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A State Multi-Sector Framework for Supporting Children and Youth with Special Health Care Needs

Child TRENDS

Lucile Packard Foundation for Children's Health

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Acronyms

ABLE: Achieving a Better Life Experience

ADA: Americans with Disabilities Act

CHIP: Children's Health Insurance Programs

CMS: Centers for Medicare and Medicaid Services

CYSHCN: children and youth with special health care needs

HHS: U.S. Department of Health and Human Services

DOJ: U.S. Department of Justice

DOL: U.S. Department of Labor

ED: U.S. Department of Education

F2FHIC: Family-to-Family Health Information Centers

HCBS: home and community-based services

HUD: U.S. Department of Housing and Urban Development

IDEA: Individuals with Disabilities Education Act

I/DD: intellectual and development disabilities

LTSS: long-term services and supports

MCHB: Maternal and Child Health Bureau

MIECHV: Maternal, Infant, and Early Childhood Home Visiting program

NCSL: National Conference of State Legislatures

OSEP: U.S. Department of Education Office of Special Education Programs

PADD: Protection and Advocacy for Individuals with Developmental Disabilities

P&A: Protection and Advocacy System

PTI: Parenting Training and Information centers (PTI)

RSA: U.S. Department of Education Rehabilitation Services Administration

SSI: Supplemental Security Income

UCEDD: University Centers for Excellence in Developmental Disabilities

Definitions

1115 waivers: Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration projects that are found by the Secretary to be likely to assist in promoting the objectives of the Medicaid program. The purpose of these demonstrations, which give states additional flexibility to design and improve their programs, is to demonstrate and evaluate state-specific policy approaches to better serving Medicaid populations.

1915 (b) waiver: Allows states to waive certain Medicaid requirements in order to implement a managed care delivery system.

1915 (c)/Home and community-based services (HCBS) waiver: Allows states to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.[1]

ABLE accounts: Tax-advantaged savings accounts for individuals with disabilities and their families.[2]

Acute care: Providing or concerned with short-term, usually immediate, medical care (as for serious illness or traumatic injury.[3]

Behavioral health (Also mental health): Health services that include mental and emotional health, psychiatric care, addiction and substance abuse treatment. Services are provided by different kinds of providers, including certified counselors, psychiatrists, psychologists and neurologists.[4]

Children and youth with special health care needs (CYSHCN): Children 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.[5]

Disability: A physical or mental impairment that substantially limits one or more major life activity.[6]

Early intervention services: A range of targeted services to help young children from birth to age 3 who have developmental delays or specific health conditions.[7]

Guardianship/conservatorship: When someone is no longer able to handle his or her own financial or personal affairs, the court can appoint an individual or professional to act on behalf of the incapacitated person. When a minor child is involved, it is generally called a guardianship. When an adult needs someone, it is called a conservatorship.[8]

Home and community-based services (HCBS): Medicaid-funded services that give beneficiaries the opportunity to receive services in their own home or community rather than from institutions or other isolated settings.[9]

Home visiting: A program that gives pregnant women and families, particularly those considered at-risk, necessary resources and skills to raise children who are physically, socially, and emotionally healthy and ready to learn.[10]

Hospice care: A team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Hospice focuses on caring, not curing, and in most cases, is provided in the patient's home.[11]

Integrated: Refers to various contexts, including housing and employment, in which people with disabilities live and work in settings where the majority of people are not people with disabilities.[12]

Intellectual/developmental disability (I/DD): Disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development.[13]

Juvenile diversion: An intervention strategy that redirects youths away from formal processing in the juvenile justice system, while still holding them accountable for their actions.[14]

Least restrictive environment: The requirement in federal law that students with disabilities receive their education, to the maximum extent appropriate, with nondisabled peers and that special education students are not removed from regular classes unless—even with supplemental aids and services—education in regular classes cannot be achieved satisfactorily.[15]

Long-term services and supports (LTSS): The broad range of paid and unpaid medical and personal care assistance that people may need—for several weeks, months, or years—when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability.[16]

Managed care: A health care delivery system organized to manage cost, utilization, and quality. Managed care provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per member per month (capitation) payment for these services.[17]

Medical home: A model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety.[18]

Natural environment: Settings that are natural or typical for a same-aged child without a disability.[19]

Palliative care: Specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness.[20]

Primary care: Care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis.[21]

Protection and advocacy systems (P&As): Agencies that work at the state level to protect individuals with disabilities by empowering them and advocating on their behalf.[22]

Respite care: A service that provides a temporary break between the family caregiver and the care recipient.[23]

Special education: Instruction specifically designed to meet the educational and developmental needs of children with disabilities, or those who are experiencing developmental delays.[24]

Supported decision-making: An alternative to guardianship that allows an individual with a disability to work with a team and make his or her own choices about his or her own life. Under this model, the individual designates people to be part of a support network to help with decision-making.[25]

Title V: Title V of the Social Security Act, otherwise known as the Maternal and Child Health Services Block Grant.[26]

Background

According to the 2016 National Survey of Children's Health (NSCH), over 19 percent of children in the United States from birth through age 17 are children and youth with special health care needs (CYSHCN).[27] As this diverse group experiences (or may be at increased risk for) chronic physical, developmental, behavioral, or emotional health conditions, they rely on a wide range of supports to meet their health, education, employment, and other needs. However, gaining access to such supports can be a complex challenge for families as they navigate different health insurance and financial assistance programs; coordinate health services across primary care physicians, specialty care providers, and schools; and seek services that support inclusion in education programs, the workforce, and the broader community as young people transition into adulthood.

A substantial proportion of CYSHCN and their families struggle to access affordable and high-quality services. According to the 2016 NSCH, nearly one-third of insured CYSHCN do not have adequate health insurance: The services they need are not covered, access to specialists is stymied, or out-of-pocket expenses for services are not reasonable. Similarly, 32 percent of CYSHCN had difficulties accessing a health care specialist when needed.[28] The time and expense needed to care for CYSHCN can be substantial, making it difficult for families to manage and coordinate their children's care. For example, the 2016 NSCH shows that 24 percent of families spend one to four hours a week coordinating and arranging services for CYSHCN.[29] In addition to the difficulties of care coordination, nearly 14 percent of families of CYSHCN reported the need to cut back or completely stop working to meet their child's needs.[30]

The state in which a CYSHCN lives can make a difference in access to care, and the quality of care the child receives. While a vast array of different federal programs support CYSHCN—such as the Maternal and Child Health Services Block Grant (Title V) programs, the Individuals with Disabilities Education Act (IDEA), Medicaid, the State Children's Health Insurance Program (CHIP), and the Supplemental Security Income (SSI) program—states often determine the eligibility criteria and requirements for receiving services. Beyond federal programs, states have different statutes and regulations that heavily influence how families care for CYSHCN, including family leave laws and statutes on guardianship, conservatorship, and supported decision making.

Given variations in the state policy landscape, it is no wonder that families report different experiences as they work to support their children. From state to state, the percentage of families of CYSHCN claiming adequate health insurance to meet the child's needs ranges from 60 percent 79.3 percent. The percentage of families who report that their children have a medical home—to provide patient-centered care and coordinate services across health care providers—ranges from 31 percent to 57 percent across states.[31]

Given this variation in experiences, state policymakers should consider improvements in how public agencies, funding sources, regulations, and other policies serve CYSHCN. Further, variations in state support point to the need for new tools to help parents and families of CYSHCN understand the costs and benefits of where they live. Such information could better equip families to advocate for themselves and their children.

A State Multi-Sector Framework for Supporting CYSHCN

With support from the Lucile Packard Foundation for Children's Health (the Foundation), Child Trends developed a *State Multi-Sector Framework* (see Table 1) to help parents, state lawmakers, and other stakeholders better understand how various child-serving systems support CYSHCN across health, education, justice, and other sectors. The effort follows previous initiatives by the Association of Maternal & Child Health Programs (AMCHP), the National Academy for State Health Policy (NASHP), and the federal Maternal and Child Health Bureau (MCHB), among others. These entities have sought to provide health officials with set standards and key outcomes to clarify how health systems ought to serve CYSHCN. MCHB has encouraged health leaders at all levels (national, state, and local) to provide CYSHCN with a system of care that includes six elements: community-based services, early and continuous screening, a medical home, adequate health insurance, family partnerships, and transition to adulthood. AMCHP and NASHP, meanwhile, have prepared *Standards for Systems of Care for Children and Youth with Special Health Care Needs* to help policymakers, health care providers, insurers, hospitals, and others strengthen their procedures, processes, and practices to improve health services.

Building on this body of work, the completion of the *State Multi-Sector Framework* represents a first step in a broader effort to specifically help state officials, as well as parents and families, compare state systems across multiple sectors, including health. Ultimately, the framework facilitates efforts to better serve CYSHCN and their families, and to advance state policies that support access to services and inclusion for CYSHCN in their communities, in the following ways:

- The framework provides a roadmap for state lawmakers aiming to improve the health and well-being of CYSHCN and their families: first, by focusing lawmakers' attention on the experiences of CYSHCN and their families as they interact with the institutions that serve them; and, second, by helping lawmakers identify the policy levers they might use to improve these experiences.
- The framework also provides CYSHCN, as well as their parents and families, with a tool that can organize their efforts to understand how states serve their communities.
- Finally, the framework provides a foundation for the creation of new tools and reporting systems to help CYSHCN, their families, and state policymakers quickly sort through vast amounts of information from different sources and better understand how states compare in the supports they offer to CYSHCN.

The *State Multi-Sector Framework* is simply organized into four domains (described in more detail in the Methodology section): health services, family support and social services, education and employment services, and law enforcement and juvenile justice contact. These domains represent a wide range of services utilized by CYSHCN and their families, organized into the system sectors responsible for delivery of those services (see Table 1). Within each domain, the framework provides a short list of systems-level outcomes—one simple sentence for each outcome—to describe the ideal experience for CYSHCN and their families as they interact with the institutions that serve them and seek the services they need.

Given the last goal of the framework—the creation of new tools and reporting systems for comparing states—this initiative did not seek to provide an exhaustive overview of the systems-level outcomes that states should strive to achieve to improve life outcomes for CYSHCN. Rather, the framework includes only those systems outcomes for which state-to-state comparisons are possible, given currently available data sets and compilations of state policies.

Table 1: State Multi-Sector Framework: Systems Outcomes[a] for Supporting Children and Youth with Special Health Care Needs, by Four Domains

Health Services	Family Support and Social Services	Education and Employment Services	Law Enforcement and Juvenile Justice Contact
• Children are screened early and continuously for special health care needs.[32] • CYSHCN receive family-centered, coordinated, ongoing comprehensive care within a medical home.[33] • Families of CYSHCN have adequate private and/or public health insurance and financing to pay for the services they need.[34] • CYSHCN have access to qualified medical health care providers within a reasonable distance of their home. • CYSHCN have access to qualified behavioral health care providers to support them in natural environments. • CYSHCN and families have access to adequate home- or community-based long-term services and supports, including respite care. • CYSHCN receive adequate support to transition from pediatric to adult medical health care providers. • CYSHCN receive adequate support to transition between children's and adult long-term services and supports (LTSS) and behavioral health service systems. • CYSHCN and their families have access to adequate palliative and hospice care.	• CYSHCN and their families have access to housing that is safe, accessible, affordable, and integrated. • Families of CYSHCN have financial security and workforce flexibility to sustain them in their role as caregivers. • CYSHCN in, and transitioning from, foster care have access to an affordable and comprehensive system of health care.[35] • CYSHCN enjoy support in exercising their legal capacity, personal autonomy, and decision-making as they become young adults while having access to appropriate legal protections that safeguard their interests.	• CYSHCN, from birth through age 2, receive timely early intervention services in a natural environment. • CYSHCN, ages 3 through 5, receive timely early childhood special education in the least restrictive environment. • CYSHCN receive education services that are appropriately ambitious and tailored to their needs, delivered in the least restrictive environment, and other appropriate education accommodations. • CYSHCN have access to the supports necessary for successful participation in higher education, as well as vocational, career and technical, and basic skills training. • CYSHCN are supported in integrated employment settings where they receive a competitive wage.	• CYSHCN in crisis receive services that promote inclusion, not exclusion, and do not include other punitive practices that place children and youth at risk of harm. • CYSHCN receive immediate assessment during intake to identify health and education needs and appropriate services. • CYSHCN are diverted into community settings whenever possible. • CYSHCN placed in the juvenile justice system receive appropriate education and health services.

[a] While "outcomes" generally refers to measurable conditions of well-being for individuals, families, or communities, we use it here to describe the intended performance of institutions that serve CYSHCN and their families. For the sake of clarity, these performance outcomes are discussed using the experiences of children or youth and their families as they interact with such institutions.

Methodology

Development of the State Multi-System Framework consisted of four steps: first, the identification of key domains by which to organize the framework; second, the review of available literature and initial drafting of the systems outcomes; third, the convening of an advisory board to solicit feedback on the systems outcomes; and fourth, the review of available datasets to determine the viability of comparing states on each systems outcome.

Identifying key domains. Domains were identified after reviewing the Foundation's comprehensive list of services on which CYSHCN and their families depend (*Care Mapping: Possible Services Used by Families of CSHCN*) and reorganizing them based on the sectors responsible for implementing those services. (See Table 2 for the reorganization.) Four domains were identified using this approach:

- **Health services** include those supports designed to assist CYSHCN in accessing high-quality health care.
- **Family support and social services** include services and supports to assist CYSHCN and their families in securing basic financial, legal, and day-to-day needs.
- **Education and employment services** include those supports and services to help CYSHCN successfully graduate from high school and pursue postsecondary education and/or a career.
- **Law enforcement and juvenile justice contact** includes supports to limit interactions between CYSHCN and the law enforcement or juvenile justice systems, and to ensure that CYSHCN are treated fairly during such interactions.

Initially, a fifth domain was identified: advocacy and legal support. However, this domain was later consolidated into family support and social services due to the narrow scope of services it covered, and the absence of available data sets to compare how states perform within this domain.

Table 2: Services Used by CYSHCN and their Families, by Domain

Health Services	Family Support and Social Services	Education and Employment Services	Law Enforcement and Juvenile Justice Contact
Physical Health • Primary pediatric care • Primary adult care • Pediatric subspecialty care • Adult subspecialty care • Surgical care • Hospitals • Emergency departments • Urgent care • Dialysis • Chemotherapy • Home health care • Palliative care • Hospice • Dental care • Nutrition education/consultation • Vision care • Complementary and alternative medical care (chiropractic, acupuncture, homeopathy, naturopathy) • Traditional healers **Mental Health** • Behavioral therapy • Family therapy • Parent/child dyadic therapy • Marital counseling • Mental health care: child • Mental health care: adult **Ancillary Services** • Interpretation/translation • Service animals • Laboratory • Radiology/imaging • Participation in research projects • Genetic counseling • Pharmacy and medication reconciliation **Developmental Disabilities & Rehabilitation** • Rehabilitative care • Developmental screening • Durable medical equipment • Equipment repair	**Formal Family Support & Advocacy** • Advocacy services • Care Navigation • Child care • Family resource center services • Homemaker services • Organizing health records • Parent-to-parent support • Respite care • Spiritual support and faith communities • Categorical/Disease-Specific organizations • Voluntary organizations • Blogs • List Serv • Social Media **Informal Family Supports** • Blogs • Extended family • Friends of child • Friends of parents • Neighbors • Support groups for child, siblings and parents • Clubs • Cultural organizations/groups **Public Safety** • 5-day supply of medication • Earthquake preparedness/Earthquake kit • Evacuation chairs • First Responders, i.e., police, EMT, fire department • Emergency backup for power outages **Social Services** • Human Services Agency (Medicaid, IHSS) • Child Protective Services • Child welfare agency and foster care • Court Appointed Special Advocates (CASA) • Financial assistance: SSI/SSDI • Home visiting • Independent living • Housing assistance • Transportation assistance: payers, dispatchers, bus drivers	**Employer/Work** • Employer • Worksite accommodations and modifications • Disability Benefits/Ticket to Work • Vocational Rehabilitation • Job placement **Education** • Schools • Accommodations, modifications and other services; 504 plan • Americans with Disabilities Act accommodations • Child care/Head Start/ Preschool/Pre-K • Home schooling • Individual Education Plan • Public libraries • School administrators • School aide • School nurse • School teachers • Special education teacher • School-based therapists • Vocational services • Sign language • Physical therapy • Occupational therapy • Speech therapy **Recreation & Community Resources** • Individual lessons • Individual recreation • Teams and group activities and clubs • Accommodations to access and use public spaces • Camps • Special programs, e.g., Special Olympics, community events • After-school care	**Juvenile Justice** • Expungement of records • Mental/behavioral health services • Substance abuse/ addiction services • Access to health care • Medication management • Special education • Trauma informed care

Table 2, cont.: Services Used by CYSHCN and their Families, by Domain

Health Services	Family Support and Social Services	Education and Employment Services	Law Enforcement and Juvenile Justice Contact
• Individual Education Planning • Individual Family Service Planning • Modification of vehicles • Needs assessment • Paratransit and other accommodated transportation; handicapped parking • Physical accommodations in home • Physical therapy • Music therapy • Equine therapy • Feeding therapy • Occupational therapy • Speech/language therapy • Psychological testing/treatment • Protective supervision **Long Term Care** • In-home health services • Private Duty Nursing • Medical supplies • Residential care • Respite **Insurance and Financing** • Private health insurance company • Health plan • Insurance advocacy • Public health plan (i.e., Medi-Cal/ Medicaid) • Special grants **Care/Service Coordination** • Assessment • Care planning • Case management • Coordination among medical providers • Coordination between medical providers and other community services • Emergency care planning • Patient advocacy • Self-management education and supports • Transition planning • Visiting nurses	• Voluntary organizations: Easter Seals, etc. • Food subsidies: food stamps; Women, Infants and Children Food and Nutrition Service (WIC) **Advocacy** • Advisory committees and councils • Public testimony • Non-profit voluntary organizations **Legal** • Private and legal aid attorneys • Conservatorship • Financial planning, wills and trusts • Guardianship • Durable power of attorney • Advance healthcare directive • Public benefits eligibility (health care, SSI, disability care) • Public benefits denial, reduction or delay (insurance, treatment) • Special education services • Accommodations • Supported decision-making		

Review of available literature and initial drafting. The systems outcomes used to populate each of the four domains were drawn from a review of available literature and existing frameworks describing how health, education, labor, and other sectors should support the needs of CYSHCN and their families. For purposes of this review, CYSHCN included the following population (based on the MCHB definition): "those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[b] This definition was interpreted to include children and youth from birth to age 21, to capture services and systems that support the transition to adulthood. Furthermore, while children receiving early intervention or special education services under IDEA are generally identified as having education disabilities, and are not always clinically diagnosed with special health care needs, such children were considered to meet the "at-risk" portion of the MCHB definition.

The review of the literature was limited to information available since 2012, and excluded "grey" literature (not commercially published), literature not related to the United States, and academic journal articles with conclusions specific to sub-populations of CYSHCN. The documents and materials used for the review were discovered using two methods: web searches focusing on non-profit entities and government agencies focused on the interests of CYSHCN; and interviews with national experts, who would later participate in the project's Advisory Board. The resulting compilation of resources included principle statements by disability rights advocates; proposed standards for supporting CYSHCN; annual performance tools used by federal agencies to monitor state implementation of various programs; existing state report cards comparing performance; and other materials. As part of the review, project staff took note of relevant policies and federal statutes and other published frameworks strongly aligned with each domain (See Table 3), as well as the public and private entities involved in delivering supports to CYSHCN (Table 4).

To draft system outcomes, project staff were asked to describe an ideal experience for CYSHCN and their families as they navigate the policies, entities, and institutions that serve them. Particular attention was paid to creating outcomes that described the experience of seeking and securing the services listed in Table 2, and to creating a concise list of outcomes that could speak to a wide range of services (in the interest of keeping the overall framework of a manageable size). Project staff were also instructed to avoid child- or family-level health, education, and life outcomes – such as mortality, graduation rates, emergency room visits, etc. As the project's focus is on the state systems – and, therefore, the policymakers and officials that design them – the challenge is to identify for states the strategies they might use to improve child and family well-being.

[b] McPherson, M., Arango, P., Fox, H., Lauver, C., Manus, M., et al. (1998). A New Definition of Children with Special Health Care Needs. *Pediatrics*, 102(1), 137–140.

Table 3: State Multi-Sector Framework Outcomes Aligned with Relevant Current Policies and Existing Documents

Domain	State Multi-Sector Framework: Outcomes	Statutes & Policies	Principles & Frameworks
Health Services	• Children are screened early and continuously for special health care needs.[36] • CYSHCN receive family-centered, coordinated, ongoing comprehensive care within a medical home.[37] • Families of CYSHCN have adequate private and/or public health insurance and financing to pay for the services they need.[38] • CYSHCN have access to qualified medical health care providers within a reasonable distance of their home. • CYSHCN have access to qualified behavioral health care providers to support them in natural environments. • CYSHCN and families have access to adequate home- or community-based long-term services and supports, including respite care. • CYSHCN receive adequate support to transition from pediatric to adult medical health care providers. • CYSHCN receive adequate support to transition between children's and adult long-term services and supports (LTSS) and behavioral health service systems. • CYSHCN and their families have access to adequate palliative and hospice care.	• Patient Protection and Affordable Care Act, Essential Health Benefits • State Children's Health Insurance Program (CHIP) • Medicaid • Medicaid Waivers (including Section 1915(c) Home and Community-Based Services Waivers and Section 1115 Demonstration Waivers) • Medicaid Managed Care Final Rule • State insurance mandates • Home- and Community-Based Settings Rule • Mental Health Parity Act • Tax Equity and Fiscal Responsibility Act/Katie Beckett Waiver • Maternal, Infant, and Early Childhood Home Visiting program (MIECHV) • Maternal and Child Health Block Grant • Statewide information systems on resources • Final Regulations Related to Parental Consent for the Use of Public Benefits or Insurance[39] • Individuals with Disabilities Education Act (IDEA) parts B and C	• Standards for Systems of Care for Children and Youth with Special Health Care[40] • Pediatric Health System: A Multidisciplinary Framework[41] • Money Follows the Person: A 2015 State Survey of Transitions, Services, and Costs[42] • Home- and Community-Based Services (HCBS) Quality Measures Report[43] • Consensus Statement on Health Care, Transitions for Youth with Special Health Care Needs[44] • Americans with Disabilities Act (ADA) Title II and Title III Regulations Fact Sheet Series[45] • Guidance on "Free Care"[46] • First-Hand Perspectives on Behavioral Interventions for Autistic People and People with Other Developmental Disabilities[47] • The Case for Inclusion[48] • National Committee for Quality Assurance's recognition requirements[49] • Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long-Term Services and Supports Programs • Transitioning LTSS Providers into Managed Care Programs[50] • CMS & CHIP Services, Informational Bulletin: Clarification of Medicaid Coverage of Services to Children with Autism[51] • HCBS settings rule on person-centered planning requirements[52] • Medicaid managed care rule[53] • Six Core Elements of Health Care Transition 2.0[54] • Position statements on health care,[55] early childhood services,[56] behavioral supports,[57] long-term supports and services,[58] and support coordination[59] (via The Arc) • Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework[60] • Concurrent Care for Children, Implementation Toolkit[61]

Table 3, cont.: State Multi-Sector Framework Outcomes Aligned with Relevant Current Policies and Existing Documents

Domain	State Multi-Sector Framework: Outcomes	Statutes & Policies	Principles & Frameworks
Family Support and Social Services	• CYSHCN and their families have access to housing that is safe, accessible, affordable, and integrated. • Families of CYSHCN have financial security and workforce flexibility to sustain them in their role as caregivers. • CYSHCN in, and transitioning from, foster care have access to an affordable and comprehensive system of health care.[62] • CYSHCN enjoy support in exercising their legal capacity, personal autonomy, and decision-making as they become young adults while having access to appropriate legal protections that safeguard their interests.	• Housing vouchers • Rehabilitation Act (Section 504) – Housing Accessibility • Fair Housing Act • ADA • Adoption and Safe Families Act • Family Opportunity Act • Family leave policies • MIECHV • Special Supplemental Nutrition Program for Women, Infants, and Children • Supplemental Nutrition Assistance Program • Temporary Assistance for Needy Families • State supported decision-making laws	• Standards for Systems of Care for Children and Youth with Special Health Care Needs [63] • Comprehensive Preparedness Guide (CPG) 301: Interim Emergency Management Planning Guide for Special Needs Populations [64] • National Response Framework[65] • Guidance on Non-discrimination and Equal Opportunity Requirements for Public Housing Authorities[66] • Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination: A Consensus Report[67] • Position statements on individual supports,[68] family support,[69] and housing[70] (via The Arc)

Table 3, cont.: State Multi-Sector Framework Outcomes Aligned with Relevant Current Policies and Existing Documents

Domain	State Multi-Sector Framework: Outcomes	Statutes & Policies	Principles & Frameworks
Education and Employment Services	• CYSHCN, from birth through age 2, receive timely early intervention services in a natural environment. • CYSHCN, ages 3 through 5, receive timely early childhood special education in the least restrictive environment. • CYSHCN receive education services that are appropriately ambitious and tailored to their needs, delivered in the least restrictive environment, and other appropriate education accommodations. • CYSHCN have access to the supports necessary for successful participation in higher education as well as vocational, career and technical, and basic skills training. • CYSHCN are supported in integrated employment settings where they receive a competitive wage.	• Individuals with Disabilities Education Act, titles B and C • Rehabilitation Act • ADA • Higher Education Act • Workforce Innovation and Opportunity Act • Olmstead Supreme Court Ruling • Elementary and Secondary Education Act of 1965 (as amended by the Every Student Succeeds Act) • Section 504 of the Rehabilitation Act • Endrew F. v. Douglas Cty. Sch. Dist. RE-1, 137 S. Ct. 988 (2017). • Cedar Rapids Community School Dist. v. Garret F., 526 US 66 (1999). • Irving Independent School Dist. v. Tatro, 468 U.S. 833 (1984)	• Reporting Manual for the Case Service Report (RSA 9-11): State Vocational Rehabilitation Services and State Supported Employment Services Programs [71] • Performance accountability guidance for Workforce Innovation and Opportunity Act[72] • A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities [73] • Disability Documentation Guidelines to Determine Eligibility for Accommodations at the Postsecondary Level [74] • National Collaborative on Workforce and Disability Guideposts for Success[75] • Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities: Final Report [76] • Final rules regarding state vocational rehabilitation services program, state-supported employment services program, and limitations on use of subminimum wage[77] • ADA Requirements: Testing Accommodations[78] • Position statements on education[79] and employment[80] (via The Arc)

Table 3, cont.: State Multi-Sector Framework Outcomes Aligned with Relevant Current Policies and Existing Documents

Domain	State Multi-Sector Framework: Outcomes	Statutes & Policies	Principles & Frameworks
Law Enforcement and Juvenile Justice Contact	• CYSHCN in crisis receive services that promote inclusion, not exclusion, and do not include other punitive practices that place children and youth at risk of harm. • CYSHCN receive immediate assessment during intake to identify health and education needs and appropriate services. • CYSHCN are diverted into community settings whenever possible. • CYSHCN placed in the juvenile justice system receive appropriate education and health services.	• Civil Rights of Institutionalized Persons Act • ADA • Olmstead • In Re: Gault Supreme Court ruling • IDEA • Section 504 of the Rehabilitation Act • Prison Rape Elimination Act	• Mental Health Needs of Juvenile Offenders[81] • Position statement on children with emotional disorders in the juvenile justice system (via Mental Health America)[82] • Model Policy for Law Enforcement on Communication with People who are Deaf or Hard of Hearing[83] • Police-Mental Health Collaboration Toolkit [84] • Interactions with Individuals with Intellectual and Developmental Disabilities [85] • Justice-Involved Youth with Intellectual and Developmental Disabilities: A Call to Action for Juvenile Justice[86] • Position statement on the criminal justice system (via The Arc)[87]

Table 4: State, Federal, and Other Actors Supporting Children and Youth with Special Health Care Needs and Their Families

Domain	State Actors	Federal Actors	Other Actors
Actors across all domains	• State legislators • State health agencies • State mental health agencies • State education agencies	• U.S. Department of Health and Human Services' (HHS) • U.S. Department of Justice (DOJ) • U.S. Department of Education (ED) • Federal court systems • U.S. Department of Labor (DOL)	• Protection and Advocacy Systems (P&As) • National disability-rights advocacy organizations
Health Services	• Medicaid state agencies • State maternal and child health programs • State agencies serving individuals with intellectual and development disabilities (I/DD) • State education agencies • State vocational rehabilitation agencies • State mental health services agencies • Medicaid managed care organizations • State health insurance marketplaces • State Family-to-Family Health Information Centers (F2F HIC)	• HHS Centers for Medicare and Medicaid Services (CMS) • Health Resources Services Administration's Maternal and Child Health Bureau (MCHB) • Federal health insurance marketplace • University Centers for Excellence in Developmental Disabilities (UCEDD)	• Local educational agencies • Commercial insurers • Acute-care providers • Medical-home providers • Behavioral health care providers • Specialty-care providers • Providers of LTSS • Schools • Child/family advocates • IDEA Part C providers • National disability advocacy organizations
Family Support and Social Services	• State housing agencies • State home visiting programs • State court systems • State F2F HIC	• U.S. Department of Agriculture Food and Nutrition Service • DOJ Office of Juvenile Justice and Delinquency Prevention (OJJDP)[88] • U.S. Department of Housing and Urban Development (HUD) • MCHB • Federal Emergency Management Agency • UCEDD • HHS Disaster Technical Assistance Center • Community-based organizations • UCEDD	• Public housing authorities • Respite-care providers • Care coordinators • Parent/family advisory boards • American Red Cross • Child protective services agencies • Parent Training and Information (PTI) centers • Social service agencies • National disability-rights advocacy organizations • Leadership Education in Neurodevelopment-mental Disabilities programs • Medicaid-funded case management providers • Faith-based and other community-based organizations • Special needs managed care entities

Table 4, cont.: State, Federal, and Other Actors Supporting Children and Youth with Special Health Care Needs and Their Families

Domain	State Actors	Federal Actors	Other Actors
Education and Employment Services	• State vocational rehabilitation agency • State agencies serving individuals with I/DD • State F2F HIC • State agencies for I/DD services • State Medicaid agency • State-supported employment services programs	• ED OSEP • ED Rehabilitation Services Administration (RSA) • ED Office for Civil Rights • DOJ Civil Rights Division • DOL • Equal Employment Opportunity Commission • UCEDD	• Local education agencies • Colleges and universities • National disability advocacy organizations • PTI centers • Paralympics • Project Search • National associations of parks and recreation programs • Sponsored internship programs
Law Enforcement and Juvenile Justice Contact	• State court systems • State agencies for I/DD (and local)	• OJJDP • DOJ Community-Oriented Policing Service (COPS) • CMS • DOJ Bureau of Justice Assistance • HHS Substance Abuse and Mental Health Services Administration (SAMHSA) • State F2F HIC • UCEDD	• National disability-rights advocacy organizations • Protection and Advocacy (P&A) • Local education agencies

Convening of the Advisory Board. To support the development of the framework, the project team convened an Advisory Board representing state health and legislative officials, clinicians, civil rights advocates, parents of CYSHCN, and people with disabilities to review drafts of the systems outcomes and provide input. In their review of the systems outcomes, Advisory Board members were asked to consider whether they saw conceptual gaps, to help identify data sources with indicators aligned to each system outcome, and to consider how amenable the systems outcomes would be to shifts in state policy. The Advisory Board reviewed and discussed two drafts of the developing framework before the project team produced a final version.

Review of Available Data Sets. As the State Multi-Sector Framework is intended to facilitate the creation to tools to better compare state support for CYSHCN, and begin discussion about how states might improve policies and programs, the project team worked to ensure that each system outcome could be measured using currently available data sets and compilations of state policy. After casting a wide net for such data sources, the project team narrowed the list down to sources that met the following set of criteria:

- Data sources must be drawn from a current and reoccurring information collection;
- Data sources must allow for disaggregation at the state level; and
- Data sources should, depending on the type of information gather, allow for disaggregation to pinpoint the experiences of CYSHCN and their families.

The resulting list of data sources (see Table 5) were reviewed for indicators that aligned with the systems outcomes. In cases where no indicator could be located to measure a proposed systems outcome, the systems outcome was removed from the framework.

Table 5: Available Datasets and Compilations of State Policies Aligned with the State Multi-Sector Framework

Domain	Datasets and Compilations of State Policies
Health Services	• National Survey of Children's Health • Developmental Screening Medicaid Policy by State Report • Presumptive Eligibility for Medicaid and CHIP Coverage • Continuous Eligibility for Medicaid and CHIP Coverage • American Community Survey Public Use Microdata • Medicaid and CHIP Eligibility, Enrollment, Renewal, and Cost Sharing Policies as of January 2018: Findings from a 50-State Survey • State Telehealth Laws and Reimbursement Policies Report • State Policies for Behavioral Health Services Covered Under the State Plan • State Medicaid Managed Care Program Design for CYSHCN Report • Medicaid Section 1915(c) Waiver Program List • Kaiser Foundation State Health Facts
Family Support and Social Services	• American Community Survey Public Use Microdata • Residential Information Systems Project • Supplemental Security Income for Children Guide • Annual Disability Statistics Compendium • State Family and Medical Leave Laws List • Medicaid Section 1115 Waiver Program List • State Medicaid Managed Care Program Design for CYSHCN Report • Managed Care State Profiles & Data Collections • Policies Extending Foster Care Beyond 18 List • National Resource Center for Supported Decision Making - Guardianship Laws by State • American Bar Association's Pro Bono and Public Services Directory • ABLE National Resource Center - State Review
Education and Employment Services	• IDEA State Performance Plans and Annual Performance Report • National Survey of Children's Health • IDEA Section 618 Data – Parts B and C • NCEO - Data Analytics • RSA Grant Program List • Integrated Postsecondary Education Data System • American Community Survey Public Use Microdata
Law Enforcement and Juvenile Justice Contact	• Civil Rights Data Collection • Juvenile Residential Facility Census • Census of Juveniles in Residential Placement • Juvenile Justice Geography, Policy, Practice & Statistics • ED Data Express

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About Child Trends

Child Trends is the nation's leading nonprofit research organization focused exclusively on improving the lives and prospects of children, youth, and their families. Child Trends' mission is to improve the lives and prospects of children and youth by conducting high-quality research and applying the resulting knowledge to public policies, programs, and systems. Since 1979, decision-makers have relied on our rigorous research, unbiased analyses, and clear communications to improve public policies and interventions that serve children and families. We are multi-disciplinary, and our workforce reflects the diversity of children and families in the U.S. Our work is supported by many of the nation's largest foundations; by federal, state, and local government agencies; and by leading nonprofit organizations.

About Lucile Packard Foundation for Children's Health[c]

The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation is a public charity, founded in 1997. Additional information regarding the foundation is available at www.lpfch.org.

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Advisory Board

The following individuals and organizations participated in the project's Advisory Board, and graciously contributed their knowledge and expertise to the development of the State Multi-Sector Framework. The views presented in this report are those of the authors and not necessarily those of the Advisory Board Members.

Elisabeth Burak, MPP, MSW
Senior Program Director
Health Policy Institute
Center for Children and Families
Georgetown University

Tahra Johnson, MPH
Program Manager
Maternal and Child Health
National Conference of State Legislatures

Elizabeth Priaulx, JD
Senior Disability Legal Specialist
National Disability Rights Network

Cathy Schoen, MS
Senior Scholar in Residence
New York Academy of Medicine

Juliet Barraza
Special Education Bilingual Advocate
Disability Rights and Education Defense Fund

Susan Chacon, MSW, LISW
Director, Children's Medical Services
Title V CYSHCN Program
New Mexico Department of Health

Paige Bussanich
Senior Program Manager
Child and Adolescent Health
Association of Maternal & Child Health Programs

Meg Comeau, MHA
Senior Project Director
Catalyst Center at Boston University

Jane Perkins, MPH, JD
Legal Director
National Health Law Program

Karen VanLandeghem, MPH
Senior Program Director
National Academy for State Health Policy

Amy Houtrow, MD, MPH, PhD
Chief
Division of Pediatric Rehabilitation Medicine
Children's Hospital of Pittsburg
University of Pittsburg Medical Center

Cara Coleman, MPH, JD
Family Voices

Shawn Ullman, JD
Director of TheArc@School
The Arc

Ari Ne'eman
Chief Executive Officer
MySupport.com

Endnotes

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