Family-centered, coordinated, ongoing, comprehensive care within a medical home;
- Services to facilitate transition to adulthood;
- Access to parent-to-parent peer support;
- Clinical services;
- Nutrition services;
- Training, education and quality assurance.

The CSHCN Program functions to support family-centered, coordinated, ongoing comprehensive care for CYSHCN within a medical home, the foundation of which is the primary care provider (PCP) and family. The CSHCN Program recognizes that each client's PCP should be intimately familiar with his/her patients' specific medical situations and will give great deference to the PCP's judgment when interpreting this Policy.

3.1 Care Coordination in the Medical Home

Research indicates that CYSHCN receiving care in a medical home experience better outcomes than children receiving care in non-medical home settings. Moreover, care coordination through the medical home for CYSHCN has been known to decrease unmet needs, improve satisfaction with specialty care and improve ratings of child health and family functioning.[11,12] The CSHCN Program works to facilitate a team approach to health care, with coordination across multiple services and settings, in accordance with the National Standards for Systems of Care for Children and Youth with Special Health Care Needs.[13]

[11] Homer CJ, Klatka K, Romm D, Kuhlthau K, Bloom S, Newacheck P, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008; 122:922-37.
[12] Farmer JE, Clark MJ, Drewel EH, Swenson TM, Ge B. Consultative care coordination through the medical home for CSHCN: a randomized controlled trial. *Maternal and Child Health Journal*. 2011;15(7):1110–1118
[13] VanLandeghem K, Sloyer P, Gabor V, Helms V. 2014. *Standards for systems of care for children and youth with special health care needs*. [Washington, DC]: Association of Maternal and Child Health Programs; [Palo Alto, CA]: Lucile Packard Foundation for Children's Health, 37 pp.

Regardless the assigned tier level, the following care coordination functions are provided to all enrolled clients;

- Advocating family-centered, coordinated, ongoing comprehensive care within a medical home;
- Ensuring an appropriate written care plan;
- Promoting communications within the medical home team and ensuring defined minimal intervals between said communications;
- Supporting and/or facilitating (as appropriate) care transitions from practice to practice and from the pediatric to adult systems of care;
- Supporting the medical home's capacity for electronic health information and exchange; and
- Facilitating access to comprehensive home and community-based supports.

To support integrated medical home teams, the CSHCN Program will ensure the provision of care coordination to eligible CYSHCN in the state. Care coordination is driven by an individualized care plan developed after a comprehensive assessment of the client and family's medical and socioeconomic needs. This care plan is collaborative tool supported and executed by all members of the medical home, including, but not limited to, the primary care provider (PCP), specialty providers, CSHCN Program care coordination team, CYSHCN and their families and others as identified.

3.2 Transition

YSHCN require services to assist them in transitioning to all aspects of adult living, specifically adult health care. The CSHCN Program transition services are aligned with the Six Core Elements of Health Care Transition 2.0, as defined by *Got Transition.*[14] These best practice standards were developed in response to the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) *Clinical Report on Transition*. The CSHCN Program will facilitate developmentally appropriate transition services through the client's pediatric primary care provider (PCP) and adult health care providers.

3.3 Parent Educators

Through contractual relationships, the CSHCN Program supports a community based program with parent educators advocating for family centered care as an effective intervention to change knowledge and attitudes regarding the delivery of chronic care to children. Parents of CSHCN, by virtue of their experience, coordinate, implement and teach this program.

[14] http://www.gottransition.org/resourceGet.cfm?id=206

3.4 Clinical Services

The CSHCN Program supports a statewide clinic system to ensure appropriate access to specialty care for CYSHCN in their communities. Some clinical services are provided through contractual agreements with specialty providers, while for others CSHCN Program care coordinators provide support to partner-sponsored clinics. This clinic system is evaluated at least annually to ensure appropriate access to services for CYSHCN and to avoid duplicative efforts. Clinic evaluations are based on the availability of specialty services in the community, available transportation services, specialty service need by the local CYSHCN population and availability of providers.

3.5 Nutrition Services

In order to decrease the burden of inadequate insurance on CYSHCN in the state of West Virginia, the CSHCN Program may provide nutrition services to eligible CYSHCN. These services include:

- Nutrition assessment and ongoing monitoring by a Registered Dietitian;
- Medical nutrition foods (pursuant to CSHCN Program eligibility);
- In collaboration with the medical home, administrative management activities that facilitate application of the Early Periodic Screening Diagnosis and Treatment (EPSDT) benefit for medical nutrition foods;[15] and
- Feeding and swallowing assessment through contractual clinic services.

3.6 Training, Education, and Quality Assurance

As mandated by the Title V Block Grant, the CSHCN Program assumes the responsibility of developing an organizational infrastructure for the quality delivery of health services for CYSHCN. The CSHCN Program will provide training and education to a variety of stakeholders including medical providers, the health/medical educational institutions, partner agencies, other government agencies and CYSHCN and their families to support evidence-based best practices for community-based services for CYSHCN. This training and education will support a quality delivery system for the entire population of children in West Virginia, not just CYSHCN and not only those served directly by the CSHCN Program.

To evaluate the impact of the CSHCN Program and community training and education, the CSHCN Program will partner with the OMCFH Quality Assurance Monitoring team to examine the implementation of best-practices and evidenced-based tools by the CSHCN Program and providers in the community (after the receipt of training and education). This will be done using standardized tools, pre- and post-tests, chart reviews and participant evaluation surveys. Quality assurance monitoring and evaluation of trainings will be completed as appropriate for the training and audience.

[15] 42 U.S.C. §§701 and 705