

OUTCOMES

that MATTER to youth and caregivers

TOP OUTCOMES THAT MATTER TO PARENTS AND CAREGIVERS

1. Accessible Services

The most frequently cited outcome that parents and caregivers identified was better access to behavioral health care services. When discussing this outcome, they referred to wanting improved access from providers and the behavioral health care system overall and easier access for themselves and their children. Caregivers often commented that providers were not delivering the services in their treatment plan or that specific services—including school-based mental health care, respite, and services to support youth transitioning to adulthood—were unavailable.

2. Provider Collaboration

The second most frequently cited outcome identified by parents and caregivers was provider collaboration. They described this outcome as a desire for increased cooperation and communication between providers within behavioral health and other systems, especially schools. Participants frequently used the phrase “being on the same page” when speaking about providers regarding how all systems would meet their child’s needs. Additionally, they wished for providers to work more closely with themselves and their children, emphasizing the importance of partnering with caregivers and youth in creating and implementing their care plans (youth and family-driven care).

3.a. Knowledge, Resources, and Tools

Another key outcome identified by caregivers and the youth who participated in the study was the need for knowledge, resources, and tools to support the mental health needs of their child. Caregivers expressed a desire for providers to provide ideas and strategies to help them support their child’s emotional and behavioral needs, manage their crises, and support skill development. They also wanted providers to share knowledge about mental health and well-being in children and youth and the community resources available to support their children. At the same time, they expressed hope for providers themselves to have access to more knowledge, resources, and tools to enhance the quality of care provided.

3.b. Effective Communication

The outcome cited by caregivers (and youth), with the same frequency as knowledge, resources, and tools, was effective communication. Caregivers emphasized the need for better communication from their children’s providers, including teachers, about the treatment process, their child’s needs, their plan of care, and their behavior and school progress.

4. Consistent and Continuous Care

The next outcome that emerged from the study was the need for consistent and continuous care. Caregivers highlighted the importance of consistency for their child from providers across the behavioral health system. They specifically mentioned the value of maintaining the same provider, support for transitioning across levels of care (e.g., moving from inpatient or residential care back to the home and community setting), and services that could support their children as they transitioned to the adult mental health care and educational systems.

5. Less Judgment and Stigma

Another critical outcome identified in the research was less judgment and stigma, which caregivers and youth both emphasized. Caregivers expressed a desire for reduced judgment of themselves as parents, their children, and their mental health needs from providers, schools, extended families, and society. Many participants discussed experiences of providers blaming them for their children's emotional and behavioral struggles, and some reported threats of being reported to child protective services. Other caregivers reported being told by family or community members how to discipline their children better.

6. Individualized Care

The next outcome, highlighted by caregivers and youth, was individualized care. Caregivers discussed the importance of receiving individualized and holistic care from their children's providers. They frequently emphasized the need for providers to take their time in getting to know their child and the family, to be flexible and creative in planning and delivering care, to consider the entire family's needs and dynamics and the whole picture of their child's history and life experiences, not rely on medication solely, and to not put their child "in a box" or use a "one size fits all" approach to working with their child/family. Some parents explicitly linked individualized care with youth and family-driven care (providers collaborating with and listening to the youth and their family): Youth and family-driven care will result in individualized care.

7.a. Personal Fulfillment

Caregivers emphasized the desire for personal fulfillment as an essential outcome of behavioral health services. They frequently mentioned their fulfillment, which included pursuing personal goals, making friends, developing hobbies and careers, and having time for self-care. Additionally, they spoke of their desires for their child and family to be happy, feel like they belong, and be able to pursue their own goals.

7.b. Support and Engagement

Caregivers identified the need for support and encouragement at the same frequency as personal fulfillment. They wanted their providers to offer support, support networks, encouragement, and positive feedback for themselves and their children.

8.a. Feeling Respected

The next outcome highlighted by caregivers was feeling respected. Caregivers expressed a desire for providers across various systems of care (including schools) to treat them, their child, and their families with respect. In addition, they mentioned wanting to feel that their child respected them.

8.b. Well-trained Providers

Another outcome identified by caregivers was the need for well-trained providers. Caregivers emphasized the importance of having knowledgeable providers who are confident and capable of addressing the complex needs of their child, who have the training to provide the care in the treatment plan, and who draw on existing evidence to inform care planning and use evidence-based practices—when indicated—to benefit their children and themselves. Several caregivers reported having difficulty finding providers willing to work with their child: “...sometimes that they prefer less challenging cases...”

9. Cultural Responsiveness

The next outcome identified by caregivers was cultural competence. Caregivers wanted providers to understand and engage their family’s culture when planning and providing services. Cultural responsiveness encompasses consideration of race and ethnicity and family dynamics such as co-parenting or where grandparents are the primary caregivers.

10.a. Improved Functioning

The next outcome cited by caregivers was improved functioning. Caregivers expressed a desire for overall improvement in functioning for their child, themselves, and their entire family. This improvement included concepts such as having a “normal” life, applying skills learned in services to daily situations, and making observable progress in treatment plan goals.

10.b. Accountable Service Systems

The final outcome frequently cited by caregivers was accountable service systems. Caregivers expressed a desire for providers and the behavioral health system to be held accountable and to take responsibility for the consistency and quality care they provide, including when they don’t provide services on the treatment plan, when they assign ill-equipped or untrained providers, or when a child in their care fails to improve or experience an increase in problems as a result of receiving services.

TOP OUTCOMES THAT MATTER TO YOUTH AND YOUNG ADULTS

1. Being Understood

The most frequently cited outcome by youth and young adults was being understood. These young individuals strongly desired to be understood, especially by their parents, caregivers, and providers. Youth expressed the desire for their parents to understand that they are different from their parents and siblings, to understand their mental health needs and feelings, and to see and accept their unique perspectives on life. They reported wanting their providers to understand their perspectives and motivations for behaviors and feelings.

2. Knowledge, Resources, and Tools

The following outcome emphasized by youth and young adults was the need for knowledge, resources, and tools to support their mental health needs. They wished their providers to educate them about mental health and teach them tools, exercises, or techniques to manage their emotional or behavioral challenges better. Youth want providers also to provide their parents or caregivers education about mental health and help them to learn skills for better supporting the mental health needs of their child.

3. Improved Relationships

The following outcome highlighted by youth and young adults in the research study was improved relationships. They expressed a strong desire for better relationships with their parents or caregivers, families, and peers. Improved relationships included spending quality time with their caregivers and families, finding ways to manage conflict more effectively, experiencing less conflict, and having healthier boundaries with peers, caregivers, and families. Trusting others is also critical to youth in supporting improved relationships—but emerged as an important outcome separate from improved relationships.

4. Being Heard

Another outcome emphasized by youth and young adults in the research study was being heard. They expressed a desire to be heard, not just by their providers but also by their parents or caregivers. They frequently framed this desire as a need for people to listen to them genuinely. Youth asserted that being heard is different from being understood – that feeling heard comes from having space to talk about your needs and perspectives and receiving feedback that the listener is paying attention and listening. Being understood--while it can result from being heard—means that listening results in learning more about the youth and being able to see their perspective.

5. Improved Self-control

The next outcome identified most frequently by youth and young adults was improved self-control. They desired better self- and emotional regulation, seeking ways to effectively manage and understand their emotions and behaviors in stressful situations.

6. Less Judgment and Stigma

Another outcome highlighted by youth and young adults was less judgment and stigma. They articulated a desire to experience reduced criticism and judgment from their providers and

parents or caregivers, and they also hoped for less stigma from the broader society. Youth cited education for other youth, their caregivers, and society as a critical pathway to this outcome.

7. Support and Encouragement

The next outcome frequently cited by youth and young adults was support and encouragement. They strongly wished to receive greater support and encouragement from their providers, parents, and caregivers, including positive feedback and praise for achievements.

8.a. Effective Communication

Another outcome emphasized by youth and young adults was effective communication. They desired better communication with their caregiver and other members of their family and peers. They wanted to talk openly with their caregivers and family members without conflict and feel confident and competent in engaging socially with their peers and other adults. They also wish to have clear and open communication with their provider and want their provider to communicate clearly and effectively with their caregivers and families to enhance personal understanding and collaboration and treatment effectiveness and safety.

8.b. Ability to Trust

The next outcome youth and young adults highlighted was the ability to trust. They expressed a strong desire to place trust in their providers and their parents or caregivers, emphasizing the importance of trustworthiness in their relationships. They also expressed a desire to trust peers and other important individuals in their lives to share personal perspectives and be vulnerable—to have more meaningful and respectful relationships.

8.c. Positive Rapport with Providers

The following outcome emphasized by youth and young adults was a positive rapport with providers. They expressed a desire for kindness, empathy, and authenticity from their providers. Youth discussed that they wanted their providers to see youth as more than “just a job” or “punching” a clock and wanted to feel that their providers genuinely cared about their well-being. Additionally, they indicated that this wish for a positive connection extended to their relationships with their parents or caregivers and family members.

9. Improved Functioning

Another outcome identified by youth and young adults was improved functioning. They defined this as achieving treatment goals, navigating their daily lives effectively and independently, noticing improvement in their “problems” or “problem behaviors,” and overall quality of life.

10. Feeling Respected

The final outcome frequently cited by youth and young adults was feeling respected. They most commonly expressed a strong desire to be treated with respect (“sees me as a person,” “we’re all human,” and “we’re still human beings”) by their providers and parents or caregivers, emphasizing the importance of mutual respect in their care and relationships. Respect also included wanting their desires, opinions, and perspectives to be respected—not criticized or dismissed—by providers and caregivers. They also expressed a desire to feel increased respect for themselves.