Summary Report

Children's In-Home and Community-Based Services Improvement Evaluation

Baseline Data Collected from Community-Based Youth and Caregivers

October 2023

Revised: January 2024

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Introduction

Evaluation Overview

West Virginia University Health Affairs Institute is conducting a longitudinal evaluation of the West Virginia Department of Health and Human Resources (WV DHHR) Children's In-Home and Community-Based Services Improvement Project. The mixed method Evaluation was designed to provide information about the perspectives and experiences of people and partners at all levels of the youth mental and behavioral health system: organizations and facilities; providers, including cross-sector partners; caregivers; and youth with mental and/or behavioral health needs.
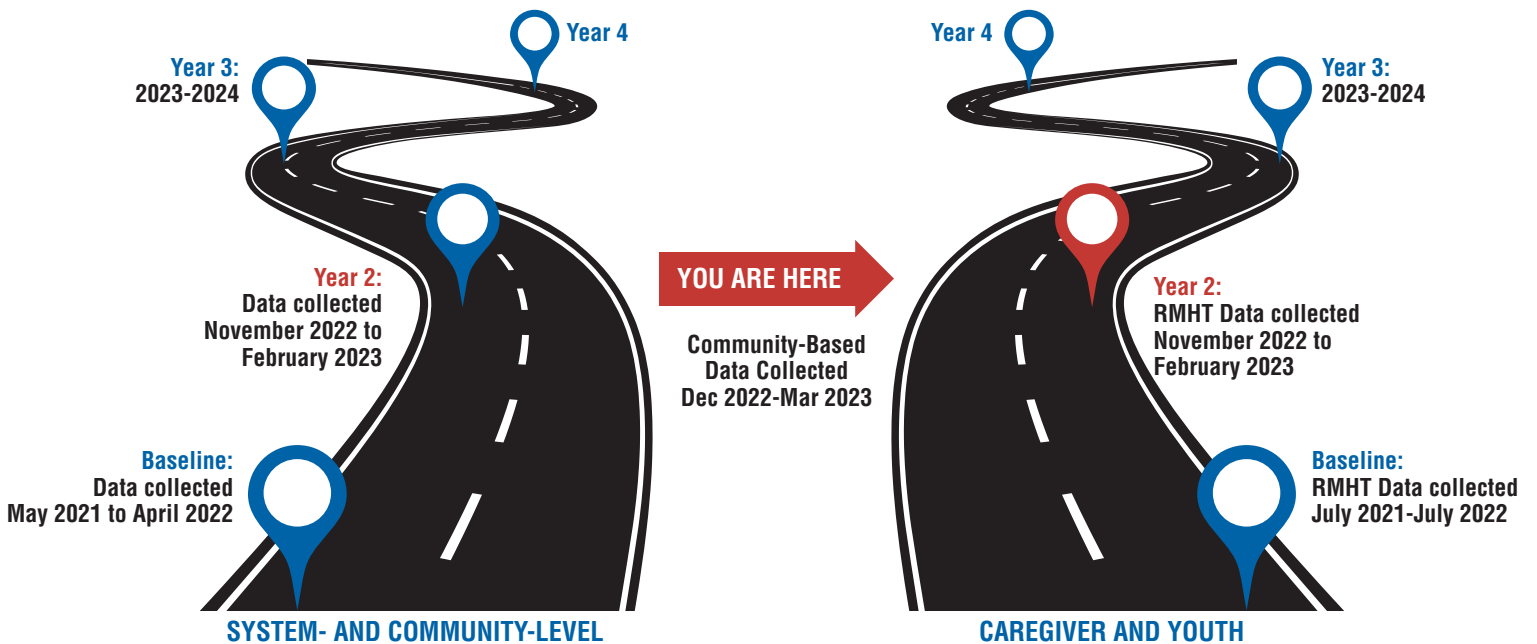
Data collection methods include:

SURVEYS **INTERVIEWS** **SECONDARY DATA**

Data collected during each year of the Evaluation are intended to provide a snapshot of the experiences of people in the field, as well as youth receiving mental and behavioral health services and their families. During and after data collection, WV DHHR and stakeholders across the system are actively engaged in making changes to policies and practices that are not reflected in the presented data. Future reporting by this longitudinal Evaluation will provide insights into the cumulative work over the course of the project.

4-YEAR EVALUATION

Year 4

Year 3:
2023-2024

Year 2:
Data collected
November 2022 to
February 2023

Baseline:
Data collected
May 2021 to April 2022

SYSTEM- AND COMMUNITY-LEVEL

YOU ARE HERE

Community-Based
Data Collected
Dec 2022-Mar 2023

Year 4

Year 3:
2023-2024

Year 2:
RMHT Data collected
November 2022 to
February 2023

Baseline:
RMHT Data collected
July 2021-July 2022

CAREGIVER AND YOUTH

Report Overview

Data presented in this report were collected from community-based caregivers and youth across West Virginia via surveys (n=225) and case series interviews (n=11). Caregivers and youth represented in the data have experience with a range of mental and behavioral health services, including:

- Children's Mobile Crisis Response and Stabilization (CMCRS)
- Wraparound: In this report Wraparound (WRAP) includes WV Children's Mental Health Wraparound and the Children with Serious Emotional Disorders (CSED) Waiver Wraparound
- Behavioral Support Services (including Positive Behavior Support; PBS), referred to below as BSS
- Assertive Community Treatment (ACT)
- Residential mental health treatment (RMHT)
- Children's Crisis and Referral Line (CCRL; 844-HELP4WV)

Findings in this report include community-based caregiver and youth perceptions of: 1) access to services (page 6); 2) experiences with services (page 14); and 3) family status/functioning (page 17). Survey and interview findings are highlighted to provide insight into caregiver and youth perspectives, share suggestions from respondents for expanding on what's working, and to inform dialogue around opportunities for system improvements.

In this report:

- **"Caregiver"** is used to refer to biological parents, foster parents, kinship care providers, or other guardians of youth of interest to this Evaluation.
- **"Youth"** is used to refer to the continuum of children, youth, and young adults, ages 0-21, who receive or are eligible for the services outlined above. Youth were further categorized as having received RMHT during the Evaluation time periods of interest or were at risk for placement in RMHT.
- **"At-risk"** refers to the criteria agreed upon by the State to identify youth who are in the community and have mental and behavioral health needs that can potentially elevate their risk for out-of-home placements. The terms "at-risk" and "community-based" are used interchangeably to describe these youth (and their caregivers) throughout this summary report, and in the main report.

Overall, evaluation results indicate that in-home and community-based services are helping WV youth with mental and behavioral health needs and their families, although opportunities exist to further expand awareness and use. Baseline data presented here are intended to capture the experiences of community-based youth and their caregivers, as well as the successes of the system and opportunities to empower West Virginians to reach their potential.
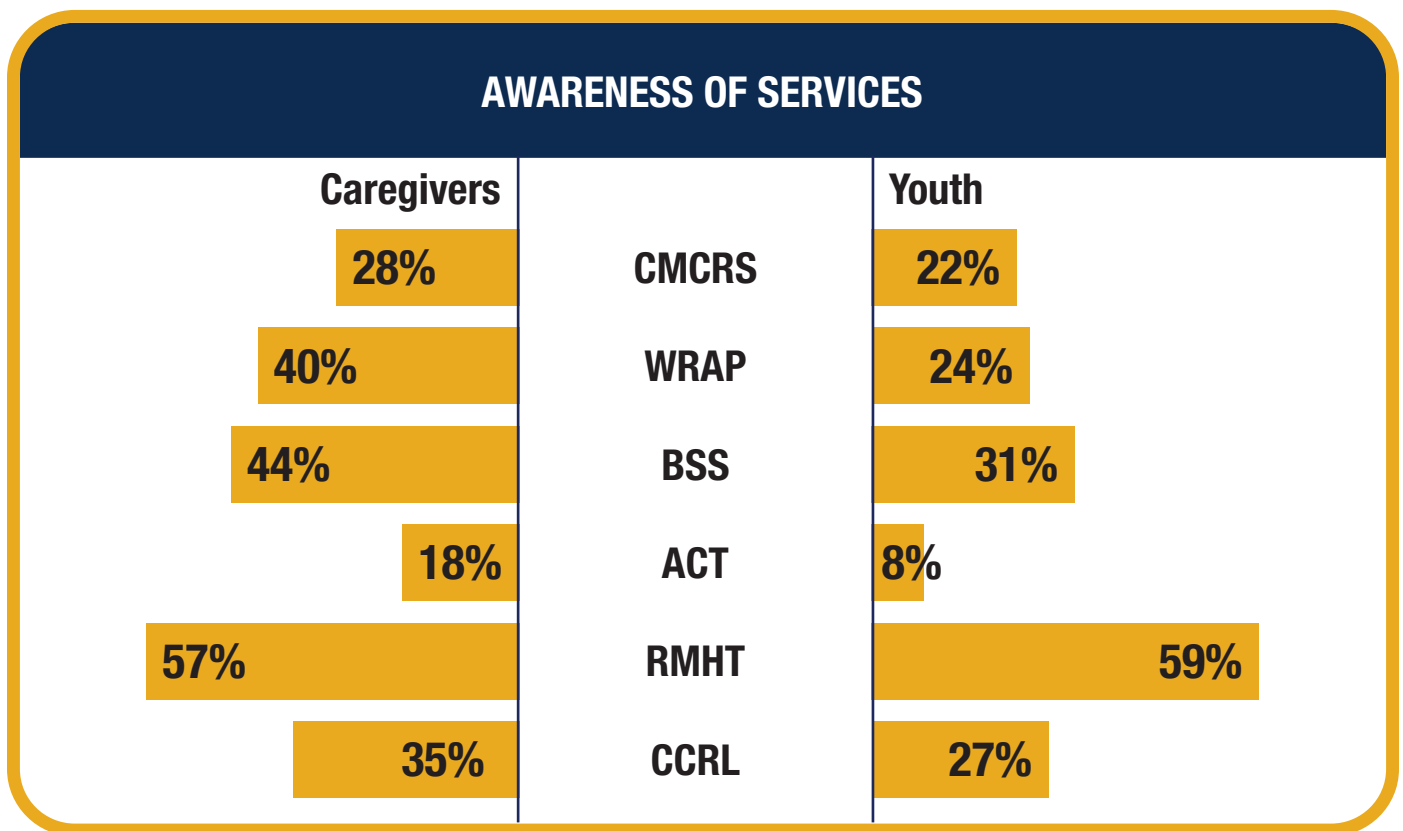
Access to Services

Access to Services

The youth mental and behavioral health system in West Virginia includes a range of opportunities for treatment, support, and engagement. Community-based and residential options are important components of the system; this baseline data collection is aimed at understanding the experiences of youth who are at-risk of entering residential mental health treatment and their caregivers to learn more about whether and how they could be treated through in-home and community-based services.

Awareness

Caregivers and youth have varying levels of awareness of community-based mental and behavioral health services. Caregivers were most aware of Wraparound and least aware of ACT. Youth were most aware of BSS and least aware of ACT.

AWARENESS OF SERVICES

Caregivers		Youth
28%	CMCRS	22%
40%	WRAP	24%
44%	BSS	31%
18%	ACT	8%
57%	RMHT	59%
35%	CCRL	27%

Awareness of CCRL was 10% higher among caregivers of community-based youth than it was among caregivers of youth in RMHT in Year 2 (2022).

Of the 52% of caregivers who reported that their understanding of how to access services improved over the last 12 months, 68% said it made them more likely to access services in the future, 23% said equally likely and 3% said less likely; only 3% said that they do not expect to need additional services in the future.

Caregivers reported hearing about services from a variety of sources, including a doctor (23%) and the internet (10%). Nearly half (45%) reported hearing about services from some "other" sources; these sources included the judi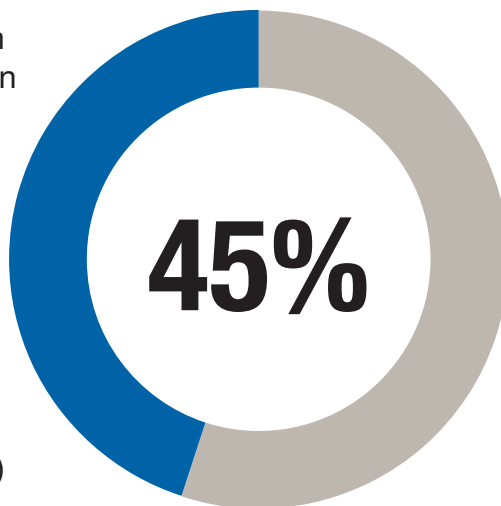cial system (such as court, probation officers), school (e.g., teachers, school officials), system-level stakeholders (e.g., DHHR, CPS, caseworkers), social networks (e.g., friends and family), foster care, referrals from providers, and through information they received in the mail. A very clear theme was that caregivers and youth both wanted to hear about services through personal interactions. Caregivers shared that they wanted to understand the purpose and goals of each of the services and to receive specific contact information to help them access those services.

HOW DID YOU HEAR ABOUT SERVICES?

DOCTOR

23%

INTERNET

10%
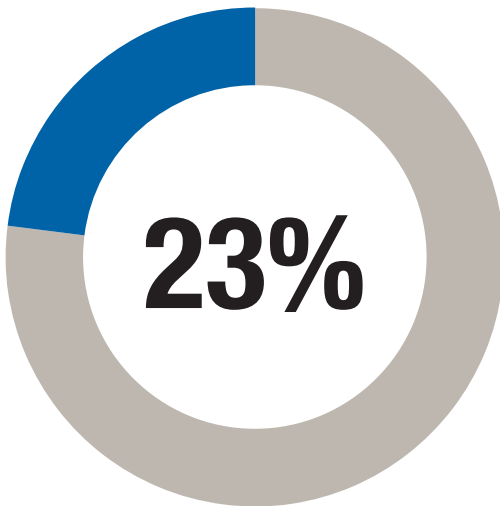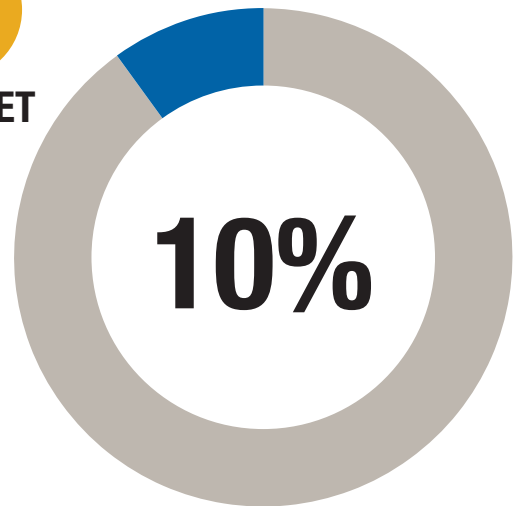
OTHER SOURCES INCLUDE:

Judicial System (court, probation officers, etc.)

School (teachers, school officials, etc.)

System-level Stakeholders (DHHR, CPS, caseworkers, etc)

45%

Foster Care

Referrals from Providers

Information received in the mail
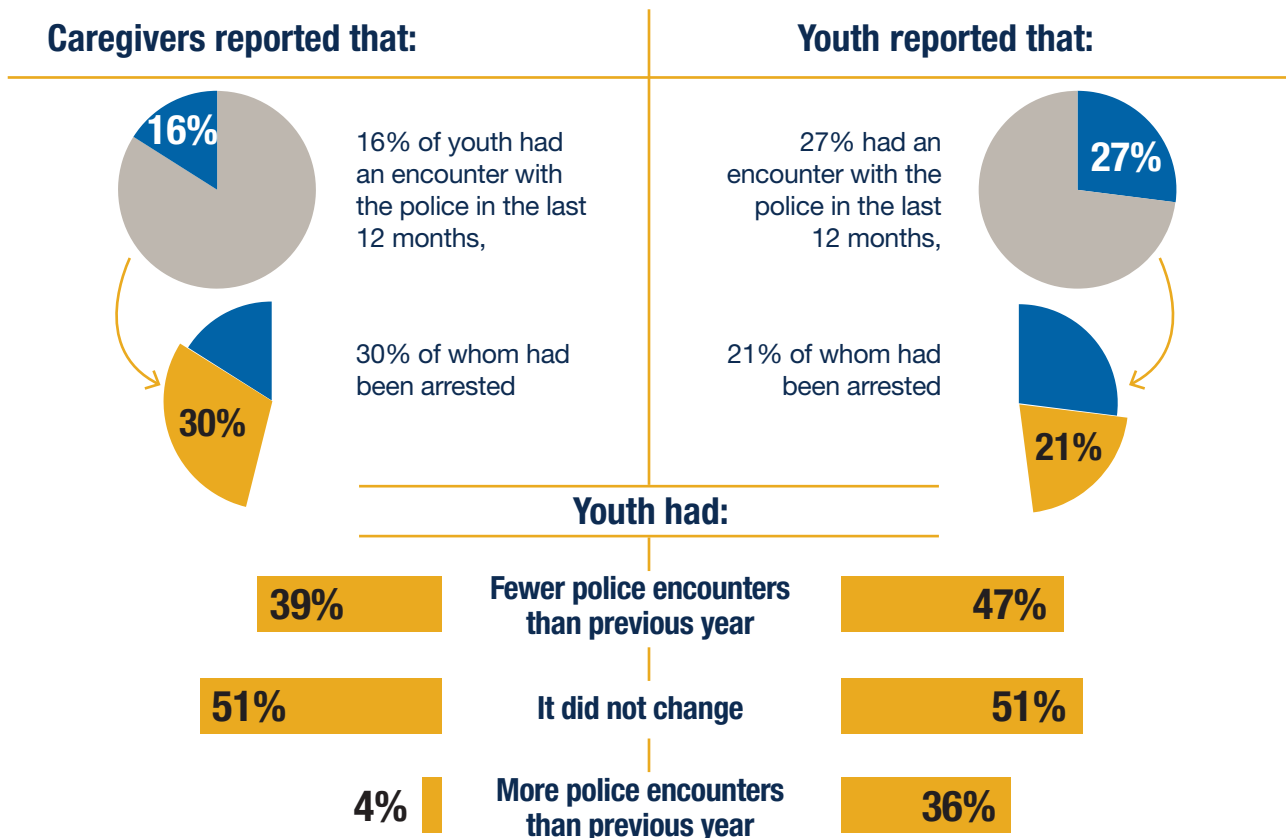
Social Networks (friends and family)

Crisis and Emergency Services

For families, access to the mental and behavioral health system is often through the police, other social services and supports, and emergency rooms. Caregivers were much more likely to have called the police or social services than youth. A similar percentage of caregivers and youth reported visiting the ED to gain access to mental and behavioral health services.
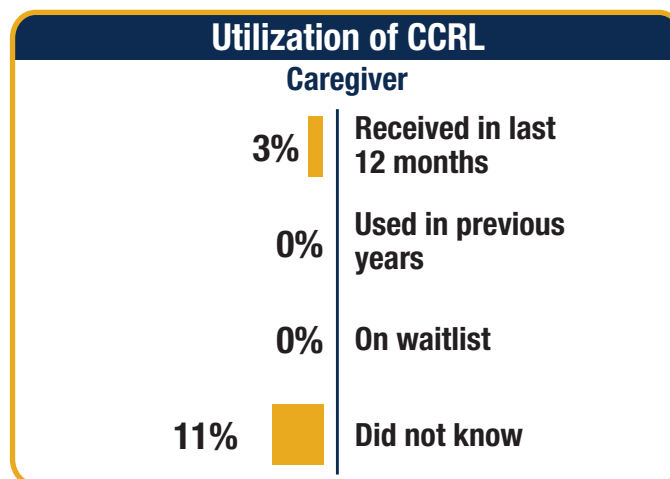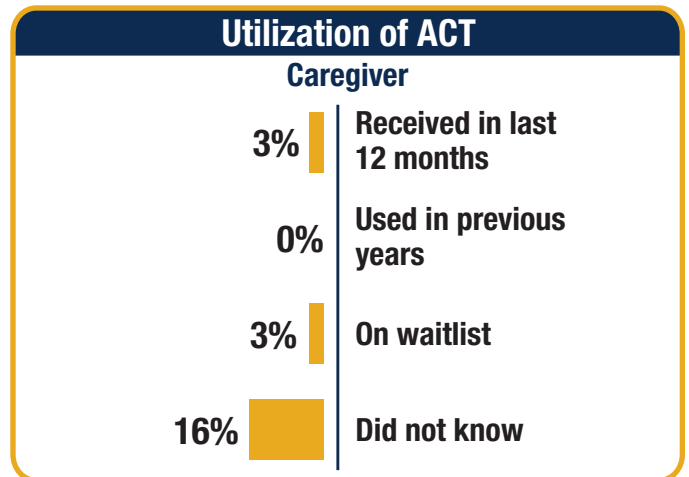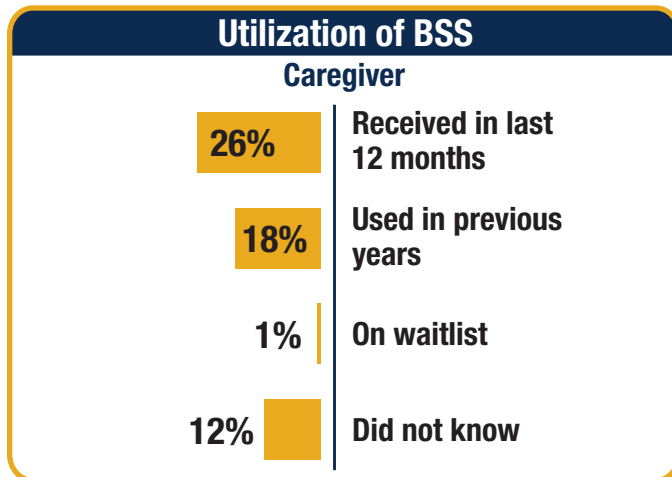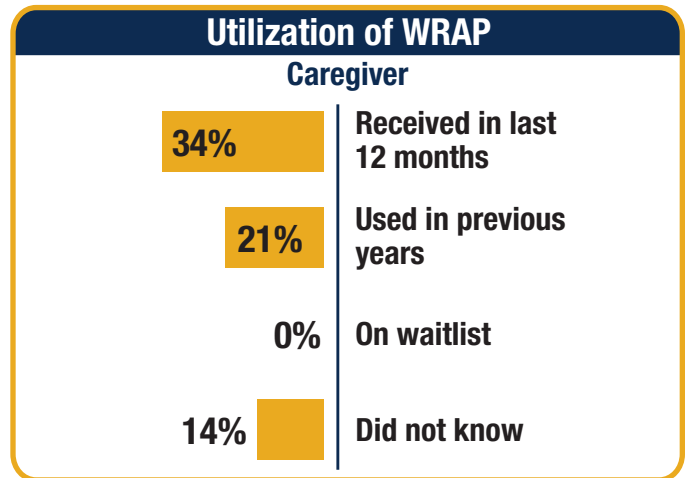
In response to youth needs, over the last 12 months:

Caregivers

9%	**21%**	**13%**
Called the police for help with a mental or behavioral health emergency	Called social services or another support system	Visited the emergency room

Youth

4%	**14%**	**14%**

Caregivers reported fewer encounters with police than youth (16% and 27% respectively). However, a higher percentage of caregivers reported that encounters with police led to an arrest.

Caregivers reported that:

16%

16% of youth had an encounter with the police in the last 12 months,

30%

30% of whom had been arrested

Youth reported that:

27%

27% had an encounter with the police in the last 12 months,

21%

21% of whom had been arrested

Youth had:

|		
39%	Fewer police encounters than previous year	47%
51%	It did not change	51%
4%	More police encounters than previous year	36%

Utilization of Services and Wait Times

Caregivers reported that at least one youth received the services of interest to this Evaluation in the last 12 months. According to caregivers, Wraparound and BSS (including PBS) were the most used services (received by 34% and 26% of youth within the last 12 months of data collection, respectively).

Utilization of CMCRS
Caregiver

6%	Received in last 12 months
13%	Used in previous years
0%	On waitlist
13%	Did not know

Utilization of WRAP
Caregiver

34%	Received in last 12 months
21%	Used in previous years
0%	On waitlist
14%	Did not know

Utilization of BSS
Caregiver

26%	Received in last 12 months
18%	Used in previous years
1%	On waitlist
12%	Did not know

Utilization of ACT
Caregiver

3%	Received in last 12 months
0%	Used in previous years
3%	On waitlist
16%	Did not know

Utilization of CCRL
Caregiver

3%	Received in last 12 months
0%	Used in previous years
0%	On waitlist
11%	Did not know

Note that 85% of caregivers who responded about their experiences with the system have youth under the age of 18 who would not be eligible for ACT services. Results suggest a need for increased awareness and outreach for ACT as youth age into the target population.
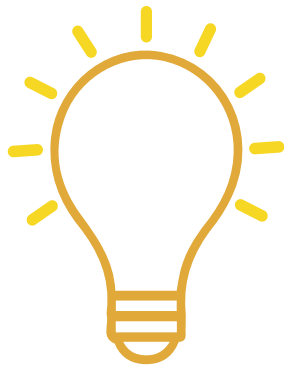
Things to Consider

- There were too few youth responses to include in the graphics on the previous page.

- Increasing awareness and utilization of the CCRL, as well as specific training on de-escalation and crisis management for caregivers, are among potential strategies to consider.

- Nearly one-third (31%) of caregivers reported that their youth received "other services" in the past 12 months outside of those listed above. "Other services" included: counseling/therapy/behavioral health services, medication management, speech/occupational/physical therapy, residential services, evaluations, Wraparound/Safe at Home, and services associated with waiver or other DHHR programs, and juvenile services.

- Stigma around mental health, especially among youth, is a continued and real issue. Youth were often reluctant to engage in services because of fear of being labeled. Once they initiated them, youth generally expressed that mental and behavioral health services helped. Finding ways to address stigma will continue to be critical to reaching youth who need community-based services.

- Non-mental health services, including social supports, were identified as critical to youth and family wellbeing. Faith-based organizations, community groups, clubs, and activities play an important role in maintaining youth mental and behavioral health.

Barriers

Mental and behavioral health systems and providers are actively working to remove barriers faced by youth and caregivers to access quality services. The surveys ask if caregivers and youth experienced specific barriers to starting and continuing services. Reports from caregivers and youth in both RMHT and community-based settings fell into three major categories: Capacity and Communication, Logistics, and Family-Level.

Overall, 26% of community-based youth and 47% of community-based caregivers reported barriers to starting services once the need was identified and 53% of youth and 48% of caregivers reported barriers continuing services after they started.

The most commonly cited challenges reported by caregivers and youth were difficulties reaching a person to start services, the system being too complicated, and long wait times before starting services.

Capacity and Communication

Caregiver		Youth
	The person you needed to contact to start/continue services was unavailable, unresponsive, or too busy	
56% (Starting) / 45% (Continuing)		40% (Starting) / 30% (Continuing)
32% (Starting) / 19% (Continuing)	System too complicated	60% (Starting) / 30% (Continuing)
44% (Starting) / 24% (Continuing)	Long wait times between choosing and starting/continuing service	40% (Starting) / 30% (Continuing)

■ Starting Services ■ Continuing Services

Logistics

Caregiver		Youth
12% (Starting) / 7% (Continuing)	Decision meetings/services were at a time you could not make	40% (Starting) / 10% (Continuing)
10% (Starting) / 12% (Continuing)	Decision meetings/services were somewhere you couldn't get to	20% (Starting) / 10% (Continuing)
N/A (Starting) / 5% (Continuing)	Decision meetings/services used technology that was unfamiliar or unavailable	20% (Starting) / N/A (Continuing)
34% (Starting) / N/A (Continuing)	Services weren't available in your area	60% (Starting) / N/A (Continuing)
5% (Starting) / 2% (Continuing)	Couldn't afford services	N/A (Starting) / 10% (Continuing)
15% (Starting) / 12% (Continuing)	Couldn't get to and from services	N/A (Starting) / 20% (Continuing)
12% (Starting) / N/A (Continuing)	Services weren't available at times when you could join	N/A (Starting) / N/A (Continuing)
24% (Starting) / 26% (Continuing)	The programs were not a good fit	60% (Starting) / 60% (Continuing)
10% (Starting) / 2% (Continuing)	Services were for a different age group	N/A (Starting) / 20% (Continuing)

■ Starting Services ■ Continuing Services

Family-Level

Caregiver			Youth
34% / **19%**		You didn't understand what was needed	**N/A** / **10%**
N/A / **N/A**		You didn't need services	**40%** / **20%**
N/A / **12%**		Unable to balance time for services and other commitments	**N/A** / **10%**
N/A / **26%**		Services didn't seem to work	**N/A** / **50%**

■ Starting Services ■ Continuing Services

Other Barriers

| Caregiver			Youth
41% / **48%**		Other	**40%** / **50%**
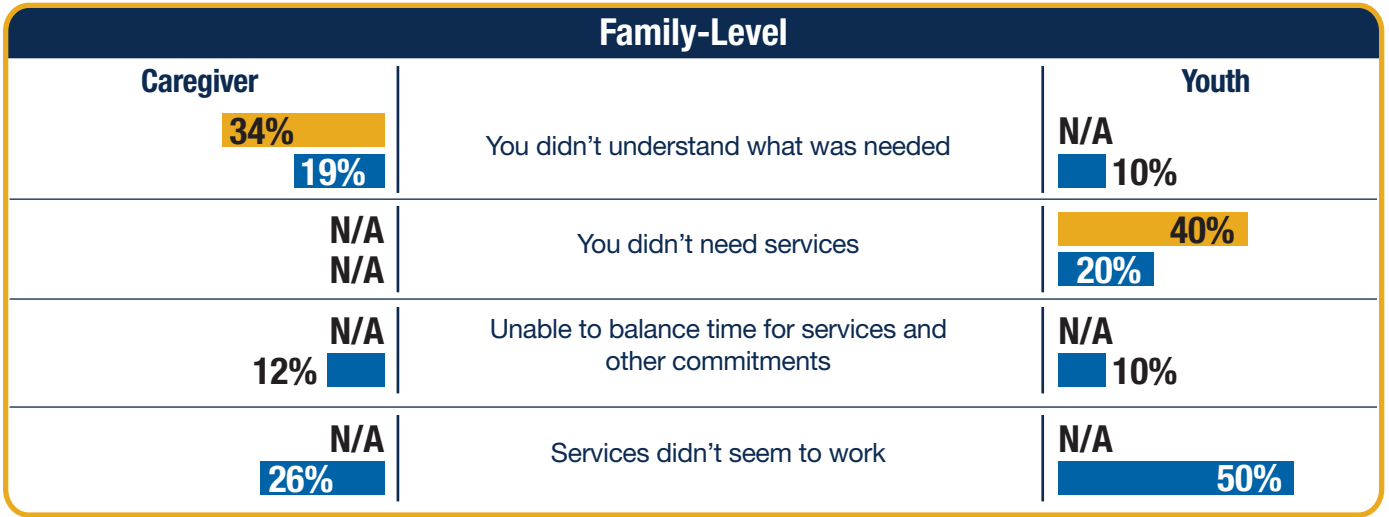
■ Starting Services ■ Continuing Services

Caregivers reported "other" challenges they encountered in starting and continuing services. Most common responses included:

- Communication issues (i.e., caregivers feel unheard and uninvolved in decision making).
- Service availability issues (e.g., long wait times, inconvenient hours, limited services designed to address the unique, intensive, and complex needs of the youth population).

Other reported challenges include COVID-19, family barriers like substance use, and youth engagement. In terms of youth engagement, across data sources, many youth reported a reluctance to engage in services, which was partly due to stigma associated with them, as well as a lack of interest in discussing problems until therapeutic benefits were experienced. For many youth, a requirement, such as probation, ultimately pushed them to engage in services, and most reported positive results as a result.
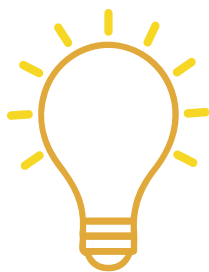
Things to Consider

- Barriers to accessing services are present throughout the system. Finding ways to create policies and practices that address what is within organization control, like timely responses to calls, can help mitigate barriers for families.

- It can take time for youth and families to find the services and providers that are the right fit to meet their needs. This should be expected, and interim support such as a Wraparound facilitator, can help make this process as easy as possible along the way.

Experience with Services

Experience with Services

Rich insights were gathered from community-based caregivers and youth across data collection tools. Survey scales capture perceptions of engagement with services and respect from provider staff, and perceptions of service accessibility and satisfaction with services. Caregivers felt engaged and involved but wanted more. Caregivers were eager for additional opportunities to contribute their experiences and perspectives during care team meetings.

Treatment Participation

Caregivers responded to survey questions about their experiences participating in their youth's treatment. The Caregiver-Treatment Participation Scale includes topics such as choosing treatment goals and services, knowing whom to contact with questions and concerns, and receiving timely information. This scale provides an overview of caregiver perceptions during the data collection period.

Caregiver Survey

Caregiver-Treatment Participation

Low
10.3%

Moderate
51.5%

High
38.2%
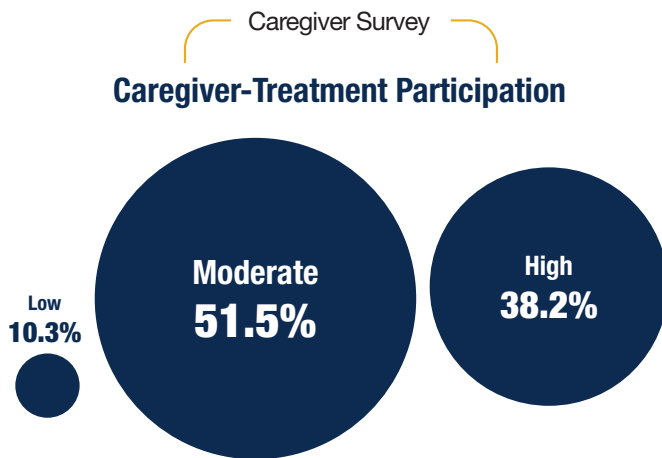
Engagement and Respect in Treatment

This scale asked caregivers and youth about their experiences with staff and providers specifically related to cultural humility, connectedness, respect, and communication.

Caregiver Survey

Engagement and Respect

Low
6.6%

Moderate
47.5%

High
45.9%
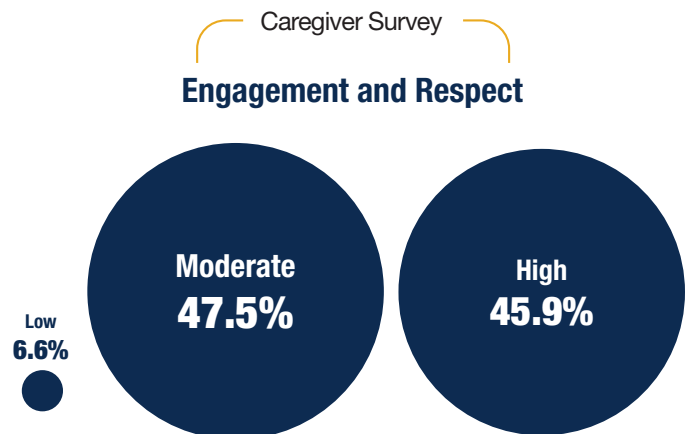
Things to Consider

- Caregiver engagement helped support youth engagement; finding ways to involve and include caregivers can help build trust and increase the opportunities to support youth.

- Not all caregivers are the same. Some are great advocates for their youth, while others struggled with meeting their own needs or caring for their households. Providers should continue to ask questions and understand individual caregiver needs, and find ways to engage and respect those needs.

Accessibility and Satisfaction

Caregivers and youth reported on their ability to access services, and their satisfaction with those services. Questions included when services were available, wait times for services, locations (including telehealth options), and satisfaction with getting help.

With 94% of youth reporting moderate or high accessibility and satisfaction, youth had higher levels of accessibility and satisfaction than caregivers.

| Caregiver	Accessibility and Satisfaction	Youth
33%	High	33%
56%	Moderate	61%
11%	Low	6%
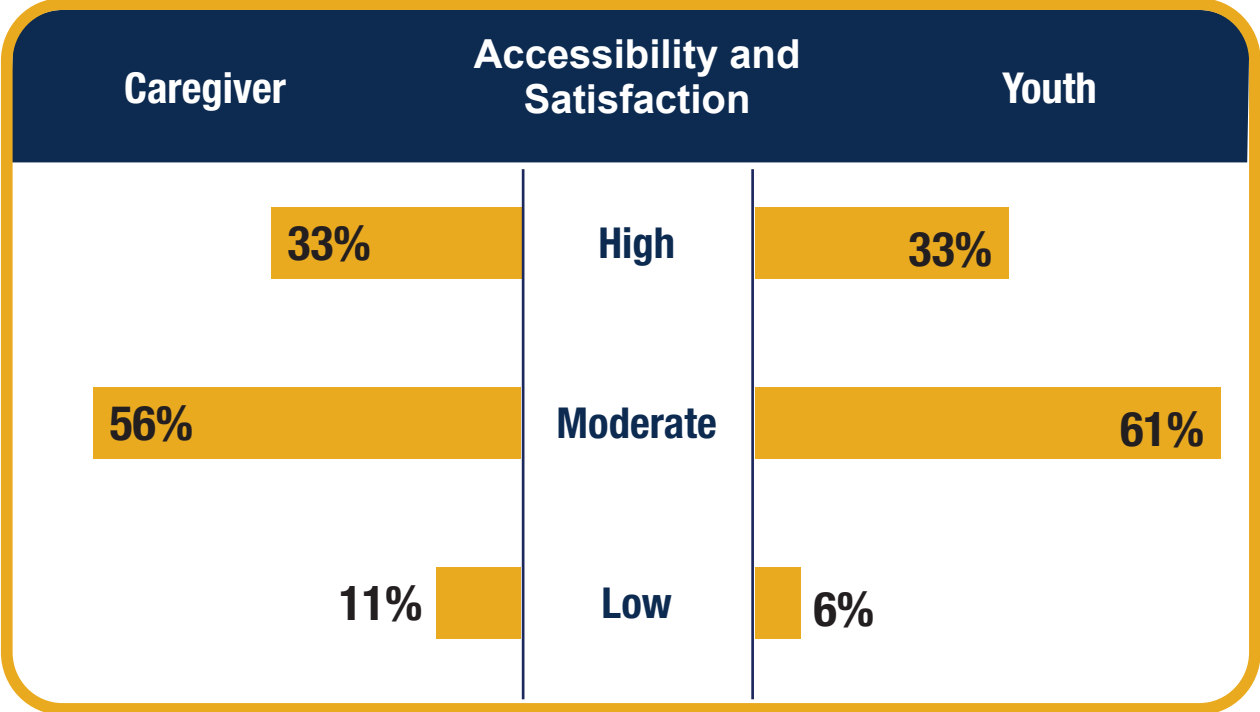
Youth- and Family-Level Outcomes

Youth- and Family-Level Outcomes

The Evaluation addressed several elements of youth and family status including social support, school attendance, and community-based caregiver and youth-reported youth functioning. Overall, both caregivers and youth reported moderate to high youth functioning, although differences emerged when accounting for whether youth had a history of RMHT. Additional data, such as scores from the Child and Adolescent Functional Assessment Scale (CAFAS), are being analyzed and will be included in future evaluation reports.

Social Support

Social support is an important component of caregiver and family wellbeing. Caregivers were asked to report whether they have access to people who they can talk to about their youth during troubled times.

The majority of caregivers reported moderate to high levels of social support, indicating that their families are supported by strong networks.

Caregiver Survey

Social Support

Moderate
27%

Low
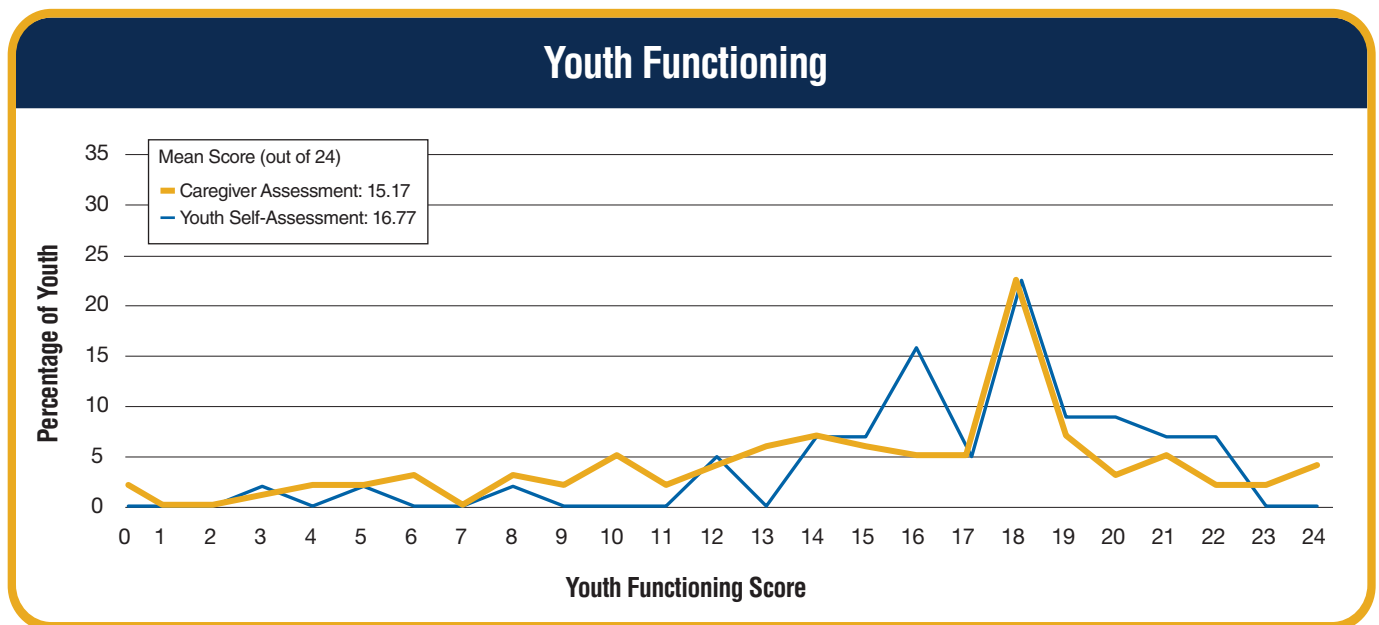6%
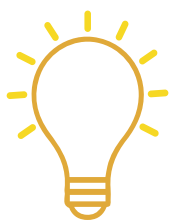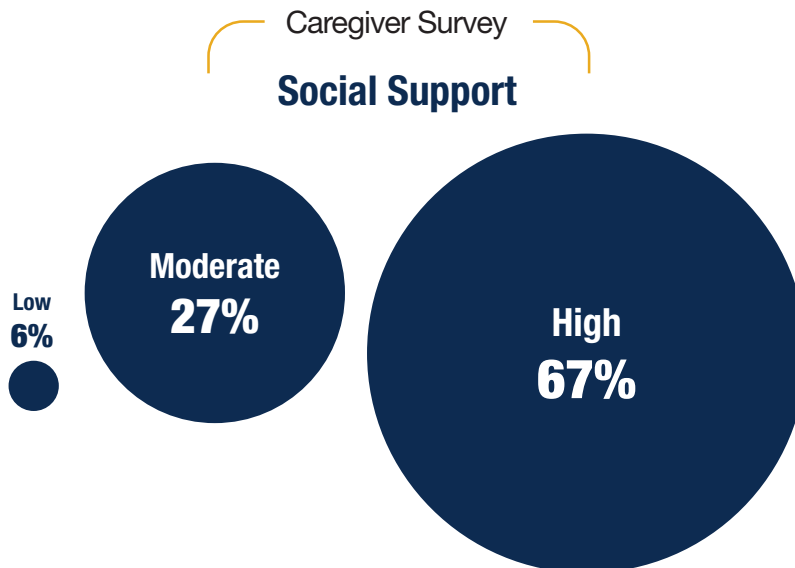
High
67%

Things to Consider

- Although few youth responded to these questions, those that did indicated high (89%) or moderate (11%) levels of social support.

- Social support can be overlooked in the delivery of services, but can play an important role in amplifying and supporting youth and family wellbeing. Consider assessing and building in social support into treatment plans. For example, Wraparound includes natural supports as an integral part of service delivery.

Perceptions of Youth Functioning

During the data collection and reporting period, WV DHHR selected the Child and Adolescent Functional Assessment Scale (CAFAS) as one of the primary decision-making tools for identifying the least restrictive environment for youth to receive mental and behavioral health services. Since the CAFAS process and data collection were being implemented at the same time as the Evaluation, scores were not available for this report. For this report, youth functioning was measured through caregiver and youth surveys that include questions about daily life, social, school, and family connections, and life satisfaction. In the community-based samples, the Youth Functioning Scale ranged from 0 to 24. Overall, youth self-reported slightly higher functioning than caregivers.

Caregiver Assessment	Youth Functioning	Youth Self-Assessment
51%	High Functioning	59%
36%	Moderate Functioning	34%
13%	Low Functioning	7%
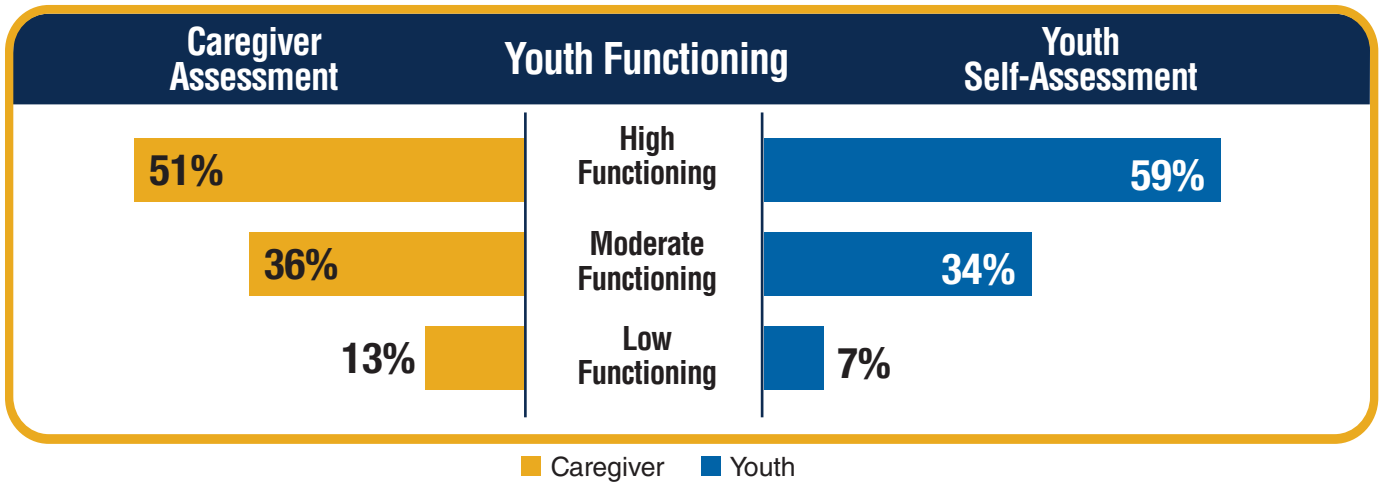
Caregiver   Youth

The scale means were also higher when comparing all caregiver (15.17 on a scale of 24) and all youth responses (16.77 on a scale of 24). However, when the scores are displayed as line graphs, the distributions of caregiver and youth responses are very similar, with a majority of scores falling within 16 and 19 on the scale of 24.

Youth Functioning

Mean Score (out of 24)
— Caregiver Assessment: 15.17
— Youth Self-Assessment: 16.77

Percentage of Youth

Youth Functioning Score

The Caregiver-Youth Functioning Scale for community-based caregivers included 6 items, one less than the scale used for caregivers of youth in RMHT. The item not included in the community-based caregiver scale asked about medication management. More community-based caregivers selected "I don't know" or "Not Applicable" to this item than did caregivers of youth in RMHT. Community-based caregivers who selected "I don't know" or "Not Applicable" or who skipped this item on medication management (n=58) reported significant differences in their youth's age, use of crisis services, and utilization of mental and behavioral health services.

Appendix: Topical Index

Community-Based Summary Report Topical Index

The topics covered in this Summary Report are reported in more detail on the following sections and pages in the Community-Based Caregiver- and Youth-Level Evaluation Report (October 2023).