National Center for a System of Services for Children and Youth with special health care needs

FROM THE AMERICAN ACADEMY OF PEDIATRICS

A Review of State Title V Block Grant Applications to Inform the CYSHCN Blueprint Roadmap

November 2024

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Executive Summary

Each state Title V program submits an annual Block Grant application/annual report that outlines planned strategies to improve the system of system for mothers and children, including children and youth with special health care needs (CYSHCN) and their families. In this analysis, each application was reviewed for distinctive strategies that align with the Blueprint for Change domains of health equity, family and child well-being and quality of life, access to services, and financing of services, as well as mentions of the Blueprint and relevant national performance measures (NPMs) and state performance measures (SPMs). Standout examples of state strategies were identified and highlighted within each Blueprint domain. The most common distinctive strategies found were as follows:

- Health equity: Data collection to address service gaps and inequities (13 strategies in 10 states)
- Family and child well-being and quality of life: Mental, behavioral, and emotional health (12 strategies in 8 states)
- Access to services: Health care transition (39 strategies in 26 states)
- Financing of services: Connection to health coverage and services (15 strategies in 13 states)

The findings from this report will inform the development of the National Center for Systems of Services for CYSHCN's Roadmap for state Title V CYSHCN agencies.

Suggested Citation: Schmidt A, Ilango S, McManus M, White P. *A Review of State Title V Block Grant Applications to Inform the CYSHCN Blueprint Roadmap*. Washington, DC: The National Alliance to Advance Adolescent Health/Got Transition, November 2024.

The National Center for a System of Services for CYSHCN is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $1,500,000 with no funding from nongovernmental sources. The information or content are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

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Introduction

The *Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN)* outlines key overarching principles and strategies to improve the lives of CYSHCN and their families.[1] The Maternal and Child Health Bureau (MCHB) defines CYSHCN as children and youth ages 0–21 years that "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."[1] New prevalence estimates find that 24.6% of US children under age 18 have a special health care need, which is up from previous estimates of 19.1%.[2] Accounting for this difference is the fact that about four million children meet the definition of having a special health care need, but did not qualify using the CYSHCN screener.[2,3]

The principles and strategies outlined in the Blueprint are categorized by four critical areas of focus: health equity, family and child well-being and quality of life, access to services, and financing of services. *Health Equity* is defined as all CYSHCN have a fair and just opportunity to be as healthy as possible and thrive throughout their lives, without discrimination, and regardless of the circumstances in which they were born or live.[4] *Family and Child Well-Being and Quality of Life* is defined as the service system prioritizes quality of life, well-being, and supports flourishing for CYSHCN and their families.[5] *Access to Services* is defined as CYSHCN and their families have timely access to the integrated, easy-to navigate, high quality health care and supports they need, including but not limited to physical, oral, and behavioral health providers; home and community-based supports; and care coordination throughout the life course.[6] *Financing of Services* is defined as health care and other related services are accessible, affordable, comprehensive, and continuous; they prioritize the well-being of CYSHCN and families.[9]

Each year, states are given guidance to write their Block Grant reports and applications. It is important to note that the guidance received to write their 2024 application, which was reviewed in this analysis, did not include reference to the Blueprint, as the guidance was published prior to the Blueprint's release. The latest block grant guidance,[8] which applies to states' 2025 applications, introduces concepts from the Blueprint and emphasizes the need for states to reference the Blueprint as they develop measures and strategies to align with the vision that CYSHCN enjoy a full life and thrive in systems that support families and their needs.

The purpose of this report, which is part of a larger environmental scan completed for the National Center for Systems of Services for CYSHCN (National Center), is to summarize findings from an analysis of state Title V Block Grant applications that examined the extent to which states incorporate strategies and activities that align with the Blueprint's four domains.

Methods

The questions that guided this analysis were:

1. To what extent did states select national performance measures (NPMs) related to CYSHCN and include reference to the National System of Care and National Care Coordination Standards?
2. To what extent did state Title V Block Grant applications address MCHB's Blueprint for Change?
3. What are examples of state performance measures (SPMs) and distinctive initiatives states are planning related to the Blueprint domains of health equity, family and child well-being and quality of life, access to services, and financing of services?

To answer these questions, we reviewed the FY 2024 Title V Block Grant applications from all 50 states and the District of Columbia. We created an abstraction form to collect a consistent set of data from each state. This form was used to abstract any language about the Blueprint for Change and any distinctive initiatives or SPMs relevant to the four domains. We also searched each application for mentions of the National System of Care Standards[9] and the National Care Coordination Standards[10] and identified whether states selected to prioritize NPMs on developmental screening (NPM 6), medical home (NPM 11), transition to adult care (NPM 12), and adequate health insurance (NPM 15).

To identify any upcoming distinctive strategies related to the Blueprint domains, we read the FY 2024 application year narratives in both the Children with Special Health Care Needs and the Cross-Cutting/Systems Building sections. We chose to focus on these two sections because of their relevance to the four Blueprint domains and the population that the Blueprint addresses.

Results

Of the four NPMs, the most commonly selected priority NPMs were developmental screening (NPM 6), medical home (NPM 11), and health care transition (NPM 12) (33, 32, and 32 states, respectively). Six states selected adequate insurance (NPM 15) as a priority. About 40% of states referenced the National System of Care Standards (21 states), and about 20% mentioned the National Care Coordination Standards (11 states).

In the following sections, we present an overview of states' inclusion of the Blueprint in their applications, followed by most common themes of distinctive initiatives and relevant SPMs, organized by Blueprint domain. Examples of standout initiatives are included for each domain. While there were many to choose from, we selected examples from a variety of states that aligned with a diverse set of themes.

Summary of Blueprint for Change Language in Block Grant Applications

Almost half (45%) of states explicitly mentioned the Blueprint for Change. The most common uses of Blueprint language, as shown in Table 1, were related to the use of the Blueprint as a framework to inform strategic efforts and services, followed by family engagement related to the Blueprint, forming partnerships/interagency groups to focus on the Blueprint, training on the Blueprint, definition of the Blueprint, and holding a summit focused on the Blueprint. Click here to see the exact language used.

Table 1. Use of Blueprint for Change in FY24 Block Grant Application Narratives

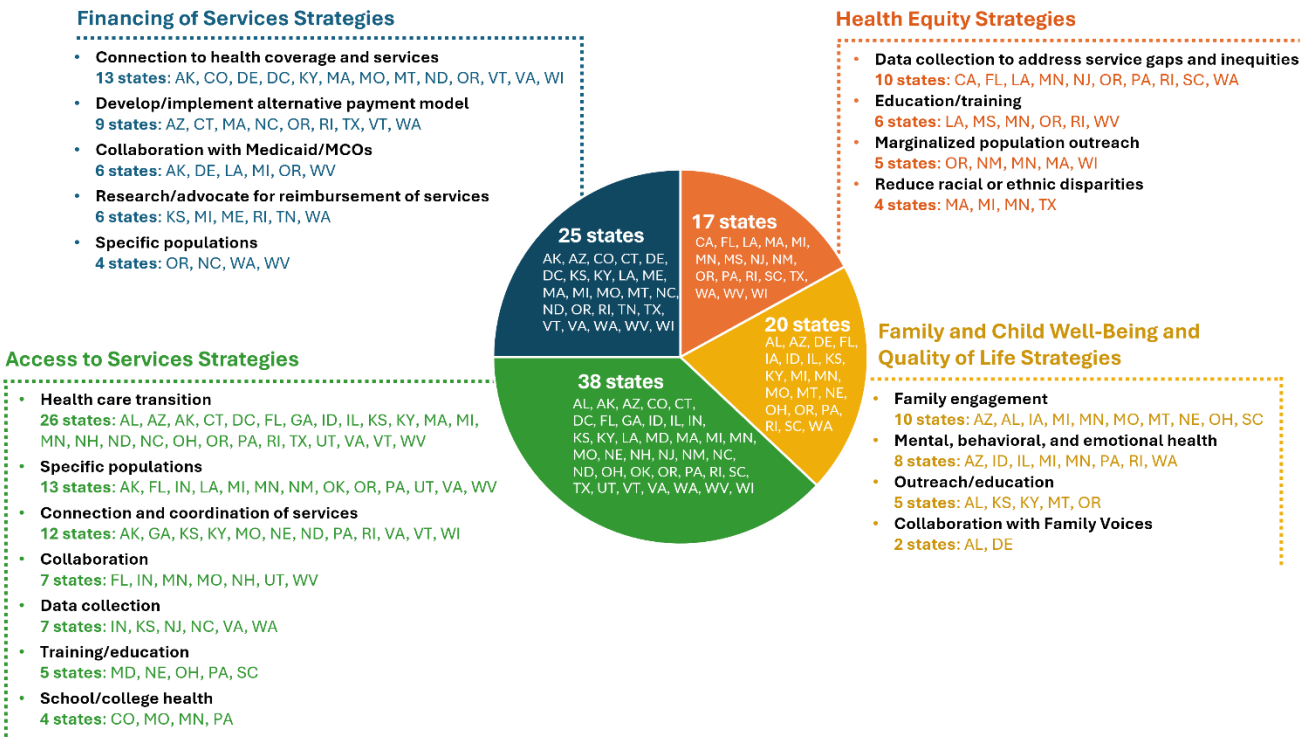
Block Grant Language that Mentioned the Blueprint for Change *56 mentions in 23 states*		
Strategy	# of mentions	# of state(s)
Use of Blueprint as a framework to inform strategic efforts and services (e.g., 5 year strategic plan, activities, assessment of project goals)	34	17 (AZ, CT, DC, GA*, IA, KY, ME, MD*, MA*, NH, NM, NC*, PA*, SC*, VA, WA*, WY*)
Family engagement related to the Blueprint	11	6 (GA*, MA*, NV, NC*, WA*, WY*)
Form partnerships/interagency groups (e.g., Medicaid, AAP, community-based organizations) to focus on the Blueprint	9	9 (AL*, AZ, IN, LA, NC, PA*, SC*, VA, WY*)
Training on Blueprint (e.g., providers, care coordinators, family support teams, Title V staff)	9	6 (AR, MA*, NC, SC*, VA, WA)
Definition of the Blueprint	8	4 (MD*, TX, VA, WA)
Summit focused on the Blueprint	1	1 (AL*)

**note: mention falls within multiple themes*

Summary of Distinctive Strategies Aligned with the Blueprint for Change

Figure 1 displays the distribution of states and distinctive strategy themes highlighted in states' block grant applications that align with the Blueprint domains. For each domain, the themes are listed in order of most to least common, along with the listing of states. The sections that follow describe the strategies in more detail.

Figure 1. Number of States with Distinctive Strategies that Align with Blueprint Domains



Health Equity

Seventeen states described health equity strategies in their application narratives, totaling 32 examples. See Table 2. The most common strategies related to data collection to address service gaps and inequities, followed by strategies related to marginalized population outreach, education/training, and reducing racial or ethnic disparities. Box 1 includes standout strategies on health equity. Fifteen SPMs across 13 states were aligned with health equity. Click here for more detail about the health equity strategies and SPMs.

Table 2. Distinctive Health Equity Strategies

Health Equity Strategies *32 distinctive strategies in 17 states*		
Strategy	# of strategies	# of state(s)
Data collection to address service gaps and inequities *13 strategies in 10 states*		
Creating a plan to measure and address inequities	5	4 (PA, RI, SC, WA)
Analyzing data to target service gaps	3	3 (FL, NJ, OR)
Oversampling for NSCH to understand needs	3	3 (CA, LA, PA)
Convening a targeted data workgroup	2	1 (MN)

Marginalized population outreach *9 strategies in 5 states*		
Native American engagement	5	3 (MN, NM, WI)
Community collaboration	2	2 (MN, OR)
Outreach to refugee and immigrant families	1	1 (MA)
Youth experiencing homelessness	1	1 (MN)
Education/training *6 strategies in 6 states*		
Equity and racism staff training	3	3 (LA, MS, RI)
Training for providers serving persons with disabilities	1	1 (MN)
Cultural responsiveness training for community health workers	1	1 (OR)
Child Protective Services training on CYSHCN	1	1 (WV)
Reduce racial or ethnic disparities *4 strategies in 4 states*		
Racial equity supports	2	2 (MA, MI)
Interagency collaboration	1	1 (MN)
Policy change	1	1 (TX)

Box 1. Standout State Strategies on Health Equity

Standout State Strategies – Health Equity

Florida: An underserved report that includes CYSHCN as well as populations known to the Medical Foster Care and the Children's Multidisciplinary Assessment Team Programs was implemented during the reporting year and will be further enhanced in the application year. The report is now called the Children's Need Index, and enhancement will include the layering of various resource maps (i.e., PCMH, behavioral health, and nonmedical resources that influence health outcomes) to identify areas of high children's needs and resource gaps for evaluation, planning, and implementation. CMS will continue to identify communities for targeted education or outreach based on the report, with the completion of the underserved report and geo-mapping activity. This includes focus groups to better understand the data gap in access to medical homes for our Black families, as compared to our White and Hispanic families.

Minnesota: Partner with the Minnesota Department of Health Center for Health Equity (CHE) to establish and lead an ongoing data workgroup to address gaps in data available related to persons with disabilities, including CYSHCN. Specific aims include identifying current data sources and existing baseline data, improving data partnerships focused on persons with disabilities with Minnesota Department of Employment and Economic Development, Minnesota Department of Human Services, and Minnesota Department of Education, and creating a workgroup focused on the creation of a disability data dashboard to address data disparities using intersectional data measures.

Pennsylvania: In 2021, the Bureau of Family Health (BFH) reached an agreement with HRSA/MCHB and the Census Bureau to conduct an oversample for a future NSCH. Oversamples can support more targeted assessment, program planning, and evaluation. BFH is planning to continue to use Title V funds for a state-wide oversample, which increases the number of completed surveys in the state and may enable reporting for smaller populations, such as CSHCN, or rarer outcomes with greater precision. The BFH is hopeful that the NSCH oversample will make it possible for MCH epidemiologists to better characterize and understand the needs of children across Pa. In 2024, the BFH will continue to consider how to identify and serve children with a higher risk of poor health outcomes or development of a SHCN due to medical, social, or structural determinants of health.

West Virginia: The CSHCN Program will develop a teaching tool that informs and educates Child Protective Services (CPS) workers on what defines a child with special physical health care needs. The goal of this tool should help the CPS worker differentiate between a child with disabilities and a child with complex medical needs with an increase in understanding of the urgency of the CSHCN CPS referral for medically complex children in state custody.

Wisconsin: The Wisconsin Medical Home Initiative will closely collaborate and communicate with the Title V program to continue supporting Wisconsin tribal health agencies. In 2022, the Title V program pivoted from using a structured work plan that included using a Shared Plan of Care to collaborating more flexibly with tribal agencies and assisting them in identifying what unique needs their community might have. The Title V program anticipates that tribes will continue to propose projects based on their unique community needs rather than using the standard Shared Plan of Care approach, with the Wisconsin Medical Home Initiative offering technical assistance to support them. The Title V program will measure the effort of this work by the number of tribal health agencies receiving technical assistance. Impact will be measured by the percent of tribal health agencies receiving technical assistance who report that the technical assistance led to successfully meeting a community need.

Family and Child Well-Being and Quality of Life

In their application narratives, 20 states included distinctive strategies aligned with the Family and Child Well-Being and Quality of Life Blueprint domain. Of a total of 33 strategies, the most common ones related to mental, behavioral, or emotional health, followed by family engagement, outreach/education, measurement, and collaboration with Family Voices. Table 3 below shows the categories of strategies that align with these well-being and quality of life themes, and examples of standout strategies are highlighted in Box 2. Of the four Blueprint domains, the highest number of SPMs (52 SPMs, 27 states) aligned with the family and child well-being and quality of life domain. Click here for more detail about the distinctive strategies and SPMs.

Table 3. Distinctive Family and Child Well-Being and Quality of Life Strategies

Well-being Strategies *33 distinctive strategies in 20 states*		
Strategy	# of strategies	# of state(s)
Mental, behavioral, and emotional health *12 strategies in 8 states*		
Behavior/Self-Care Supports Program in schools	5	4 (AZ, IL, MI, RI)
Facilitate linkages and support of community well-being	5	3 (ID, MN, PA)
Anti-bullying effort for students with developmental disabilities	1	1 (WA)
Fee reduction for adopting standards that support child well-being	1	1 (AZ)
Family engagement *10 strategies in 10 states*		
Placing YA or families as advisors	3	3 (AZ, MI, OH)
Parent Train the Trainer/Family mentorship program	2	2 (MT, NE)
CoP using Charting the LifeCourse framework	1	1 (MN)
Families sharing their stories	1	1 (IA)
Service Coordination Assessments that make the family feel like a partner	1	1 (MO)
Training on family-centered care	1	1 (SC)
Using the Family Engagement in Systems Tools (FESAT)	1	1 (AL)
Outreach/education *6 strategies in 5 states*		
Family education on relaying medical information to first responders	2	2 (KY, OR)
Systems navigation education for youth and families	2	2 (KS, OR)
Peer match community program	1	1 (MT)
Provider education on engaging families/youth in decision-making	1	1 (AL)

Measurement *3 strategies in 3 states*		
Assessment of care plan family-centeredness	1	1 (OR)
Identify levels of public participation	1	1 (AZ)
Tracking family partner engagement	1	1 (FL)
Collaboration with Family Voices *2 strategies in 2 states*		
Family Leadership Training	1	1 (AL)
Forum for families to discuss Medicaid issues	1	1 (DE)

Box 2. Standout State Strategies on Family and Child Well-Being and Quality of Life

Standout State Strategies – Family and Child Well-Being and Quality of Life

Alabama: Children's Rehabilitation Service will readminister the FESAT to assess progress on strengthening family/youth engagement within CRS. The Applied Evaluation and Assessment Collaborative will provide a detailed report of the consensus scoring discussions to include a comparison of the FESAT baseline scores. Information from the report will be utilized to foster conversations among the CRS management team and the local parent consultants.

Kentucky: OCSHCN will guide families on how to best relay vital medical information about their special needs child to first responders. OCSHCN will equip families in preparation for a medical emergency by instructing them on care in the home prior to the first responders' arrival. To enhance the comfort of the child in a medical emergency, OCSHCN will teach children how to identify different first responders by their uniforms and appropriate responses should they encounter a first responder. OCSHCN will seek to develop partnerships with first responders so that OCSHCN staff may educate them about unique and often complex needs of CYSHCN in a medical emergency. To assist first responders to identify CYSHCN, OCSHCN will create identification methods such as window stickers or other identification tags that alert first responders to the presence of a special needs child.

Michigan: Handle With Care (HWC) promotes school-community partnerships so that children who are exposed to trauma in their home, school, or community receive appropriate interventions to help them achieve academically despite experiences of trauma. If a child needs more intervention, on-site trauma-focused mental healthcare is available at the school, or a referral is made to a community provider. Going forward, there will be enhancement, expansion and tracking of a centralized online notification system that streamlines and automates HWC notices from law enforcement to the appropriate school liaisons. The system also stores all data about notices sent for law enforcement and schools to access at any time and to provide reports and data to community partners.

Nebraska: Parent Resource Coordinators (PRC), who are CYSHCN family members, are placed in medical clinics throughout the state to help other CYSHCN families get connected to early intervention services, special education services, and other community social and health resources because they have experience with relevant systems of care.* Each PRC must complete a training curriculum on Nebraska services so they can support other families in need of services in Nebraska's statewide systems. PRC support includes mentorship with families and medical clinic providers to enhance the coordination between education, medical, and social supports for families. The project allows PRC to provide face-to-face mentorship to families and medical clinic providers to enhance the coordination between educational, medical, and social services programming.

Washington: The CYSHCN program will partner with the Injury and Violence Prevention unit to provide subject matter expertise on reducing bullying for students with developmental disabilities who experience bullying and lack of social connection. We will work with community-based organizations such as School's Out Washington and YMCA to develop inclusive out-of-school learning opportunities that are accessible and promote social connection and access to community, to address barriers to resilience.

**This application narrative uses the terminology "systems of care" as opposed to "systems of services" (note: this is a placeholder footnote; we will use language that the AAP sends)*

Access to Services

More than half of all states (38) described access to services strategies in their application narratives, totaling 107 examples. See Table 4. The most common strategies related to strategies addressing health care transition followed by specific populations, connection and coordination of services, collaboration, data collection, medical home, training/education, and school/college health. A total of 38 SPMs across 24 states were aligned with access of services. Sample standout strategies are listed in Box 3. Click here for more detail about the access to services strategies and SPMs.

Table 4. Distinctive Access to Services Strategies

Access to Services Strategies *107 distinctive strategies in 38 states*		
Strategy	# of strategies	# of state(s)
Health care transition *39 strategies in 26 states*		
Structured HCT process	11	11 (AL, CT, ID, KS, KY, MA, NH, ND, TX, VA, WV)
Quality improvement/assessment	8	8 (AZ, IL, MI, OH, OR, RI, VT, WV)
School/college health	8	7 (DC, IL, MI, MN, NC, ND, OR)
HCT resources/education for youth and family	6	6 (AK, GA, KS, MA, PA, UT)
Accreditation standards	1	1 (MI)
Behavioral health transition	1	1 (FL)
Follow-up after aging out	1	1 (KY)
Helpline	1	1 (MA)
Identifying adult health care providers	1	1 (FL)
MCO contract language	1	1 (MI)
Specific populations *17 strategies in 13 states*		
Sickle cell disease	8	5 (LA, MI, OK, PA, VA)
Foster care	5	4 (AK, FL, IN, WV)
Those experiencing homelessness	2	2 (MN, UT)
Autism	1	1 (OR)
Native American	1	1 (NM)
Connection and coordination of services *14 strategies in 12 states*		
Connection to health care coverage	7	7 (AK, GA, KY, NE, VT, VA, WI)
Referral services/navigation/care coordination	7	7 (AK, KS, MO*, ND, PA, RI, VT)
Collaboration *10 strategies in 7 states*		
Interagency collaboration	6	6 (IN, MN, MO*, NH, UT, WV)
Learning collaborative/Community of Practice	4	3 (FL, MN, NH)
Data collection *9 strategies in 7 states*		
Quality improvement and assurance	3	3 (NJ, NC, VA)
Identification of services	2	2 (IN, WA)
Missed appointments	2	1 (WV)
SHCN screener	1	1 (KS)
Centralized system	1	1 (VA)
Medical home *7 strategies in 7 states*		
Health care provider training	2	2 (FL, LA)
Quality of care assessment	2	2 (MO, UT)

Accountability	1	1 (KY)
Advisory committee	1	1 (CT)
Integrated care pilot	1	1 (NC)
Training/education *6 strategies in 5 states*		
Emergency preparedness education	4	4 (MD, OH, PA, SC)
Behavioral health training for community health workers	1	1 (NE)
Family support training for parent resource coordinators	1	1 (NE)
School/college health *6 strategies in 4 states*		
Care plan	3	2 (MO, PA)
Behavioral health	2	2 (CO, MN)
Training	1	1 (MO)

Box 3. Standout State Strategies on Access to Services

Standout State Strategies - Access to Services

Alaska: Statewide coordinated intake and referral services (CIRS) for families and primary care providers of CYSHCN service has expanded to serving 0-26 years, offering resources and care coordination services to families to improve access to medical and specialty care. Medical providers are also supported by the CIRS through education that increases their knowledge and access to resources used to assess and treat pediatric medical, developmental, and behavioral needs.

Connecticut: The Connecticut Medical Home Initiative (CMHI) care coordinators meet with individual YSHCN to develop a transition plan that addresses 3 critical areas. The transition plan is then implemented and revised as needed. DPH has incorporated transition meetings as a deliverable into all 5 CMHI CC contracts. Each region has a care coordinator identified as a transition resource person. CT Children's CMHI continues to work with the CT Children's Transition Task Force within the hospital.

Louisiana: The medical home/EPSDT coordinator will complete a Statewide Health Provider Graduate Education Landscape Assessment with AAP state chapter and other higher education programs to shape expansion strategies for provider-in training educational offerings on comprehensive family-centered medical home services, including care coordination, developmental screening, and youth health transition.

Massachusetts: The Care Coordination Program will continue to incorporate the Six Core Elements of Health Care Transition by Got Transition for moving from pediatric to adult healthcare into their work with families and providers. The Care Coordination Program will continue to implement its revised standards and processes on health transition, providing readiness assessments, information, and transition support for all enrolled youth ages 14 and over and their families. Care Coordination practice standards require staff to send letters to families of youth receiving services at ages 14, 17 and 21.

Missouri: The School Health Program (SHP) considers school nurses as a component of a medical home; assuring students have insurance, and children with a potential for a life-threatening event, or a special health care procedure have written procedures and emergency action plans in place. These plans are developed in collaboration with the parent/guardian and approved by a medical provider. The SHP will continue to promote the School Nurse Chronic Health Assessment Tool (SN-CHAT) to engage school nurses and parents in developing emergency action plans and individualized health plans.

Financing of Services

About half (25) of states described distinctive strategies related to the Financing of Services Blueprint domain in their application narratives, totaling 42 strategies. The most common strategies related to connection to health coverage and services, followed by developing/implementing alternative payment models, researching/advocating for reimbursement of services, collaborating with Medicaid/MCOs, and strategies related to specific populations. Table 5 shows the subcategories of distinctive financing of services strategies, organized by most common to least common, and Box 4 shows some example standout strategies. Of the four Blueprint domains, the fewest number of SPMs (4 SPMS, 4 states) aligned with the financing of services domain. Click here for more detail about the distinctive strategies and SPMs.

Table 5. Distinctive Financing of Services Strategies

Financing of Services Strategies *42 distinctive strategies in 25 states*		
Strategy	# of strategies	# of state(s)
Connection to health coverage and services *15 strategies in 13 states*		
Education/assistance with applying for coverage and benefits	11	11 (AK, DE, DC, KY, MA, MO, MT, ND, VT, VA, WI)
Expansion of eligibility for waivers	2	1 (OR)
Identify application resources/barriers	1	1 (AK)
Referrals to community services	1	1 (CO)
Develop/implement alternative payment model *10 strategies in 9 states*		
Integrated care	3	3 (CT, NC, TX)
Care coordination/case management	2	2 (MA, WA)
Health care transition pilot	2	2 (OR, RI)
Provider incentive payment	2	2 (AZ, OR)
Payment for personal care providers	1	1 (VT)
Research/advocate for reimbursement of services *7 strategies in 6 states*		
Health care transition services	2	2 (KS, ME)
Services for children with medical complexities	2	2 (MI, WA)
Community health workers	1	1 (KS)
Primary care/care coordination	1	1 (TN)
Paid training for nurse care managers/care coordinators	1	1 (RI)
Collaboration with Medicaid/MCOs *6 strategies in 6 states*		
Collaboration to identify and address gaps in care and coverage	2	2 (DE, WV)
Analyze MCO CM reports to identify areas of intersection and collaboration	1	1 (LA)
Collaboration to develop contract language	1	1 (MI)
Collaboration to implement waiver	1	1 (OR)
Collaboration to reduce uninsurance	1	1 (AK)
Specific populations *4 strategies in 4 states*		
Autism	2	2 (OR, WA)
Behavioral health	1	1 (NC)
Foster care	1	1 (WV)

Box 4. Standout State Strategies on Financing of Services

Standout State Strategies – Financing of Services
Arizona: Medical Services Project, a partnership with the AZ AAP Chapter, aims to increase access to health care for AZ's uninsured children by increasing the network of pediatric providers and pediatric subspecialists statewide who are willing to take a limited number of patients without insured or Medicaid, ensuring that children have necessary acute care. Most referrals come through the school system. Providers receive a pre-determined fee of $5 or $19 as payment in full for each office visit, including needed diagnostic lab services, prescriptions, and/or eyeglasses.
Delaware: MCH will continue to support the Family Voices Managed Care (MCO) Calls in Spanish and English as these calls have continued to be a wanted resource. The Parent Information Center oversees the Family Voices program and they have scheduled this forum where parents/caregivers can ask questions and/or discuss issues they are having with their Medicaid MCO (Highmark Health Options or AmeriHealth Caritas). Common issues discussed have included: care coordination requests, denials, private duty nursing, and medication. During the call, MCO's and Medicaid representatives along with other partner organizations can help problem solve.
Michigan: CSHCS will recommend additional Medicaid Health Plan (MHP) contract changes to further strengthen HCT efforts. Topics being explored include the utilization of HCT readiness assessments, how HCT education is provided to CYSHCN, and the network capacity for adult providers to service adults with pediatric conditions. In addition, CSHCS will ensure that MHPs report HCT outcomes during the compliance review process. CSHCS will attend site visits to engage with MHPs, provide additional resources if necessary, and provide technical assistance.
Oregon: Collaborate with OHA Health Policy Division to operationalize YSHCN eligibility criteria for expanded services through the 1115 Medicaid waiver. More specifically, we will collaborate with OHA to ensure that (a) medical complexity criteria specified in the waiver include youth with behavioral health conditions, and (b) the CYSHCN screener items (for caregivers and for youth) are acceptable and understandable to racially, ethnically, and linguistically minoritized populations. OCCYSHN will inform implementation of Oregon's Medicaid 1115 Waiver and help define eligibility and operationalize expansion of Medicaid for young adults with special health needs aged 19 through 26 years.
Rhode Island: the RIDOH and the CTC will continue to build on the success of the initial HCT Pilot facilitated during the last reporting period to offer another application opportunity for the next cohort of RI pediatric and adult practice dyads. The new cohort will also provide a vehicle for initial project pediatric or adult practices to continue transition efforts (with a new or existing dyad partner) and expand on their practice transition structure to include an increased number of youths including those with complex medical conditions. In addition, the CTC and RIDOH will continue to work with system partners including health plans and Medicaid to address payment and sustainability of HCT services.

Limitations

It is important to note that states varied in the amount of detail they provided in their application year narratives, and thus the number of initiatives abstracted varied greatly by state. States with little to no initiatives included in this report could still have related activities or plans; they were just not written about in the application narratives. Some initiatives were also not included if the descriptions were too brief or general to be informative to a reader. In addition, while certain strategies and activities written about do align with Blueprint domains, they may not have been captured as a distinctive strategy for this report as they are commonly occurring among states. Some common examples of this include states forming family advisory groups, creating partnerships with federally qualified health centers or mobile clinics in rural areas, non-English translations of resources, encouraging use of 2-1-1 hotlines, Project ECHO, and direct services.

Conclusions

This report offers many themes of Blueprint-related initiatives that state Title V agencies plan to undertake this year. The distinctive examples shared could inspire states as they plan for additional future activities. These findings also shed light on the existing state activities that can be expanded on to better align with the Blueprint domains. The themes in this report are important to consider in the development of the roadmap for state Title V agencies to advance the system of services for CYSHCN.

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