THE LINKCENTER

Cross-System Strategies to Support Children with Complex Behavioral Health Conditions

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A PLACE THAT IS SAFE **TREATMENT TO HEAL** **OPPORTUNITIES TO GROW**

A Product of The Link Center: The Link Center is a Project of National Significance led by the National Association of State Directors of Developmental Disabilities (NASDDDS) in partnership with the National Association of State Mental Health Program Directors (NASMHPD), the National Association of State Head Injury Administrators (NASHIA) and NADD. The Link Center is funded by the Administration of Community Living (ACL), in collaboration with the Substance Abuse and Mental Health Services Administration (SAMHSA).

Executive Summary

Children with complex behavioral health conditions and their families face significant barriers to accessing effective services and state agencies struggle to meet their needs. What unifies the children with complex conditions is dysregulated behavior — conduct that is difficult to understand and manage, and that may pose a danger to the child or others. Because the children are often served by multiple systems simultaneously, meaningful support requires collaboration across agencies, reconciliation of conflicting rules, and coordination of different funding sources and authorities.

Neuroscience offers essential insight into dysregulated behavior. Understanding how the brain develops, how neurodevelopmental disabilities and trauma affect that development, and how the brain's plasticity enables recovery and growth provides a foundation for effective intervention.

A neuroscience-informed approach to serving children with complex behavioral health conditions rests on three essential pillars: each pillar is necessary but not sufficient alone—all three must be present and integrated for children to thrive.

A Place That is Safe

A place that means more than physical and emotional safety. It must be a place that understands behavior as communication, that offers connection to others, that incorporates physical and brain health practices into daily routines and makes sure that life is full of fun.

Treatment to Heal

Healing occurs from evidence-based treatment, daily activities and practices that promote brain health and reduce stress, learning self-regulation skills, and getting support to function in school and at home.

Opportunities to Grow

Children’s brains are growing. They need opportunities, structure and guidance through both education programs and in their home and community. Both education and Home and Community-Based Services can provide those opportunities.

Ultimately, meeting the needs of children who have complex conditions and their families demands that systems be structured not just to deliver services, but to actively collaborate on solutions — coordinating care across agencies with shared purpose and accountability.

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Introduction

Children with complex behavioral health conditions and their families face significant barriers to accessing the services and support necessary to meet their emotional, developmental, and behavioral needs. This publication responds directly to those challenges — and to the ongoing struggles of state agencies across behavioral health, child welfare, Medicaid, developmental disabilities, acquired brain injury, education, and juvenile justice — to deliver effective, community-based services and support to this population.

The most pressing challenge reported by both families and states is behavior that is difficult to understand, manage, and that may pose a danger to the child or others. When appropriate services and support cannot be identified or accessed in a timely way, the consequences are serious: children may spend extended periods in emergency rooms, be temporarily housed in hotels or child welfare offices, or be placed in out-of-state residential facilities far from their families and communities.

Understanding children with complex conditions requires examining multiple dimensions of their lived experience, including developmental history, trauma exposure, neurodevelopmental disabilities, co-occurring mental and physical health conditions, and family context. While each child presents a unique constellation of needs, recognizable patterns emerge that can meaningfully inform service planning and delivery.

In this report you will find information to strengthen systems of care for children with complex behavioral health conditions. The report:

- Describes what makes children's needs complex
- Identifies evidence-informed services and supports that are effective
- Illustrates state strategies to provide services and create a system of care

State leaders will find information to make informed decisions related to policy, service design, financing strategies, data use, and capacity building.

Providers will find the report valuable for deepening their understanding of children with complex needs and learning about service approaches and supports that have demonstrated effectiveness in meeting those needs.

Families and advocates may find the report useful as a resource for understanding the range of conditions often associated with complexity, as well as the services and supports necessary to address them, strengthening their ability to advocate for appropriate care and system change.

METHODOLOGY:

This project employed a multi-faceted methodology to gather comprehensive data and provides a thorough understanding of current practices and innovative approaches.

- **Data Scan:** Comprehensive review of current research on neurodevelopmental disorders and evidence-based interventions, state and subject matter expert surveys from twenty-two unique states and thirty subject matter experts, and expert interviews with 30+ subject matter experts including people with lived experience, psychologists; psychiatrists; neuropsychologists; medical doctors; therapists; training directors; parents and caregivers; and state agency administrators
- **State-Level Policy Review and Analysis:** Examination of policies, funding mechanisms, and service delivery models in nine states.
- **Focus Groups:** Five focus groups involving state representatives and subject matter experts to discuss challenges and solutions
- **Children's Summit:** A multi-organizational in-person, full-day summit with over sixty state administrators, subject matter experts, and federal partners in attendance

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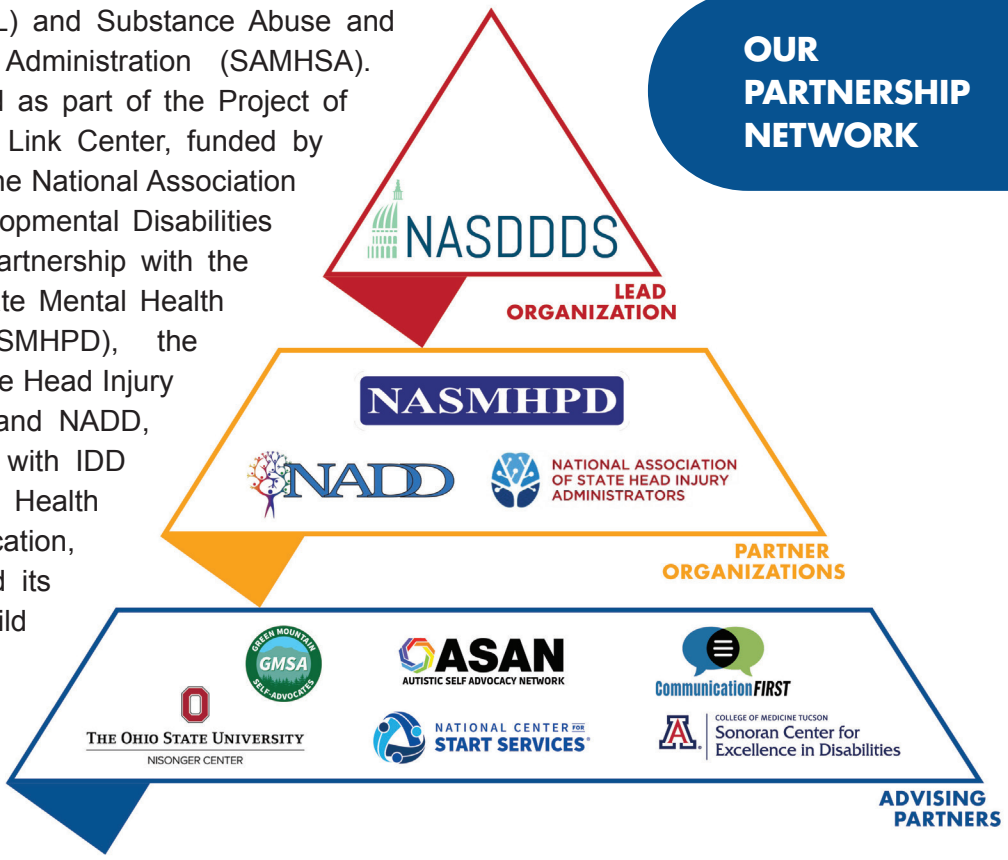
OUR PARTNERSHIP NETWORK



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"When you see a child differently, you see a different child."

— Dr. Stuart Shanker

1. Understanding Children with Complex Behavioral Health Needs

This section provides a profile of children with complex behavioral health conditions:

- Age and gender
- Behavior challenges and emotional dysregulation
- Neurodevelopmental conditions
- Mental health conditions
- Diagnostic overshadowing
- Trauma history
- Family context

Source: Survey of State Agencies and Subject Matter Experts.

The term “children with complex behavioral health conditions” describes children and youth whose behavioral, emotional, and developmental needs are so challenging that traditional service systems struggle to support them effectively. These children often experience multiple, interconnected challenges that require coordinated, intensive, and highly specialized interventions across multiple systems of care.

Understanding children with complex conditions requires examining multiple dimensions of their experience, including their developmental history, trauma exposure, neurodevelopmental profiles, mental and physical health conditions, and family context. Each child presents a unique constellation of needs, but common patterns emerge that can guide service planning and delivery.

This document presents information about children who have complex conditions as described by state agencies. It is a summary of the responses from 21 state agencies to a survey conducted in May 2025. The results are a composite picture of children and do not describe every child or any one child. Each child is unique, as are their conditions and life experiences. The following are the major characteristics of children viewed as presenting complex conditions by age, behavior, trauma history, types of neurodevelopmental disorders, and types of physical and mental health conditions.

Age and Gender

Children with complex behavioral health conditions are typically identified during middle childhood through adolescence (ages 8-18), with boys more frequently diagnosed, though warning signs often emerge earlier. While the underlying condition may be long-standing, the transition to adolescence brings significant physical, psychological, and emotional changes. As these young people grow larger, stronger, and more physically mature, they become both more capable of actions that may endanger themselves or others and more vulnerable to dangerous situations. Although behavior is what brings them to the attention of state leaders, it is their increasing size, strength, and maturity that intensify concerns about these behaviors and their potential consequences.

State Survey Results:

1. 13-17 yrs
2. 6-12 yrs
3. 18-21 yrs
4. 0-5 yrs

(Type of developmental diagnosis in order of the most frequent to least frequent response)

Behavioral Challenges – Emotional Dysregulation

The defining characteristic of this population is persistent, severe dysregulation—difficulty managing emotions, impulses, and behavioral responses. This dysregulation manifests in various ways: physical aggression, property destruction, rapid and intense mood shifts that are difficult to predict or de-escalate; impulsivity–acting without consideration of consequences, leading to dangerous or disruptive behaviors; elopement; rejection of caregivers; fire setting; sleep disturbance; enuresis; feces smearing; attempted suicide; self-abuse and self-mutilation (e.g., cuts, burns, rectal digging); pica; and sexual acting out such as public masturbation or promiscuity. **Children may exhibit behaviors considered problematic when they are in fact efforts to self-soothe or self-regulate. Examples of such behaviors include head or body rocking, flicking fingers, spinning, or shaking hands in the air.**

Emotional dysregulation may be a result of things like trauma, neurological injury, genetic predisposition, psychiatric disorders, and developmental disabilities. These factors can reduce a person's ability to identify and regulate emotions, resulting in impulsive and intense behavior and may affect communication, motor function, cognitive processing, sensory integration, and memory.

It is critical to understand that these behaviors are not volitional misbehavior—they are responses to underlying conditions and unmet needs and attempts to communicate. The behaviors represent a physiological response to overwhelming internal or external experiences.

> *". . .neuroscience research shows that very few psychological problems are the result of defects in understanding; most originate in pressures from deeper regions in the brain that drive our perception and attention. When the alarm bell of the emotional brain keeps signaling that you are in danger, no amount of insight will silence it."*
>
> — **The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma,** Bessel A. van der Kolk

State Survey Results

- Physical aggression
- Disruption/dysregulation in structured settings
- Suicidal ideation/self-harm
- Property destruction
- Inappropriate sexual behaviors
- Elopement

(Type of developmental diagnosis in order of the most frequent to least frequent response)

Neurodevelopmental Disorders

Many children with complex behavioral health conditions have underlying neurodevelopmental disorders that affect brain structure and function such as:

- **Autism Spectrum Disorder (ASD):** Differences in social communication, sensory processing, and behavioral flexibility

- **Intellectual and Developmental Disabilities (IDD):** Limitations in intellectual functioning, adaptive behavior, communication, social skills, and daily living
- **Attention-Deficit/Hyperactivity Disorder (ADHD):** Persistent inattention, hyperactivity, and impulsivity that interferes with functioning
- **Fetal Alcohol Spectrum Disorders (FASD):** Brain damage from prenatal alcohol exposure, affecting cognitive function, impulse control, and learning
- **Brain Injury:** Acquired brain injury that can cause cognitive, emotional, and behavioral changes

Children with neurodevelopmental disorders may experience difficulties in multiple areas, including:

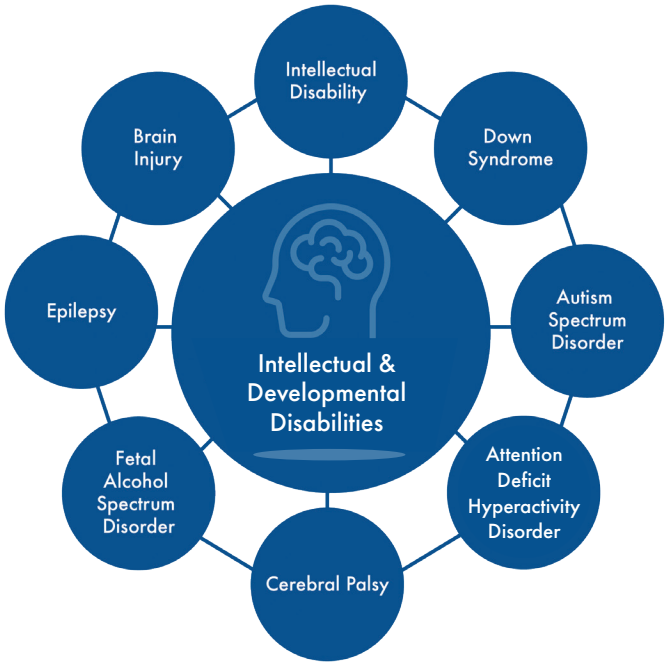
- **Communication:** Problems with receptive and expressive language, speech, and interpreting social cues
- **Motor function:** Challenges with motor skills and motor planning
- **Behavioral regulation:** Sensory sensitivities, physiological hyperarousal, low tolerance for uncertainty, and poor emotional and impulse control (emotional dysregulation)
- **Cognitive function:** Difficulties with memory, learning, focus and concentration, reasoning, problem-solving, decision-making, and applying knowledge and skills across settings

These neurodevelopmental conditions interact with trauma and environmental stressors to create complex clinical presentations, meaning these combine to impact how a child "shows up" in terms of their support/treatment needs. Services must be based on an understanding of the child and designed to accommodate these neurological differences rather than expecting children to adapt to standard approaches.

State Survey Results: Co-occurring Diagnoses

- Autism
- I/DD
- ADHD
- Complex Medical Conditions
- FASD
- Learning Disability

(Type of developmental diagnosis in order of the most frequent to least frequent response)



Mental Health Conditions and Diagnostic Overshadowing

Children with complex conditions often carry multiple mental health diagnoses, including:

- Post-traumatic stress disorder (PTSD) and complex PTSD
- Mood disorders (depression, bipolar disorder)
- Anxiety disorders
- Reactive attachment disorder
- Disruptive behavior disorders

Diagnostic overshadowing is a critical concern: when behavioral challenges are automatically attributed to a known disability (such as intellectual disability or autism) without adequate assessment for co-occurring mental health conditions or medical issues. This can result in under-treatment and/or inappropriate or excessive treatment of treatable conditions. Comprehensive assessment by professionals trained in both neurodevelopmental and mental health conditions is essential to ensure accurate diagnosis and appropriate intervention.

Certain mental health conditions frequently co-occur with specific neurodevelopmental disabilities. For example, children with ASD, ADHD, or Prader-Willi syndrome commonly experience depression, anxiety, OCD, and tics. However, the reverse can also happen–mental health symptoms may mask an underlying neurodevelopmental disorder. In these cases, the child receives treatment for the mental health condition while their developmental needs go unrecognized and unaddressed.

State Survey Results: Co-occurring Diagnoses

- Oppositional Defiant Disorder
- PTSD
- Anxiety
- Conduct Disorder
- Depression

(Type of behavioral health diagnosis in order of the most frequent to the least frequent response)

It's Both/And

It is not a question of what the primary diagnosis is ***– it is both/and***. The convergence of neurodevelopmental disability with mental health conditions is the basis of a child's complexity.

Physical Health Conditions

Physical health problems are common in this population and can significantly impact behavior and emotional regulation:

- Chronic pain (dental problems, gastrointestinal issues, headaches)
- Crohn's disease, celiac, and other autoimmune disorders
- Sleep disorders
- Seizure disorders
- Sensory processing difficulties
- Nutrition deficiencies
- Asthma

Physical discomfort can trigger or exacerbate behavioral challenges. Regular medical care and proactive health monitoring are essential components of behavioral support. Many children have unmet medical needs due to barriers in accessing healthcare or difficulties communicating symptoms.

Trauma History

The vast majority of children with complex behavioral health conditions have experienced significant trauma. In the Link Center State Survey, states reported that over 85% of the children were diagnosed with post-traumatic stress disorder (PTSD). Adverse Childhood Experiences (ACEs) are strongly associated with emotional and behavioral dysregulation and include:

- Abuse (physical, sexual, emotional)
- Neglect (physical, emotional)
- Household dysfunction (substance abuse, mental illness, domestic violence, parental separation, incarcerated household member)
- Multiple placement disruptions
- Community violence
- Discrimination and systemic oppression

State Survey Results:
Co-occurring Diagnoses

- Diabetes
- Seizure Disorder
- Asthma

(Physical health conditions in order of the most frequent to the least frequent response)

There is a complex relationship between physical conditions, developmental disorders and mental health conditions, one condition masking the other unless the child's condition is carefully assessed. Children may be unable to report or describe pain or discomfort from medical conditions, allergies, or injuries. Screening and assessment must take into consideration the child's self-awareness and ability to communicate, exploring whether behavior is in fact an indication of a physical health problem.

Children with disabilities are at least three times more likely to be abused or neglected than their peers without disabilities, and they are more likely to be seriously injured or harmed by maltreatment (**The Risk and Prevention of Maltreatment of Children with Disabilities**)

Data from the Adoption and Foster Care Analysis and Reporting System (AFCARS) suggests that 25% of children in foster care have a special health-care need. However, *many children do not receive clinical assessments. Some sources estimate 30-80% of children in foster care have a disability.*[1]

Developmental or **complex trauma**[2] is trauma that begins early in life and is pervasive during developmental years. Traumas occurring during early developmental years "create more profound problems than those associated with post-traumatic stress disorder."[3] Pervasive trauma impacts child development, including the ability to develop relationships, process information, and regulate emotions. It can cause a child "to go backwards" in their development such as regressing in toilet training or speech.

Children who have experienced complex trauma often develop hypervigilance, difficulty trusting others, and heightened reactivity to perceived threats. Their behaviors often represent adaptations that were necessary for survival in dangerous environments but become problematic in safer settings.

Trauma is not just abuse and neglect. Trauma in children is their subjective experience – an event can be traumatic for one child but not another. Traumatic grief, witnessing violence or disasters may disrupt sleep, change stress hormones, and alter behavior. Social experiences such as bullying, rejection, social isolation, humiliation, and extensive medical procedures with or without consent cause trauma. Sustained stress that may not be recognized as trauma can activate the same flight/fight/freeze response that leads to dysregulation. For children with sensory integration challenges, everyday sounds, sights, and activities can overwhelm their nervous systems to the point of being traumatic.

Family Context

Effective intervention must engage and support families, recognizing them as essential partners in the child's healing and development. Services should strengthen family capacity rather than simply removing children from homes when challenges arise. At the time of a crisis, children and families need immediate assistance. Following resolution of a crisis or serious event, collaboration with the family is necessary. During interviews with states agencies, many reported focusing their attention on children who may be at risk of developing serious behavior challenges to intervene with services earlier, both in the home and in school.

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1 *Supporting the Well-Being of Children with Disabilities Bulletin Sept. 2025 Child Welfare Information Gateway Children's Bureau/ACYF/ACF/HHS*

2 *Ford, J. D. (2023). Why We Need a Developmentally Appropriate Trauma Diagnosis for Children: a 10-Year Update on Developmental Trauma Disorder. Journal of Child & Adolescent Trauma, 16(2), 403-418.*

3 *Daniel A. Hughes, Kim S. Golding, and Julie Hudson, *Healing Relational Trauma with Attachment-Focused Interventions* (New York: W.W. Norton & Company, 2019).*

Family factors play a crucial role in both the development and resolution of complex behavioral health conditions:

- **Household demands:** caregiving responsibilities for other children or disabled or older family members may draw on their resources and personal capacities
- **Personal capacity:** strong family support, a wide social network as well as medical health conditions and/or disability are all factors that affect capacity.
- **Resource scarcity:** poverty, housing instability, food insecurity, lack of insurance coverage, and limited access to services create stress on families
- **System involvement:** involvement with child welfare, juvenile justice, or other systems can be both a source of support and additional stress
- **Caregiver burnout:** The intensity of caring for a child with complex conditions often leads to exhaustion, secondary trauma, and relationship strain

A family's resources, strengths, and challenges affect how they support their child and directly influence what types of interventions will be effective and what supports will be useful to the family. Treatment planning must be tailored to the family's unique circumstances to achieve positive long-term outcomes for the child.

Advances in neuroscience provide insights into how trauma, neurodevelopmental conditions, and chronic stress affect brain development and function. This understanding fundamentally changes how we view behavioral challenges and design interventions. Rather than viewing difficult behaviors as willful defiance or manipulation, we recognize them as symptoms of brain-based difficulties with self-regulation, emotional processing, and stress. These findings hold true for all children, including those with a neurodevelopmental disability.

Key Implications for Services

- Children referred to as having complex behavioral health conditions typically present multiple conditions that are physical or mental health related and most likely included a neurodevelopmental disability.
- A neurodevelopmental disability affects brain function and the child's capacity for self-regulation.
- A trauma history must be thoroughly understood to interpret its effects on brain function, identify the child's trauma triggers, and inform the creation of a trauma-sensitive environment and treatment approach.
- Physical, emotional, and behavioral changes that are a normal part of adolescence contribute to the complexities.
- Challenges may arise from relationships with family members and other caregivers.

2. A Neuroscientific–Informed Approach to Understanding Children and Providing Services

This section is the foundation for understanding children with complex conditions. Neuroscience is science – it is based on research and provides a framework to understand the problem and develop solutions. In this section you will learn about:

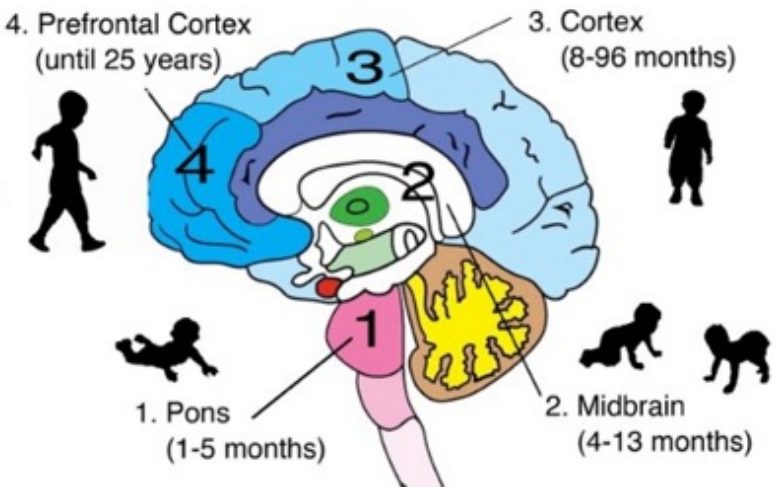
- Brain development and the brain's vulnerabilities
- The brain's role in growth and recovery
- Resilience

Brain Development and the Vulnerabilities at Each Stage

Early Childhood (Ages 0–5)

The brain grows most rapidly during the first few years of life, reaching 90% of its adult size by age 5. Key developments are basic sensory processing, motor control, language acquisition, and early emotional regulation. The limbic system, involved in emotions and memory, is highly active.

Attachment relationships and early experiences have an outsized impact on the development of emotional self-regulation because of the brain's heightened plasticity.



Developmental Vulnerability: Disruptions in attachment during this period can be especially harmful, as they interfere with a child's ability to develop healthy relationships.

Middle Childhood (Ages 6–12)

The prefrontal cortex–responsible for planning, impulse control, and executive function–begins maturing but is far from complete. Children develop stronger working memory, attention, logical reasoning (particularly for concrete problems), and the ability to follow multi-step instructions. Social cognition deepens as children become better at understanding others' perspectives (theory of mind).

Developmental Vulnerability: Disruptions in the child's development can have a detrimental effect on executive functions including choice making and impulse control.

Early Adolescence (Ages 11–14)

The limbic system surges in activity — heightening emotional reactivity, reward-seeking, and sensitivity to peer evaluation — while the prefrontal cortex is still catching up. This imbalance is often described as a "dual systems" model and helps explain risk-taking behavior and emotional volatility in early teens.

Developmental Vulnerability: The brain becomes particularly sensitive to dopamine and other reward signals during this phase, making adolescents more motivated by social rewards and novelty.

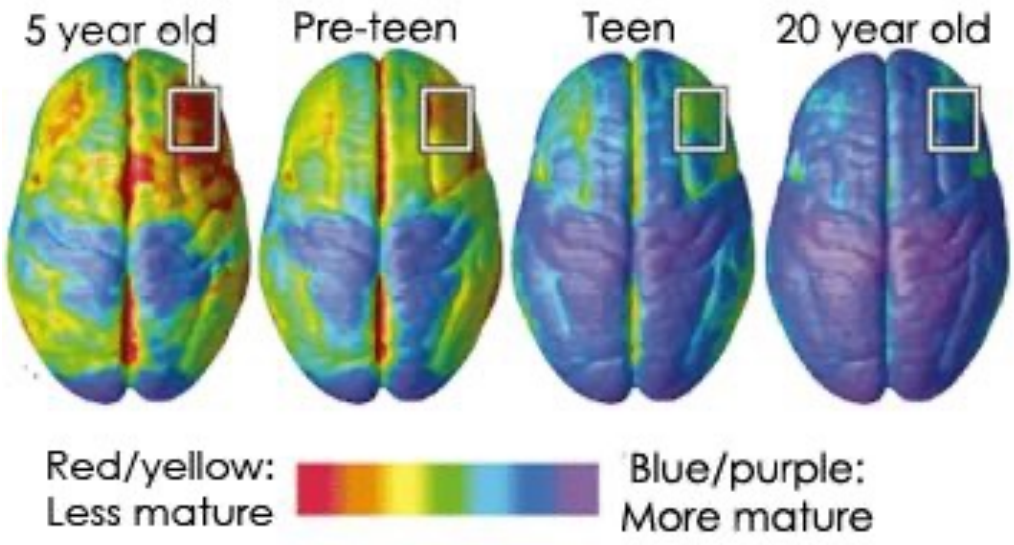
Late Adolescence (Ages 15–21)

The prefrontal cortex (PFC) continues maturing into the mid-20s. During brain development, neural circuits that are not used are “pruned” for efficiency. This improves impulse control, long-term planning, emotional regulation, and abstract reasoning.

Plasticity, the brain’s ability to change, reorganize and adapt its physical structure, is highest early in life but persists throughout adolescence, making the brain both adaptable and vulnerable to adverse experiences. What and how much a child learns, how the child relates to others and forms relationships, the skill to evaluate and make choices are all affected by stress, nutrition, sleep, relationships, and life experiences.

The prefrontal area of the brain – the part that controls emotions and behavior – is the last area to fully develop. Full development occurs in females in their early 20s and in males, closer to 30.

Developmental Vulnerability: Although it may seem obvious, it is worth noting that we often expect adolescents to make fully rational decisions when their brains are not yet developed for such thinking.[45]

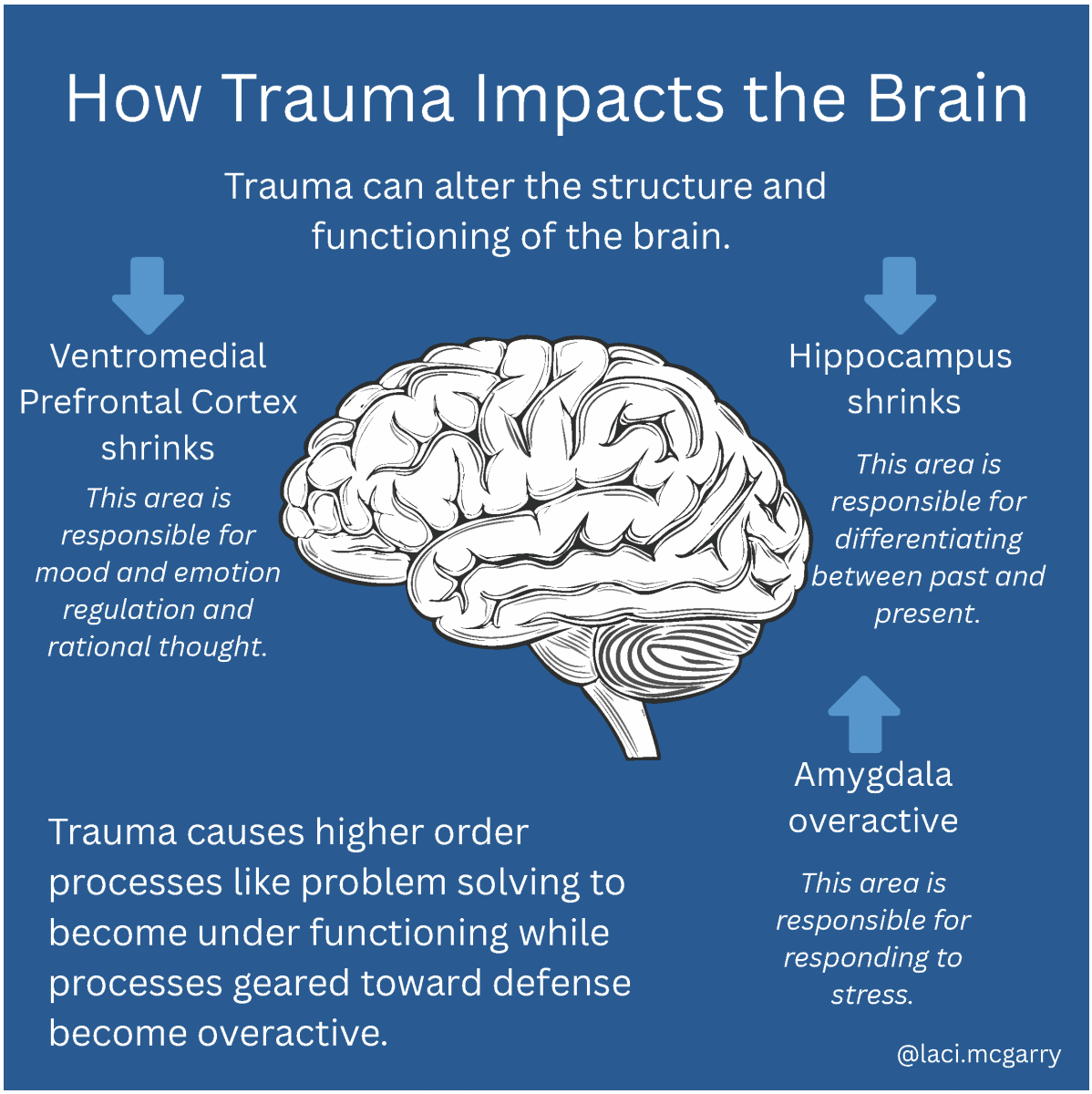


4 *Parenting and the Amazing Teen Brain Part 1* **Parenting and the Amazing Teen Brain Part 1 | Psychology Today**

5 *Daniel J. Seigel, Tina Payne Bryson, “Brainstorm: The Power and Purpose of the Teenage Brain” (Penguin Random House LLC 2013)*

Stress and Trauma's Impact on Self-Regulation

Trauma and chronic stress disrupt brain function and the brain's developmental process. Trauma — particularly chronic, early, or overwhelming trauma — doesn't just affect mood or behavior. It physically alters the structure, function, and integration of the brain. Understanding *which* regions are affected helps explain why trauma responses can feel so automatic, involuntary, and resistant to change.



- **The brainstem governs the most primitive survival functions: heart rate, breathing, arousal, and the fight-flight-freeze response**. During trauma, the brainstem is essentially hijacked by threat. The autonomic nervous system (ANS) — particularly the sympathetic branch — floods the body with stress hormones like cortisol and adrenaline to mobilize a survival response. With repeated or chronic trauma, the brainstem becomes chronically dysregulated. **The nervous system gets stuck in a state of high alert** (hyperarousal) or, alternatively, collapses into shutdown and dissociation (hypoarousal). This is why trauma survivors often describe feeling perpetually on edge or, conversely, numb and disconnected — the brainstem is operating as though the threat never ended.
- **The amygdala is the brain's threat-detection center, sometimes called the smoke alarm**. It processes incoming sensory information for signs of danger and triggers the stress response before conscious awareness even kicks in. In trauma, the amygdala becomes hyperreactive — essentially lowering its threshold for what counts as a threat. Sounds, smells, facial expressions, or physical sensations that resemble aspects of the original trauma can trigger a full alarm response, even in objectively safe situations. **In people with PTSD and complex trauma, neuroimaging studies consistently show increased amygdala activation and reduced ability to inhibit it.** The amygdala essentially dominates, overriding more reflective brain processes. This is the neurological foundation of triggers and flashbacks.
- **The hippocampus is critical for memory**. This is specifically true for encoding experiences in their proper context of time and place, and for distinguishing past from present. It is highly sensitive to cortisol, and prolonged stress exposure can actually reduce hippocampal volume, impairing its function. This has profound implications for how traumatic memories are stored. Instead of being filed away as a coherent narrative in the past ("this happened to me then"), **traumatic memories can become fragmented, sensory-based, and context-free. They are stored more like a collection of vivid sensory impressions** — images, sounds, physical sensations — that lack a clear "time stamp." This is why trauma can feel like it's happening *now* rather than being remembered. The hippocampus is not properly tagging the experience as finished.
- **The prefrontal cortex (PFC) is responsible for reasoning, planning, impulse control, emotional regulation, and the ability to contextualize experience**. During acute trauma and stress, the PFC is functionally suppressed. High levels of cortisol and norepinephrine literally impair its activity, which is adaptive in a true emergency (you don't want to be deliberating when you need to act fast) but deeply problematic when it becomes chronic. In people with ongoing trauma histories, the PFC shows reduced volume and diminished activity, particularly in the ventromedial and orbitofrontal regions involved in emotional regulation and integrating reason with feeling. **The loss of PFC function means that the "thinking brain" goes offline precisely when it is most needed**, leaving the person at the mercy of more reactive subcortical systems.

THE INTEGRATION PROBLEM

The most important way to understand trauma's effect on the brain is as a failure of integration. The different systems that should work together — brainstem and cortex, left and right hemispheres, emotion and reason, body and mind — become fragmented and poorly coordinated. The trauma response, which was adaptive in the moment of threat, becomes locked in place because the integrative circuits that would allow the brain to process, contextualize, and move past the experience are disrupted.

This is why effective trauma treatment — whether through Eye Movement Desensitization and Reprocessing (EMDR), somatic therapies, narrative therapy, or relational approaches — tends to work by restoring integration: helping the brain reconnect its fragmented pieces, bring the PFC back online, and allow the hippocampus to properly file the experience as something that happened in the past.

NEURODEVELOPMENTAL DISABILITIES AND SELF-REGULATION

Children with neurodevelopmental disabilities may or may not have a history of abuse, neglect, or trauma. When they do, their experience is through the lens of their disability. Their difficulty in processing what they see and hear and their inability to communicate compounds their trauma. They are left, like all children, with no sense of personal control. They cannot control what is happening to them and later may not be able to communicate their experiences.

Despite reports of abuse, neglect, or trauma, children with neurodevelopmental disabilities are very likely to not understand what is going on around them and to have no sense of personal control in situations like bullying and harassment, isolation, and restraints or seclusion. Assuming some level of trauma promotes an empathetic approach to the child.

Lastly, dysregulation can simply be a component of neurodevelopmental disabilities. Children with autism, brain injury, fetal alcohol syndrome, and other conditions can exhibit behavior that is highly disruptive, demanding, impulsive, and physically aggressive. The issues are the same. The dysregulation is neurologically based and the recommendations in this publication are fully applicable.

The Brain's Role in Growth and Recovery

THE GOOD NEWS: PLASTICITY AND THE POSSIBILITY OF RECOVERY

Perhaps the most important and hopeful insight from modern neuroscience is this: **the brain that was changed by trauma can be changed again.** The same plasticity that made the developing brain vulnerable to the effects of adverse experience is also what makes recovery genuinely possible — at any age.

For decades, it was assumed that the brain was largely fixed after childhood, and that the damage done by early trauma was more or less permanent. We now know this is not true. Neuroplasticity, the brain's capacity to reorganize itself by forming new neural connections, pruning old ones, and even generating new neurons in certain regions, continues throughout the lifespan. It is most robust in childhood and adolescence, but it never fully stops.

Studies of **the hippocampus** have shown that effective trauma treatment, aerobic exercise, mindfulness practice, and enriched social environments can actually increase hippocampal volume in trauma survivors, reversing some of the structural damage caused by prolonged cortisol exposure.

The amygdala's hyperreactivity is not fixed either. Therapeutic approaches that repeatedly pair safety cues with previously threatening stimuli — as in trauma-focused cognitive behavioral therapy and EMDR — gradually recalibrate the amygdala's threat threshold. New learning does not erase old fear memories, but it creates new neural pathways that can override and inhibit them.

The prefrontal cortex responds robustly to practices that engage it deliberately. Mindfulness meditation, for example, has been shown in multiple studies to increase gray matter density in the PFC and strengthen its connectivity with the limbic system — essentially rebuilding the top-down regulatory pathways that trauma weakened. Therapy modalities that encourage mentalizing, self-reflection, and narrative coherence similarly strengthen PFC function by repeatedly exercising these circuits.

Relational experience is perhaps the most powerful driver of neural change in trauma recovery. Because much early trauma occurs within relational contexts, healing often happens relationally too. Safe, attuned relationships — whether with a therapist, caregiver, partner, or community — provide the co-regulatory experiences that help recalibrate the nervous system from the bottom up. The brain learns safety the same way it learned threat — through repeated experience.

Integration can be rebuilt. The fragmentation that trauma creates between the left and right hemispheres, between body and mind, between emotion and reason is not permanent. Therapies specifically designed to restore integration, such as EMDR, somatic experiencing, and internal family systems therapy, work in part by creating conditions in which the brain's disparate systems can reconnect and process incomplete experiences.

What all of this points to is a fundamentally optimistic view of the traumatized brain. Not naive optimism that minimizes suffering or suggests recovery is easy, but a grounded, neuroscience-supported recognition that the brain retains the capacity to heal throughout life.

Recovery is not about erasing the past or returning to an earlier developmental state. Rather, it involves building new capacities while accommodating neurological differences. For children with neurodevelopmental disabilities, the goal is not to make them "normal" but to help them develop their full potential within the context of their neurological profile.

The timeframe for healing varies considerably. Some children show rapid improvement with appropriate support, while others require years of patient, consistent intervention. Systems must be designed for long-term engagement rather than expecting quick fixes.

RESILIENCE

Resilience is an adaptive response in the face of significant adversity. It is often referred to as "bouncing back." But resilience is not an immutable trait–it is not within the child. It is developed through a combination of supportive relationships, adaptive skill-building, and positive experiences. According to the working paper **Supportive Relationships and Active Skill-Building Strengthen the Foundations of Resilience** published by Harvard University, "*multiple lines of research have identified a common set of factors that predispose children to positive outcomes in the face of significant adversity:*

- *The availability of at least one stable, caring, and supportive relationship between a child and the important adults in his or her life. These relationships begin in the family, but they can also include neighbors, providers of early care and education, teachers, social workers, or coaches, among many others.*
- *Helping children build a sense of mastery over their life circumstances.*
- *Those who believe in their own capacity to overcome hardships and guide their own destiny are far more likely to adapt positively to adversity.*
- *Children who develop strong executive function and self-regulation skills. These skills enable individuals to manage their own behavior and emotion- and develop and execute adaptive strategies to cope effectively with difficult circumstances.*
- *The supportive context of affirming faith or cultural traditions. Children who are solidly grounded within such traditions are more likely to respond effectively when challenged by a major stressor or a severely disruptive experience.*

Key Implications for Services

- Abuse, neglect, and trauma during childhood negatively impacts a child's capacity to learn and remember; develop relationships; and, regulate their emotions and behavior.
- Children with neurodevelopmental disabilities may not have experienced reportable abuse or trauma but may have trauma from coping with the challenges that come with their disability.
- Understanding the brain's basic functions establishes the foundation to understand behavior, the reasons for it and how to help.
- The brain's plasticity offers generous opportunities for the child to both overcome challenges and develop new competencies.
- Relationships that are constant and supportive are critical to children developing resilience and the capacity to self-regulate.

3. Building a Service Paradigm Based in Neuroscience*

A neuroscience-informed approach to serving children with complex behavioral health conditions rests on three essential pillars:

- A place that is safe
- Treatment to heal
- Opportunities to grow

**Paradigms are mental frameworks or "maps" that organize how individuals interpret the world, setting boundaries for what is possible and guiding decision-making.*

A Place That is Safe

This section explains that, regardless of the living arrangement, a place that is safe means more than physical and emotional safety. It must be a place that understands behavior as communication, that offers connection to others, which incorporates physical and brain health practices into daily routines and makes sure that life is full of fun. Tools such as person-centered practices, trauma-informed approaches, child- and family-centered practices and positive behavioral support can be the foundation to build A Place that is Safe.

Treatment to Heal

This section is a resource that offers a wide range of evidence-based treatments and therapies. It also provides physical and mental health daily practices that promote brain health. The section includes strategies to teach children how to self-regulate and offers a wide range of approaches to working with families, including adoptive families and foster families. You will also find a description of habilitation as a therapeutic support to treatment.

Opportunities to Grow

While brief, this section of the report points to one of the most critical aspects of children with complex behavioral health needs – they and their brains are growing. They need opportunities, structure and guidance through both education programs and supports provided in their home and community.

A Place that is Safe

Safety is the foundation upon which all other interventions rest. For children whose brains have developed in conditions of threat and unpredictability, establishing a felt sense of safety is the first priority. This goes beyond physical safety to include psychological, emotional, relational, and sensory safety.

In this section we will address

- **Safety**
- **Environment and activities**
- **Relationships**
- **Behavior as communication**
- **Empathy**
- **Physical space**
- **Brain health,**
- **Planning for crises**
- **Do no harm**
- **Living arrangements**
- **Physical health**
- **Training and support for caregivers**

SAFETY FIRST

Creating safety requires attention to multiple dimensions:

- **Physical safety:** Environments must be free from violence, abuse, and physical harm. This includes protection from both external threats and the child's own self-injurious behaviors.
- **Psychological safety:** Children need environments where they feel safe to explore, take appropriate risks and make mistakes without fear of punitive responses.
- **Emotional safety:** Children need environments where they can express emotions without fear of rejection, punishment, or abandonment. Shame-based discipline approaches undermine emotional safety.
- **Predictability:** Consistent routines, clear expectations, and transparent decision-making help children feel secure. Surprises and unpredictable transitions can be deeply destabilizing.
- **Cultural safety:** Children need to see their identities, cultures, and communities reflected and valued in their care environment.

ENVIRONMENT AND ACTIVITIES

- **Create structure** through predictable routines and consistent, reliable practices
- **Offer activities that a child is interested in and enjoys** as frequently as possible
- **Facilitate empowerment -** assists the child to make choices and decisions
- **Consider a pet for companionship,** unconditional love, practicing responsibility, motivation to get outdoors, and providing the experience of being needed

- **Involve the child in activities and with children in the community** so they can develop friendships
- **Develop daily and weekly routines** that are dependable and under the child's control
- **Integrate mental and physical health** practices into life routines
- **Coordinate with the education program** to build consistency in practice

RELATIONSHIPS

Relationships are the mechanism through which safety is established and healing occurs. Children with complex conditions require:

- **Consistent caregivers:** High staff turnover and placement disruptions are profoundly harmful. Systems must prioritize relationship continuity.
- **Attuned adults:** Caregivers who can read and respond to the child's emotional states, providing co-regulation when the child is dysregulated
- **Rupture and Repair:** Reconciliation and reconnection is a fundamental relationship cycle and is essential to building trust and secure attachments.
- **Opportunities to develop healthy friendships with other children**
- **Unconditional positive regard:** Adults who maintain connection even when behavior is challenging, communicating through their actions that the child is valued and worthy of care
- **Adequate staffing ratios:** Caregivers cannot provide relational care when they are overwhelmed by having to care for a high number of children and competing demands.

Supporting caregiving relationships – the front-line therapists in a child's care. Treatment occurs through caregivers' sustained daily involvement with the child and making caregivers core members of the child's team. The caregiver's ability to understand a child's behavior, respond therapeutically and empathetically in the moment, and implement planned interventions is the single most critical component of effective service delivery.

"Being able to feel safe with other people is probably the single most important aspect of mental health; safe connections are fundamental to meaningful and satisfying lives."

— **The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma,** Bessel A. van der Kolk

Service agencies must actively support the maintenance of caregiving relationships. Whether these adults are family members, foster caregivers, or paid staff, they require comprehensive training and ongoing coaching to be successful.

The importance of co-regulation – the process where one person's calm nervous system helps another person regulate their own emotions – is fundamental for children to develop self-regulation skills. Through consistent training and coaching in co-regulation techniques, caregivers can be equipped with the tools they need to support children effectively.

BEHAVIOR AS COMMUNICATION

Challenging behaviors must be understood as communication of unmet needs rather than as problems to be eliminated. Every behavior serves a function, whether seeking connection, escaping an overwhelming situation, expressing physical discomfort, or attempting to regain control.

Intervention should focus on teaching more effective communication and coping skills while modifying the environment to reduce triggers and meet needs proactively. Treatment for underlying trauma is a critical component. Punishment and consequences are ineffective because they do not address the underlying causes of behavior or build new skills and can potentially build upon previous trauma.

EMPATHY

Accepting behavior as communication requires empathy– the ability to understand and share the feelings of another person, often described as "stepping into their shoes" to see the world from their perspective. It involves not just recognizing what someone is going through, but also feeling with them, which can lead to a caring and understanding response.

***"Don't ask what the child is doing, ask what has happened to the child."* -Dr. Dan Hughes**

"Long after a traumatic experience is over, it may be reactivated at the slightest hint of danger and mobilize disturbed brain circuits and secrete massive amounts of stress hormones. This precipitates unpleasant emotion, intense physical sensations, and impulsive and aggressive actions."

— **The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma,** Bessel A. van der Kolk

Confidentiality: A Caution – While it is important to keep protected information confidential, people who provide direct support have a need to know what has happened in the person's life. Knowing what the trauma events were in a person's life is what builds empathy, understanding, tolerance, and patience.

PHYSICAL SPACE

The physical environment significantly impacts children's sense of safety and ability to regulate:

- **Sensory considerations:** Lighting, noise levels, textures, smells, and visual complexity should be carefully managed. Many children have sensory sensitivities that trigger dysregulation.
- **Safe spaces:** Access to quiet, calming spaces where children can self-regulate when overwhelmed
- **Homelike environment:** Residential settings should feel like homes, with personalized spaces and appropriate age amenities.
- **Nature access:** Outdoor spaces and connection to nature support regulation and healing.
- **Safety without institutionalization:** Environments can be safe without being sterile, locked, or punitive in appearance.

PHYSICAL AND BRAIN HEALTH

Basic physical health and wellness are essential supports for behavioral regulation:

- **Sleep:** Consistent sleep schedules and bedtime routines, reduce caffeine and screen time, and treatment of sleep disorders
- **Diet:** Regular, nutritious meals that account for sensory preferences and medical needs- Encourage a diet rich in nutrients including vegetables and fruit for brain health
- **Exercise and access to outdoors:** Regular physical activity supports mood regulation, stress reduction, and brain health.
- **Healthcare:** Proactive healthcare including dental care, vision and hearing screening, and management of chronic conditions

PLAN FOR CRISES

Despite best efforts, behavioral crises will occur. Crisis planning should be proactive rather than reactive:

- **Crisis prevention:** Identify early warning signs and intervene before full escalation
- **De-escalation strategies:** Use trauma-informed approaches to help children regain regulation
- **Physical intervention protocols:** When safety requires physical intervention, use the least restrictive methods for the shortest time possible, with proper training and oversight

- **Crisis stabilization services:** Access intensive support during acute crises without automatically moving to more restrictive placements
- **Post-crisis support:** Debrief with the child and team to learn from the incident and strengthen prevention strategies

DO NO HARM

A fundamental principle of all interventions should be to avoid causing additional harm:

- **Eliminate harmful practices:** Do not use seclusion, restraint, or other coercive practices except when necessary for imminent safety and with strict oversight. Do not withhold food, items, or activities important to the child as part of behavior management program.
- **Avoid re-traumatization:** Understand how system processes (interviews, physical exams, placement changes) can trigger trauma responses
- **Cultural humility:** Recognize power dynamics and avoid imposing dominant culture values without understanding family and community context
- **Informed consent:** Children and families should understand interventions and have genuine choice in treatment decisions.

LIVING ENVIRONMENTS

Children with complex behavioral health conditions live in various settings, each with unique considerations:

Family

Family Preservation should be the priority whenever possible. This requires:

- **Intensive in-home services:** Providing support directly in the family home, including parent coaching, crisis intervention, and skill building
- **Respite care:** Regular breaks for parents to prevent burnout while ensuring continuity of care for the child
- **Parent/caregiver support and education:** Training and peer support for parents complex needs

- **Service coordination:** Help accessing and coordinating multiple services and supports
- **Financial support:** Addressing basic needs (housing, food, utilities) that impact family stability

Adoptive Families

Adoptive families need specialized support recognizing the unique challenges of parenting children with complex needs:

- **Pre-adoption preparation** that honestly addresses challenges
- **Post-adoption supports** including attachment-based parent/caregiver support and training such as Circle of Security, Trust-Based Relational Intervention, and respite care.
- **Financial support** including adoption subsidies and access to specialized services
- **Peer support** with other adoptive families

Kin Care and Foster Care

Foster families and relatives who provide foster care require comprehensive support to care for children with complex needs:

- **Enhanced training:** Trauma-informed care, co-regulation and de-escalation training as well as medical/disability-specific training
- **Higher reimbursement rates:** Recognition of the intensity of care required
- **Wraparound services:** In-home therapy, respite, mentoring, and crisis support
- **Professional support team:** Regular consultation with clinicians, ongoing training, and 24/7 crisis support
- **Placement stability:** Support to maintain placements through challenging periods rather than moving children

Youth with disabilities constitute 31.8% of the child welfare population. (Slayter, 2016)

Group Homes

Small, community-based group homes can provide intensive support with a family-like environment:

- **Small size:** 3-6 children maximum to allow for individualized attention and family-like atmosphere
- **Enhanced staffing:** Well trained staff, ratios that allow for significant time with children, staff support and supervision to retain staff.
- **Integrated clinical support:** On-site or closely coordinated therapeutic services
- **Community integration:** Located in residential neighborhoods with access to community resources and activities
- **Family involvement:** Active engagement with biological families when appropriate and safe

Congregate Care

Maintain the child's connection with adults they trust and who care about them.

Congregate care facilities should be used only when children require intensive support that cannot be provided in smaller, more family-like settings. Care facilities for children should include:

- **Intensive clinical programming:** Daily therapeutic activities, psychiatric support, and skill building
- **Small living units:** Even within larger facilities, children should live in small groups with consistent staff
- **Trauma-informed environment:** Minimize institutional aspects, maximize choice and normalcy
- **Family engagement:** Regular contact and involvement in treatment
- **Aggressive step-down planning:** Planning for transition back to their home and community should begin immediately after admission.

IMPROVING PERMANENCY THROUGH LONG-TERM PLANNING

Every child deserves a permanent, stable family connection. For children with complex needs, this requires:

- **Lifelong connections:** Maintain relationships with family, community, and culture even when children cannot return home
- **Creative permanency options:** Guardianship, adult adoption, committed foster care relationships, supported independent living
- **Post-permanency support:** Services do not end at adoption or reunification—families need ongoing support
- **Transition planning:** Early planning for transition to adulthood, including connecting to adult services when needed

- For children and adolescents who have experienced multiple out-of-home placements, thoughtful long-term planning becomes critical—particularly as they approach late adolescence. Continued placement instability does not serve these children well and may compound their existing trauma. Instead, comprehensive permanency planning that extends into adulthood can provide children with:
- A sense of hope and a future to look forward to
- Continuity of care and relationships
- Proactive engagement from service systems to prevent gaps in support

While reunification with family or permanency through adoption should never be abandoned as goals, practitioners must also recognize when the focus should shift toward preparing the adolescent for adult life. Even without formal adoption, a sense of permanency can be developed by incorporating caring adults who know the youth into their transition planning. This includes helping potential supporters identify and define specific, meaningful roles they can realistically commit to maintaining in the young person's life as they move toward independence.

By committing to long-term planning, we ensure that young people are not left to navigate the transition to adulthood alone but instead have the foundation and support they need to build successful futures.

Key Implications for Services:

- The living environments that the child calls home must be the first and ongoing consideration.
- Relationships will be the foundation for everything.
- Whether living with family, foster families, or in residential care, the environment is the foundation and requires supporting caregivers. Do not underestimate the caregiver's need for support.
- Safety is determined through the eyes of the child. Knowing the child's history and preferences is necessary to creating a place that is safe.

Treatment to Heal: Physical and Mental Health

Treatment is the second essential pillar for supporting children with complex needs. While safety provides the foundation, healing requires active intervention to address underlying mental and physical health conditions, process trauma, and develop new skills and capacities.

In this section you will learn about a wide range of treatment options and therapeutic approaches.

- How physical health can directly influence behavior
- Why a comprehensive mental health assessment conducted by professionals with both neurodevelopmental and mental health credentials is important
- Types of assessments to help fully diagnosis a child's conditions.
- Psychopharmacology
- Types of therapies
  - Therapies based on verbal communication
  - Somatic therapy that addresses the mind-body connection
  - Therapeutic strategies for self-regulation
  - Treatment that is family-based
- Habilitation's role in treatment

ASSESSMENT AND TREATMENT OF PHYSICAL HEALTH CONDITIONS

Physical health directly impacts behavioral and emotional regulation. Comprehensive medical assessment and treatment are essential components of behavioral health treatment:

- **Comprehensive medical evaluation:** Full physical exam, developmental history, review of systems to identify undiagnosed or untreated medical conditions
- **Pain assessment and management:** Many children cannot verbally report, nor do they have behavioral indicators of pain. Migraines, sinus pain, menstrual cramps, or gastrointestinal conditions can be serious and even extreme.
- **Sleep evaluation and treatment:** Sleep disorders are common and treatable. Good sleep hygiene practices and treatment of sleep disorders significantly impact behavior.
- **Nutritional assessment:** Evaluate dietary intake, food sensitivities, gastrointestinal issues, and nutritional deficiencies.
- **Neurological evaluation:** Screen for seizure disorders, assess for evidence of neurological conditions and cognitive challenges
- **Sensory and motor assessment:** Occupational therapy evaluation of sensory processing, fine and gross motor skills

- **Preventive care:** Regular well-child visits, immunizations, dental care, vision, and hearing screening

ASSESSMENT OF MENTAL HEALTH CONDITIONS

A comprehensive mental health assessment by professionals trained in both neurodevelopmental and psychiatric conditions is essential:

- **Developmental history:** Understanding the child's developmental trajectory, early experiences, and acquisition of milestones
- **Trauma assessment:** Detailed trauma history using validated tools, assessment of trauma symptoms and PTSD
- **Brain Injury Assessment:** Accidents, incidents, injuries or hospitalizations involving head or neck injuries, high fever or infection (meningitis or encephalitis), lack of oxygen or abusive head trauma may be indicators of a brain injury event.
- **Neurodevelopmental evaluation:** Assessment of intellectual disability, autism, ADHD, learning disabilities, and other neurodevelopmental conditions using appropriate standardized tools
- **Psychiatric evaluation:** Assessment for mood, anxiety, psychotic, and other mental health disorders, recognizing that behavioral indicators and symptoms may present differently in children with developmental disabilities
- **Functional assessment:** Understanding how the child functions in various settings and what supports are needed
- **Physical health assessment:** Evaluate physical causes of distress, test for common conditions that cause discomfort and consider genetic testing to identify genetic conditions predictive of behavior
- **Strengths assessment:** Identifying areas of competence, interest, and resilience to build upon
- **Diagnostic clarity:** Careful differential diagnosis to avoid diagnostic overshadowing and ensure all conditions are identified and treated

*"Conducting a **Biographical TimeLine** is both a person-centered and trauma-informed foundation for treatment and support. The biographical timeline process is a facilitated process through which a team of people, having researched the events, passages, and interventions in a person's life, lay out those facts in a linear fashion to correlate information in a meaningful manner. Events and personal experiences thought of as "insignificant" or stored in compartmentalized reports are grouped according to occurrence along a linear life timeline. The transformation of attitudes that occurs during this process is as important as the facts that emerge from the research."*

— Beth Barol PhD, LSW, BCB, NADD-CC

- Conducting other case conceptualizations like **Functional Behavioral Assessment (FBA) that are based on trauma informed practices** can also assist in ruling out medical functions of behavior and identifying additional triggers, setting events, and antecedents that may be related to the negative behavior that can be targeted for treatment and intervention.
- Common assessment instruments include: **The Child and Adolescent Needs and Strengths (CANS)** designed to support decision making and service planning and commonly used by state child welfare and mental health agencies. **The Child and Adolescent Service Intensity Instrument** (CASII) provides a determination of the appropriate level of service intensity needed by a child or adolescent and his or her family. It is unique in its capacity to determine a service intensity need, guide treatment planning, and monitor treatment outcomes in all clinical and community-based settings. An edition for children and adolescents with an **Autism Spectrum Profile** is also available. Brain injury screening tools include the **Online Brain Injury Screening and Support System**, the **Brain Injury Screening Questionnaire**, **The Brain Check Survey** and **The Safe Child Screening Tool**.

TREATMENT OF MENTAL HEALTH CONDITIONS

Recognizing the interplay between neurological and physiological factors underscores the need for a broad, coordinated approach to therapy. Effective treatment for children with complex needs typically requires multiple, integrated therapeutic approaches. No single therapy works for all children; treatment must be individualized based on comprehensive assessment.

THERAPIES BASED ON VERBAL COMMUNICATION

Traditional talk therapies can be effective for children with adequate verbal and cognitive abilities:

- **Cognitive behavioral therapy (CBT):** Helping children identify and change unhelpful thought patterns and behaviors. Adaptations may be needed for children with neurodevelopmental disabilities.

"How many mental health problems, from drug addiction to self-injurious behavior, start as attempts to cope with the unbearable physical pain of our emotions? If Darwin was right, the solution requires finding ways to help people alter the inner sensory landscape of their bodies."

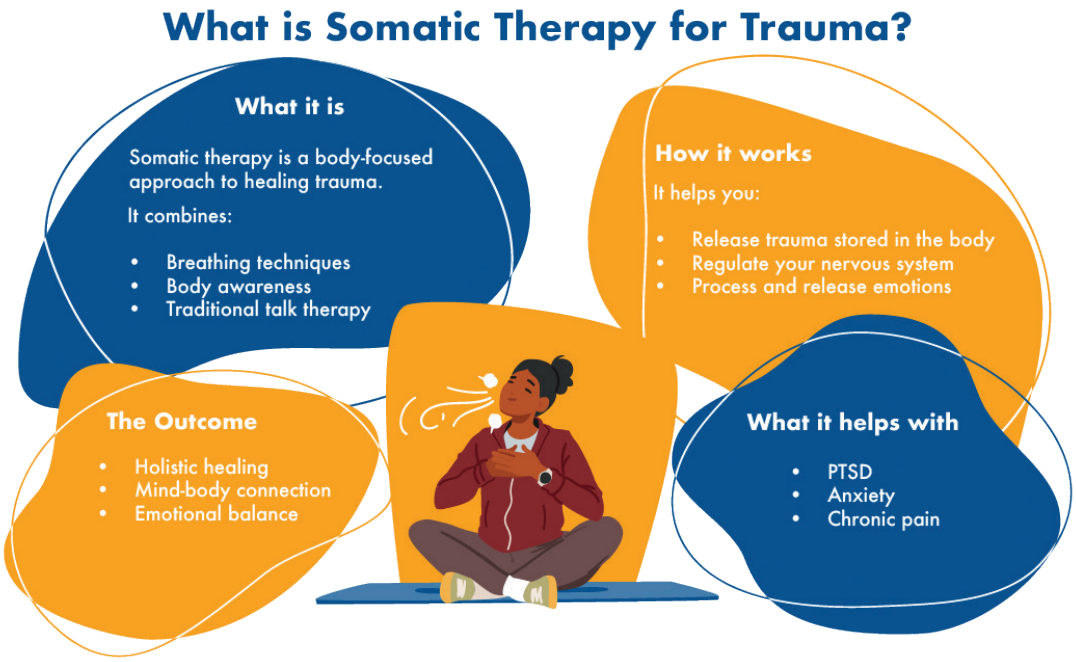
— Bessel A. van der Kolk, **The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma**

- **Trauma-focused CBT:** Specifically designed to address trauma symptoms through gradual exposure, cognitive processing, and skills training.
- **Dialectical behavior therapy (DBT):** Teaching mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness skills.
- **Play therapy:** Using play as the medium for expression and processing for younger children or those with limited verbal abilities.
- **Narrative therapy:** Helping children construct coherent narratives about their experiences and develop preferred stories about themselves.

SOMATIC-BASED THERAPIES

Current developments in treatment for trauma and stress are based on the realization that trauma and stress leave an imprint on the body.[6] Sounds, smells, and touch as well as thoughts and memories lead to physiological responses including the production of cortisol, overstimulation of the amygdala, a rapid heart rate, and sensory shutdown.

These triggers activate the sympathetic nervous system (the fight/flight/freeze response), which in turn disrupts the parasympathetic nervous system (the rest and digest system), affecting sleep, digestion, heart rate, and breathing. Treatment approaches that help regulate these systems and restore a sense of safety open pathways to healing and learning. The ranges of therapies and therapeutic practices that can calm the parasympathetic system include those guided by a licensed or certified therapist and others that are practices that can be guided by skilled practitioners.



6 *Complementary & Alternative Techniques and Interventions used with Complex Trauma Clients*

- **Occupational therapy** interventions to address sensory processing difficulties
- **Biofeedback-based techniques** such as heart rate variability (HRV) retraining and clinical neurofeedback[7]
- **Eye Movement Desensitization and Reprocessing therapy (EMDR)**
- **Brain stimulation therapy and other bilateral stimulation therapies**
- **Neuro affective relational model therapy**
- **Expressive therapies: art therapy, music therapy, play therapy, psychodrama**
- **Aqua therapy:** Trauma-informed water therapy
- **Somatic experiencing**: Addressing trauma through body awareness and sensation, releasing stored survival energy
- **Mindfulness-based therapies**: Mindfulness stress reduction; trauma-centered yoga; somatic-based regulation therapies – to build body awareness, breath control, and present-moment focus
- **Therapeutic massage:** When appropriate and with proper consent, massage can support regulation and body awareness
- **Movement therapies**: Dance, martial arts, and other movement-based approaches that integrate body and mind
- **Animal assisted interventions** included equine-facilitated therapy and service animals

THERAPEUTIC STRATEGIES FOR SELF-REGULATION

Teaching children practical skills for managing emotions and behavior:

- **Zones of regulation:** Teaching children to identify their emotional state and use strategies to return to optimal arousal
- **Self-regulation training:** Teaching specific coping skills including progressive muscle relaxation, **grounding techniques, and breathing exercises**
- **Social skills training:** Explicit instruction in social communication, perspective-taking, and relationship skills
- **Know your triggers work sheets bilateral stimulation**
- **Emotional freedom tapping (EFT)**
- **WRAP Wellness Recovery Action Plan**
- **Dan Siegle's Hand Model of the Brain**
- **Mobile apps** as guides for calming, breathing, mindfulness, and meditation
- **Weighted blankets**
- **EQ2** co-regulation training for direct care staff
- **Emotional regulation skills system**

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7 *Neurofeedback in the Treatment of Developmental Trauma: Calming the Fear-Driven Brain, Sebern F. Fisher*

TREATMENT THAT IS FAMILY-BASED

Family involvement in treatment is critical for generalization and maintenance of gains but may require adaptations for children who have neurodevelopmental disabilities:

- **Parent-child interaction therapy (PCIT):** Coaching parents in real-time to improve parent-child interactions
- **Trust-based relational intervention (TBRI):** Attachment-focused approach teaching caregivers to meet children's needs through connecting, empowering, and correcting principles
- **Family peer support:** Connecting families with others who have similar experiences for mutual support and learning
- **Attachment, regulation and competency (ARC)**
- **Child-parent psychotherapy (CPP)**
- **Tuning in to Teen (TINT**): A parent-focused program designed to improve the relationship between parents and adolescents by teaching emotion coaching skills
- **Intensive instructional therapy (IST)**
- **Wraparound services**
- **Co-regulation:** Connecting with a child who is in distress and being able to evaluate what that child needs at the moment to help calm themselves

HABILITATION'S ROLE IN TREATMENT

For children with neurodevelopmental disabilities, habilitation services are a critical component of treatment. Habilitation services staff help children acquire, keep, and improve skills, support the elements of providing a safe place, implement treatment plans, guide the child to use self-regulation strategies, and work in collaboration with schools and mental health professionals. Habilitation services can support:

- **Predictable daily routines**
- **Physical exercise:** outdoor activity; building OT and PT recommendations into daily routines
- **Meaningful activity**: play, games, and other group activities
- **Good diet**
- Building **mindfulness and body awareness** activities into daily routines
- **Learning new skills**
- **Communication:** Speech and language therapy, alternative, and augmentative communication (AAC), teaching communication skills
- **Daily living skills:** Teaching self-care, household tasks, community skills, and independence
- **Social and relationship skills:** Building capacity for friendship, intimacy, and community connection

- **Vocational skills:** Preparing for employment through skill development and supported work experiences
- **Behavioral support:** Implementing plans to teach replacement behaviors and coping skills as alternatives to challenging behaviors

Habilitation is not separate from treatment but an integral component. Children cannot fully benefit from therapy if they lack the foundational communication and self-care skills needed for daily functioning.

PSYCHOPHARMACOLOGY

Medication can be a valuable tool when used appropriately as part of comprehensive treatment:

- **Clear indication:** Medication should target specific symptoms associated with a mental health condition (ADHD, depression, anxiety). Medication should never be used as a chemical restraint.
- **Prescriber expertise:** Psychiatrists or other prescribers with specialized training in neurodevelopmental disabilities and child psychopharmacology
- **Start low, go slow:** Conservative dosing with careful monitoring for effectiveness and side effects
- **Regular review:** Ongoing assessment of whether medication remains beneficial and safe
- **Integrated with other treatments:** Medication alone is rarely sufficient, should support, not replace, psychosocial interventions
- **Shared Decision Making:** Children and families should understand the medication's role in treatment, potential benefits and risks, anticipated duration and alternatives
- **Minimize polypharmacy:** Avoid using multiple medications when possible, to decrease risk for adverse effects and medication interactions

Key Implications for Services:

- The living environments that the child calls home must be the first and ongoing consideration.
- Relationships will be the foundation for everything.
- Whether living with family, foster families, or in residential care, the environment is the foundation and requires supporting caregivers. Do not underestimate the caregiver's need for support.
- Safety is determined through the eyes of the child. Knowing the child's history and preferences is necessary to creating a safe place.

Opportunities to Grow

In this section you will see that education and habilitation are two sides of the same coin. Both are therapeutic and together provide the overall environments and life that will support a child's recovery, healing, and growth.

In this section we will address

- Habilitation services
- Education
- What service providers need from a service system

Beyond safety and treatment, children need opportunities to learn, develop skills, build relationships and participate meaningfully in their communities. Growth and development continue throughout childhood and adolescence and require appropriate supports and opportunities.

The brain is plastic, which means that it is dynamic, flexible and is constantly reorganizing its structure, functions and connections. Beyond safety and treatment, children need opportunities to learn, develop skills, build relationships, and participate meaningfully in their communities. Growth and development continue throughout childhood and adolescence and require appropriate supports and opportunities.

Children with neurodevelopmental disabilities cannot grow and learn without direct support and guidance. Cuing, coaching, providing guidance, role modeling – these are all the tools of habilitation that help a child learn.

HABILITATION SERVICES

As discussed in the treatment section, habilitation is essential for children with neurodevelopmental disabilities. Children need both habilitation and treatment. Treatment addresses clinical needs, while habilitation builds daily living and social skills that enable children to function successfully in their homes and communities.

- Assistance by trained staff can support the child through daily activities and wellness routines at home, managing social situations and participating in community activities.
- Caregiver training, coaching and respite services can provide important support to families, foster families and other caregivers.
- Assistive technology, home modifications, and transportation can fill critical gaps.
- Community participation and employment related services will prepare the child for transition into more independence and adult life.

EDUCATION

Education is a critical foundation for lifelong success. School plays a vital role in children's lives, developing essential cognitive and social skills while fostering personal growth and critical thinking. Beyond academics, schools promote communication abilities, build a sense of community and belonging, and provide crucial support for children's mental, social, and emotional well-being through engaged teachers and staff.

Education requirements, policies, and practices align with expectations in children's social service system. These include: an individual assessment, an individual education plan that includes functional as well as academic goals, expectations that children will be educated with their non-disabled peers, the application of positive behavioral interventions, and the use of assistive technology and accommodations for communication needs.

COMMUNICATION BETWEEN EDUCATION AND SOCIAL SERVICES PROVIDERS

Children with complex needs typically receive services from multiple systems simultaneously. Effective coordination between education, parent/caregiver, and social services systems can be executed through:

- **Individual plan development:** Joint meetings where educational and clinical teams coordinate goals and strategies
- **Information sharing:** With appropriate consent, sharing relevant information about the child's needs, strengths, and effective strategies
- **Consistent approaches:** Using similar behavioral strategies and supports across settings for consistency
- **Joint problem-solving:** When challenges arise, education and social services staff work together to understand and address them
- **Transition coordination:** When residential placements change, ensuring educational continuity and appropriate school placement

Key Implications for Services:

- Most children who are complex have a neurodevelopmental disability that requires services and support for their overall growth and development.
- Children must be in school. Education provides a learning environment for knowledge and skill acquisition.
- Habilitation provides the environment for personal development through guided experiences and implementation of therapeutic recommendations.
- Mental health treatment is not enough on its own.
- Habilitation is therapy when it includes teaching, coaching, supporting decision making, and following through on treatment programs designed by teachers and clinicians. Habilitation services can provide training and support to caregivers.

4. System of Care – An Organized Approach to Serve Children Who Need Help from More than One System

In this section we will address:

- Common System Philosophies and Service Approaches
- System of Care: Responsibility for Providing a Place that is Safe
- System of Care: Responsibility for Providing Treatment to Heal
- System of Care: Responsibility for Providing Opportunities to Grow

SYSTEM PHILOSOPHIES AND SERVICE APPROACHES ARE MORE ALIKE THAN DIFFERENT

Collaboration across systems is sometimes impeded by the assumption that program philosophies and service approaches differ fundamentally. Each system has developed unique terminology and language over time, creating distinct cultures with their own norms and standards. However, closer examination reveals more similarities than differences. When these varied philosophies are compared, clear alignment emerges across systems. They share common principles, approaches, and goals.

- All acknowledge and respect the values and culture of individuals and their families.
- All provide support and services that build unique strengths through genuine collaboration.
- All base services and supports upon comprehensive assessments that incorporate the person's and family's own definition of need.
- And all seek to empower individuals and families as active partners in their care.

Child-centered focuses on placing the child at the heart of all decisions and processes, ensuring their needs, rights, and voices are respected and prioritized.

A youth guided approach means that young people are empowered, educated, and given a decision-making role in their care and in the policies that affect all youth.

Person-centered is an approach that puts the individual's personal preferences, needs, and goals at the forefront of planning and service provision.

Life course approach views development as a lifetime of interconnected and continuous experiences, emphasizing that early events, experiences and decision influence health and behavior later in life.

Trauma-informed care[8] recognizes the pervasive impact of trauma and organizes services to avoid re-traumatization.

Family-focused and family-centered approaches are grounded in the belief that families are the primary unit of care. By actively engaging, involving, strengthening, and supporting the entire family unit, these approaches provide the most effective pathway to ensuring children's safety, permanency, and well-being.

The system of care approach was initially conceptualized in the 1980s to address problems in mental health services for children and youth with serious emotional disturbances (SEDs). In a system of care (SOC) approach, leaders work across systems to improve behavioral health and related outcomes for children and their families by ensuring strategic, coordinated, effective upstream service delivery. Cross-system collaboration — developed in partnership with children, families, and communities — is

8 *SAMHSA (Substance Abuse and Mental Health Services Administration). (2014). SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD*

essential since no single system can provide all necessary services. The SOC approach requires shared accountability for outcomes regardless of which system families enter to access services.[9]

Children with complex behavioral health needs require services from more than one system and need those systems to coordinate with each other. A System of Care must include all child-serving agencies such as child welfare, developmental disability, mental health, juvenile justice, education, and health.

The published principles and practices for a system of care can and must be shared by all systems if the needs of children are to be met.[10]

Core Principles[11]

- **Family and Youth Driven –** families and young people are supported in determining the types of treatments and supports are provided
- **Community Based –** services and supports are provided in home, school, primary care and community settings
- **Culturally and Linguistically Competent –** services and supports are responsive to cultural, ethnic, racial, and linguistic characteristics of populations served

Guiding Principles

- A comprehensive array of services and supports provides a full continuum of services from prevention through intensive treatment, available in home and community settings
- Individualized, strength-based services and supports are tailored to the strengths, preferences, and needs of the young person and family
- Evidence-based practices are based on research and evidence to ensure effectiveness
- Trauma-informed approaches recognize the impact of trauma and incorporate this understanding into policies and practices
- Least restrictive natural environments include the home, school and community
- Partnership with families and youth at the systems level in policy, governance, system design, implementation, evaluation and quality assurance
- Interagency collaboration involves multiple public and private agencies working together in a coordinated network
- Care coordination integrates and coordinates services to support the needs of the individual and family
- Physical Health-Mental Health Integration assures that both physical and mental health needs are addressed and coordinated

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9 ***25.07-QFF-TS-SOC-issue-brief.pdf***

10 ***National Training and Technical Assistance Center (NTTAC),***

11 *Stroup, B.A. Blau, G.M. & Larsen, J. (2021)* ***The Evolution of the System of Care Approach.*** *Baltimore. The Institute for Innovation and Implementation, School of Social Work, University of Maryland*

- Developmentally appropriate services and supports are provided and there is a coordinated transition process as children move into adult systems.
- Public health approach that includes mental health promotion, prevention, early identification and intervention
- Mental health equity assures access to all services

System of Care: Responsibility for Providing a Place that is Safe

Child welfare, developmental disabilities, mental health and education systems responsible for providing home and daily care are positioned to create a safe and therapeutic living environment, one that is free of harm and trauma. This can be the family's home, foster care, or a small group living arrangement in the community. These environments lend themselves to individualization, a range of typical learning experiences, and opportunities to develop trusting relationships with adults.

Institutional and congregate options such as residential treatment facilities or schools, homeless shelters, and detention facilities present barriers to providing a child with an environment that can be customized to meet their needs, including providing the opportunity to establish a sustained or trusting relationship with an adult. When placement in such facilities is necessary for some time, it is important to make every effort to adapt the environment to meet the child's needs. Failure to do so can contribute to the child's trauma and interfere with progress.

Create and maintain safety system-level structures and functions across all systems:

- **Provider capacity:** An adequate number of providers of services with relevant experience and training.
- **Background checks:** Comprehensive background screening for all staff working with children
- **Licensing and oversight:** Rigorous licensing standards for residential programs with regular monitoring and enforcement-Standards should address staffing ratios, staff training, physical environment, programming, and rights protections.
- **Incident reporting:** Mandatory reporting of injuries, use of restraint or seclusion, medication errors, and other serious incidents with investigation and corrective action.
- **External monitoring:** Independent oversight through licensing or quality review organizations.
- **Crisis response:** Mobile crisis teams, crisis stabilization services, and respite care to prevent placement disruptions.
- **Restraint and seclusion reduction:** System-wide initiatives to eliminate or drastically reduce use of restraint and seclusion through training, monitoring, and accountability.

System of Care: Responsibility for Providing Treatment to Heal

Child welfare, developmental disabilities, and mental health systems are all responsible for some components of treatment. While mental health treatment must be designed and provided by clinically trained staff, it is the daily caregivers–family members, paid caregivers, and teachers- who must incorporate good clinical responses and interventions into the child's environment and daily routines. Functioning as a team of clinical and nonclinical individuals, treatment is wrapped around the child and integrated into their environment.

Treatment happens every minute of the child's life, in every environment.

- Every child needs a trusting relationship with adults.
- Every parent, caregiver and teacher must know what the child needs to feel safe and respected–Every person must know about the child's history of trauma.
- Every child needs a day that is structured with predictable routines.
- Every child needs a good diet, exercise, and opportunities to be outside and play.
- Every child needs their physical and mental health needs assessed and treated.
- Every child needs an appropriate form of treatment integrated into their lives.
- Every child needs opportunities to gain experience, make decisions, and have new experiences.
- Every child needs a plan for setbacks or crises so the response from adults is constructive and dependable.

To make sure treatment happens in every minute of the child's life, service providers have to collaborate with the child, family, and each other. Communication needs to be frequent – whether just checking in with each other or meeting as a team.

Treatment may also include treatment for members of the child's family. Counseling and individual family therapy strengthen the family's capacity to support the child.

An obstacle to meeting the needs of children is limited or no access to the therapies most effective for children with complex behavioral health conditions. Services are often limited to individual and group therapy, and peer support. An additional obstacle in some states is the exclusion of individuals with intellectual disabilities from behavioral health services entirely. In these cases, willing providers cannot be reimbursed for providing a service.

To ensure the needs of children can be met, states should both assess whether the types of services eligible for reimbursement include evidence-based interventions effective for children with complex needs and examine whether their state plan contains exclusionary criteria that makes children with intellectual disabilities ineligible for mental health services.

System of Care: Responsibility for Providing Opportunities to Grow

THE NEURONS THAT FIRE TOGETHER, WIRE TOGETHER

Neuroscience has revealed that the brain is not a static organ—it continuously adapts and changes throughout our lifetime. The prefrontal cortex, responsible for decision-making and impulse control, doesn't fully mature until our mid-to-late 20s or even early 30s. This phenomenon, known as neuroplasticity, underlies the common expression "use it or lose it," which highlights the importance of continually challenging the brain through mental activities and social engagement to maintain cognitive function and build neural connections.

EDUCATION

Too often, children with complex conditions who, like all children, need training, education and interactions with their peers are excluded from school. They may be suspended or even expelled, assigned to home bound instruction or instruction in an institution. School is critically important for children's development. Every effort must be made to advocate for the child, to work with the education system and in some cases, provide consultative or other supportive services in the school. The benefits of education in both recovery and growth include:

- **Learning and cognitive development:** School provides structured opportunities for children to develop literacy, numeracy, and critical thinking skills.
- **Socialization**: School is where children learn to interact with peers, navigate social relationships, collaborate, handle conflicts, and develop emotional intelligence. They learn to function as part of a community beyond their family.
- **Structure and routine:** Regular attendance provides children with predictability and teaches them about responsibility, time management, and meeting expectations.
- **Opportunities:** Education is one of the most reliable pathways out of poverty and toward economic mobility. It opens doors to careers and opportunities.
- **Broader development**: Schools often provide exposure to arts, sports, different perspectives, and experiences that families might not be able to offer alone. They can also identify learning differences or developmental needs early.

HABILITATION

Beyond school, daily life offers rich opportunities for growth and learning. Habilitation services provide structured support outside the classroom, helping children develop essential skills in communication, daily living, social relationships, and vocational preparation. By following each child's preferences and interests, these services create

space for exploration—allowing children to discover new activities, try unfamiliar experiences, and navigate different environments at their own pace. Educating family members and caregivers about brain development and recovery empowers them to turn ordinary daily activities into meaningful interventions that significantly support a child's progress.

WHAT SERVICE PROVIDERS NEED FROM SERVICE SYSTEMS

Community providers play a pivotal role in delivering services that positively impact children's lives. Rules, requirements, authorization processes, and payment structures are typically designed for accountability—ensuring regulatory compliance and responsible use of funds. However, these accountability-focused policies can inadvertently create barriers to providing quality, person-centered, trauma-informed care for children with complex needs. The following system elements can facilitate effective service delivery:

Service Definitions that communicate expectations including qualifications and training requirements to create a therapeutic environment through, the types of activities that can occur during service delivery and the range of environments the services can be provided in.

- Example: Residential habilitation for individuals with complex needs that include behavioral support service, art therapies, and clinically trained supervisors
- Example: Life sharing for individuals with complex needs that include supplemental habilitation staff, behavior support, clinically trained supervisors, and respite care

Reimbursement Practices that Support the Service

Rates should reflect the competencies and amount of clinical support and supervision necessary to provide the service.

- Example: Factoring in requirements for staff certified in trauma-informed practices and trained clinical oversight.

Service unit definitions determine the documentation requirements for billing and should be customized for the service.

- Example: A daily or weekly rate for 24-hour residential service rather than hourly.

Service limits determine the amount of support provided to families, foster families, other caregivers, and children. Frequency and duration may need to be modified for children with complex behavioral health conditions.

- Example: Supported employment for individuals with complex needs may require more hours and for an indefinite period of time

Service authorization practices: Requiring frequent (90 Day) reauthorizations, frequent requests for an exceptional case review or excessive documentation to substantiate continued need for the service.

- Example: A higher staff ratio in residential habilitation; the number of hours of respite for a family

Single fee-for-service vs. bundled rate: When a child requires multiple services—such as in-home assistance, respite care, behavioral support, and community integration—fee-for-service billing can fragment care delivery. A bundled rate structure that groups related activities under a single service definition can enhance coordination, streamline service delivery, and simplify accountability while better meeting the child's comprehensive needs.

- Example: A definition of in-home support that includes habilitation, behavior support, community integration, supplemental therapies, and crisis response.

Care Coordination: Children with complex needs typically require support from multiple systems, making coordination and collaboration essential. However, individual providers often lack both the authority and the billing mechanisms to dedicate time to cross-system coordination. An effective solution is to designate a lead care coordinator who is formally recognized across all systems with the responsibility to convene multidisciplinary teams, monitor service delivery, and ensure that services align with the child's evolving needs.

Developing Capacity: Currently, few professionals have the specialized training or credentials needed to serve children with complex needs. While individual providers may build expertise, their organizational capacity often remains limited. Most states face a shortage of qualified providers, making statewide capacity-building essential. States can develop this workforce through partnerships with **University Centers for Excellence in Developmental Disabilities** and **Developmental Disability Councils**, federally funded training programs, such as **SAMHSA TA Resources**, and experienced clinicians already practicing within the state. Training and technical assistance should include:

- Initial and ongoing training in evidence-based practices
- Consultation from subject matter experts
- Peer learning opportunities
- Access to curricula and training materials

Support during crises: Even when assessment, planning and services are optimal, crises happen. Planning for them reduces trauma to the child and strengthens the capacity of caregivers and providers so they do not give up on the child. Caregivers and providers need:

- Mobile crisis response to assist with acute situations and to avoid calling law enforcement and use of emergency medications
- Ready access to psychiatric consultation
- Respite for families or short-term stabilization services
- Rapid convening of the child's treatment team to evaluate the plan and need for modifications

Key Implications for Services:

- Both education and habilitation services are important to children with complex behavioral health conditions and collaboration and coordination are necessary to achieve positive outcomes
- To ensure the needs of children can be met, states should both assess whether the types of services eligible for reimbursement include evidence-based interventions effective for children with complex needs and examine whether their state plan contains exclusionary criteria that makes children with intellectual disabilities ineligible for mental health services.
- Provider capacity must be developed through training, technical assistance, and support for continuous learning. State structures to govern and reimburse providers should be designed to facilitate the delivery of services.

5. State Leadership, Interagency Collaboration and Strategies

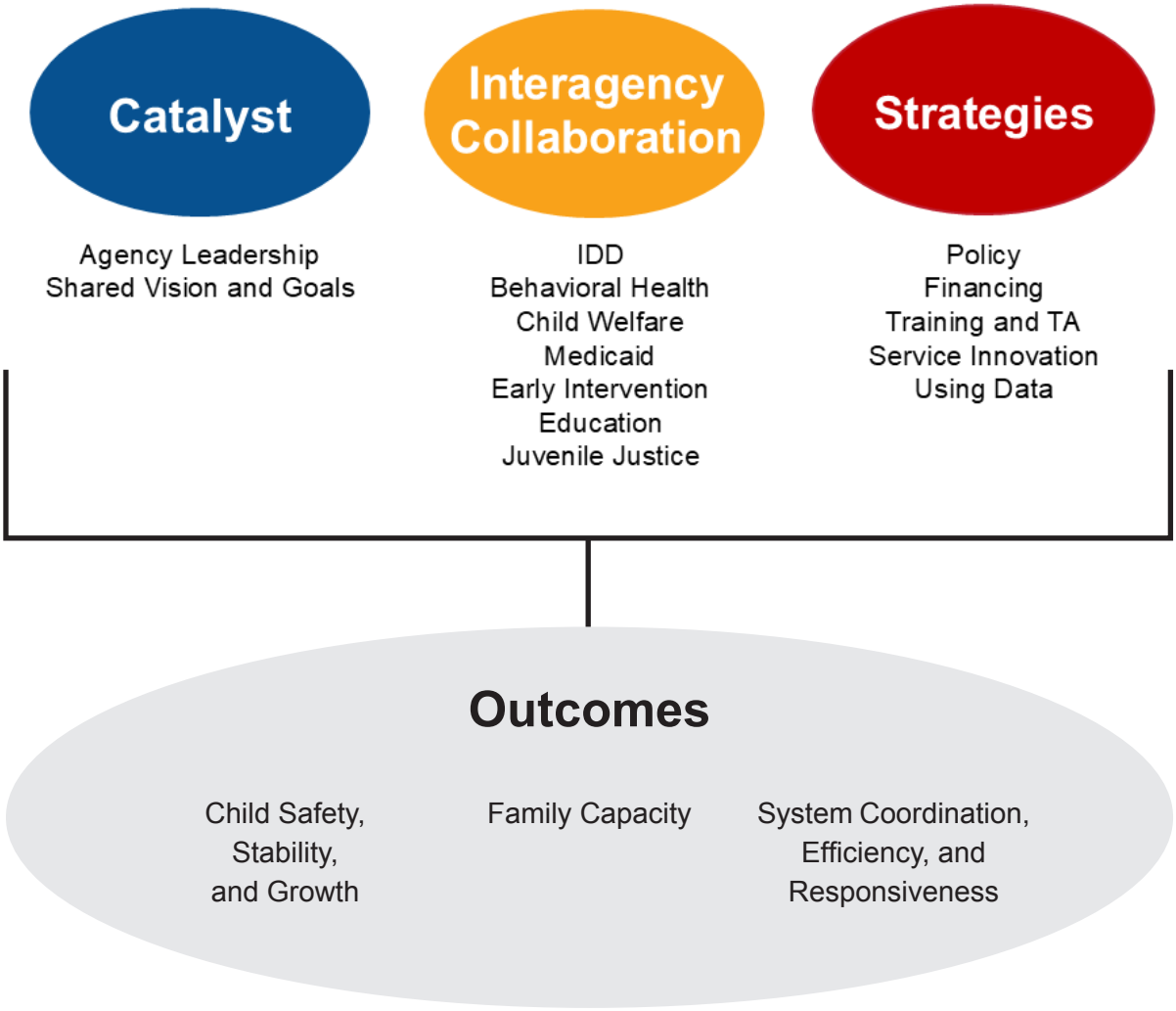
Putting It Together: In this section we will provide information on state practices including:

- Agency leadership, shared vision and values
- Interagency collaboration
- State policy
- State service innovation
- State financing
- State training and technical assistance
- Using data to manage

During the course of this project, we conducted interviews with nine states selected based on recommendations from project partners and subject matter experts. While our scope was necessarily limited, these states offered valuable insights into diverse approaches to serving children with complex behavioral health needs.

We have organized our findings using a framework developed by John Butterworth, Senior Research Fellow at the Institute for Community Inclusion at UMass Boston. This framework, which has successfully guided the work of the NASDDDS State Employment Leadership Network (SELN), provides a comprehensive view of the service system domains that have the greatest impact on outcomes. While states employ various approaches to leadership, collaboration, and system strategies, this report illustrates how the interviewed states are applying their chosen methods within each domain.

A Systemic Approach to Meeting the Needs of Children with Complex Behavioral Health Conditions



Agency Leadership, Shared Vision, and Goals

Public services advance when stakeholders share a common vision and maintain urgency around achieving it. In states making progress on services for children with complex behavioral health conditions, leadership drives this alignment. Governors and senior executives announce initiatives and propose budgets. Legislatures enact statutes and appropriate funding. These actions succeed when everyone understands both the destination and the path to reach it.

Stakeholder engagement builds the buy-in necessary for sustained progress. Involving people with lived experience, families, service providers, and community members deepens understanding and commitment to shared goals. This inclusive approach ensures that system improvements reflect real needs and ground-level realities.

Meaningful system change requires strategic planning, decisive action, and sustained resource commitment. Over time, consistent implementation creates organizational practices that endure. States that succeed describe more than procedural changes—they report cultural transformation as people throughout their systems expand their knowledge, capabilities, and collaborative capacity.

Colorado

- Colorado's Behavioral Health Task Force, established by Governor Polis in 2019, released a blueprint to guide reform of the state's behavioral health system. House Bill 24-1038 (2024) addresses high-acuity crisis care for children and youth requiring residential services, mandating implementation of a standardized assessment tool, intensive care coordination, expanded support services, access to treatment foster care, and establishment of a leadership team to oversee the system of care.
- The Colorado System of Care Plan, issued by the Department of Health Care Policy and Financing (HCPF) in May 2025, focuses specifically on reforming service delivery for members under age 21 with complex behavioral health needs. Implementation efforts include a Workforce Capacity Center operated by Colorado State University; provider forums and education; promotion of Enhanced High-Fidelity Wraparound with Intensive Care Coordination; Child and Adolescent Needs and Strengths (CANS)-based Plans of Care; evidence-based practices such as multisystemic therapy and functional family therapy; and multiple advisory committees that include individuals with lived experience.

Delaware

- Recommendations emerging from the **Division of Developmental Disabilities Services Task Force** under **Senate Concurrent Resolution 62 (SCR62)** encouraged the Division to develop a more comprehensive approach to serving individuals with intellectual and developmental disabilities who also exhibited the need for significant behavioral health supports to successfully navigate the community. In collaboration with the State's Division of Substance Abuse and Mental Health and **The Center for Disabilities Studies** (the State's UCEDD), a multiyear strategy emerged focused on assessment, capacity building, and integration into existing support structures. This "all-in" approach ensures behavioral health resource development includes individuals with IDD rather than maintaining segregated services. The creation and growth of the State's Behavioral Health Consortium elevated the statewide need for a stronger behavioral health support system that can meet the needs of all populations.

Kentucky

- **Families First**, spearheaded by the Kentucky Cabinet for Health and Family Services (CHFS), is a comprehensive, multi-year initiative aimed at enhancing the existing system of care for all Kentucky children and youth. The initiative focuses on cross-system collaboration and family-centered approaches to support children with complex needs.

New Jersey

- In response to the advocacy of **New Jersey Parents' Caucus** for a coordinated service system**, t**he **Children's System of Care (CSOC)** began in 1999 with a grant from the federal Substance Abuse and Mental Health Services Administration (SAMHSA) in one specific community. Core system partners were developed and expanded statewide by 2006, when CSOC was embedded in the newly created Department of Children and Families (DCF). DCF also supports a Division of Child Protection and Permanency, which enables cross-system collaboration and coordination between behavioral health services and child welfare.

Ohio

- Ohio has made youth with complex behavioral health needs a statewide priority through **OhioRISE** (Resilience through Integrated Systems and Excellence) the state's specialized Medicaid managed care program for high-complexity children. OhioRISE formalizes coordination across child welfare, juvenile justice, developmental disabilities, behavioral health, and education, creating shared accountability and clearer pathways to services.
- The Ohio Department of Developmental Disabilities (DODD) further reinforces this vision through strong family-centered values and investments aimed at preventing custody relinquishment. Programs such as, Multi-Disciplinary Comprehensive Assessment Team (MCAT), Family Coaching, and Keeping Families Together (KFT) provide structure, resources, and expert consultation that help families stabilize youth at home and reduce the need for institutional or out-of-state placements.

Oklahoma

- **House Bill 4106** directs each public school district to develop and maintain a protocol for responding to students in mental health crisis to prevent suicide, self-harm, and harm to others. Districts must develop these protocols in partnership with one or more local mental health treatment providers certified by the Department of Mental Health and Substance Abuse Services (ODMHSAS). Organizations certified as community mental health centers or certified community behavioral health clinics must serve as school partners when requested by districts in their service areas. Districts and their mental health provider partners must jointly review protocols and working agreements every two years. Both the Department of Mental Health and the Department of Education must provide technical assistance to districts and their mental health provider partners.

Pennsylvania

- The Blueprint Workgroup is a multi-disciplinary, multi-system team of professionals and families with lived experience who developed and published **Improving the Lives of Children, Youth, and Young Adults with Complex Needs and Their Families** in February of 2024. Recommendations aim to improve outcomes for youth with complex behavioral health needs and their families, ranging from amending state law to identify youth with complex needs earlier in life, developing cross-system service innovations, and addressing administrative inefficiencies related to information sharing and provider credentialing. The Blueprint Workgroup is currently focused on further defining recommendations, making them actionable, and presenting each to county and state leadership

Tennessee

- Through **Governor Lee's TN Strong Families initiative**, the Department of Intellectual and Developmental Disabilities (DIDD) partnered with the Department of Children's Services (DCS) to support children with IDD who are in state custody or at risk of entering custody. DID provides additional care coordination including the creation of a support plan specific to the child's health and developmental needs, as well as a Health Reimbursement Arrangement (HRA) account of up to $20,000 to offset out-of-pocket expenses for foster families.

Utah

- **Utah describes a "culture of collaboration"** represented through an unwritten but actively promoted policy principle "we will not send children out of state." This is a paradigm shift from asking "How do we manage these difficult children?" to "How do we understand and support children whose brains work differently because of trauma, genetics, or injury?"
- **Utah** issued the **Utah Behavioral Health Assessment and Master Plan** with seven priorities that include "Improve the availability of services and supports for individuals with serious mental illness and complex behavioral health needs and their families and **Brief #5 – Trends for Supporting People with Complex Medical and Behavioral Needs** identifying opportunities for change and future considerations.
- **Utah DHHS Youth with Complex Behavioral Health Needs Initiative** has launched ISTEP–Intensive Stabilization and Treatment Program and HABAT–High Acuity Behavioral Assessment and Treatment

The Call

States interviewed for this project reported that collaboration often starts with a call – a call to solve a crisis situation for one specific child. The crisis may be a hospital ready to discharge a child with no home for the child to go to, the lack of a provider to serve a child or the involvement of the criminal justice system.

The calls generally involve multiple state agencies including child welfare, juvenile justice, behavioral health, developmental disabilities, managed care organizations, hospitals, law enforcement, and others. Various agencies contribute ideas and resources to create both interim and long term solutions.

Over time, these ad hoc responses to individual cases evolve into regular weekly calls and eventually expand to address broader system-level issues.

COLLABORATION AMONG STATE ADMINISTRATIVE AGENCIES

States differ in their organizational structures. Some have singular integrated departments under the governor that encompass multiple services areas while states maintain separate agencies that challenge collaboration. In each case, states must work through the challenges of siloed agencies, regulatory barriers, and resource limitations.

Delaware

- Case review meetings initially brought together staff from multiple divisions: Family Services and Prevention, Behavioral Health (both within the Department for Services for Children, Youth, and Families), Developmental Disabilities Services (Department of Health and Social Services), and Exceptional Children Resources (Department of Education). These meetings evolved into regular coordination between DSCYF and DHSS focused on early intervention and prevention.

New Jersey

- **The Department of Children and Families (DCF)** houses several key programs under one roof: the **Children's System of Care**, Child Protection and Permanency, and prevention services through the Division of Family and Community Partnerships. This integrated structure enables cross-system collaboration. DCF also partners closely with the Department of Human Services' Division of Medical Assistance and Health Services to coordinate Medicaid funding, service authorization, and claims payment.

Pennsylvania

- The **Department of Human Services** is an umbrella agency for Child Welfare, Mental Health, Developmental Programs, and Medicaid. PA DHS is also partnered with the PA Department of Education. Leadership from the Office of the Secretary oversees this coordination, unifying child-serving systems within DHS.

Utah

- The **Office of Coordinated Care and Regional Supports (CC&RS)** provides intensive care coordination for children and youth with serious emotional disorders. CC&RS conducts independent reviews of residential placements, improves access to evidence-based treatment, identifies service gaps, develops service plans, and connects families with resources across the Department of Health and Human Services.

Leadership is what matters most: Agency leaders with decision-making authority are directly involved in both individual cases and system-level improvements. These leaders have the power to make policy, program, and resource decisions.

Collaboration Across Levels of Government

States face a dual challenge – they must align at the executive level of government even as services are delivered locally through regional offices, county or tribal government, or private agencies. Coordination becomes even more complex when local entities contribute funding.

States adapt their collaboration strategies to fit their geography, government structures and organizational culture.

Colorado

- **Colorado Behavioral Health Taskforce**
- **Colorado System of Care Colorado System of Care:** County departments that reach capacity while serving a child with complex needs can escalate cases to the state level. A specialized response team then provides support. The state uses a standardized placement request form that serves dual purposes: tracking state-level placements and facilitating referrals to provider agencies.

Delaware

- As a small state with centralized programs, emphasis has been given to coordination across departments and divisions to move from shared cases to shared or overlapping systems. For instance, coordination between programs serving youth and adults has highlighted the need and possibility for coordinated provider networks to ensure more seamless transitions across service programs and supports. As next steps, the state imagines moving towards shared or unified application processes, authorization systems for providers, and strengthened service navigation. The partnership also means more collaborative emphasis on building resources in the community and not just those provided explicitly by the State.

Kentucky

- Has a nearly four-decade long-standing governance structure in place. The State Interagency Council (SIAC) for Services and Supports to Children and Transition-Age Youth was established by statute in 1990 to serve as the governing body for Kentucky's system of care for children and youth with or at-risk of developing behavioral health (inclusive of mental health, substance use, and co-occurring mental health and substance use) challenges. In this role, the SIAC has served as the governing body for all past and present SAMHSA SOC and adolescent CSAT grants, as well as other federal grants (including suicide prevention, healthy transitions, Children's Bureau trauma, and others), and state-level initiatives focused on these populations and their families. The SIAC membership includes state agency leaders, family and youth representatives, and organizational partners committed to improving outcomes for children, transition-age youth, and families and meets monthly.

Ohio

- Ohio administers developmental disabilities services through county boards that fund a portion of the non-federal Medicaid share. This local authority, paired with statewide expectations and Technical Assistance from Department of Developmental Disabilities (DODD), creates a decentralized but responsive system. The Assessment Team (MCAT), Family Coaching, and flexible funding help counties work together on complex cases and prevent custody relinquishment. Statewide supports strengthen consistency across Ohio's 88 counties while preserving local flexibility.
- **Ohio RISE**: The state's child welfare program, partners with 18 regional Care Management Entities (CMEs). Each youth is connected with a care coordinator who provides individualized, community-based support tailored to the youth's emotional, behavioral, and physical health needs. The 18 regional CMEs coordinate behavioral health services and partner closely with county DD boards, schools, courts, and child welfare

Oklahoma

- The state operates eleven treatment provider organizations that deliver comprehensive services for children with complex emotional and behavioral needs, including Individual, group, family therapy using various evidence-based techniques, and 24-hour crisis assessment and stabilization services. Oklahoma also utilizes Certified Community Behavioral Health Clinics (CCBHCs) to expand access.

New Jersey

- New Jersey's Children's System of Care contracts with 15 Care Management Organizations (CMO) to provide care management for youth with moderate and complex needs. CMOs are county based, nonprofit organizations responsible for face-to-face care management and comprehensive service planning. They coordinate Child Family Team (CFT) meetings and implement Individual Service Plans (ISP) for each youth and his/her family. Additionally, they are responsible for building strong local relationships and collaborations to support education of partners and connections that support individual youth and family planning.

Pennsylvania

- The state's child welfare and developmental disabilities service systems are county based; behavioral health services operate through county-based HealthChoices managed care program. To provide direct technical assistance to its counties, Pennsylvania established a formal complex needs planning process that begins with county level planning efforts, regional cross-agency coordination and state level multi-agency collaboration. Youth-specific technical assistance to county planning teams covers licensed settings, funding, best practices, clinical resources, and successful strategies from other counties.

Tennessee

- Operates both a direct support program and a foster family and child support program. These programs are codified through an MOU between both DDA and DCS and funded directly by the General Assembly and Governor of Tennessee.
- Tennessee Strong Families & Homes (TSFHs) Tier 1: Provides impatient admission for medically acute custodial youth at three strategically located homes (12 total beds) to prevent nursing facility or out-of-state placements. Funding is through cost-based reimbursement.
- Tennessee TSFHs Tier 2: Provides intellectual/developmental disability- specific care coordination and up to $20k in annual funding, delivered through an HRA account. Funding is appropriated on a per person served basis.

Utah

- The state's mental health system provides services through 13 local authorities across 43 counties and the Division of Children and Families has five geographically defined regions. There is a long-standing practice of regional teams meeting that include representatives of local child service agencies to develop solutions for children. The state agency is involved on an as needed basis.

FACTORS THAT IMPACT COLLABORATION

- Structural Alignment: How well do substate arrangements match the state's geography and existing governmental structures?
- Authority Distribution: What decisions are made locally versus at the state level? Clear escalation pathways are essential.
- Resource Allocation: How are funding responsibilities shared between state and local entities?
- Communication Mechanisms: What formal processes exist for information sharing and case coordination?
- Cultural Fit: Do collaboration models align with existing organizational cultures and relationships?

Effective interagency collaboration with nonstate entities requires ongoing attention to these factors, with regular assessment and adjustment to ensure systems remain responsive to the populations they serve.

State Strategy: Policy

Policy encompasses all aspects of a service system, including system structure, eligibility criteria, program and service design, program and financial rules, reimbursement rates, and oversight. States establish policy through statutes, regulations, policy bulletins, and licensing and certification requirements.

All states interviewed have established policy foundations—through statute or regulation–that promote:

- Child permanency
- Person-centered and family-centered practices
- Community inclusion
- Trauma-informed practices
- Accountability through standards and oversight

POLICY TRENDS

The most common policy trends among interviewed states are expanding eligibility to serve more children, broadening service offerings, and implementing early prevention strategies.

Expanding access:

Medicaid Eligibility: Most interviewed states have expanded Medicaid eligibility by excluding parent income from the eligibility determination process.

- **Delaware:** The state's **Division of Prevention and Behavioral Health Services:** Provides behavioral health assistance to youth who are enrolled in Medicaid or the Children's Health Insurance Program (CHIP); who lack Medicaid or private mental health/substance abuse benefits, or who have exhausted private benefits.
- **New Jersey**: **Children's System of Care**: CSOC services are available to all youth in NJ up to the age of 21, regardless of system involvement, income level or insurance eligibility.

Expanding Services:

- **Colorado and Utah –** Fund training for EMDR therapy
- **Ohio –** Offers family coaching
- **Oklahoma** – Offers Eye Movement Desensitization and Reprocessing (EMDR) Therapy,
- **Pennsylvania –** Offers somatic therapy including equine therapy and music therapy in their HCBS Medicaid Waivers.
- **Utah –** Offers massage therapy

Developing Prevention Programs

States are implementing early intervention and prevention programs to support children and families before needs escalate:

- **Colorado's I Matter Program**: Provides six free counseling sessions for anyone under age 18, or age 21 with an Individualized Education Program (IEP). No insurance is required.
- **Ohio's Parent and Youth Ambassadors (PYAs):** Provide regional supports that help individuals, families, and youth find answers and access services at the local level. Support is available before, during, or after a crisis at no cost.
- **Pennsylvania's Early Intervention System** offers a wide array of services and supports to infants, young children, and their families with developmental delays. Pennsylvania continues to explore preventative services across systems.
- **Tennessee's Early Intervention System (TEIS):** Offers therapy and other services to families of infants and young children with developmental delays or disabilities. Services are provided at no cost to families.

State Strategy: Service Innovation

Effective service systems for children with complex needs require more than traditional approaches. States are developing innovative programs that create safe environments, integrate therapeutic interventions, and provide developmental opportunities. These innovations span care coordination, family support, therapeutic foster care, school-based services, and crisis stabilization—all designed to keep children with their families and in their communities.

Colorado:

- Brain injury screening – Integrates the Teach Acute Concussion Tool (TACT) with education systems to identify and support children with brain injuries.

Delaware:

- **Support for Every Family:** Every individual found eligible for Division of Developmental Disabilities Services (DDDS) receives service support. Even before individuals begin accessing services for adults, individuals and their families receive access to a Community Navigator to offer targeted case managers. Adults participating in the DDDS system receive service support from either a Community Navigator (for those residing in their own or family home), or a Support Coordinator (for those living in a provider-managed residence). Individuals choosing to receive services through the State's LTSS program, managed by the State's Medicaid agency and an affiliated MCO, have access to a Resource Coordinator to offer a bridge between the MCO's Care Coordinator and the Division's services.
- **Enhanced Behavioral Residential Services:** The Division began piloting a new service designed to provide home-based support services for individuals with extensive histories of trauma, engagement with law enforcement, and ongoing use of emergency services (hospital-based and in-patient mental health). The enhanced behavioral residential service was designed with input from current residential service providers to meet the needs of individuals requiring this higher level of support. Built on a model of strengthening the home and providing quick access to a variety of skills and expertise (LCSWs, psychiatric prescriber, nurse, trained frontline staff) the program launched in January of 2023 and serves six people. In the first eighteen months of use, the service participants have had a collective decrease in critical incidents of more than 90%. Originally funded through ARPA/9817 funds, the program is slated to become a waiver approved service in July of 2026.
- **Moving away from diagnosis-based eligibility:** Delaware updated its eligibility regulations in 2023, shifting the language and emphasis away from eligibility based on diagnosis and towards assessment of adaptive function and level of need.

Kentucky

- **Intensive In-Home Supports:** The Medicaid Waiver program provides in-home supports for up to 16 hours per day, enabling families to care for children with complex needs at home while receiving substantial professional assistance.
- **Proposed CHILD Waiver: T**he Cabinet for Health and Family Services (CHFS) is developing the Community Health for Improved Lives and Development (CHILD) 1915(c) waiver to serve children and youth until the age of 21 who meet a Hospital-Psychiatric Residential Treatment Facility (PRTF) or Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) level of care. The waiver aims is to keep children, youth, and young adults with multi-system needs and complexities safe, healthy, and, to the extent feasible, independent, within their communities and families. Additionally, the CHILD waiver aims to serve children, youth, and young adults regardless of custody arrangement and is dedicated to a holistic approach to addressing high intensity needs with a support system as determined by the enrolled participant.

New Jersey

- The Children's System of Care's (CSOC) **Family Support Organizations (FSOs)** are nonprofit, county-based organizations that provide peer support, education and advocacy through an array of services to caregivers of youth with emotional, behavioral, developmental, intellectual and/or substance use needs. FSOs are led and staffed by family members who have lived experience as the primary caregiver or parent, and who have been successful in navigating one or more systems for their youth.
- **Coordinated Health Care for Children in Out-of-Home Resource Care:** Child Health Units that consist of nurses and support staff are embedded in the NJ Division of Child Protection and Permanency offices to support the delivery of coordinated health care for children in out-of-home placement. This includes ensuring each child has a medical home, receives Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) examinations, comprehensive medical exams, dental exams, regular mental health screening and assessments, and follow up care as needed.

Ohio

- **Multi-System Youth Resources** – A family-centered set of innovations to stabilize youth at home
    - **Multi-Disciplinary Comprehensive Assessment Team (MCAT) and Regional Coaches** provide multidisciplinary assessment with follow-along coaching to help families and teams apply recommendations.
    - **24/7 Foster Family Support Pilot:** Around-the-clock assistance for treatment foster families caring for high-needs youth.
    - **Second Opinion Psychiatric Consultations:** Specialized MI/ID psychiatric assessments through the MI/ID CCOE.
    - **Intensive Behavior Support Rate Add-On (IBSRAO):** Time-limited, intensive stabilization in ICFs with strong family involvement and transition planning
    - **Ohio RISE Care Coordination:** A tiered approach to care coordination that matches intensity of support to child and family needs, with clear pathways for escalation when complexity increases.

Oklahoma

- **Therapeutic Foster Care (TFC) –** Residential behavioral management in foster homes for children ages 3-18 with psychological, social, behavioral, and emotional needs who can accept family relationships but require more intensive therapeutic services than traditional foster care.
- **Enhanced Foster Care (EFC)** Designed specifically for children in state custody with complex behavioral, medical, developmental, and mental health needs. EFC provides individualized services and supports based on each child's specific needs, with strong coordination and collaboration among providers.
- **Evidence-based treatments** available include Trauma-Focused Cognitive Behavior Therapy (TF-CBT), Eye Movement Desensitization and Reprocessing (EMDR) Therapy, Parent-Child Interaction Therapy (PCIT), Trust Based Relational Therapy (TBRI), Child Parent Psychotherapy (CPP), and Systems of Care Wraparound services.

- **Post-Adoption Supports:** The state's Department of Human Services operates a post-adoption clinical team providing adoption-competent mental health care to families facing rising challenges with an adoptee. **The EFF Foster and Adoptive Parent Toolkit** provides comprehensive information on available services.
- **Extensive Residential Supports**: This Home and Community Based Waiver developed jointly with Child Welfare Services supports children with significant behavioral health needs who otherwise would require out of state treatment and supports. Using an agency foster care model with a person-centered approach, wraparound behavioral supports and creative staffing to keep children in their home state and the community.

Pennsylvania

- **Dual Licensure:** Allows homes to be licensed as Shared Living (under the HCBS waiver) and as Foster Care eliminating barriers that would otherwise separate siblings and providing continuity as youth transition to adult services.
- **Home and Community Based Waivers:** Includes a range of somatic therapies including music, art and equine assisted therapies, behavior support, physical and occupational therapy, speech/language therapy.
- **Family Peer Support:** The Pennsylvania Office of Mental Health and Substance Abuse Services (OMHSAS), in partnership with a group of stakeholders, is creating a structure for a Certified Family Peer Support training and credentialing.

Tennessee

- **TN Strong Families** – Support foster families caring for children with intellectual and developmental disabilities:
    - Health Reimbursement Benefit of up to $20,000 to cover out-of-pocket medical expenses.
    - IDD independent support coordinator to assist families with navigation and care coordination.
    - Weekly clinical consultation network for ongoing professional guidance
- **TN-TAN (Tennessee Technical Assistance Network)** provides free assistance to schools and families supporting students with disabilities, ages 3-22, ensuring educational needs are met alongside clinical services.
- **Tennessee's School-Based Prevention Program** provides nearly 400 school-based behavioral health liaisons—master's-level therapists, one per school—funded by state dollars. This program provides early intervention and ongoing support in the educational setting where children spend most of their time.

Utah

- The Neurobehavior Home is a unique program established by the University of Utah Departments of Psychiatry and Pediatrics in partnership with the state. The **Neurobehavior Home**, which falls under the umbrella of the **Huntsman Mental Health Institute**, is a program for children with cognitive or developmental disorders because that provides integrated care to meet both medical and mental health needs.

KEY INNOVATION THEMES

Across these state examples, several important themes emerge:

- **Trauma-informed practices** – Integrating trauma-informed approaches into policy and services
- **Intensive family support** – Investing in enhanced in-home services, respite care, coaching, and 24/7 support systems to keep families together
- **Embedded clinical support** – Integrating clinical professionals (nurses, therapists, behavioral specialists) directly into family homes, schools, and foster care programs
- **Flexible service arrays** – Offering multiple evidence-based treatment modalities with individualization based on specific needs
- **Family-to-family peer support** – Leveraging the unique value that families with lived experience provide to other families
- **School-based services** – Meeting children where they are through behavioral health supports and technical assistance in schools
- **Specialized foster care** – Developing multiple therapeutic foster care models that provide alternatives to congregate care while meeting complex needs
- **Removing system barriers** – Eliminating artificial barriers through innovations like dual licensure that better serve children and families

These innovations demonstrate that with creativity, investment, and family-centered values, states can build systems that truly create places of safety, provide treatment that heals, and offer opportunities for children to grow and thrive.

States Strategy: Financing

Financing is often the limiting factor in developing and sustaining services for children with complex behavioral health needs. Three major federal programs provide primary funding: Medicaid and the Children's Health Insurance Program (CHIP), Individuals with Disabilities Education Act (IDEA) funds, and Child Welfare Title IV-E funds. States supplement these core programs with additional federal, state, and local sources.

MEDICAID

Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

For children with complex care needs—particularly those in the child welfare system—Medicaid ensures access to necessary services. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit guarantees access to all needed physical and behavioral health care in children's homes, communities, and institutional settings.

EPSDT provides comprehensive and preventive health care services for children under age 21, ensuring they receive appropriate preventive, dental, mental health, and specialty services through:

- **Early** – Assessing and identifying problems early
- **Periodic** – Checking children's health at age-appropriate intervals
- **Screening** – Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- **Diagnostic** – Performing diagnostic tests when a risk is identified
- **Treatment** – Controlling, correcting, or reducing health problems found

EPSDT requires states to provide any medically necessary service to Medicaid-eligible children that could be included in the Medicaid State Plan under Section 1905(a) of the Social Security Act. Children are entitled to EPSDT services regardless of whether they live in a family home, foster home, or another setting.

All EPSDT components are relevant for identifying and treating children with complex behavioral health needs, but "Early" is most critical. Children whose extreme conditions states find difficult to treat can often be identified in early childhood. Timely interventions and family support could prevent the crises states frequently face. Effective treatments for children with complex behavioral health needs include traditional counseling services as well as somatic therapies and family-based therapies.

Many states have incorporated Medicaid into public school systems to integrate treatment into educational settings. In September 2024, the Centers for Medicare & Medicaid Services released **formal guidance** outlining states' obligations and opportunities under EPSDT. In February 2026, the Centers for Medicare & Medicaid Services again released additional guidance through the **State Medicaid & CHIP Toolkit for Children's Behavioral Health Services and the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Requirements.**

Home and Community-Based Services (HCBS)

HCBS can be critical to creating A PLACE THAT IS SAFE and providing opportunities for growth. However, HCBS is not an entitlement under EPSDT—states must voluntarily create an HCBS waiver.

States have considerable latitude in designing HCBS programs. They may target specific populations by condition, age, and geographic location, and choose which waiver services to provide. HCBS waivers can be designed to serve children with complex behavioral health needs of any age, whether living with biological families, foster families, adoptive families, or in small community residences. Children in the child welfare system can be made eligible if they meet HCBS eligibility requirements.

Medicaid Eligibility

Exclusionary Barriers – In some states, Medicaid rehabilitation provisions exclude children with intellectual disabilities from mental health treatment. The phrase "we don't serve people with I/DD," too often heard from practitioners, is founded on the outdated presumption that individuals with intellectual disabilities cannot benefit from mental health treatment. Developments in neuroscience have debunked this belief.

Financial Eligibility – Not all children meet state Medicaid eligibility criteria when family income exceeds the threshold. States have options to qualify children for Medicaid regardless of family income:

Excluding parental income – States may adopt rules making children who are eligible for Supplemental Security Income (SSI) also eligible for Medicaid, regardless of parental income. Family income information may be collected but is disregarded in determining eligibility.

State Examples:

- **Delaware** – **Children's Community Alternative Disability Program** – Children's Community Alternative Disability Program provides Medicaid coverage for severally disabled children who do not qualify for SSI dues to parent's income and/or resources.
- **Oklahoma** – Tax Equity and Fiscal Responsibility Act **(TEFRA)** option makes Medicaid (SoonerCare) benefits available to children with physical or mental disabilities who would not ordinarily be eligible for SSI due to parental income or resources. This allows children who are eligible for institutional services to be cared for at home.
- **Pennsylvania–PH-95** – Pennsylvania's PH95 program provides full and free Medical Assistance to children up to age 18 with disabilities who do not qualify for Medicaid due to parent's income and/or resources.

1915(c) HCBS Waivers: Many states use 1915 (c) waivers, which can include "institutional deeming" rules that count only the child's income, not the parents' income when determining eligibility.

1115 Demonstration Waiver: Under the Section 1115 Medicaid authority, states may cover populations not traditionally eligible, provide services not typically provided, implement alternative payment structures, different care coordination models and managed care models; and modify benefit packages for different populations.

- Example: New Jersey **New Jersey Family/Care Comprehensive Demonstration**
- Children with complex behavioral health needs may be eligible for HCBS services if they meet two thresholds:
    - Level of Care (LOC) – The child would otherwise need services in a hospital, nursing facility, or Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID).
    - Functional Eligibility – The child meets state-established functional requirements across domains including activities of daily living (ADLs)—such as personal care—and instrumental activities of daily living (IADLs)—such as managing money, maintaining a household, shopping, and maintaining health.

Functional Eligibility

Autism and Intellectual Disabilities are the most common diagnoses targeted in HCBS waver programs. However, some states use Developmental Disability defined as a chronic disability of a person which appears before 22 years of age and results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency. For children with developmental disabilities, states typically assess functional limitations across major life activities.

Children with Complex Behavioral Health Conditions may have both mental health conditions and neurodevelopmental disabilities. The child's functioning in the areas of ADLs and IADLs, and meeting the eligibility for an ICF/ID would be the determining factors in their eligibility for an HCBS waiver program.

EDUCATION PROGRAMS

IDEA (Individuals with Disabilities Education Act) – The primary federal program funding special education services for children ages 3-21. This includes:

- Part B grants to states for school-based services.
- Part C for early intervention services (birth to age 3)

Child Welfare – Title IV-E

This program provides funding for states to operate foster care, adoption assistance, guardianship assistance, and prevention services programs for children and youth involved in the child welfare system.

Title IV-B: Family Reunification and Prevention Services

Supports family reunification services and prevention efforts, including:

Treatment and Therapeutic Services:

- Mental health services and counseling (individual, group, family)
- Substance abuse treatment (inpatient, residential, outpatient)
- Therapeutic services for families
- Sex offender treatment programs
- Psychosocial assessments

Support Services:

- Domestic violence assistance
- Temporary child care
- Crisis nurseries
- Transportation to services (bus passes, taxi, metro/subway, train)
- Prescription medications not covered by private insurance, Medicaid, or other programs

Prevention and Capacity Building:

- Services to increase protective factors
- Programs to promote social connection
- Resources to build knowledge, skills, and capacities that help families meet basic needs and prevent family instability

MENTAL HEALTH PROGRAMS

- **Children's Mental Health Initiative (CMHI)** – Part of the Substance Abuse and Mental Health Services Administration (SAMHSA) funding, CMHI supports comprehensive community-based mental health services guided by a systems of care (SOC) approach
- **Circles of Care (COC)** – A systems of care planning grant for American Indian and Alaska Native (AI/AN) organizations
- **Community Mental Health Services Block Grant** – This block grant includes dedicated funding streams for children's mental health services within broader community mental health programs.
- **Project AWARE** (Advancing Wellness and Resiliency in Education) – Supports the implementation of mental health awareness training and services in schools and educational settings.

INCOME SUPPORT

- **Supplemental Security Income (SSI)** – Provides cash assistance to families of children with significant disabilities.

Flexible Funding Streams

- **Social Services Block Grant (Title XX)** – States can use these flexible funds for various services including those for children with disabilities and families.
- **Maternal and Child Health Services Block Grant (Title V)** – Supports state programs specifically designed for children with special healthcare needs, including care coordination and family support services.
- **Time Limited Federal grants – Various federal initiatives provide targeted resources for service development and enhancement, including:**
    - American Rescue Plan Act (ARPA) funds for behavioral health infrastructure
    - Money Follows the Person demonstration grants to support community-based care transitions.

STATE AND LOCAL FUNDS

State and local governments provide additional funding to supplement federal program and address gaps in coverage. These flexible funds enable states to:

- Extend eligibility to additional children beyond federal requirements
- Provide services not covered by federal programs
- Fill gaps in federal coverage
- Support innovative pilot programs and initiatives

Common State and Local Funding Sources

- State general revenue allocations for children's services.
- County or local behavioral health funding
- State-funded insurance programs and subsidies.
- Local education agency funds beyond federal requirements
- State mental health authority allocations.
- Special state initiatives and pilot programs

PRIVATE INSURANCE

State agencies face significant challenges in coordinating private insurance to ensure that non-Medicaid-eligible children can access the same services available to Medicaid-eligible children. This gap in coverage can lead to:

- Untreated behavioral health conditions
- Serious mental health crises
- Families relinquishing custody to the child welfare system to access necessary car

State Solutions and Models

New Jersey: Universal Access Model (CSOC): New Jersey's Children's System of Care (CSOC) provides universal access regardless of financial status:

Key Features:

- Access based on clinical need, not income, assets, or insurance coverage
- Service authorizations determined by clinical necessity
- Services not funded or reimbursed by private insurance
- Funding structure:
    - Medicaid-eligible youth: Services covered by Medicaid with federal matching funds
    - Non-Medicaid-eligible youth: State-only coverage option using a Medicaid look-alike number that allows providers to bill through the state Medicaid system using state-only funding (no federal match)

Pennsylvania: Mental Health Parity Enforcement: As of January 1, 2024, Pennsylvania requires insurers offering commercial health insurance policies with autism services coverage to administer claims in compliance with:

- Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)
- Pennsylvania's state mental health parity requirements

Tennessee: State-Funded Programs with Limitations: Tennessee currently funds its Strong Families and Homes programs entirely with state dollars, but faces ongoing challenges:

Current Status: Tennessee is currently covering the cost of Tennessee Strong Families and Homes programs with State funding. However, this does not address the "at-risk" population as custodial status is still required for our current programming. Discussions about accepting private insurance payments for services like planned or unplanned respite are currently underway but are problematic due to contracting and payment realities. Ongoing Discussions are exploring acceptance of private insurance payments for services such as planned and unplanned respite care but are facing complications related to contracting and payment realities

States Strategy: Training and Technical Assistance

The Challenge: The shortage of services and providers with the knowledge and skills to support children with complex behavioral conditions represents a significant barrier to effective care. States have recognized the critical need to assume a leadership role in providing comprehensive training and technical assistance to build workforce capacity.

STATE CAPACITY-BUILDING APPROACHES

States employ multiple, ongoing strategies to develop provider expertise and system capacity:

Training Formats:

- Low and high-intensity training programs
- Conferences and seminars
- Clinical networks with case presentations
- Certification and credentialing requirements
- Specialized provider development programs

Supporting Infrastructure:

- Payment practices that incentivize specialized skills
- Clinical case consultation and peer learning
- Cross-system training initiatives

Key Partners in Training Development and Delivery

States collaborate with diverse organizations to develop and deliver effective training and technical assistance:

- Universities and academic medical centers
- Medical schools and teaching hospitals
- National subject matter experts
- Private training organizations
    - Professional associations

Funding Sources: Federal agency grants and foundation funding have been instrumental in helping states build and sustain training infrastructure.

Cross-System Training Benefits: Training programs that span multiple systems serve dual purposes:

1. **Building workforce capacity** across child-serving agencies
2. **Creating collaborative relationships** by providing platforms for professionals to meet, learn together, and develop working partnerships

This cross-pollination strengthens the overall system of care and improves coordination among providers.

State Models: Training and Technical Assistance

Colorado

The Colorado Pediatric Psychiatry Consultation & Access Program (CoPPCAP): CoPPCAP was developed to support Colorado pediatric primary care providers in assessing and treating behavioral and mental health conditions in primary care settings.

Program Goals:

- Improve access to child mental health care through a statewide teleconsultation service
- Serve as a central hub for training and information on pediatric mental health care
- Provide direct support to pediatric primary care providers

Services Offered:

- Statewide teleconsultation for behavioral health cases
- Training and educational resources for primary care providers
- In-person or telehealth patient consultation to guide treatment planning
- Support for identifying and connecting families with local resources

Impact: By embedding psychiatric consultation into primary care settings, CoPPCAP extends mental health expertise to communities that may lack specialized child psychiatry services, while building the capacity of primary care providers to address behavioral health needs.

Delaware: Building Workforce Capacity Through Certification

Registered Behavioral Technician (RBT) Training Initiative: Delaware's Division of Developmental Disabilities Services strategically invested American Rescue Plan Act (ARPA) and Section 9817 funds to expand behavioral health expertise across its workforce.

Program Components:

- Training frontline care providers, including Direct Support Professionals, as Registered Behavioral Technicians (RBTs)
- Strengthening the knowledge base for supporting individuals with developmental disabilities and behavioral health needs
- Cross-system expansion to the Department of Services for Children, Youth, and Families (DSCYF)

Impact: By extending RBT training beyond traditional developmental disabilities services to child welfare and juvenile justice systems, Delaware has broadened access to evidence-based behavioral support for a wider population of children and families in need.

Clinical Provider Capacity Expansion: The Division is partnering with its University Center for Excellence in Developmental Disabilities (UCEDD) to:

- Develop specialized training programs
- Conduct targeted outreach to recruit and develop clinical providers
- Expand the state's overall clinical provider capacity

Kentucky

System of Care (SOC) Academy : Annual Statewide Training Initiative: The System of Care (SOC) Academy is convened annually by the Department for Behavioral Health, Developmental & Intellectual Disabilities (DBHDID) in partnership with stakeholders across child-serving systems.

Priority Themes:

- Promoting equity in access and outcomes
- Reducing health disparities across populations
- Strengthening collaboration among interagency state and community partners
- Prevention, early intervention, and treatment strategies
- Building resilience in youth, families, and communities

Purpose: The Academy serves as a central gathering point for cross-system learning, relationship building, and alignment around shared values and evidence-based practices. By bringing together diverse stakeholders annually, Kentucky creates sustained momentum for system improvement and collaborative problem-solving.

New Jersey

- **Rutgers' University Behavioral Health Care (UBHC) Training and Technical Assistance (TTA)** program trains the Children's System of Care (CSOC) workforce through live webinars, on-demand modules, and in-person professional development at partner agencies. The program uses competency-based curriculum design and adult learning principles to equip professionals with the knowledge and skills needed to support families and children with complex needs.
- **Autism NJ- Home** (ANJ) offers specialized training and resources for professionals serving individuals with autism, including virtual sessions for newly diagnosed families, statewide connection sessions, and a library of hour-long pre-recorded videos created specifically for CSOC system partners.
- **Boggs Center** provides training, technical assistance, and consultation to enhance provider capacity for children with intellectual/developmental disabilities who are dually diagnosed with psychiatric disorders or exhibit challenging behaviors unresponsive to ABA or other standard interventions.
- **Parents of Autistic Children (POAC)** is a nonprofit member of the NJ Governor's Council on Autism, POAC hosts hundreds of annual events including training for parents, educators, police, and first responders. The organization also provides recreational and support services while advocating for autism-related legislation.
- **CCIS Clinical Capacity Improvement Project** equips interprofessional behavioral health teams on children's crisis units with trauma-informed care strategies and cultural safety principles to support healing environments for children who have experienced trauma.
- **Infant and Early Childhood Mental Health Initiative** (CSOC) partners with **Montclair State University's Center for Autism and Early Childhood Mental Health** to build workforce capacity in early relational health, helping professionals support young children and caregivers in identifying and meeting developmental needs.

Ohio

Ohio has established a coordinated **TA structure** to expand provider capacity and ensure consistent support statewide:

- **Complex Needs Technical Assistance Team:** On-site and virtual consultation focused on maintaining youth safely at home.
- **Multi-Disciplinary Comprehensive Assessment Team (MCAT) and OCALI Coaching:** Expert case review followed by practical, ongoing implementation support.
- **Supporting Youth with Intensive and Complex Needs Training:** Required for the Intensive Behavior Support Rate Add-On (IBSRAO) program and based on the Ziggurat Model.

- **OCALI Navigation Essentials:** Easy-to-use tools, videos, and templates for educational and behavioral collaboration.
- **Keeping Families Together (KFT) Crisis Intervention Grants:** Funding for counties to develop local crisis-trained teams.
- This integrated model strengthens clinical, educational, and community capacity across all regions.

Oklahoma

Oklahoma offers two adoption-focused training programs:

- **Adoption Competent Mental Health Training**: The National Adoption Competency Mental Health Training (NTI)
- Training in Adoption Competency (TAC). The training program includes a virtual meeting on a regular basis for mental health providers to learn about new resources.

Pennsylvania

Pennsylvania has developed comprehensive, multi-layered training initiatives:

- **Community Capacity Building Institutes** – Annual yearlong programs, including one with a lifespan focus and another for the pediatric population with multisystem involvement.
- **HealPA** – Trauma-informed training serving 3,800+ residential facilities.
- **START Model Pilots** – Two pilots underway in cooperation with the University of New Hampshire in Philadelphia and Allegheny Counties.
- **Project Reassure** – Created with ODP, **ASERT**, and Penn State School of Medicine, offering web-based learning modules for self-advocates, families/caregivers, and direct support professionals. The collaboration also established a Project ECHO focused on trauma and fostering resilience in neurodiverse communities.
- **TRAIN Project** – Trauma Recovery for Autistic, Intellectually Disabled, and Neurodiverse Individuals, launched in 2021 to increase licensed therapist capacity. Through October 2025, 106 licensed therapists have participated.
- **DHS Trauma-Focused Initiative** – OMHSAS developed assessment tools and provides technical assistance to behavioral health and child welfare providers, youth, families, and stakeholders to advance Pennsylvania toward becoming a healing-centered state.
- **Youth Suicide Prevention** – Partnership with the Garrett Lee Smith Youth Suicide Prevention Grant team to promote comprehensive prevention efforts.
- **School Crisis Response** – Collaboration with the PA Department of Education to build statewide capacity by funding annual instructor trainings in PREPaRE.
- **Project AWARE** – Supporting two grants for local education agencies to develop and implement mental health approaches for students.
- **ASERT (Autism Services, Education, Resources and Training)** is a statewide partnership of medical centers, autism research and service centers, universities, and providers dedicated to supporting individuals of all ages with autism and their families.

ASERT provides training and education in best practices while facilitating connections between individuals with autism, developmental disabilities, and special populations, their families, and key stakeholders at local, state, and national levels.

Tennessee

- **Clinical Consultation Network** (CCN) Produces a weekly podcast with NADD and hosts an annual local conference providing training and support for caregivers and clinicians.
- **Clinical Education Team (CET)** – Monthly in-person meetings across seven regions featuring case presentations and didactic training for law enforcement, mental health, and crisis providers, and DDA providers.
- Potential legislation in development would position DDA in a lead role to train educators, foster families, and service providers working with children with IDD.

Utah

- **EMDR Training** – The Division of Child and Family Services (DCFS) covers training costs for providers to deliver EMDR services to families.
- **The Training for Adoption Competency (TAC)** is a nationally recognized, evidence-based postgraduate training program for licensed clinicians working with adoptive families. TAC is accredited by the Institute for Credentialing Excellence and is the only accredited certificate program in adoption competency in the country.
- The **Utah MHIDD Training Initiative** A three-phase initiative concluding in 2026, consisting of statewide landscape analysis, action plan development, and implementation. The program currently offers an **ECHO** training series for health professionals and disability service providers with objectives to increase mental health provider knowledge and capacity for serving individuals with IDD, enhance awareness of available mental health services, and strengthen collaboration between disability and mental health service providers.

State Strategy: Using Data

States are increasingly leveraging data to demonstrate measurable improvements in child well-being, system efficiency, and family outcomes. The states interviewed provided compelling metrics showing enhanced placement stability, reduced hospitalizations, improved school attendance, fewer behavioral incidents, cost savings, and increased family satisfaction

Delaware

Monitors progress in two pilot residential programs by tracking reduced incidents and hospitalizations. Over a year, critical incidents were reduced by 19%; in-patient stays were reduced from 513 to 2; and, one youth reconnected with adoptive parents while another moved to his own apartment.

New Jersey

The **NJ Child Welfare Data Hub | Data Hub** is a collaboration between the New Jersey Department of Children and Families (DCF) and the Institute for Families at the Rutgers University School of Social Work. In the interest of transparency, the Data Hub disseminates New Jersey child welfare and well-being data. The Data Portal allows users to view key indicators of child well-being, population characteristics, and socioeconomic variables at the state and county-level. Users can explore the interaction between social environments and the children and families served by NJ's Children's System of Care and child welfare systems.

Ohio

Tracks outcomes across its complex needs programs to monitor progress and guide practice improvements, including:

- Placement stability and use of short-term Intermediate Care Facilities for People with I/DD (IC/IDD) stabilization
- Multi Systems Youth (MSY) funding trends and custody-relinquishment prevention
- Multi-Disciplinary Comprehensive Assessment Team (MCAT) recommendations follow-through and family-reported stability
- Intensive Behavior Support Rate Add-On (IBSRAO) outcomes, including reduced incidents and successful transitions

Ongoing standardization within DODD's Complex Needs work is enhancing the state's ability to use data to inform policy and technical assistance.

Pennsylvania

PeopleSTAT Office – The Pennsylvania Department of Human Services' PeopleSTAT office supports efforts to understand and track trends among youth with complex behavioral needs and their families. Analysis includes diagnoses across physical health, mental health, and developmental disability domains; out-of-home placement history; child welfare involvement; short and long-term outcomes; and other critical areas. This data informs decision-making and strengthens Pennsylvania's child-serving systems.

Tennessee

TN Strong Families Program Impact: Tennessee measures program success through placement stability during enrollment, tracked by the reduced number of moves experienced by children in custody.

Year One Results:

- 87% of enrolled children maintained placement stability with zero moves
- 99% of enrolled children had one move or fewer

- By comparison, DCS data for the same period showed only 23% of children in custody maintained placement with zero moves and 38% had one move or fewer

Year Two Results:

- 87.5% of children maintained placement stability with zero moves
- 99% of children had one move or fewer
- Comparable DCS data for this period is pending

TN Strong Homes Program measures impact by tracking reduced hospitalizations among medically fragile children whose complex needs are met in community-based foster homes with specialized expertise. Children in TN Strong Homes are enrolled in public education in the least restrictive environment or participate in early intervention programs for those not yet school-eligible.

Your Voice Matters

Our understanding of the brain and body is growing every day — and with it, our ability to offer better treatment and support for children with complex behavioral health conditions.

This publication belongs to its readers as much as it does to its authors. We encourage you to share your thoughts, your personal experiences, and any suggestions you have for how we can better serve children with complex behavioral health conditions.

We would like to hear from you. Send your comments to **thelinkcenter@nasdddds.org**

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Resources

Resources: The following resources informed the work of this project and may provide helpful information to policy makers, families and advocates, clinicians, and service providers.

A PLACE THAT IS SAFE

Casey Family Programs. *Creating Healing Pathways for Children with Behavioral Health Needs.*

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- Children with Intellectual and Developmental Disabilities Can Experience Traumatic Stress: A Fact Sheet for Parents and Caregivers
- Choosing Trauma-Informed Care for Children with Intellectual and Developmental Disabilities: A Fact Sheet for Caregivers
- The 12 Core Concepts for Understanding Trauma Responses in Children with Intellectual and Developmental Disabilities and When to Seek Help
- Building Resilience in Families Contending with Intellectual and Developmental Disabilities
- The Road to Recovery: Supporting Children with Intellectual and Developmental Disabilities Who Have Experienced Trauma
- Complex Trauma: Affects, Screening and Assessment, Interventions
- Integrative Treatment of Complex Trauma for Adolescents
- Understanding Trauma Responses in Children with Intellectual and Developmental Disabilities and When to Seek Help
- Tailoring Trauma-Focused Cognitive Behavior Therapy for Children with IDD
- Understanding and Addressing the Needs of a Vulnerable Population
- Children with Intellectual and Developmental Disabilities Who Have Experienced Trauma

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