Cross-System Collaboration to Support Children and Youth With Behavioral Health Needs and Their Families

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Cross-System Collaboration to Support Children and Youth With Behavioral Health Needs and Their Families

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Abstract

Children and youth with behavioral health needs and their families often are involved with multiple child- and family-serving systems, including child welfare and juvenile justice systems. These youth, many of whom are enrolled in or eligible for Medicaid, may experience or be at risk for out-of-home care. These settings might include restrictive environments, particularly when one or more systems designed to support children and families are unable to provide, coordinate, or maintain accessible services at the necessary intensity to address their behavioral health and service needs across the family unit.

State, territorial, tribal, and local behavioral health, Medicaid, and public health leaders need to understand their state's systems to develop and support collaboration and efforts to help maximize positive development of children and youth. However, each state has a different structure and approach to financing and delivering services across public child- and family-serving systems. Further variations exist within systems, based on federal, state, and local laws and rules; how populations are defined; how access is structured; which financing strategies are used; the available service array for each population and geographic area; and whether there is a justice overlay that mandates certain restrictions on the child or youth.

Once leaders identify the children and youth with unmet behavioral health needs and the public child- and family-serving systems available in their states and communities, they will be better positioned to collaborate and implement strategies, including many that are already available to them, to improve access to high-quality, effective services and supports.

Highlights

- An estimated 22 percent of the child population in the United States experiences mental, emotional, or behavioral health challenges.[1] Children and youth with unmet needs often struggle to get access to timely, responsive, high-quality, and effective interventions and treatment in their homes and communities, resulting in unmet behavioral health needs that are associated with numerous poor outcomes.[2]
- An estimated 16.2 percent of children enrolled in Medicaid or the Children's Health Insurance Program (CHIP) received a behavioral health service in 2019. Those figures increase for children involved with child welfare, with 45 percent receiving services in 2019.[3]
- Families who have children with behavioral health needs are more likely to experience financial burdens and out-of-pocket costs, particularly when they have private insurance. This places families at risk of involvement in multiple public child- and family-serving systems, including child welfare and juvenile justice, due to increased stressors in the home. Many of these families may ultimately tap into Medicaid resources once more systems become involved.
- Public child- and family-serving systems are structured differently in every state, though there are several key federal statutes that provide foundational requirements. Some systems are administered at the state level while others are locally administered, or there

may be a hybrid combination. Systems and agencies vary organizationally in terms of placement under different administrative hierarchies.
- Numerous opportunities exist for Medicaid, behavioral health, and public health leaders to collaborate with other public child- and family-serving systems to implement strategies, including leveraging existing Medicaid authorities, streamlining access to care, and ensuring meaningful use of data and partnerships.

Recommendations

Medicaid, mental health, substance use, and public health leaders and administrators should consider the following recommendations:

- Familiarize themselves with the public child- and family-serving system structures in their state, learning how each system is organized, who the state and local leaders are and what their priorities are for improving care for children with behavioral health needs and their families.
    - Utilize a systems of care approach, collaborating with the other public child- and family-serving leaders, including child welfare, juvenile justice, intellectual and/or developmental disabilities departments, education, and housing services, along with families, youth, and community partners, to improve access to timely, effective, and high-quality services and supports:
    - Using Medicaid State Plan Amendments and waivers to support children and youth to receive behavioral health treatment and services in their homes and communities and ensure full implementation of Early and Periodic Screening, Diagnostic, and Treatment
    - requirements.
    - Partnering to support effective provision of services to children, youth, and families through available and emerging Certified Community Behavioral Health Centers.
    - Ensuring that the provisions of the Consolidated Appropriations Act, 2023, Section 5121 are fully implemented to reduce fragmented care for youth involved with the juvenile justice system.[4]
    - Supporting single points of access or entry along with “no wrong door” approaches to ensure that children and families can access behavioral health treatment and services when they need them.
    - Ensuring meaningful participation of Medicaid, behavioral health, and public health leadership and administrators in interagency children’s systems governance structures, including Children’s Cabinets and Councils.
    - Engaging in ongoing, meaningful use of data, including for strategic planning and quality improvement.

Introduction

PURPOSE

It is common for youth with behavioral health needs and their families to be involved with multiple child- and family-serving systems, including child welfare and juvenile justice systems.[a] These youth, many of whom are enrolled in or eligible for Medicaid, may experience or be at risk for out-of-home care. These settings may not be home- or community-based services compliant and might include restrictive environments, particularly when one or more systems designed to support children and families are unable to provide, coordinate, or maintain accessible services at the necessary intensity to address unmet behavioral health and service needs across the family unit. These youth and their families may face overwhelming and conflicting requirements from various agencies or even through court mandates, and experience additional stress and burden from having to navigate fragmented care across siloed public child- and family-serving systems.

It is important for state and local behavioral health, Medicaid, and public health leaders to understand their state's child- and family-serving systems to develop and support collaboration to improve access to effective services to address needs. When these leaders have a foundational understanding about other public child- and family-serving systems, they can collaborate across those systems to leverage financing, interventions, and infrastructure to sustain a broad, coordinated, and accessible array of effective services and supports. This reduces barriers and increases efficiencies, which has benefits for both families and systems. Ideally, these leaders will also be aware of children and families' needs as youth begin to transition into adult services.

However, children and families experience and interact with public child- and family-serving systems and agencies in different ways, depending on the agency, state, and identified need. No one public child- and family-serving agency is solely responsible for providing and coordinating behavioral health care. Many variations exist within systems, based on federal, state, and local laws and rules; how populations are defined; how access is structured; which financing strategies are used; the available service array for each population and geographic area; and whether there is a justice overlay that mandates certain restrictions on youth.

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[a] A note about language: Throughout this paper, the term "Medicaid" is generally meant to be inclusive of CHIP. Similarly, the terms "child" and "youth" are used somewhat interchangeably. The term "behavioral health" is used to include mental and emotional health. Behavioral health as used in this paper includes substance use treatment needs, either in conjunction with other mental health or emotional needs or on their own. The authors recognize that this language is an oversimplification of the experiences of children and families, and that not every youth with behavioral health needs will have challenges in multiple domains. Moreover, it does not reflect the complexity of needs nor how individual disorders may co-occur with other disorders or symptoms. It does not fully account for evidence regarding intellectual and developmental disabilities and how they may co-occur with other behavioral health needs. Finally, the authors recognize that needs and behaviors exist on a continuum, and children exist within families, homes, and communities, all of which must be considered when examining behavioral health needs and when planning and engaging the youth and their supports to improve access and care.

This paper introduces behavioral health, Medicaid, and public health agency leaders, administrators, managers, and policymakers to selected public child- and family-serving systems. It also describes the population of youth with unmet behavioral health needs; reviews the child welfare, juvenile justice, intellectual and/or developmental disability (I/DD), education, and housing/homelessness prevention systems in brief; and identifies opportunities to build and maintain systems and support collaboration to prevent multisystem involvement and keep children and families in their homes and communities.

While this paper elevates some of the relevant statutes, regulations, policies, and approaches within each system, it is evident that the responsibility for accessible, affordable, effective, and high-quality care and support for children with behavioral health needs and their families is diffused across the public and private sector at the federal, state, and local levels. Although each individual agency or system may have a mandate and responsibilities, the children's behavioral health system is, in fact, a complex web of agencies, requirements, approaches, funding, access points, and services. At its best, public and private systems partner with families and youth, providing a clear locus of accountability for services and outcomes with coordination across providers, settings, and domains. Frequently, however, many children, families, and providers experience fragmented systems with both areas of duplication and gaps that can exacerbate needs. The charge, therefore, is for the children's behavioral health system—inclusive of public and private child- and family-serving agencies—to recognize the challenges and embrace opportunities to collaborate, coordinate, and align within and across agencies and systems in partnership with and on behalf of children, youth, and families.

Although each individual agency or system may have a mandate and responsibilities, the children's behavioral health system is, in fact, a complex web of agencies, requirements, approaches, funding, access points, and services.

BACKGROUND

An estimated 22 percent of the child population in the United States experiences mental, emotional, or behavioral health challenges.[5] The likelihood of these challenges increases significantly depending on the number and type of risks a child has faced, ranging from 15 to 60 percent for some populations.[6,7]

For decades, children and youth with behavioral health needs have struggled to get access to timely, responsive, effective, and high-quality treatment and interventions in their homes and communities,[8] with one study finding that half of U.S. children with a mental health condition did not receive needed treatment.[9] Unmet behavioral health needs are associated with numerous poor outcomes,[10] including long-term negative impacts related to health, functioning, and transition to adulthood.[11]

An estimated 16.2 percent of children enrolled in Medicaid or CHIP received a behavioral health service in 2019.[12] Those figures increase for children involved with child welfare, with 45 percent receiving services in 2019.[13] In 2022, total behavioral health expenditures for youth ages 6–17 across payors (including Medicaid, private insurance, and out-of-pocket) was $41.8 billion, and an average of 8.5 million children had some type of behavioral health expenditure annually from 2011 to 2022.[14] During that period, almost 40 percent of all behavioral health spending for children ages 6–17 was paid for by public insurance.

Spending has increased over the past decade due to several factors, and families in the United States have been experiencing increased financial burden and out-of-pocket costs for children’s behavioral health care.[15] Behavioral health spending on a child in the family was found to be independently associated with high and extreme family financial burden. In many states, services available through Medicaid are more robust than what are available through commercial or private insurance,[16] in part because of CMS’ early and periodic screening, diagnostic, and treatment requirement.[17] Families who are publicly insured are *less likely* to experience high or extreme financial burden for behavioral health compared with families who have private insurance.[18]

When children and families cannot access services through Medicaid because they are privately insured, they are more likely to become involved with more restrictive child- and family-serving systems, such as child welfare and juvenile justice, in order to access services through those systems. Landmark reports in 2000[19] and 2003[20] found that families across the country were relinquishing custody of their children because accessing mental health care for them was too difficult. Families who relinquished custody expressed that they were stressed, at their “wit’s end,” and were surrendering custody to get their children needed services.[21]

Many states do not collect data on the action of custody relinquishment for the express purpose of obtaining mental health treatment[22] and many states use strategies like voluntary placement agreements to reduce the use of custody relinquishment for that purpose. Even the use of voluntary placement agreements can have negative outcomes, with youth being more likely to be placed in restrictive settings and to experience multiple placement moves. This may increase the risk of the youth and their families experiencing trauma, grief, and diminished decision-making authority, as well as challenges in exiting from care.[23]

The Substance Abuse and Mental Health Services Administration (SAMHSA) defines SED as someone under the age of 18 having (within the past year) a diagnosable mental, behavioral, or emotional disorder that resulted in functional impairment that substantially interferes with or limits the child’s role or functioning in family, school, or community activities.

SED does not include intellectual and/or developmental disability alone, but individuals with other mental, behavioral, or emotional disorders and I/DD can qualify as having SED if the SED is what is causing the functional impairment.

Children and youth with behavioral health needs who become involved with multiple systems, including child welfare and juvenile justice systems (regardless of whether they are entering for ostensibly behavioral health treatment reasons), often meet the criteria for what is broadly referred to as serious emotional disturbance or disorder (SED). SED is not a diagnosis but a category that is used to help identify children and youth who may need significant support to improve their social and emotional well-being across life domains.[b] An estimated 4.6 million U.S. children ages 9–17 were identified as having an SED in 2024.[24]

The Link Center is a federal program that bridges disability and mental health systems by supporting state agencies with policy development, service design, and service coordination to help support children and adults with intellectual and developmental disabilities, brain injuries, and other cognitive disabilities who also have mental health conditions.

There are numerous pathways to care, some more direct than others. In many systems, whether a child accesses services through a mental or behavioral health service versus the child welfare or juvenile justice system may be random, or the result of inaccessible systems or insufficient availability of services. Children involved with child welfare, juvenile justice, or with I/DD are disproportionately represented within this population of children and are more likely to have any number of behavioral health conditions and increased trauma than youth who are not involved in multiple systems.[25] Across systems, children with I/DD are less likely to receive mental health diagnoses and related treatment, as their behavior may be attributed to their I/DD. Psychiatric and behavioral symptoms can be misattributed to and overshadowed by their I/DD, which can reduce who is assessed and then determined to have a behavioral health treatment need.[26] Families of children with co-occurring I/DD and behavioral health needs are more frequently referred to the child welfare system.[27,28,29] A recent study found that adults diagnosed with autism spectrum disorder (ASD) when they were children were less likely to have a current diagnosis of a mental illness (in addition to ASD) as an adult than adults who did not receive their ASD diagnosis until adulthood. Researchers note that this could be related to various factors, including earlier misdiagnoses or co-occurring mental health conditions that delayed ASD diagnosis.[30] Regardless, this further emphasizes the complexity of the issue and the need for improved education among treating providers.

Comparisons of absolute prevalence rates of youth with behavioral health diagnoses in different systems are fraught, since different data sources, different means of discerning diagnoses, and different years are examined in relevant studies or administrative datasets. For example, a 2016 meta-analysis examined eight studies that investigated child welfare populations across five different countries from 1996 to 2013, and found that 49 percent of youth had common diagnoses, including disruptive disorder (conduct disorder, oppositional defiant disorder), ADHD, anxiety, depression, or trauma.[31] A 2019 study based on U.S. Medicaid/CHIP data found that 43 percent of Medicaid/CHIP beneficiaries ages 3–17 in child welfare had at least one behavioral health condition.[32] Each of these reports also noted that many of these children did not receive treatment despite a diagnosis. The various sources share a common theme: children in these systems have a higher likelihood of having a behavioral health condition compared with children in the general

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[b] See *Serious Emotional Disturbances in Children, Youth, and Young Adults*, a companion paper prepared for the Substance Abuse and Mental Health Services Administration (SAMHSA) under Task 2.2 of NASMHPD's Technical Assistance Coalition Contract/Task Order, for more information on SED. This paper includes a more detailed overview of SED, the role of functional impairment in identifying youth with SED, important developmental considerations, best practices in assessment and treatment approaches, and a discussion of long-term maintenance strategies and policy supports to sustain functioning gains.

population, and despite their involvement in public systems, they often do not have access to appropriate diagnostic assessments or treatment.

Public Child- and Family-Serving Systems

As discussed above, children and youth with behavioral health needs are often involved with multiple public child- and family-serving systems, each of which is structured differently within states and communities. The sections below provide a high-level overview of key systems to support opportunities for collaboration, improved coordination, and financing of care. This paper provides an expanded look at the child welfare system because of the high proportion of children and youth with behavioral health needs who are involved with the child welfare system and the high behavioral health service utilization of children and youth involved with child welfare.

CHILD WELFARE

The public child welfare system in the United States has evolved through multiple eras. The New York Society for the Prevention of Cruelty to Children, established in 1875, marks the birth of the formal child protective service system through nongovernmental organizations. The modern child welfare system has its origins in the Social Security Act of 1935, but the federal government did not play a significant role in child protection until the passage of the Child Abuse Prevention and Treatment Act (CAPTA) of 1974, which has been reauthorized multiple times since.[33,34]

"CAPTA provides federal funding and guidance to states in support of prevention, assessment, investigation, prosecution, and treatment activities and also provides grants … for demonstration programs and projects."[35] Additionally, CAPTA identifies the federal role in supporting research, evaluation, technical assistance, and data collection activities; establishes the Office on Child Abuse and Neglect; and establishes a national clearinghouse of information relating to child abuse and neglect. CAPTA also sets forth a federal definition of child abuse and neglect.

Federal statute defines child abuse and neglect (commonly referred to as child maltreatment) as, "Any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or an act or failure to act, which presents an imminent risk of serious harm."[36] CAPTA was modified in 2015 to expand the definition to include youth who are identified as being a victim of human trafficking.[37] However, each state maintains its own definition of child maltreatment within that framework and further defines the standards used to screen referrals for maltreatment, conduct investigations or offer voluntary or alternative responses, and determine whether maltreatment has occurred. States vary considerably in their definitions.[38, 39]

The Congressional Research Service[40] notes that public child welfare agencies work to strengthen families and prevent abuse and neglect; when they are unable to do this and when maltreatment occurs, public child welfare agencies will intervene to ensure the safety and well-being of children. When children are unable to safely remain in their own homes, even with services and safety plans, they will be placed by the child welfare agency in an out-of-home setting, known as foster care. The total number of children entering foster care has decreased in recent years, with 170,943 children entering foster care during federal fiscal year (FFY) 2024 down from 252,198 in FFY2019. The number of children in the foster care system overall also decreased, down to 328,947 in FFY2024 compared with 425,974 in FFY2019.[41] The rate of children entering the foster care system has also decreased, from 2.9 per 1,000 children and youth from birth up to age 20 in 2019, to 2.1 in 2023.[42]

Children are more likely to enter the foster care system if they are under age one and/or for reasons of neglect. Most children have a permanency plan of reunification to help them return to their family of origin, and 43 percent live with a relative or kin upon entry into foster care—placement in kinship homes is generally preferred. A small percentage of children and youth are admitted into an institution (4 percent) or residential care (6 percent) upon entry into foster care.[43]

State and local funds supported more than half of all child welfare spending in FFY2022.[44] The majority of federal funding for child welfare, foster care, and adoption activities within states is authorized through Titles IV-B and IV-E of the Social Security Act. Each state receives funding of this type to use for these purposes, generally administered via the child welfare agency. States have the primary public responsibility to ensure the well-being of children and their families and partner with federal, local, and tribal governments; nonprofit organizations; court systems; education; behavioral health providers; and other entities to fulfill this responsibility.[45]

Child welfare agency structure varies by state. Most states have a centralized administrative child welfare system and are considered “state administered.” However, nine states (California, Colorado, Minnesota, New York, North Carolina, North Dakota, Ohio, Pennsylvania, and Virginia) are “county administered,” with greater responsibility for child welfare funding, policymaking, licensing, training, and other activities held at the county rather than the state level. Two states—Nevada and Wisconsin—are considered “hybrid” states because they are partially administered by the state and partially administered by the counties or regions.[46]

The modern public child welfare system is organized around three broad goals that were established in updates to the Social Security Act: safety, permanency, and well-being. These outcomes are operationalized through a variety of measures, including seven objectives that are measured through the Child and Family Service Review (CFSR) process:

- Safety
  - Children are, first and foremost, protected from abuse and neglect.
  - Children are safely maintained in their homes whenever possible and appropriate.
- Permanency
  - Children have permanency and stability in their living situations.
  - The continuity of family relationships and connections is preserved for children.
- Well-Being
  - Families have enhanced capacity to provide for their children’s needs.
  - Children receive appropriate services to meet their educational needs.
  - Children receive adequate services to meet their physical and mental health needs.[47]

The CFSR process is a five-year cycle. However, each year, states must submit an Annual Progress and Services Report (APSR), often referred to as a Title IV-B report, to provide a narrative report on progress made toward meeting goals and objectives.[48] This is often an opportunity for states to showcase their interagency initiatives across public child- and family-serving systems to improve well-being for children and families in their state.

State, local, and tribal governments design and implement a variety of prevention and early intervention services and often provide services to children and families within their homes, even if a report of potential child maltreatment has been received.[49] Many states have leveraged opportunities within the Family First Prevention Services Act (FFPSA, PL 115-123), Title IV-B, and Medicaid to provide services and supports to children and families so that they remain in their homes and communities. During FFY2023, 25 states, the District of Columbia, and one tribe claimed Title IV-E prevention services funding for approximately 18,300 children each month who were identified as being at imminent risk of foster care.[50] Although almost all states have an approved IV-E prevention plan, designing and implementing these prevention plans remains a challenge.[51,52] Additionally, 11 states and Puerto Rico have approval to claim Title IV-E kinship navigator funds to support kin caregivers to access supports.[53] Like with behavioral health services, while core services are available in every state, the specific service array available to children involved with child welfare varies by state and even county or region. FFPSA also established new requirements for states to access Title IV-E funds for eligible children living in child caring institutions (CCI). This included creating qualified residential treatment programs (QRTPs), which are a type of CCI that meets a specific set of quality criteria, overseen by each state in accordance with FFPSA requirements.

JUVENILE JUSTICE

The first juvenile court was established in 1899 in Chicago. By 1924, there was a functioning juvenile court in almost every state with "jurisdiction over neglected, dependent, and delinquent children under 16."[54] The early juvenile courts' goal was rehabilitation instead of punishment and children under 12 were barred from detention in jails. In the second half of the 20th century, three Supreme Court decisions (*Kent v. United States, in re: Gault,* and *in re: Winship)* led to more procedural formality in juvenile court while maintaining differences between juvenile and criminal courts.[55] In the 1960s, many states modified laws so that status offenders (youth who were involved in unlawful acts that are unlawful due to age, such as truancy, running away, curfew violations, etc.) and nonoffenders could be addressed under other categories, such as *persons or children in need of supervision*. However, reports of youth being abused in training and reform schools and high numbers of youth being held in adult facilities led to the passage of the seminal Juvenile Justice and Delinquency Prevention Act (JJDPA) of 1974.[56]

JJDPA established core requirements to protect youth in the juvenile justice system, including deinstitutionalizing youth found guilty (known as "delinquent" in juvenile justice parlance) of status offenses, and separating youth from adults in secure facilities (the "sight and sound separation" requirement). It also established the Office of Juvenile Justice and Delinquency Prevention (OJJDP) within the Justice Department and charged it with providing national leadership, funding, and resources to help state, local, and tribal communities to prevent delinquency and improve juvenile justice systems. In 2018, JJDPA was reauthorized and amended to include a core requirement that emphasized the need for concrete actions and added an expanded jail removal requirement for youth who are charged as adults.[57]

Regardless of the state, multiple opportunities for diversion are available to youths who become involved with the juvenile justice system; multiple decision points can result in various outcomes, including dismissal, release, probation, or residential placement. Serious offenses can result in a youth being waived to the adult criminal system.

While some federal laws guide how youth are treated, the structure of juvenile justice systems varies by state. A 2019 review found considerable variation even in the way that states define the purpose of their juvenile justice systems: Some referenced the idea that the state is the designated protector of children, others note the need for due process, and many speak to balanced and restorative justice, a reform approach that was especially promulgated in the 1990s. A small number of states also mention the use of adolescent development or require the use of evidence-based practices.[58]

States structure their juvenile justice services differently and the language used to refer to youth in various phases of justice involvement, the sentencing process, the places youth are held, and the names of courts all vary across states. As of 2022, 11 states operated juvenile justice services at the state level and all but one of those states had centralized authority within a single agency. Almost half of states (22) organize services mostly at the state level and many (18) organize most or all services locally.[59] As of 2020, 42 states had implemented a statewide uniform risk/need assessment related to juvenile probation. Five states have a layered/regional assessment and four have a locally administered assessment.[60] Juvenile detention alternative initiatives created major reforms in the early 2000s, which helped reduce the number of youth held in detention pretrial.[61] Still, juvenile justice systems have secure facilities for both detention and commitment after adjudication. The juvenile justice system may impose mandates and prohibitions on the activities of the youth even when they are in community settings.

Juvenile and other courts may have specialty treatment courts to also affect disposition, including juvenile drug courts and other treatment courts. In 2024, the United States had 51 juvenile mental health courts, 256 juvenile drug treatment courts, and 7 juvenile co-occurring disorder courts.[62] Although beyond the scope of this paper, juvenile courts are also increasingly ordering examinations of a youth’s competence to stand trial; statutes around the country are specifically written to address this area.

In 2022, the National Governors Association conducted a series of learning calls and hosted a roundtable focused on addressing the collateral consequences and needs of justice-involved youth. They identified that youth and families can experience adverse impacts from interaction with the juvenile justice system that can extend well beyond the original incident. They identified that systems would benefit from a comprehensive, multisystem response, and noted that improving data collection and meaningful data use, raising the minimum age for a youth to be transferred to adult court, increasing the use of diversion and deflection programs, and supporting reentry programs for youth leaving the juvenile justice system, can all mitigate the impact on youth and their families.[63]

INTELLECTUAL AND DEVELOPMENTAL DISABILITY SERVICES

In the 1950s and 60s, state services for children and adults with I/DD were mostly provided through institutional settings or some limited subsidized day activity centers. In 1961, President

John F. Kennedy appointed an expert panel, which offered 97 recommendations to improve research, training, income maintenance, and service programs for individuals with I/DD.[c]

Prior to 1975, children with disabilities were denied access to public education or segregated from schools' general populations. The Individuals with Disabilities Education Act (IDEA) of 1975 gave eligible children with disabilities the right to a free appropriate public education in the least restrictive environment. It also established requirements for individualized education programs (IEPs) and due process protection for families. The Americans with Disabilities Act (ADA) of 1990 (now amended through the ADA Amendments Act of 2008) expanded these civil rights protections beyond education and prohibit discrimination based on disability.[d] For children, it also granted access to various community programs and accommodations, where states leverage Medicaid waivers to finance services and supports in the home and community.[64, 65]

Figure 1: Definition of Developmental Disability (2000)

Definition According to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, a developmental disability is a severe, chronic disability of an individual that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in 3 or more of the following areas of major life activity (Self-care, Receptive and expressive language, Learning, Mobility, Self-direction, Capacity for independent living, Economic self-sufficiency) and
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 was established "to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration in all facets of community life."[66] This law was first passed in 1975 and amended multiple times before being further updated and enhanced in 2000, when it authorized state councils on developmental disabilities in each state; protection and advocacy systems in each state; university centers for

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[c] The language in use at the time of the panel and subsequent recommendations and legislation was to address "mental retardation." However, this paper is using the language of intellectual and/or developmental disabilities (I/DD) to reflect an updated understanding and preferred nomenclature.

[d] It is important to note that a "disability" in accordance with the ADA includes any number of diagnoses and circumstances, including mental illnesses, and is not particular to intellectual and developmental disabilities.

excellence in developmental disabilities education, research, and service; and funding for various initiatives related to data collection and technical assistance.[67] In 2000, the law also clarified that a child under 9 years old can be considered to have a developmental disability without meeting three or more of the criteria (**Figure 1)** if the individual has a high probability of meeting these criteria later in life if they do not receive services and supports.

Today, services for children with I/DD involve a network of public agencies, community organizations, schools, and health centers that aim to help children reach their potential and protect their rights. At the federal level, just as SAMHSA has the purview over mental health and substance use services, the Administration for Community Living has the federal mandate to oversee the services and needs of people with I/DD. This responsibility includes focus on protection and advocacy, the DD Councils, data collection, and projects of national significance to enhance full integration and inclusion in the community. In FY2023, total public spending on I/DD services for children and adults reached $104.6 billion; $86.9 billion of those funds were from Medicaid (including the state share of funds). Title XX/Social Services Block Grant, administered by HHS's Office of Community Services within the Administration for Children and Families, which has its focus on youth and their families, was the largest non-Medicaid source of federal funds in FY2023 ($296 million). Funds have continued to be used increasingly for community services.[68]

As discussed above, many children with I/DD are involved with other systems and have co-occurring needs. As such, many of the services and supports for children with I/DD are provided through the education systems (described below), Medicaid, and even child welfare and juvenile justice agencies. Children and youth who require additional or ongoing supports to address I/DD service needs as they transition to adulthood may need assistance to ensure that there are no gaps in care or coverage. A new federally supported Center for Transition to Adult Health Care for Youth with Disabilities was established to support youth and young adults ages 12–26 with I/DD to transition to adult care.

EDUCATION SYSTEMS

States and local governments have the primary responsibility for establishing policy and providing funding for education. Numerous federal laws impact education:

- the Elementary and Secondary Education Act (ESSA), enacted in 1965 and last reauthorized in 2015;
- IDEA, which guarantees access to a free appropriate public education in the least restrictive environment to every child with a disability;
- the Rehabilitation Act of 1973, which includes support for vocational rehabilitation to help individuals with disabilities, and includes Section 504,requiring organizations that receive federal funds to ensure that people are not prevented from participating in programs, including receipt of benefits, based on barriers ascribed to their disability; and
- the Higher Education Act of 1965, last reauthorized in 2008 (PL110-315).

Early childhood, K-12, and post-secondary education and services are structured differently in every state. The Education Commission of the States observes that multiple agencies often oversee different programs across early care and education, including home visiting, childcare, and quality systems.[69] They note that most states have one of three structures: an agency created to oversee several early care and education programs (11 states), a consolidated agency that has pulled several agencies or programs into one agency (14 states and DC), or a coordinated approach, with various agencies providing services and programs (25 states).[70] Each state is required to have a State Advisory Council on Early Childhood and Care. These councils are charged with developing high-quality and comprehensive early childhood systems and promoting statewide coordination and collaboration.

A recent scan[71] found that states offer an average of 17 different early childhood education, health, and family and economic support programs. Nearly half of states house programs across three or four different departments or agencies. This mirrors the federal structure, where these programs are spread across agencies of HHS, Education, and Agriculture. Examples of these programs include Medicaid and CHIP, Early Intervention (Part C), Pre-K, childcare subsidies, the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program, Head Start, and WIC. The K-12 education structure varies across states, with half of state constitutions outlining a formal role for their governor specific to education. Every state has language in their constitution related to education, and state board of education authorities are outlined across state constitutions and statutes.[72] As of 2020, 34 states have an executive-level secretary or administrator of education, and all but two states (Minnesota and Wisconsin) have a state board of education. The specific responsibilities and powers of the state boards also vary, from providing guidance and advisory functions to appointing the commissioner or secretary and approving budgets.[73]

Most of the funding for education comes from state and local sources, with federal funding accounting for only about 10 percent of the total budget.[74] Federal funding for education is provided by multiple agencies. The funding can be provided to state educational agencies (SEA), local educational agencies(LEA), and other organizations. For example, early intervention funds (Part C of IDEA) are provided by the Office of Special Education and Rehabilitative Services in the U.S. Department of Education to SEA through formula grants.[75] However, MIECHV funds are awarded using a base funding amount with additional funds awarded, subject to availability of funds; funds are awarded to states, jurisdictions, and nonprofit organizations.[76] Some federal funds are provided to SEA to be passed through to LEAs or other entities, such as the formula funding for special education under IDEA Part B.[77]

HOUSING AND HOMELESSNESS PREVENTION SERVICES

Housing availability can impact overall health[78] and youth experiencing housing instability are less likely to receive mental health services and more likely to experience anxiety and depression.[79] The U.S. Department of Housing and Urban Development (HUD) is a key player in preventing homelessness and increasing access to safe and affordable housing. However, a broad network of programs, resources, and supports exists to address this need.[80]

SAMHSA's Homeless and Housing Resource Center is a federal resource that assists states and providers to meet the housing needs of individuals with serious behavioral health challenges, including children and youth. In October 2025, the Resource Center updated a report that includes examples of how local communities partner across housing and behavioral health to support individuals and families with unmet behavioral health needs.[81] Additionally, Medicaid is a critical support for individuals experiencing homelessness and housing instability, and *A Primer on How to Use Medicaid to Assist Persons Who are Homeless to Access Medical, Behavioral Health, and Support Services* was developed to support state and local officials to access and coordinate supports for individuals experiencing homelessness.

The responsibility for policy, planning, and programming to prevent and address homelessness and housing instability spans numerous entities. The Family Unification Program (FUP), which supports families involved with child welfare systems, and the Foster Youth to Independence (FYI) program, which helps youth exiting foster care to be stably housed, are administered by state or local public housing agencies in partnership with child welfare agencies using federal funds from HUD. [82] Other funding and support comes from entities like the Family and Youth Services Bureau's Division of Runaway and Homeless Youth, which is part of the Administration for Children and Families.

In addition to public housing agencies, states have state housing finance agencies (HFAs), which are chartered entities that help meet the affordable housing needs of residents. Some HFAs are entities of state government and may be the same as the state public housing agency while others are independent entities with a relationship to the state government. HFAs may administer housing credits, housing bonds, Section 8 Housing Assistance, McKinney-Vento Homeless Assistance Act funds, or Community Development Block Grant Funds.[83]

Opportunities for Medicaid, Behavioral Health, and Public Health Leaders to Improve Public Systems to Limit Multisystem Involvement and Improve Outcomes

For decades, children and youth with behavioral health needs and their families have faced challenges in accessing quality, affordable, and effective care and services, particularly when their needs span multiple public child- and family-serving systems. *Systems of care* is a set of values and principles providing an organizing framework for systems on behalf of children, youth, and their families.[84,85] Within systems of care, intentional planning, structures, coordination, services, care pathways, quality improvement, and other support strategies share a comprehensive spectrum of effective services and supports that include meaningful partnerships with families and youth and incorporate behavioral health promotion, prevention, early identification, and intervention to improve outcomes for and with children and families.[86] Leveraging a systems of care approach can enable states and communities to more effectively support families in their homes and communities without necessitating or prolonging involvement with multiple public child- and family-serving systems. It can also help states to meet Medicaid's early and periodic screening, diagnostic, and treatment requirement, through a shared focus on comprehensive and preventive services.[87,88]

"A **System of Care** is defined as a coordinated network of effective mental health and essential supportive services organized to address and meet the varied needs of children, youth, and young adults, and their families. The systems of care approach strives to ensure that mental health services are family-driven and youth-guided, community based, and culturally and linguistically appropriate." https://www.samhsa.gov/sites/default/files/grants/pdf/fy-2026-cmhi-sm-26-013.pdf

As discussed above, a lack of available behavioral health services can drive other child- and family-serving system involvement. Children, youth, and their families generally receive services based on the particular "door" they first enter. Some access points are voluntary, such as when families seek services for behavioral health needs or substance use services. However, depending in part on how a state has structured its systems, some access points may relate to nonvoluntary interventions, such as court commitments.

Having desirable, accessible, and practical supports for emotional and behavioral needs can help youth and families feel empowered to engage in services. Being mandated to participate can be a barrier to engagement. When services are required, it is significantly harder to develop trust and buy-in from youth and families, which can delay or decrease support effectiveness. Depending on the authority and priorities of the public systems they enter, access and services can look and feel different for each family.

A recent report[89] identified six key strategies that support successful implementation of systems of care, resulting in lower costs and improved outcomes for children with complex behavioral health and related needs and those of their families:

- building trust with families, providers, and other stakeholders;
- advancing a paradigm shift: centering the experiences and voices of individuals with lived experience in designing and implementing services and supports;
- embracing shared decision-making with partners, clarifying the differences among advisory roles, system governance, and system management;
- communicating with intention, using shared language;
- prioritizing home- and community-based services, including mobile response and stabilization services, intensive care coordination using wraparound, intensive in-home services and treatment, peer support, respite care, and trauma-responsive treatment; and
- continuously monitoring and evaluating to track fidelity to models, quality of service provision, satisfaction with services, and key performance measures related to accessibility, quality, and effectiveness.

Many of these strategies are also echoed in the 2023 National Governors Association report on approaches to reduce the impact of justice-system involvement on youth and their families.[90]

Medicaid, behavioral health, and public health leaders and administrators should familiarize themselves with the public child- and family-serving system structures in their state. As described above, each state is structured differently, and it is critical that they know how each system is organized, who the state and local leaders are, and what their priorities are for improving care for children with behavioral health needs and their families. From there, these leaders and administrators can collaborate with the other public child- and family-serving leaders, including in child welfare, juvenile justice, intellectual and/or developmental disabilities, education, and housing services, along with families, youth, and community partners, to improve access to timely, effective, and high-quality services and supports:

- **Using Medicaid State Plan Amendments and waivers to support youth to receive behavioral health treatment in their homes and communities and ensure full implementation of early and periodic screening, diagnostic, and treatment requirements.**
    - The Centers for Medicare & Medicaid Services (CMS) State Health Official letter on *Best Practices for Adhering to Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Requirements*[91] provides numerous examples of strategies[92] that states can leverage to support eligible children and families to access appropriate and needed

behavioral health care. In 2026, CMS issued a *State Medicaid & CHIP Toolkit for Children's Behavioral Health Services and the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Requirements*[93] to provide additional strategies and examples for effective implementation.
  - CMS houses a website of school-based resources that includes information on payment for school-based mental health services, including sample state plan amendments, time study implementation plans, and cost reports.
  - Medicaid and CHIP authorities and flexibilities support implementation of a full continuum of behavioral health crisis and response services, as described in a September 2025 guidance.
  - Many states have included key services identified in the 2013 *Joint CMCS and SAMHSA Informational Bulletin*[94] in their Medicaid service array. States that utilized a 1915(c) Home- and Community-Based Services waiver for children with behavioral health needs were less likely to have children with unmet behavioral health care needs experiencing involvement with the child welfare system.[95]
- **Partnering across agencies to support effective provision of services to children, youth, and families through Certified Community Behavioral Health Centers (CCBHCs).** The number of CCBHCs across the country have been growing; CCBHCs are required to provide the majority of the required services across the lifespan. All CCBHCs must have the capacity to serve children directly, even if they are using designated collaborating organizations that have sufficient expertise and knowledge to provide these supports. Effectively serving children, youth, and families requires unique partnerships across child- and family-serving agencies, particularly since many of the children and youth may be involved with multiple systems.[96,97]
- **Ensuring that the provisions of the** Consolidated Appropriations Act, 2023, Section 5121 are fully implemented to reduce fragmented care for youth involved with the juvenile justice system.[98] The Act requires the provision of screenings and diagnostic services, including behavioral health screening or diagnostic services, and targeted case management and referrals to appropriate services for eligible youth. These youth are defined as individuals who are under 21 years of age and determined eligible for any Medicaid eligibility group, or an individual determined eligible for the mandatory eligibility group for former foster care children, immediately before becoming an inmate of a public institution or while an inmate of a public institution for youth. It also includes youth who were in CHIP and were incarcerated under age 19. States may also suspend or continue providing services rather than terminate CHIP coverage while a child is an inmate of a public institution, which can help mitigate potential gaps in coverage and service provision.[99]
- **Supporting single points of access or entry along with "no wrong door" approaches to ensure that children and families can access behavioral health treatment and services when they need it.** Providing effective and sustainable support for children and youth with behavioral health needs and their families requires constructing a comprehensive behavioral health system: one that is easily accessible to families at the earliest point they need it, and gives options by providing a broad array of services to meet families where they are. One key aspect of moving away from multisystem involvement is to provide seamless access to care for children, youth,

A seamless access to care experience should ensure that families are not required to be the experts on all services and system processes, they need only be experts on their family and needs.

and their families. A single point of entry is an ideal strategy to ensure a streamlined experience for families as they only need to call one number to receive services and support that meet their needs. A seamless access to care experience should ensure that families are not required to be the experts on all services and system processes, they need only be experts on their family and needs.

- **Ensuring meaningful participation of Medicaid, behavioral health, and public health leadership and administrators in interagency children's systems governance structures, including children's cabinets and councils.**
  - Governance structures must have the necessary expertise and staffing to be effective, including having dedicated resources. It is important that the governance structures have sufficient capacity: "Systems of care cannot be governed out of hip pockets. Lack of capacity to govern obviously affects outcomes, builds resentment among stakeholders, unfairly assigns responsibility without providing power, and sends a message that system of care governance is not valued."[100]
  - Many states use children's cabinets as governance structures for their public child- and family-serving systems. Children's cabinets are generally defined as formal, sustained coordinating structures that work across agencies to improve outcomes for children and families involved with public child- and family-serving systems.[101] These structures are helpful to improving public child- and family-serving systems, particularly with regard to youth at risk of involvement with multiple systems, because, "The increasing specialization of government services has led to silos and disconnected services that can be inefficient or ineffective. Moreover, the distribution of responsibility and the specialization within agencies often means that no one entity is responsible for listening to and holistically responding to the needs and aspirations of children and families, the intended beneficiaries of the public investments."[102]
- **Engaging in ongoing, meaningful use of data, including for strategic planning and quality improvement.** To achieve an accessible system that provides equal access for all who need behavioral health services regardless of where they live in the state and the demographic group they belong to, states can conduct a self-assessment and identify structural gaps that impede access and delivery. A self-assessment can include analysis of Medicaid expenditure and utilization for health services using the Faces of Medicaid state toolkit and then developing a strategy to help get to the optimal state for providing children's behavioral health. Spending time on self-assessment can provide data and context for identifying where to deploy existing resources (within and across systems) and clarifying where additional financing is needed to support the vision.
- **Facilitating compliance with mental health parity, consistent with federal law and regulations associated with the Mental Health Parity and Addiction Equity Act (MHPAEA).**[103] MHPAEA requires coverage for mental health conditions and/or substance use disorders to be no more restrictive—meaning it must not be more limited or harder to access—than coverage for physical health conditions. SAMHSA developed a brochure that gives an overview of MHPAEA for individuals and a separate training tool for policymakers on how to implement and comply with federal parity laws. CMS provides tools and guidance for states to ensure they provide comparable access to necessary behavioral health care. A parity exercise that is conducted specifically for children and their families would be beneficial across all health plans, including commercial and Medicaid managed care organizations, as the analysis for

what is covered for children may be indistinguishable when the population is aggregated to include adults.

Conclusion

Families with children who have behavioral health needs that require involvement with multiple systems often face overwhelming and conflicting demands from various agencies, especially when the youth's needs are more complex. Services are often fragmented, with poor coordination between them, placing the burden of navigating these systems squarely on the family. Families must also contend with a wide variety of regulatory realities, community differences, and even variations in whether and how requirements can be imposed. This leaves them juggling multiple plans of care, care managers, treating professionals, and eligibility criteria, making it harder to achieve their goals and often trapping them in a cycle of repeated system involvement.

Each public child- and family-serving system has its own mandates and priorities, but also has a responsibility to serve these children and their families. It can be challenging for public systems to determine how they can best support families to address behavioral health needs, and it can be daunting for Medicaid, behavioral health, and public health leaders and administrators to engage in children's systems when they have more experience and are more familiar with adult systems. All too often, barriers stem from a lack of awareness or knowledge about a different system, thereby foreclosing further dialogue. Fostering an effort to learn is critical, because it allows leaders to come to the table ready to share their expertise and engage in dialogue about possible solutions to addressing pressing needs.

The solutions are not easy, but many strategies are known. Some strategies suggest emphasizing upstream approaches to focus on prevention while still addressing and building resources for youth with complex and intensive needs. States can lead coordinated efforts to bridge gaps in care by requiring system collaboration to reduce a segmented and ineffective service delivery system and by actively working to ensure the availability of a broad array of services so that children, youth, and families have service options available where and when they need them. Investing in a service array that is steeped in system of care values and principles and provides a single point of entry or access to receive behavioral health and other needed supports, can have a meaningful impact on children and families, resulting in diversion from child welfare and juvenile justice systems, and thereby preventing the need for multisystem involvement in the first place.

Appendix: Additional Resources to Learn More About Child Welfare and Juvenile Justice

CHILD WELFARE

- Child Welfare Information Gateway. (2025). How the child welfare system works. U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. https://www.childwelfare.gov/resources/
- Child Welfare Information Gateway. (2025). *Major federal legislation concerned with child protection, child welfare, and adoption.* U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau: https://www.childwelfare.gov/resources/major-federal-legislation-concerned-child-protection-child-welfare-and-adoption/
- National Academies of Sciences, Engineering, and Medicine. (2019). Child Welfare System (Chapter 8). *The Promise of Adolescence: Realizing Opportunity for All Youth.* Washington, DC: The National Academies Press. https://doi.org/10.17226/25388.
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