

Issue Brief

Wraparound Case Management for Children with Serious Emotional Disturbance: A Qualitative Look at Caregivers' Experiences

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Wraparound treatment has been described as “a unique set of community services and natural supports for a child/adolescent with serious emotional disturbance (SED) based on a definable planning process, individualized for the child and family to achieve a positive set of outcomes.¹ Research has focused on many components of wraparound interventions,² but little attention has been paid to experiences of the caregivers of children receiving services. One of the few studies addressing this issue found higher levels of caregiver satisfaction with wraparound services than with treatment-as-usual.³ The critical role of caretakers in the wraparound process suggests many important research questions including: What is it about wraparound services that meet caregivers' needs? What aspects of wraparound do caregivers feel work best for their child and family? Are there components of wraparound that could be improved? Findings could suggest strategies for informing and potentially improving services to children with SED and their families.

WRAPAROUND IN MASSACHUSETTS

Coordinated Family Focused Care (CFFC) is a wraparound program for children and youth with SED ages 3 - 18 in five Massachusetts' communities. Each child and family is assigned a Care Manager, who is a Master's level clinician, and a Family Partner, who has been a primary caregiver for a child with SED. Families work with their Care Manager, Family Partner and other identified supports to form a wraparound team to assess family strengths and needs, to develop a crisis and treatment plan, and to provide support and advocacy for the child and family.



The Center for Mental Health Services Research (CMHSR) at the University of Massachusetts Medical School is conducting an evaluation of CFFC. Domains measured include child symptoms and functional impairment, parental stress, child strengths, time spent in out-of-home placements (e.g. inpatient hospitalization), and school disciplinary information, e.g. attendance, suspensions. As part of the evaluation, caregivers completed semi-structured telephone interviews three and nine months after enrollment into CFFC, during which standardized measures of fidelity, involvement in services, and parent empowerment were administered.

In addition, CMHSR evaluators asked caregivers three open-ended questions to assess satisfaction with the CFFC program. Questions included:

1. What is your favorite thing about the program?
2. What would you change, if you could?
3. Do you have anything else to say about the team?

Responses to these questions, as well as spontaneous comments offered by caregivers during the telephone interview protocol, were recorded. These data were coded into thematic categories by two raters: inter-rater reliability of 93% was computed.

RESULTS

Four themes emerged from the analysis of the data.⁴ Identified themes included: encouragement to participate in treatment planning; support during the wraparound process; focus on child and family strengths; and concerns surrounding discharge.

Caregivers were encouraged to participate in the treatment planning process

Caregivers reported that teams listened to their ideas and didn't make decisions without them. "They listen to everything we have to say even if they don't like it. We're never pushed into anything

we don't like." One caregiver stated **"I run the meetings, suggest the changes and they make it happen."**

Caregivers felt supported

Caregivers described receiving generous amounts of concrete and emotional support from CFFC. **"They are there to help in every sense of the word."** Concrete support, for example, providing transportation and helping to navigate complex service systems, was identified as very important to caregivers. "One good thing is they will pick me up if needed and drive me home. They are really good about that stuff [and I need it] because I don't have a car."

Emotional support, such as encouragement, respect, and overall caring about the families, was also identified by many caregivers as an important factor in their care. One mother explained "they don't only help [my child], but they help me." In addition, some caregivers reported receiving help from parent support groups coordinated at some sites "I go to group every Wednesday. They're there to support me, they are my family...I've learned a lot and I really enjoy the group."

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Wraparound teams focus on the strengths of children and families

Caregivers reported that wraparound teams maintained a focus on the strengths of their children and the family, and that identifying and focusing on strengths helped caregivers feel hopeful about the future. **"They are constantly reminding me of his strengths"** said one parent. Another parent noted that her team tries "to get us to focus on the positive on days when [it feels] there are none." Another caregiver explained, "I used to spend too much time on the negative, but they've changed my ways."

Caregivers were concerned about discharge planning

Some caregivers expressed concerns about discharge planning; many caregivers wanted the program to continue after their child met graduation goals. As one caregiver noted, **"We are about to graduate and I feel we aren't ready; we still need the support."** Another parent suggested it would be helpful to have "better planning for when we are ready to leave." A number of families stressed the need for better preparation before exiting CFFC services.

Lending validity to the present study, a separate qualitative research effort by Consumer Quality Initiatives (CQI)

with 36 families randomly chosen across the five sites identified common themes to those listed above.⁵

SUMMARY AND FUTURE DIRECTIONS

Findings from the CMHSR evaluation suggest that in general caregivers felt supported and encouraged by wrap-around teams in CFFC, and desired to stay in the program for as long as possible. As one caregiver noted, "This is the first [service plan] I found that works. The only one I have felt comfortable with."

These results suggest future areas of research regarding the experiences of caregivers with wraparound services.

For example, caregivers identified the significance of receiving emotional and concrete support from the CFFC program. Additional research could explore these themes further and ascertain what specific types of emotional and concrete support are most useful to caregivers. Understanding "what works" for caregivers could help wrap-around team members target their efforts to focus on the types of support recognized as most helpful. Future research could also explore caregivers' concerns about early discharge from the wraparound program in an effort to provide as needed supports to families as they transition from wraparound services.

References

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