Findings and Visualization Report

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

Baseline Youth and Caregiver Level July 2022
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Introduction

Evaluation Overview

West Virginia University Office of Health Affairs (WVU OHA) is conducting a four-year evaluation of the West Virginia Department of Health and Human Resources (WV DHHR) Children’s In-Home and Community-Based Services Improvement Project. The goal of the improvement project is to expand and improve access to children’s mental and behavioral health services, so that more West Virginia children can receive care in their homes and communities. Information gathered from community partners, families and youth is being used to provide the WV DHHR information about the perspectives and experiences of people and partners serving or receiving care across children’s mental health system continuum, such as organization and facility administrators; health providers; cross-sector partners; caregivers; and youth.

Data collection methods include:

WV DHHR and program partners are actively engaged in making changes to policies and practices that are not reflected in the presented data, as data collected during each year of the evaluation are intended to provide a snapshot of the experiences of people in the field, and youth and families who are at-risk and/or receiving residential mental health treatment. Future reporting will provide additional insight into WV DHHR’s cumulative work over time throughout the project.

4-YEAR EVALUATION

Year 3: 2023-2024
Year 4: 2024-2025
Year 2: 2022-2023
Baseline: Data collected May 2021 to April 2022

Year 3: 2023-2024
Year 4: 2024-2025
Baseline: Data collected July 2021-July 2022

SYSTEM LEVEL
CAREGIVER AND YOUTH

YOU ARE HERE
Report Overview

This report is a supplement to the Caregiver and Youth-level Evaluation Report (July 2022) and includes baseline data collected from July 2021 to July 2022. The Findings and Visualization report provides an overview of key findings from baseline data collection, which was aimed at understanding the experiences of youth in residential treatment to learn more about if and how they could be treated through community-based services. For additional data and analysis, please refer to the full report; a topical index is provided in the Appendix to facilitate navigation.

Data presented in this report were collected from caregivers and youth across West Virginia via 229 surveys, more than 20 one-on-one interviews, and a case series study of 10 caregiver and youth pairs. Caregivers and youth represented in the data have experience with a range of children’s mental health services, including:

- Assertive Community Treatment (ACT)
- Children’s Mobile Crisis Response and Stabilization (CMCRS)
- Wraparound Facilitation Services: West Virginia Children’s Mental Health Wraparound and Children with Serious Emotional Disorders (CSED) Waiver Wraparound (Wraparound)
- Positive Behavior Support (PBS), which is now part of Behavioral Support Services
- Residential Mental Health Treatment (RMHT) that was provided in Residential Mental Health Treatment Facilities (RMHTFs)
- Statewide Children’s Crisis and Referral Line (SCCRL)

Findings in this report include caregiver and youth perceptions of: 1) access to services (page 4); 2) experiences with services (page 10); and 3) family status/functioning (page 14). 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. Quotes are used to illustrate themes and/or to highlight unique perspectives.

During the data collection period, the COVID-19 pandemic caused significant changes to service delivery. The potential impacts of those changes are discussed in the full Baseline Youth and Caregiver-Level Report (July 2022).

In this report:

- “Caregiver” is used to refer to biological parents, foster parents, adoptive parents, and kinship care providers.
- “Youth” is used to refer to the continuum of children, youth, and young adults, ages 0-21, who resided in a RMHTF as of October 1st, 2021 according to DHHR.

Overall, the evaluation results were clear: behavioral health services make a difference for youth and their families in West Virginia. Community-based services are valued, although there is a need for more of them and areas of opportunity exist to expand awareness and use. Baseline data presented here are intended to capture a snapshot of their experiences, which included reflections on the 12 prior months.
Access to Services
Access to Services

The children’s mental health system in West Virginia includes a range of opportunities for treatment, support, and engagement. Baseline data in this report focused on youth who received residential mental health treatment and their caregivers. Caregivers and youth think that services are making a difference, and like providers (from the March 2022 report) they want more. Community-based services that keep youth in their homes and communities and keep caregivers more involved are a priority. But access to services is a challenge: for 46% of caregivers who said that they encountered challenges initiating services, it was due to lack of selected services in their area.

Awareness

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

<table>
<thead>
<tr>
<th>Caregiver awareness of service</th>
<th>Youth awareness of service</th>
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<tbody>
<tr>
<td>16% ACT</td>
<td>24%</td>
</tr>
<tr>
<td>27% CMCRS</td>
<td>32%</td>
</tr>
<tr>
<td>52% CMHW</td>
<td>25%</td>
</tr>
<tr>
<td>21% PBS</td>
<td>44%</td>
</tr>
<tr>
<td>24% SCCRL</td>
<td>35%</td>
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</table>

Mental health system terminology does not always resonate with caregivers and youth. When asked about residential or community-based services, only 67% of caregivers of youth in residential care, and 87% of youth, reported awareness of RMHT. Likewise, during interviews, caregivers and youth didn’t identify that they received PBS, though supplemental data showed that three of ten youth participants had received the service. Similarly, one caregiver disclosed the use of CMCRS; records showed that eight of ten had received the service. Neither caregivers nor youth are consistently using the naming conventions established by WV DHHR, which may impact service access. Moreover, further rebranding may present a challenge for stakeholders to find and access specific services. As program branding evolves, it must be clearly and consistently communicated to recruit and retain stakeholders, evaluate and improve services, and continue to meet the needs of West Virginians.
There were 47% of caregivers who reported that their understanding of how to access services improved over the last 12 months, and as a result, of those 47%:

- 55% said it made them more likely to access services in the future
- 28% said equally likely
- 4% said less likely
- 17% said that they do not expect to need additional services in the future.

**Crisis and Emergency Services**

For families, access to the mental health system is often through the police, other social services and supports (as defined by respondents), and emergency rooms. Caregivers were much more likely to have called the police than youth to address youth needs. A similar percentage of caregivers and youth had called social services in crisis and emergency scenarios. A greater percentage of youth reported visiting the Emergency Department for mental health services.

**In response to youth needs, over the last 12 months:**

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th>Youth</th>
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<tbody>
<tr>
<td>Called the police for help with a mental or behavioral health emergency</td>
<td>40%</td>
<td>10%</td>
</tr>
<tr>
<td>Called social services or another support system</td>
<td>38%</td>
<td>37%</td>
</tr>
<tr>
<td>Visited the emergency room</td>
<td>20%</td>
<td>28%</td>
</tr>
</tbody>
</table>
More than a third of youth had an encounter with police. Caregivers reported that 43% of those encounters resulted in an arrest, compared to 30% of youth who self-reported arrests. Overall, most caregivers and youth felt that there were fewer encounters in the last 12 months than there were in previous years.

While fewer police encounters and arrests may indicate a positive trend, two points are worth considering. First, caregivers and youth were asked to reflect on the last 12 months, which includes youth’s time in residential treatment. Residential treatment includes 24-hour monitoring, so it perhaps would not be surprising that encounters and arrests have gone down in the last 12 months, when compared to previous years. Second, there may be social desirability effects, in that caregivers and youth might have underreported encounters and arrests to downplay the severity of the situations.
Utilization of Services and Wait Times

All youth used at least one community-based service in the last 12 months. However, overall awareness and usage of community-based services was low. Caregivers and youth who had heard of the services being evaluated reported the following about youth utilization:

Caregivers and youth both reported PBS as the most utilized community-based service.

Caregivers reported during interviews that there are significantly longer wait times for in-state residential treatment than for out-of-state placement. Caregivers reported that youth might wait as long as 36 months to be placed in a facility in state, compared to just a few weeks wait time for out-of-state facilities.

Few youths were waiting for community-based services at the time of data collection. However, caregivers of youth in residential treatment reported that long wait times were one of the top barriers for initiating and continuing services. For example, 41% of caregivers encountering challenges with initiating services attributed it to long wait times, and for 11% this was the biggest barrier. Caregivers neither agreed nor disagreed that they could access services in the future without having to wait too long.
Workforce

Some caregivers and youth (27% and 21% respectively) reported the need for additional services and supports that they were unable to access at the time of data collection.

- Both caregivers and youth expressed the need for more psychiatric and therapeutic services, and professional services such as alternative providers and recreational activities.
- Caregivers wanted more residential services, and home- and community-based specialty services such as therapy and counseling services of varying intensity and duration that focus on keeping youth in their homes or helping reintegrate them after placement in residential.
- Youth expressed the need for activities that help maintain the progress they had made during residential treatment.

Caregivers praised mental health workers. One caregiver stated that their Wraparound worker was exceptional, working “above and beyond the call of duty.” Another caregiver reported that Wraparound workers, “were absolutely fantastic. They really, really helped us; they did everything they could. […] I think it really opened [Youth’s] eyes a little bit to see like, hey there are people that care, there are people that want to help me.”

Things to Consider:

- Caregivers indicated the need for more in-home and in-state services
- Caregivers and youth seemed aware of service and staffing shortages
Experience With Services
Caregiver and youth perspectives on their experiences with mental and behavioral health services were gathered through surveys and interviews. Both caregivers and youth reported on their experiences of engagement and respect during service delivery and accessibility and satisfaction with services. Caregivers were also asked about their participation in treatment. Caregivers want to be engaged and involved in treatment and discharge planning; there is a need for more strategies that create opportunities for treatment participation. Overall, staff in mental and behavioral health services respect and engage youth and families, although demands on their time make it challenging at times.

**Treatment Participation**

Caregivers responded to survey questions about their experiences participating in their youth's treatment. The 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. Generally, caregivers report a moderate level of participation in their youth's treatment.

<table>
<thead>
<tr>
<th>Caregiver Survey</th>
<th>Family Treatment Participation</th>
</tr>
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<tbody>
<tr>
<td><strong>Low</strong> 41.6%</td>
<td><strong>Low</strong> 28.1%</td>
</tr>
<tr>
<td><strong>Moderate</strong> 38.4%</td>
<td><strong>Moderate</strong> 30.3%</td>
</tr>
<tr>
<td><strong>High</strong> 20.0%</td>
<td><strong>High</strong> 30.3%</td>
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Caregiver engagement is impacted by their experiences navigating the system, which they report as being too complicated. Some caregivers cite a lack of understanding of their role in the treatment process. For example, 39% of caregivers encountering challenges initiating services for their youth reported that they did not understand what they needed to do to start services, and this remained an issue for 19% of caregivers experiencing barriers to continuing services.

In some instances, the distance from the family home to the service affected participation in treatment. Caregivers report that they see the demands of staff time and capacity. Processes that facilitate caregiver involvement while managing staff time demands may be useful.

Caregivers also expressed the desire for better communication and information sharing processes with providers. They felt that providers were not always responsive to their or their youth's needs.
Engagement and Respect in Treatment

Both caregivers and youth were asked about their experiences with staff and providers specifically related to cultural competence, connectedness, respect, and communication. Questions explored engagement in treatment and whether caregivers and youth felt that providers respected their cultural and spiritual or religious beliefs.

Overall, youth reported higher levels of engagement and respect during treatment than caregivers did. Across all caregivers and youth:

- 13% of caregivers and 4% of youth reported engagement and respect as low
- 51% of caregivers and 26% of youth reported engagement and respect as moderate
- 36% of caregivers and 70% of youth reported engagement and respect as high

Things to Consider:

- Many caregivers are motivated and learn from experience; they are more confident in future actions, knowing who to talk to, and becoming more engaged, than they were previously
- Investments in cultural competence training are reflected in high levels of engagement and respect
- Continuing to prioritize community-based services where youth can receive the care they need while at home can promote stronger family relationships and make it easier for caregivers to stay in the loop and involved
Accessibility and Satisfaction

Caregivers and youth reported on their ability to access services, including community-based and residential treatment, 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.

More than nine-in-ten (91%) youth reported moderate or high accessibility and satisfaction, compared to 76% of caregivers who reported moderate or high accessibility and satisfaction.

Most caregivers and youth reported moderate to high levels of service accessibility and satisfaction. Twenty-four percent of caregivers rated accessibility and satisfaction as low, compared to only 9% of youth. Caregiver perceptions of accessibility and satisfaction may be impacted by challenges with initiating services. 46% of caregivers who reported challenges with initiating services indicated that the services chosen for their youth were not available in their area, and 15% said the services were not available at times they could participate.

21% of caregivers say the value of community-based services is better than it has been in previous years.

- Caregivers and youth are moderately to highly satisfied with the accessibility of services.
- Some caregivers encounter challenges with finding services in their area.
Youth and Family Status

The evaluation addressed several elements of youth and family status including social support, school attendance, and caregiver and youth-reported youth functioning. Overall, both caregivers and youth report moderate to high youth functioning, although differences in caregiver and youth perspectives on youth functioning are highlighted. Additional data, such as scores from the Child And Adolescent Functional Assessment Scale (CAFAS), will be included in future evaluation reports.

Caregiver Support

Social supports are an important component of caregiver and family wellbeing. Caregivers responded to questions about their access to and comfort with someone that they can talk to and crisis support. The majority of caregivers reported moderate to high levels of social support, indicating that their families are supported by strong networks.

Although caregivers felt respected by staff, they neither agreed nor disagreed that:

- The care team checked in when updating the care plan.
- That the people helping their youth stuck by them no matter what.

They also felt removed from the development of treatment goals and care planning.

Caregiver Survey

Social Support

- High: 72.8%
- Moderate: 23.3%
- Low: 3.9%

Things to Consider:

- Caregivers would like to have more communication and have more opportunities to engage in care planning with staff
- Most caregivers reported high levels of social support

Youth Attendance in Public Schools

School-aged youth who were in residential treatment and their caregivers were asked about school attendance, specifically for those who self-identified as attending public school. Results suggest several things to consider:

Continuing education is important for school-aged youth who are in residential treatment and is an important indicator of functional wellbeing. Half of youth in residential self-reported or were reported by caregivers as attending public school in the last 12 months.

While attendance has either stayed the same or improved for most of the youth who received mental and behavioral health services, there are still more than a third who had been suspended or expelled in the last 12 months. That said, few youths had dropped out of school completely, which is consistent with a low national drop out rate of 5.3% (National Center for Education Statistics, 2021).

Future surveys will include questions to better understand differences in experiences, performance, and wellbeing among youth who attend school in versus outside of RMHTFs.
Perceptions of Youth Functioning

During the data collection and reporting period, WV DHHR selected the Child And Adolescent Functional Assessment Scale (CAFAS) to distinguish youth who are eligible for residential mental health treatment from those who are at-risk of placement. 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.

Caregivers and youth differed on their report of youth functioning. Most of the youth in residential self-reported that they were moderate to high functioning. Youth were almost twice as likely to report high functioning than caregivers.

![Perceptions of Youth Functioning](image)

Additional data, including CAFAS scores, are needed to better understand youth functioning across the system. The implication is that higher functioning youth might be able to be treated in their homes and communities if those services are available.

Things to Consider:

- Caregivers and youth have different perspectives on functioning; youth self-report that their functioning is higher. Understanding these perspectives in relation to the system’s assessment, the CAFAS, will be an important step in understanding need for community-based and residential services.

- Higher functioning suggests that there may be an increased demand for community-based services, such as wraparound and ACT, to support transition out of residential treatment.

- As continuum of services continue to grow and services become more widely available, there will be a need for education on what aspects of mental and behavioral health can “safely” be treated at homes and in communities.

- Findings suggest several bright spots of service participation, including more youth going to school and an increase in youth medication administration.
The topics covered in the Findings and Visualization Report are reported in more detail on the following sections and pages in the Caregiver and Youth-level Evaluation Report, July 2022.

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