

Fixing the District's Youth Behavioral Health System

Ending the Cycle of
Institutionalization and Achieving
True Community Integration through
Intensive Community-Based Services

Disability Rights DC
at University Legal Services
220 I St., NE Suite 130
Washington, DC 20002



(202) 547-0198 (voice)
(202) 547-2657 (tty)
(202) 547-2083 (fax)
www.uls-dc.org

WHY WE WROTE THIS REPORT

As the federally mandated Protection and Advocacy (P&A) Program for the District of Columbia, Disability Rights DC at University Legal Services, Inc. (“Disability Rights DC”) staff directly serve hundreds of individual clients with disabilities each year. Part of this work involves assisting District children and youth with mental and behavioral health disabilities to access services that would enable them to thrive in their communities. But we have observed a distressing pattern: all too often, children do not receive the mental health services they need in their homes, schools, and neighborhoods. When this happens, they face months’—or years’—long placements in residential treatment facilities, psychiatric hospitals, and juvenile detention centers.

These placements isolate children from their families and communities and disrupt their educations. Many of these children lose their ability to act independently in their lives following the regimented environment of a facility. The return to the family is oftentimes brief, resulting in another institutionalization when the same unmet mental health needs that initiated the original placement resurface. Long wait times for intakes, disconnects between service providers, and poor transition planning result in these children cycling in and out of institutions, with each return characterized by the same or worsening issues integrating into their home communities.

The goal of this report is to shine a light on the District’s broken youth behavioral health system, identifying the cracks and elevating the stories of the children and families who have fallen through them. Then, based on our work with local advocates,^[1] national experts, and the children and families themselves, we propose a solution that could transform the system: Intensive Community-Based Services.^[2]



THE LANDSCAPE: THE YOUTH MENTAL HEALTH CRISIS

From American pediatric health experts[3] to the United States Surgeon General's Office, [4] public health entities across the country have raised the alarm about the youth mental health emergency. In the U.S., mental health issues were the leading cause of disability in children before the COVID-19 pandemic, with up to 1 in 5 children having a mental, emotional, developmental, or behavioral disorder.[5] Rates of childhood and adolescent mental health challenges have been steadily rising in recent years. From 2009 to 2019, the share of high school students reporting persistent feelings of sadness or hopelessness increased by 40%, to more than 1 in 3 students.[6] Between 2011 and 2015, there was a 28% increase in youth psychiatric visits to emergency departments for depression, anxiety, and behavioral challenges.[7] These dramatic changes likely stem from various societal forces and stressors, including increasing digital media use, heightened academic pressure, limited access to mental health care, rising income inequality, systemic racism, gun violence, and climate change.[8]

During the decade preceding COVID-19, the share of high school students seriously considering attempting suicide increased by 36%, suicide plans increased by 44%, and suicide rates among youth ages 10-24 increased by 57%.[9]

COVID-19 has exacerbated what was already a dire situation. In October 2021, a coalition of leading pediatric health experts declared a national state of emergency in child and adolescent mental health.[10] And in March 2022, in his State of the Union address, President Biden discussed the unprecedented American mental health crisis more broadly and among youth in particular, outlining strategies for transforming U.S. mental and behavioral health systems.[11]

According to CDC data, from March 2020 to October 2020, the proportion of mental health-related emergency department visits increased 24% for U.S. children ages 5 to 11 and 31% for those ages 12 to 17, as compared with 2019 emergency department visits. [12] Moreover, although mental health-related emergency department visits among children and adolescents ages 0 to 17 remained stable during 2021 and January 2022, they accounted for a larger proportion of all emergency department visits as compared with 2019.[13]

Children have faced unprecedented challenges during the pandemic, including disruptions to in-person learning and extracurricular activities, fewer opportunities to socialize with friends and family, missed milestone life events, economic instability, and reduced access to mental health care, social services, and other necessary services.[14]

These disruptions have disproportionately affected young people in communities of color, with the ongoing struggle for racial justice inextricably tied to the worsening youth mental health crisis.[15] During the pandemic, more than 140,000 children in the U.S. experienced a life-altering death of a primary or secondary caregiver, with children of color disproportionately impacted.[16]

The landscape in the District of Columbia closely mirrors what has been happening on a national level, with District children who have behavioral health disabilities experiencing an ever-worsening crisis. Approximately 22% of District children—more than 20,000 individuals—have a mental, emotional, developmental, or behavioral problem.[17] Moreover, 47% of District children have experienced risk factors for developing behavioral health issues, known as adverse childhood experiences (ACEs).[18] In a 2019 study, more than one-third of District high school students reported feeling sad or hopeless almost every day for at least two weeks during the past year.[19] And, alarmingly, 14% of District middle school students and 15% of District high school students attempted suicide in the past year, with even more youth considering attempting suicide.[20]

22%

of District children have a mental, emotional, developmental, or behavioral problem

47%

of District children have experienced risk factors for developing behavioral health issues

Victoria is 21, and she loves to draw.[21] She has a quick sense of humor and values her role as a daughter, sister, and friend. Victoria experienced traumatic loss at the age of ten when her grandmother and primary caregiver died. Since this loss, Victoria has cycled through numerous institutionalizations in psychiatric hospitals and longer-term psychiatric residential treatment facilities in other states. She has also experienced a number of arrests and long-term placements at the District’s juvenile detention facilities. During these placements, Victoria struggled to maintain contact with her father. When transitioning back into the community from these institutional placements, she was almost always discharged without community-based mental health services in place. And when she did receive intermittent community-based mental health services, they were continually disrupted because providers failed to work with her father in a responsive and supportive way. When she tried to resume services in the community, she faced significant delays and often ended up back in a psychiatric or juvenile detention facility.

Victoria explains her frustration: “I have never had a team that really listened to what I wanted and helped me get the services that I thought would help me. Instead, I was bounced around from hospital to hospital, from placement to placement. I didn’t receive the services and support I needed in order for me to be mentally healthy, to have a proper education, and to feel loved and safe. I wish the District could have provided me with help.”

As seen nationally, the COVID-19 pandemic has only worsened the youth mental health landscape in the District. Families of children admitted to Children’s National Hospital for mental health-related reasons have reported a concerning new onset of behavioral and emotional health concerns since the start of the public health emergency.[22] However, despite the widely-documented negative impact of COVID-19 on youth mental and behavioral health, the number of District children receiving behavioral health care has decreased since the start of the pandemic. Children receiving Mental Health Rehabilitation Services (MHRS) decreased by 6% between fiscal year 2020 and fiscal year 2021,[23] and the percentage of children receiving MHRS upon discharge from psychiatric residential treatment facilities (PRTFs) decreased by 11 percentage points.[24] There was a 21% decrease in the number of children receiving certain community-based mental health services called Evidence-Based Practices (EBPs),[25] and children served by the Children and Adolescent Mobile Psychiatric Service (ChAMPS) decreased by over 40%.[26]

FEWER DISTRICT CHILDREN RECEIVING MENTAL HEALTH SERVICES BETWEEN 2020 AND 2021



THE PROBLEM: THE DISTRICT'S YOUTH BEHAVIORAL HEALTH SYSTEM

Compounding the District’s youth mental health crisis are problems specific to the District’s youth behavioral health system that predate the pandemic. Disability Rights DC has been sounding the alarm about the system’s failures for years.[27] When the District did not respond to our calls for action, we filed a lawsuit alleging that the District operates a system designed to provide, at most, a limited array of services on a limited basis with limited effect.[28] As a part of this lawsuit, we have talked with children and families who have been impacted by this broken system, as well as the advocates who support them. We have also worked with national experts in children’s behavioral health, learning what we can about why the District’s system is failing our children and what the District can do about it.

In fiscal year 2020, the District served more than 2,500 District children with mental health disabilities through its public mental health system.^[29] As experts and advocates have attested in support of class certification for the lawsuit, District children with serious mental health disabilities lack the community-based mental and behavioral health services necessary to enable them to remain in the community. As a result of the system’s limitations, children cycle in and out of institutions—including psychiatric hospitals, psychiatric residential treatment facilities (PRTFs) and other residential treatment facilities, the District’s detention centers, and group homes—to children’s detriment.

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In my experience, District children who are sent to residential placements are away from their families a long time, and they do not come back in better shape. Too often they come back in worse shape than before they left . . . Too often the family makes a sacrifice for the residential placement, but does not reap benefits from that sacrifice.

—Advocate from Advocates for Justice and Education, Inc.

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When children leave institutional placements and return to their families, homes, and communities, they frequently receive few or ineffective follow-up community-based behavioral health services due to inadequate discharge planning. If new to the system, children and their families often do not have sufficient information about selecting a core service agency (CSA).^[30] Moreover, it can take weeks or even months to get a first appointment with a CSA, causing lengthy gaps in critical services.^[31]

INSTITUTIONALIZATION OF DISTRICT CHILDREN BETWEEN SEPTEMBER 2016 AND SEPTEMBER 2019:^[32]

At least

98

Medicaid-eligible District children were admitted to PRTFs

More than

400

Medicaid-eligible District children were institutionalized in other residential treatment centers under DYRS custody

More than

200

Medicaid-eligible District children were admitted more than once to a psychiatric hospital

When community-based services are finally delivered, there are often many problems. In our conversations with advocates for children with mental health disabilities, we heard again and again about long waiting lists for certain services, the time-limited nature of more intensive services, and high rates of staff turnover. In fiscal year 2021, there was 50% staff turnover among the District’s Evidence-Based Practice providers.^[33] Advocates have also noted a consistent lack of client and family involvement and engagement by providers in the service planning process, as well as a lack of support for family members. Many children in the District are involved in more than one child-serving government system—for example, the behavioral health, special education, child welfare, or delinquency systems—and advocates have observed little coordination of care between these systems.

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Being sent away makes [children] see themselves as not worthy of being at home with their families.

—Advocate from Total Family Care Coalition

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A big part of the problem is that, oftentimes, provider staff do not timely or effectively engage children in services. In many cases, a child may not get the support they need until a crisis occurs. Even then, the support is often inadequate. With respect to the District’s mobile crisis team—the Children and Adolescent Mobile Psychiatric Service (ChAMPS)—advocates have observed numerous problems, including inadequate staffing, long wait times for crisis response deployments, deployments far too often resulting in psychiatric hospitalization or police encounters, and a lack of follow-up to ensure proper connection to community-based services. Once a new crisis happens, a child may be institutionalized again or placed at serious risk of institutionalization.

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It is a common scenario that a child is sent home from a residential placement, faces a gap in services due to a late start on planning and waitlists for services, does not receive services for a month or more, and then receives additional charges, which prompts yet another residential placement.

—Advocate from the Public Defender Service for the District of Columbia

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This pattern of institutionalization affects children in profoundly detrimental ways. Many children spend their formative years moving in and out of institutional placements, isolated from their families and communities.^[34] This causes significant disruption not only to the child’s home and social life, but also to their existing mental health treatment. Oftentimes, service providers lose contact with a child who enters a residential treatment center or juvenile detention facility. As a result, children cycle through case workers and service providers, which prevents them from establishing and maintaining the stable relationships they need to access their treatment. Repeat institutionalization also disrupts a child’s education, jeopardizing the child’s ability to perform in school. This disruption increases the likelihood of involvement in the delinquency and criminal systems while decreasing employment and independent living opportunities in adulthood.

THE LAW: A CHILD'S RIGHT TO RECEIVE SERVICES IN THE COMMUNITY

The District's children deserve more. And under federal law, they are entitled to more. When the District denies children with mental health disabilities the services they need to live and participate in their communities, it is discriminating against these children based on their disabilities. This discrimination violates the Americans with Disabilities Act,^[35] the Rehabilitation Act,^[36] and the Medicaid Act.^[37]

The Americans with Disabilities Act and the Rehabilitation Act

Title II of the Americans with Disabilities Act (ADA) forbids state and local governments from excluding or discriminating against people with disabilities.^[38] The ADA also requires cities and states to provide services and programs for people with disabilities in the most integrated setting possible.^[39] Governments cannot limit the provision of necessary treatment to institutional settings. If certain supports would allow a person with a disability to live in the community, the city or state must make those supports available.^[40]

Congress wrote the ADA to ensure that people with disabilities have the same rights and opportunities as everyone else. For children with mental health disabilities, this means receiving the necessary supports to fully participate in their schools and communities. When a state or local government fails to provide supports needed to avoid placement in residential treatment centers, psychiatric hospitals, or juvenile detention facilities, this is discrimination under the ADA.

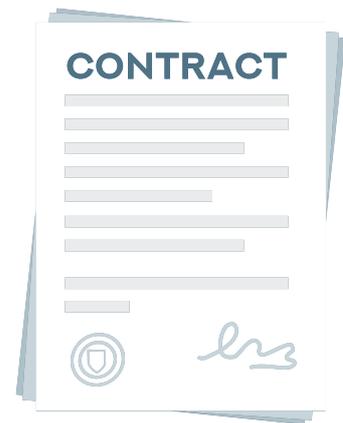


Section 504 of the Rehabilitation Act applies the same “most integrated setting” requirement to programs and activities that receive federal funding.^[41]

The Medicaid Act

The Medicaid Act is designed to provide medically necessary health and mental health services to children and families from underresourced communities.^[42] States (including the District of Columbia) can decide whether to participate in the Medicaid program, but if they do opt to receive these federal matching funds, they must abide by certain regulations^[43] and create a Medicaid state plan that describes how they run their program and which services they provide.^[44]

Participating states must follow the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) regulations.^[45] These regulations require participating states to ensure children receive appropriate diagnoses and treatment to “correct or ameliorate” physical and mental illnesses.^[46] This means both identifying children who have these conditions^[47] and providing them with medically necessary treatments.^[48] If a treatment is medically necessary, the participating state must provide it, regardless of whether that treatment is already included in the state’s plan.^[49]



Because the District participates in the Medicaid program, it must comply with the EPSDT provision, making medically necessary services available to all Medicaid-eligible District children who need them.

Isaac is 17.^[50] He enjoys listening to music, and he is devoted to his family. He grew up living with his grandmother, and her unexpected death when he was a child caused a major disruption for Isaac. After experiencing worsening behaviors at school, he was admitted to the District’s two youth psychiatric hospitals a number of times. But upon discharge from these hospitals, he was never connected to mental health or grief counseling services in the community. He would be hospitalized, released without services or crisis planning, and then re-hospitalized. When Isaac was in the sixth grade, his school referred him to a psychiatric residential treatment facility in Virginia. He lived there for a full year. Again, when he returned to the District, he received no community-based mental health services.

DRDC began representing Isaac in 2018 when his great-grandmother requested help connecting him with community-based services. We encountered numerous obstacles dealing with multiple District agencies, and it took nearly eight months to secure consistent services from a reliable provider. During this turbulent period, Isaac cycled between the District’s juvenile detention centers and more out-of-state psychiatric residential treatment facilities. Despite warnings from his great-grandmother, his DRDC attorneys, and Isaac’s own expressed wishes, the District repeatedly placed him in group homes away from his family. And he repeatedly left those homes to find his family. His transition services were largely nonexistent, with his most recent discharge occurring before he had been enrolled in school, connected to services, or provided a stable place to live.

Isaac has spent much of his adolescence in institutional placements due to the District’s recurring failure to provide him the intensive community-based services that he needs. His great-grandmother has advocated for him every step of the way, but her recommendations are ignored. She told us, “[Isaac] has many strengths, but I don’t think that his service providers have actually followed through for him. He always wants to be home with me, but his service providers haven’t given him the option of getting services at home. I don’t think he would have had to go to residential placements if he had received services that helped him live at home.”

A SOLUTION: TRUE COMMUNITY INTEGRATION THROUGH INTENSIVE COMMUNITY-BASED SERVICES

Evidence from multiple states demonstrates that with a specific set of well-researched services, children with mental health disabilities can be served and thrive in their own communities.^[51] These services include Intensive Care Coordination, Intensive Behavioral Support Services, and Mobile Crisis or Response Services. Collectively, they may be referred to as Intensive Community-Based Services (ICBS).

INTENSIVE COMMUNITY-BASED SERVICES (ICBS)



ICBS are intensive, multi-faceted services that engage children with mental health disabilities and their families to support the child's full participation in community life. When children experience difficulties in just one environment—such as school, home, or the community—focusing on that single environment can be effective. But when a child struggles in multiple environments and these struggles are negatively affecting their development, behavior, and relationships with others, the child may well need the multi-layered approach of ICBS.

These children are often involved with multiple systems in addition to the mental health system, such as developmental disability services, special education, medical care, child welfare, and the juvenile and adult criminal legal systems. Without coordination, each system will offer its own plan to the family based on its own priorities, which can result in conflicting and overwhelming requirements as well as fragmented and duplicative services. Instead of trying to address each of the problem areas through a separate system, ICBS wrap around the child and family to develop an individualized, comprehensive, and coordinated response focused on the vision, strengths, and needs of the child and family.

A key feature of Intensive Community-Based Services is the inclusion of the child and family as full partners in supporting the child. The family (including the child) and other natural supports should play a central role in developing, implementing, monitoring, and adjusting the child's service plan. Their vision for success, their needs, and their

resources should drive the service delivery. ICBS must also be prompt, consistent, flexible and responsive to the child. Children and families should not experience lags in services during a child’s transition to or from residential placements, nor should the quality or availability of services differ based on the service provider or caseworker. If a child’s disabilities mean that traditional service delivery and clinical interventions will not work for them, services must be modified to accommodate their disability.

Engagement of the child and family is another critical piece of ICBS: it is the responsibility of the ICBS provider to engage the child and family, not the child and family’s responsibility to engage based on the provider’s expectations. Instead of labeling families as treatment-resistant, providers adapt their approach to meet the unique circumstances of the child and family. If service providers are not engaging the child and family, Intensive Community-Based Services are not being delivered. If the child’s parents or legal guardians are not involved, the team draws upon extended family members and other adults in the child’s life who are invested in their success and are willing to provide care or support.

Intensive Community-Based Services include three key components:[\[52\]](#)

Intensive Care Coordination

Intensive Care Coordination (ICC) is an intensive form of team-based case management that uses clinical intervention along with professional and natural support systems to impact every area of the child’s life. Intensive Care Coordination is the ICBS answer to the problem of siloed systems overwhelming children and families with conflicting plans that are unresponsive to their individual needs.



Intensive Care Coordination treats families as true partners in their child’s care. A Care Coordinator’s first step should be to get to know the child and family: What are their strengths? What kinds of supports do they have? How is their culture relevant? Are there other family members, friends, or neighbors who they trust and can call on when they need help? What are their needs? Where do they struggle? And then, what do they see as success? What are the family’s goals? What are the child’s goals? How do they define what they need and what it would look like to have those needs met? And finally, what supports and services—including newer approaches encompassed in services like mentoring or peer support, but also non-traditional services such as tutoring or enrollment in music or art classes—does the child and family see working for them? Based on responses from the child, family, and people familiar with the child’s needs,[\[53\]](#) the Care Coordinator convenes a team of identified providers and informal supporters to create an individualized, flexible care plan for the child. This team, known as a “child-and-family team,” is the centerpoint of Intensive Care Coordination.

Noah, 19, is quick to share his hope that his life will get better, particularly now that he is a father to a little girl.[54] Noah has several serious mental health disabilities as well as indications of a developmental disability. He endured significant trauma in his childhood. Despite being identified as a child who had experienced trauma and was at risk for sex trafficking, Noah's records indicate no follow-up services for either issue. His father acted as his primary caregiver, but their relationship was strained, and Noah often ran away from his father's home. While Noah received some community-based services, none of the providers successfully navigated his relationship with his father, nor did they engage other family or community members in his care.

Between 2017 and 2020, Noah was removed from his family home and institutionalized at least 18 times. These institutionalizations began when he was arrested and given into the custody of the Department of Youth Rehabilitation Services (DYRS). DYRS placed him in a juvenile detention facility before transferring him to a series of group homes. Most of these placements were complete failures: Noah did not receive the services he needed and repeatedly ran away.

After completing a therapeutic and educational program in Maryland for youth involved in the juvenile justice system, he was placed in a foster home where he was able to form a strong relationship with the home's supervisor. This was a meaningful moment for Noah: he described the man as the father he wished he had had. But despite the stability and success of this placement, the District decided to move him again. When he learned of this disruption, Noah ran away. Again, he was arrested and returned to the juvenile detention facility.

According to a national expert in youth mental and behavioral health, "ICBS would have been extremely effective . . . while [Noah] was finding his way to the group home where he experienced some stability. Had a child and family team been formed with a focus on building on [his] strengths, and building on the strengths of his relationships with individuals like his group home supervisor and his Credible Messenger mentor, [he and his team] could [have] then explore[d] ways to meet his underlying needs."

The child-and-family team should include the child, the child's family, service providers from multiple areas of the child's life (including teachers), and other natural supports. "Natural supports" are people in the child and family's lives who can work with the child to assess needs, build skills, and respond to challenges. These supports may include extended family, friends, neighbors, coaches, faith leaders, and other community members.

With Intensive Care Coordination, a child-and-family team's work should include providing individualized assessments; service planning (including crisis and transition planning); developing, accessing, and arranging for services; coordinating multiple services across different systems; working with the family and child to meet basic needs; and advocating for the family and child.[55] The child-and-family team works together to monitor whether the plan is working and adjust it when it falls short. Additionally, the ICC team collectively

defines what constitutes a crisis for the child and family and explores interventions and strategies for immediate implementation in the event of a mental health crisis situation. This process should result in a comprehensive crisis plan that serves to both prevent and respond to the crisis situation. Calling 911 should not be the default response for children who are experiencing a mental health crisis.

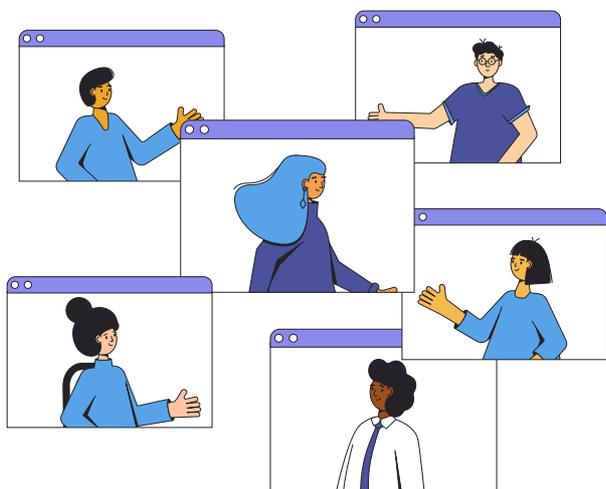
Intensive Care Coordination requires organization to work. A single case manager acts as the accountable party for leading the team and ensuring necessary services are accessible to the child and family. The Care Coordinator should facilitate discussions that encourage the various providers on the team to think beyond their own systems to dynamically engage with the child and family's strengths, goals, and needs. This approach extends beyond the necessary components of care coordination and individualized services: coordinated, individualized services are critical, but they must be done in partnership with the families and provided in the most natural and least restrictive environment for the child. Limiting service delivery to a provider's office during defined hours without regard for the preference or constraints of the family is unacceptable.

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Our clients often tell us that they feel beaten down by the system in the District, or that they feel that the system has failed them. They are often very cynical about whether anyone cares about them.

—Advocate from the School Justice Project ”

Intensive Care Coordination provides a response to the fragmented approach of uncoordinated systems. Disability Rights DC and other advocates have seen multiple clients experience the negative outcomes of systems working at cross purposes: service providers drop out of a child and family's life upon the child's entry into a residential treatment center or a juvenile detention facility. Children lose connections to trusted service providers as the facility takes over their behavioral health care, only to return home without the supports of the facility or reengagement with their previous provider.

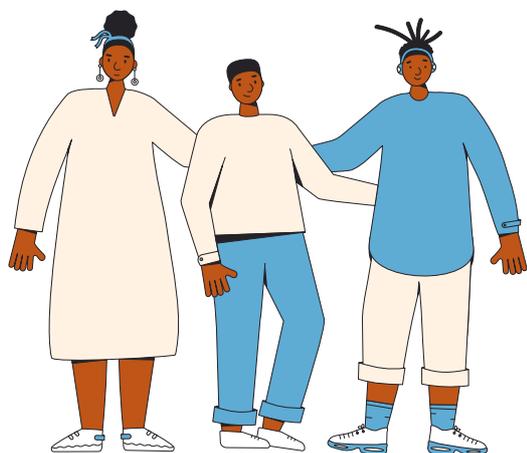


With Intensive Care Coordination, the child-and-family team follows the child through every step of institutionalization, engaging in individualized, strengths-based transition planning. This planning ensures that the child can successfully rejoin their community upon their return and prevents further unnecessary institutionalization because supports are in place before they leave the institution.

Intensive Behavioral Support Services

Intensive Behavioral Support Services (IBSS) aim to reduce problem behaviors while improving a child’s social, educational, employment, and home life by offering frequent, consistent therapeutic interventions that meet the individual child’s needs.^[56] Following the plan developed by the child-and-family team, as facilitated by the Intensive Care Coordinator, these services should be delivered to children and families in the child’s natural environment, whether that is a family home or elsewhere in the community. Services are not restricted to a practitioner’s office or offered only during limited time-slots. Like Intensive Care Coordination, Intensive Behavioral Support Services center on the person receiving services, assessing how the child’s life could improve based on their interests and preferences.^[57] Intensive Behavioral Support Services can include Positive Behavioral Intervention Plans. These plans involve person-centered planning; collaborative teaming; assessing the person’s behavior, including analyzing the antecedents and consequences of that behavior; hypothesizing about the reasons the person behaves in the way they do; multi-component planning for behavioral interventions; and evaluating how those interventions are working.^[58]

Intensive Behavioral Support Services center on “person-centered planning,” similar to the child-and-family team approach used in Intensive Care Coordination. This must be done in coordination with the child’s family. If the child does not have a permanent caregiver, IBSS providers must work with other natural supports in the child’s life. Intensive Behavioral Support Services must also follow the child, adapting to where the child is and what the child needs rather than confining services to locations or environments preferred by the provider. If the child is institutionalized in a long-term residential facility or sent to a group home, Intensive Behavioral Support Services should engage the child in that environment. An IBSS provider cannot lose contact with the child or family simply because the child’s circumstances have changed; the service must conform to the child’s needs.



Intensive Behavioral Support Services must be responsive to the individual needs of the child and family. Available services should involve not only therapy, as appropriate, and clinical interventions, such as skills building, but other services based on the child’s age and needs. These additional services could include peer supports, transition services, and mentoring. Parents should have access to parenting support and parent advocacy

services. If a child or family needs another service to be provided in the community but that service is not available in the existing menu of supports, the service should be created. Consistency is also critical to Intensive Behavioral Support Services. The services must be available to the child when the child needs them. If a provider's quality, regularity, or family engagement differs from case worker to case worker, that provider is not offering Intensive Behavioral Support Services with fidelity to the child's plan.

When done properly, Intensive Behavioral Support Services are effective in decreasing problem behaviors, including destructive and self-harming behaviors in children.^[59] When combined with Intensive Care Coordination, Intensive Behavioral Support Services can significantly reduce institutionalization of children in psychiatric facilities.^[60]

Gabriel, 20, is dedicated to making music and parenting his infant daughter.^[61] He remembers that he started having trouble with his emotions when he was in elementary school. He would get in trouble for fighting, but he says, "Nobody ever talked to me about how I was feeling when I got in fights except my mom." His clinical history indicates significant childhood trauma, but he received no evidence-based trauma treatment. He remembers receiving an evaluation in fourth or fifth grade, but he did not understand why he was receiving it: "I don't know what they were looking for. After it was over, I don't remember anything changing. No social workers came to my house, and I didn't get any therapy. It was just my mom helping me."

Since his early teenage years, Gabriel has been institutionalized over 30 times in juvenile detention facilities, group homes, and shelters. During these institutionalizations, he was isolated from his family and his long-time girlfriend. And oftentimes, he received no treatment. He says, "We would just sit in a room all day. There was no therapy, no services. After I got out . . . I didn't get any services. Nobody came to my house or talked to me about how I was doing."

When Gabriel did receive services, they failed to capture his spectrum of needs. While Gabriel has diagnoses for bipolar disorder and attention deficit/hyperactivity disorder, he also has indications of a developmental disability and cognitive limitations. But the services he received both in facilities and in the community were unresponsive to these cognitive needs. There was never an appropriate crisis plan in place, and the service providers failed to engage his mother or other important people in his life to support his transition to the community.

During his most recent institutionalization, Gabriel lost contact with his community service providers, disrupting his employment services application so that he had to reapply when he left the placement. He also missed the birth of his daughter. He says, "I think that was the worst part of everything: DYRS sent me out to a residential placement away from home when my daughter was about to be born . . . I only got to see her on Zoom for months . . . I felt like my DYRS case coordinator and the staff at [my Residential Treatment Center] didn't get what was important to me. Or they didn't care. I wanted to stay in the community, but DYRS sent me off anyway."

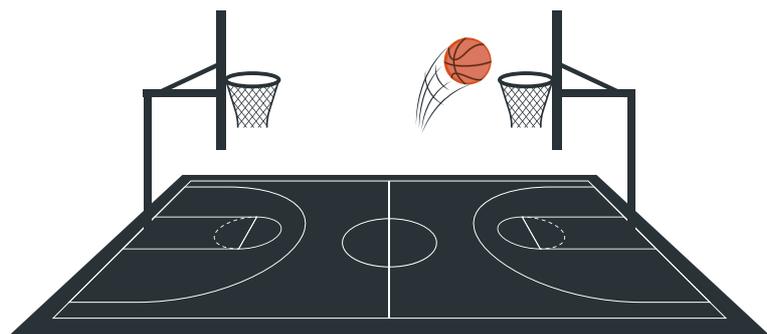
Mobile Crisis or Response Services

Mobile Crisis or Response Services provide a 24/7, onsite response to a child experiencing a mental health crisis. These services are an alternative to traditional emergency services that often initiate unhelpful involvement by police and other first responders who lack necessary training in children’s mental health. Instead, Mobile Crisis or Response providers employ specialized staff with training tailored to working with children experiencing a mental health crisis. These teams should not rely on adult-focused crisis response or hospitalization. Mobile Crisis or Response teams identify and assess the child’s needs and stabilize the situation, reducing the risk of immediate harm to the child or others. These services should be delivered whenever and wherever the child experiences the crisis, including at school, at home, or elsewhere in the community.

Mobile Crisis or Response Services extend beyond the moment of crisis—these services should be employed before, during, and after a child needs acute support. Mobile Crisis or Response Service providers should proactively work with child-and-family teams and Intensive Behavioral Support Services providers to review the previously developed crisis plan, identify the child’s past triggers as well as strategies and people that have been effective in responding to the child during a crisis, and make revisions as appropriate.[62] These plans must be individualized, enabling the child and family to define what types of behaviors constitute a “crisis” and choosing interventions that are both tailored to the child and responsive to more and less severe circumstances.



When a crisis occurs, these teams should stabilize a child in a natural environment. Once the child is stable, these teams should build on the child and family’s network of natural supports to provide meaningful, timely connections to follow-up services, including clinical treatment.[63] Mobile Crisis or Response Services should keep children out of institutions and connect them to services in their communities designed to preempt future crises.[64] These child-specific, holistic crisis services work to support children with mental health disabilities and enable them to maintain their lives in their



communities. In one hallmark example of these services’ success, 94% of New Jersey children who experienced crisis and received Mobile Crisis or Response Services were able to avoid hospitalization.[65]

CONCLUSION

Intensive community-based services work.[66] With the proper services, children with mental health disabilities can live in their own homes or with a kinship or foster family, succeed in school, and participate in community life with their non-disabled peers. These services help children build the skills they need to fully engage in their community while aiding families in understanding their child's disability and supporting their child in the home.

There are at minimum hundreds of children in the District who need these services to stay in their homes and out of facilities. But because the District has failed to provide Intensive Community-Based Services, these children cannot participate in their communities or attend their neighborhood schools. Disability Rights DC is committed to continuing our advocacy for these children and their families until they can access the services they need, the services federal law guarantees them, and the services the District owes them. Every child deserves the chance to grow up where they feel at home. For children with mental health disabilities, we must provide them the services they need to access this opportunity.



REFERENCES

[1] Along with the Judge David L. Bazelon Center for Mental Health Law, the National Center for Youth Law, and Schulte Roth & Zabel LLP, Disability Rights DC—also acting as a plaintiff—filed a class action lawsuit in 2018 under Title II of the Americans with Disabilities Act and the Medicaid statute on behalf of District youth with significant mental and behavioral health challenges seeking Intensive Community-Based Services (ICBS) to prevent institutionalization. The Plaintiffs filed for class certification in July 2021. As part of this lawsuit, Disability Rights DC and our co-counsel have spoken with advocates from several DC-based organizations to increase our understanding of the District’s behavioral health system for children. These organizations include: Advocates for Justice and Education, Children’s Law Center, DC Action, Open City Advocates, Public Defender Service for the District of Columbia, School Justice Project, and Total Family Care Coalition. We have drawn from these conversations to build this report.

[2] Disability Rights DC is grateful for the contributions made to this report by our law clerk, Elle Jimenez, J.D. Candidate, Georgetown Law 2024.

[3] *A Declaration from the American Academy of Child and Adolescent Psychiatry, American Academy of Pediatrics, and Children’s Hospital Association* (Oct. 2021), https://www.aacap.org/App_Themes/AACAP/Docs/press/Declaration_National_Crisis_Oct-2021.pdf [Coalition Declaration].

[4] *Protecting Youth Mental Health, The U.S. Surgeon General’s Advisory*, Dec. 2021, <https://www.hhs.gov/sites/default/files/surgeon-general-youth-mental-health-advisory.pdf> [Surgeon General Advisory].

[5] Surgeon General Advisory at 8.

[6] Surgeon General Advisory at 8.

[7] Surgeon General Advisory at 8.

[8] Surgeon General Advisory at 8.

[9] Surgeon General Advisory at 8.

[10] Coalition Declaration at 1.

[11] See White House Press Release, *FACT SHEET: President Biden to Announce Strategy to Address Our National Mental Health Crisis, As Part of Unity Agenda in his First State of the Union* (Mar. 1, 2022), <https://www.whitehouse.gov/briefing-room/statements-releases/2022/03/01/fact-sheet-president-biden-to-announce-strategy-to-address-our-national-mental-health-crisis-as-part-of-unity-agenda-in-his-first-state-of-the-union/>.

[12] Centers for Disease Control and Prevention, *Mental Health-Related Emergency Department Visits Among Children Aged <18 Years During the COVID-19 Pandemic – United States, January 1-October 17, 2020* (Nov. 13, 2020), https://www.cdc.gov/mmwr/volumes/69/wr/mm6945a3.htm?s_cid=mm6945a3_w.

[13] Centers for Disease Control and Prevention, *Pediatric Emergency Department Visits Associated with Mental Health Conditions Before and During the COVID-19 Pandemic – United States, January 2019-January 2022* (Feb. 18, 2022), <https://stacks.cdc.gov/view/cdc/114657>.

[14] Surgeon General Advisory at 9.

[15] American Acad. of Pediatrics, *Pediatricians, Child and Adolescent Psychiatrists, and Children's Hospitals Declare National Emergency in Children's Mental Health* (Oct. 19, 2021), <https://www.aap.org/en/news-room/news-releases/aap/2021/pediatricians-child-and-adolescent-psychiatrists-and-childrens-hospitals-declare-national-emergency-for-childrens-mental-health/> [Coalition Declaration News Release].

[16] Coalition Declaration News Release (citing S.D. Hillis et al., *COVID-19-Associated Orphanhood and Caregiver Death in the United States*, 148(6) *Pediatrics* (2021), <https://publications.aap.org/pediatrics/article/148/6/e2021053760/183446/COVID-19-Associated-Orphanhood-and-Caregiver-Death>). The death of a caregiver increases the risk for childhood short-term trauma and lifelong negative consequences, as it is an adverse childhood experience (ACE) linked to myriad mental health struggles, including lower education levels, lower self-esteem, riskier behaviors, and increased risk of substance abuse, violence, sexual abuse, exploitation, and suicide. National Institutes of Health, *More than 140,000 U.S. children lost a primary or secondary caregiver due to the COVID-19 pandemic* (Oct. 7, 2021), <https://www.nih.gov/news-events/news-releases/more-140000-us-children-lost-primary-or-secondary-caregiver-due-covid-19-pandemic>.

[17] Children's Law Center et. al., *A Path Forward: Transforming the Public Behavioral Health System for Children, Youth, and their Families in the District of Columbia* at 28 (Dec. 2021), https://childrenslawcenter.org/wp-content/uploads/2021/12/BHSystemTransformation_Final_121321.pdf [A Path Forward].

[18] A Path Forward at 28.

[19] A Path Forward at 28 (citing Government of District of Columbia: Office of the State Superintendent of Education, 2019 DC YRBS Data Files, <https://osse.dc.gov/page/2019-dc-yrbs-data-files> (last visited Apr. 3, 2022)).

[20] A Path Forward at 28.

[21] Pseudonym.

[22] A Path Forward at 26.

[23] D.C. Dep't of Behav. Health, *FY21 DBH Written Performance Oversight Responses* at 265-68 (Jan. 2022), <https://dccouncil.us/wp-content/uploads/2022/01/dbh.pdf> [DBH Oversight].

[24] DBH Oversight at 215-16.

[25] DBH Oversight at 217-20.

[26] DBH Oversight at 82-84.

[27] Disability Rights DC at Univ. L. Servs., *The Way Home: Child and Youth Access to Community-Based Services Post-Psychiatric Hospitalization in the District of Columbia* (Mar. 1, 2015), <https://www.uls-dc.org/thewayhome.pdf>.

[28] See *supra* note 1. To read the Complaint, visit <https://secureservercdn.net/198.71.233.111/d25.2ac.myftpupload.com/wp-content/uploads/2018/08/DC-ADA-EPSDT-complaint.pdf>.

[29] U.S. Dep't of Health & Human Servs., Substance Abuse and Mental Health Servs. Admin. (SAMHSA), *District of Columbia 2020 Mental Health National Outcome Measures (NOMS): SAMHSA Uniform Reporting System* at 7 (June 25, 2021), <https://www.samhsa.gov/data/report/2020-uniform-reporting-system-urs-table-dc>. Almost all of these children are Medicaid-eligible.

[30] CSAs are community mental and behavioral health providers that contract with DC's Department of Behavioral Health (DBH) to provide community-based services to Medicaid-eligible youth in DC.

[31] We drew this information from our own client experience and our conversations with advocates as part of our litigation. See *supra* note 1.

[32] These figures derive from information we and our co-counsel received from the District during litigation. The District provided figures from September 1, 2016 to September 27, 2019 regarding Medicaid-eligible DC children under the age of 21 with serious emotional disturbance. These numbers indicate that there was a total population of 5,500 children with serious emotional disturbance.

[33] DBH Oversight at 217-20.

[34] Because there are no psychiatric residential treatment facilities (PRTFs) in the District, all youth admitted to PRTFs are sent to other states, in some cases hundreds or thousands of miles away. See *supra* note 31.

[35] 42 U.S.C. § 12132 *et seq.*

[36] 29 U.S.C. § 794.

[37] 42 U.S.C. §§ 1396a(a)(43), 1396d(a)(4)(B), 1396d(r) [Medicaid Act].

[38] Under Title II of the ADA, "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132; 28 C.F.R. § 35.130.

[39] *Olmstead v. L.C.*, 527 U.S. 581 (1999) (interpreting Title II); see also 28 C.F.R. § 35.130(d) ("most integrated setting" regulation).

[40] Public entities also must make reasonable modifications in policies, practices, or procedures when necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that the modifications would fundamentally alter the nature of the service, program, or activity. 28 C.F.R. § 35.130(b)(7).

[41] See, e.g., 45 C.F.R. § 84.4(b)(2) ("most integrated setting" regulation).

[42] See Title XIX of the Social Security Act, 42 U.S.C. § 1396 *et seq.*

[43] 42 C.F.R. § 430.0 *et seq.*

[44] Medicaid Act § 1396a.

[45] Medicaid Act §§ 1396a(a)(43), 1396(a)(4)(B), 1396d(r).

[46] Medicaid Act §§ 1396a(a)(43)(C), 1396d(r)(5).

[47] Medicaid Act § 1396d(r)(1).

[48] Medicaid Act § 1396d(r)(5).

[49] 42 C.F.R. § 441.56(c).

[50] Pseudonym.

[51] “Studies have shown that intensive community-based services of this nature effectively address the needs of children with mental illness while maintaining their connection to their families and communities. Programs across the country, including those in Wisconsin, Maine, New Jersey, and California have greatly reduced the rate of institutionalization and related costs while producing positive outcomes for children. Children with comparable levels of need who receive intensive services in their natural settings have improved school attendance and performance, increased behavioral and emotional strengths, improved clinical and functional outcomes, reduced suicide attempts, and decreased contacts with law enforcement when compared to children who received such care in segregated residential treatment facilities. Other benefits include reduced costs of care, more stable living situations, and improved attendance at work for caregivers.” U.S. Dep’t of Justice, *United States’ Investigation of the West Virginia Children’s Mental Health System Pursuant to the Americans with Disabilities Act* at 9 (June 1, 2015), https://www.justice.gov/sites/default/files/crt/legacy/2015/06/01/wv-ada_findings_6-1-15.pdf.

[52] To fully benefit from Intensive Community-Based Services, some children and families may need an option for short-term, intensive therapeutic treatment, typically known as therapeutic foster care (TFC). TFC programs provide an out-of-home space within the child’s community that looks more like a family home than a traditional group home or a residential treatment center. These short-term respite services can reduce stressors on parents and families without isolating the child for long periods of time. TFCs are designed to serve children with emotional and behavioral needs, with no more than one to two children in each home at a time. TFC uses many of the same features of ICBS, including individual treatment plans, a treatment team, training and supports for the TFC parent, access to behavioral services, 24/7 crisis support, and structured activities to maintain the child’s connections to family and community. U.S. Dep’t of Health & Human Servs., *State Practices in Treatment/Therapeutic Foster Care* at 2-1 (Apr. 2018), <https://aspe.hhs.gov/system/files/pdf/259121/TREATMENTFOSTERCARE.pdf>.

[53] This could include former and current provider staff, teachers, and other individuals who have worked with the child.

[54] Pseudonym.

[55] C. Mann & P.S. Hyde, *Joint CMCS and SAMHSA Informational Bulletin: Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions*, Substance Abuse and Mental Health Servs. Admin. (SAMHSA) and Center for Medicaid and CHIP Services (CMHS) (2013), <https://www.medicare.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf>.

[56] See, e.g., E.G. Carr et al., *Positive Behavior Support: Evolution of an Applied Science*, 4 J. Pos. Behav. Interventions 4 (Winter 2002), https://kuscholarworks.ku.edu/bitstream/handle/1808/6147/PBS16_PBS%20Evolution.pdf?sequence=1&isAllowed=y.

[57] D. Kincaid & L. Fox, *Person-Centered Planning and Positive Behavior Support*, in *Person-Centered Planning: Research, Practice, and Future Directions* (S. Holburn & P.M. Vietze eds., 2002).

[58] Ass’n of Positive Behav. Support, *Positive Behavior Support Standards of Practice: Individual Level* (Mar. 2007), https://www.apbs.org/files/apbs_standards_of_practice_2013_format.pdf.

[59] See, e.g., G. Dunlap et al., *A Descriptive, Multiyear Examination of Positive Behavior Support* 35 Behav. Disorders 259 (2010); G. Dunlap et al., *Overview and History of Positive Behavior Support*, in *Handbook of Positive Behavior Support* 3-16 (W. Sailor et al. eds., 2009); K. Kutash et al., *School-based Mental Health Services in Systems of Care*, in *The System of Care Handbook: Transforming Mental Health Services for Children, Youth, and Families* (B.A. Stroul & G.M. Blau eds., 2008); G. Sugai & R.H. Horner, *Introduction to the Special Series on Positive Behavior Support in Schools* at 130-35, 10(3) J. Emot. & Behav. Disorders (2002); L. Eber et al., *Wraparound and Positive Behavioral Interventions and Supports in Schools* at 171-80, 10(3) J. Emot. & Behav. Disorders (2002).

[60] K. Matthews et al., *Putting the Pieces Together: Perceptions of Longitudinal Wraparound, Systems of Care, and Positive Behavior Support Implementation*, Cmty. Mental Heal. J. (2019).

[61] Pseudonym.

[62] B. Kamradt et al., *Services for High-Risk Populations in Systems of Care*, in *The System of Care Handbook: Transforming Mental Health Services for Children, Youth, and Families* (B.A. Stroul & G.M. Blau eds., 2008).

[63] Nat'l Assoc. of State Mental Health Program Directors, *Making the Case for a Comprehensive Children's Crisis Continuum of Care* (Aug. 2018), https://nasmhpd.org/sites/default/files/TACPaper8_ChildrensCrisisContinuumofCare_508C.pdf.

[64] U.S. Dep't of Health & Human Servs., Substance Abuse and Mental Health Servs. Admin. (SAMHSA), *Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies at 10-11* (2014), <https://store.samhsa.gov/product/Crisis-Services-Effectiveness-Cost-Effectiveness-and-Funding-Strategies/sma14-4848>.

[65] See CGS ResourceNet, *About New Jersey's Children's System of Care (CSOC)*, <http://www.cgsresourcenet.org/about/about-new-jersey-s-children-s-system-of-care-csoc/> (last visited May 3, 2022); New Jersey Dep't of Children & Families, *Children's System of Care 15 Year Anniversary* (Oct. 2016), https://www.nj.gov/dcf/about/divisions/dcsc/CSOC_15.Year.Conference.Presentation.pdf.

[66] In jurisdictions that have received funding to develop and implement Intensive Community-Based Services, the services resulted in "decreased behavioral and emotional problems, suicide rates, substance use, and juvenile justice involvement, as well as increased strengths, school attendance and grades, and stability of living situations." Nat'l Tech. Assistance Ctr. for Children's Mental Health, *Return on Investment in Systems of Care for Children with Behavioral Health Challenges* at vi (2014), https://gucchd.georgetown.edu/products/Return_onInvestment_inSOCsReport6-15-14.pdf.

ABOUT DISABILITY RIGHTS DC

Since 1996, Disability Rights DC at University Legal Services, Inc. (“Disability Rights DC”), a private, non-profit legal service agency, has been the federally mandated protection and advocacy (P&A) program for individuals with disabilities in the District of Columbia. Additionally, Disability Rights DC provides legal advocacy to protect the civil rights of District residents with disabilities.

Disability Rights DC staff directly serves hundreds of individual clients annually, with thousands more benefiting from the results of investigations, institutional reform litigation, outreach, education, and group advocacy efforts. Disability Rights DC staff addresses client issues relating to, among other things, abuse and neglect, community integration, accessible housing, financial exploitation, access to health care services, discharge planning, special education, and the improper use of seclusion, restraint and medication.

For more information about this report, please contact:

Jane Brown
Executive Director
University Legal Services, Inc.
220 I Street, N.E.
Suite 130
Washington, D.C. 20002
202.547.0198 (voice)
202.547.2657 (tty)

Website
www.uls-dc.org

