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Caregivers' Experience in Wraparound: A Qualitative Study

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Running head: CAREGIVERS' EXPERIENCE IN WRAPAOUND

Caregivers' Experience in Wraparound: A Qualitative Study

by

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M.S., Antioch University New England, 2017

DISSERTATION

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A QUALITATIVE STUDY**

presented on March 8, 2019

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Table of Contents

Acknowledgements.....	iii
Abstract.....	1
Introduction.....	2
SED Takes a Serious Toll on Youth and Their Families.....	2
The Current Service System is Not Working for Youth with SED	3
System of Care Approaches Seek to Improve Care for Youth with SED	4
Wraparound is a Cornerstone of SoC Approaches	5
Wraparound Uses a Backward Mapping Approach.....	7
Wraparound is a Philosophy and a Care Coordination Intervention	9
Wraparound has Ten Key Principles	9
Wraparound Unfolds over Several Phases.....	12
Wraparound is Proven to be Effective When Faithful to its Mission.....	13
Providers and Administrators Have Taught Us Much About Wraparound	14
Need for a qualitative approach	14
Qualitative approaches on the systems/service-level.....	15
We Still Have Much to Learn About Wraparound from the Caregiver Perspective	17
Research gap	17
Reasons for limited consumer voice in the literature.....	19
Caregiver voice in the literature.....	20
Exploring and Honoring the Experiences of Caregivers	22
Research questions.....	23
Methodology.....	24
Research Methodology	24
Research setting	24
Participants.....	25
Data Source.....	26
Data Analysis	27
Issues of Trustworthiness.....	27
Credibility	28
Confirmability.....	28
Ethical Considerations	30

Confidentiality30

Informed Consent.....30

Results.....31

Demographic Information.....31

Overview.....32

Cluster 1: Initiating Wraparound Services.....32

 Child’s difficulties with severe and complex mental illness33

 Caregivers felt helpless prior to the start of wraparound.....33

 Experiences varied accessing FAST Forward to initiate services33

 The initial phase of FAST Forward was slow34

Cluster 2: FAST Forward Coordinator and Family Support Specialist.....35

 Characteristics of FFC and FSS35

 FFC’s and FSS’s personal experiences.....36

 FFC and FSS availability and responsiveness varied36

Cluster 3: Wraparound Team.....37

 Formation of the wraparound team.....37

 Team process38

Cluster 4: Supports and Services38

 Lack of services in New Hampshire38

 Accessing services and supports.....39

 Helpful supports and services40

 Experience with school system.....40

Cluster 5: Family Engagement.....41

 Family members impacted by child’s mental health needs41

 FAST Forward supported the entire family41

 Family participation in the decision-making process42

Cluster 6: Program Outcomes.....42

 Termination of services due to unmet needs.....42

 Positive program outcomes.....43

 Attitudes about the FAST Forward process.....43

Discussion44

 Summary.....44

Findings and Implications of the Study	45
Cluster 1: Initiation of the process	45
Cluster 2: Foundational relationships	47
Cluster 3: Creations and expansion of the wraparound team	48
Cluster 4: Program implementation with insufficient infrastructure	50
Cluster 5: Family engagement is critical	53
Cluster 6: A reflection on outcomes	55
Implications for practice	56
Limitations	57
Archival data.....	57
Limited generalizability	59
Varying levels of interviewer experience and different interview techniques	60
Directions for Future Research	62
Conclusion	63
References.....	65
Appendix A: Family Experience of Wraparound Recruitment Letter	69
Appendix B: Consent to Participate in Research.....	70
Appendix C: Assent to Participate in Research	74
Appendix D: Interview Invitation Reminder	76
Appendix E: Family Experience of Wraparound Interview Introduction	77
Appendix F: Family Experience with Wraparound Interview Questions.....	78
Appendix G: Table 1: Qualitative Data Table	79

Abstract

A large number of youth in the United States suffer from a severe emotional disturbance (SED). Due to a number of factors (e.g., lack of access to services, siloed service providers), many of these children have unmet severe emotional and behavioral health needs. Wraparound has been identified as a care philosophy and intervention to meet the needs of these youth. Wraparound programs aim to provide individualized, comprehensive, community-based care for children and their families. Although this intervention is widely spread across the United States, research findings on the efficacy of the approach are mixed. Previous research aimed to identify and understand the most beneficial components of wraparound, while noting how contextual and regional factors can impact the delivery of these components. Some explorations have utilized a qualitative methodology; however, to date, most of the qualitative research focuses on the perspectives of service providers while neglecting the essential perspectives of caregivers and youth served by wraparound programs. This dissertation aimed to better understand a wraparound program in New Hampshire from the perspective of the caregiver. This phenomenological study used semi-structured interviews to explore the perspective of eight caregivers. Interpretive Phenomenological Analysis (IPA) of the data resulted in six main themes: (a) Initiating wraparound services, (b) FAST Forward Coordinator (FFC) and Family Support Specialist (FSS), (c) Wraparound Team, (d) Supports and Services, (e) Family Engagement, and (f) Program Outcomes. Implications, limitations, and future research suggestions are explored.

Keywords: wraparound, system of care, caregiver, qualitative method, backwards mapping, fidelity

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Caregivers' Experience in Wraparound: A Qualitative Study

In this dissertation, I explored the perspective of caregivers¹ enrolled in a wraparound program in the state of New Hampshire. Families involved in wraparound have at least one child experiencing serious emotional disturbances (SED). This first section provides a social and family context for the challenges faced by caregivers who are struggling to raise a child with SED, describes wraparound both as a philosophy of care and intervention to help these families, and explores the need for the study.

Serious Emotional Disturbance (SED) Takes a Serious Toll on Youth and Their Families

In 2005, Mendenhall and Frauenholtz (2014) estimated that 2.7 million children suffered from a severe emotional disturbance (SED) in the United States. A child with a SED is defined as a child under the age of 18 who currently has, or at any time during the past year has had, a diagnosable mental, behavioral, or emotional disorder that is associated with impairment in one or more of the following areas: (a) feeling, mood, and affect; (b) thinking; substance use; (c) family; (d) interpersonal; (e) role performance; (f) socio-legal; (g) self-care or basic needs; or (h) caregiver resources (Friedman, Katz-Leavy, Manderscheid, & Sondheimer, 1996). The care and support for these children places a large burden on their families and communities, often exceeding available services and community resources. Indeed, the research evidence suggest that many of these youths' needs are unmet (Burns, 1999). For example, one study concluded that of those who have been diagnosed with a serious mental illness, only about 50% have contact with specialty mental health professionals (Mendenhall, Kapp, Rand, Robbins, & Stipp, 2013). Another finding by the U.S. Department of Education estimated that only 1% of youth

¹ For the purpose of this dissertation, the term caregiver will be defined as the person who takes primary responsibility for the youth enrolled in a wraparound program. These individuals can include, but are not limited to, a parent, grandparent, guardian, or foster parent.

with SED are identified and provided with special education services (Mendenhall et al., 2013). Thus, children contending with SED are vastly underserved, even in the rare circumstances in which they are identified as needing treatment and support.

The Current Service System is Not Working for Youth with SED

These sobering statistics suggest that significant gaps in services exist in supporting children's mental health. One common explanation for the inadequacy of services for children with SED is the lack of communication across agencies. Poor communication results in insufficient coordination across agencies tasked with helping youth with SED, resulting in overlapping, and sometimes conflicting management, of services. The current system is problematic for caregivers already overwhelmed at home who try to access help from siloed sectors including, for example, mental health, education, juvenile justice, developmental disability, legal, public health, child welfare services, and other services (VanDenBerg, 2008). Often, these various agencies have widely incongruent agendas and piecemeal, inadequate resources that further fragment efforts to help youth and families at the policy-, agency-, and practice-levels.

Better collaboration across agencies providing services is not sufficient to improve behavioral health outcomes (VanDenBerg, 2008). In fact, as VanDenBerg and Rast (2006) suggest, siloed systems need to be integrated, in part through the utilization of a single, targeted plan to adequately care for a particular youth and family; ideally, such a plan would also somehow meet the disparate requirements for funding each agency. Despite the obstacles inherent in implementation, a more integrated and unified approach to care is a first step in improving delivery of services. Given the estimated number of youth with SED, and the significant proportion of those who are not treated, underserved, or inappropriately cared for,

comprehensive and effective treatments have been identified for these high-risk children and families.

System of Care (SoC) Approaches Seek to Improve Care for Youth with SED

The System of Care movement began in the 1980s as an alternative for institutionalizing youth with SED (Eber, Breen, Rose, Unizycki, & London, 2008; VanDenBerg, Bruns, & Burchard, 2008). Stroul and Friedman (1986) define a system of care as “a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbance and their families” (p. 3). Core system of care values include a family driven and youth-guided, community-based, and culturally and linguistically competent intervention process (Stroul, Blau, & Friedman, 2010).

The Substance Abuse and Mental Health Services Administration (SAMHSA) provided nearly \$1.5 billion towards the development of local wraparound systems of care across the United States from 1993 to 2010 (Mendenhall et al., 2013). SAMHSA developed the Comprehensive Community Mental Health Services for Children and their Families Program (CCMHS) to invest in federally funded grants to promote these efforts and make coordination of care a priority of health care reform. With the help of the CCMHS, the use of wraparound has increased over the past 20 years and has now served over 400,000 children and families (Mendenhall et al., 2013). A recent national survey conducted in 2013 found that 89% of states (50 states, 4 territories, and the District of Columbia) reported having some type of wraparound program, serving an estimate 75,000 children in just that year (Sather & Bruns, 2016).

Wraparound is a Cornerstone of SoC Approaches

As a result of the increasingly widespread use of wraparound services across the United States, SAMHSA and the Center for Medicare and Medicaid Services encouraged states to include in their package of health care benefits wraparound programs for SED youth (Mendenhall et al., 2013). The push towards this philosophy of care, supporting the coordination of once-fragmented mental health services, resulted in documented cost-effective and improved clinical and functional outcomes for children and their families providing tailored interventions that keep youth in their homes and communities (e.g., Stroul, Pires, Boyce, Krivelyova, & Walrath, 2014).

One example of such a program is Wraparound Milwaukee. Wraparound Milwaukee started in May 1996 in response to the exorbitant cost of placing and treating youth within the child welfare and juvenile justice system (Kamradt, 2000). Kamradt's summative evaluation reported a 60% decrease of use of residential treatment, 80% decrease of inpatient hospitalizations, and an increase in functioning of the participants as measured by the Child and Adolescent Functional Assessment Scale (CAFAS) compared to their baseline. The average score on the CAFAS at time of enrollment was 74—in the high average range; the average score with one year of treatment was 48—in the moderate impairment range. Furthermore, Kamradt describes, "The average overall cost of care per child has dropped from more than \$5,000 per month to less than \$3,300 per month" (p. 20). Saved money was reinvested into the program to help serve more youth.

Although some reports are more equivocal, these positive findings of wraparound outcomes have been replicated in other studies and evaluations. In the Children's Mental Health Initiative (CMHI), a national evaluation that evaluates both system-level implementation

assessments and outcomes of wraparound programs, notable outcomes of wraparound included “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 situation” (Stroul et al., 2014, p. 7). Furthermore, Stroul et al. (2014) state: “The cost related findings presented in the 2011 congressional report indicated 21% reduction in psychiatric inpatient costs and a 32% reduction in per child arrest costs” (p. 27). Evaluations that demonstrate the positive outcomes and cost-effectiveness of wraparound programs increased the adoption of the program across the nation.

As implementation of wraparound has spread, so has the need for in-depth investigation of the effectiveness of wraparound programs as they are implemented in individual states. Despite some encouraging findings, quantitative and qualitative studies have reported inconsistent results.

On the positive side, some studies suggests that the daily functioning and quality of life of children who take part in wraparound programs improves, compared to no treatment or “treatment as usual” (Walker, Bruns, Conlan, & LaForce, 2011). In a similar vein, Suter and Bruns (2009) conducted a meta-analysis that showed consistent and significant outcomes for youth when they participate in wraparound programs compared to control groups of youth and found improved outcomes included reduction in frequency in residential placement, improvement in mental health, increases in school success, and decreases in juvenile justice recidivism.

Despite these positive findings, the empirical literature on wraparound outcomes is equivocal, with implementation and outcomes varying from state to state. Indeed, the adoption of wraparound has been found to vary significantly across the country (Walker & Koroloff, 2007).

Accordingly, Painter, Allen, and Perry (2011) found that some state-wide wraparound programs produced positive outcomes, whereas others did not.

Research results also vary by methodology, with some examining efficacy and others looking at effectiveness. In efficacy studies, the intervention is implemented under ideal circumstances. The study uses methodological features, including the actual design of the study (e.g., use of control conditions), rigorous training of those implementing the intervention, and very specific criteria for participants who receive the treatment, to maximize internal validity of the study (Hunsley, 2007). Efficacy studies are more likely to have funding to put these “ideal” conditions into place, thus reporting more promising results. On the other hand, effectiveness studies aim to study the intervention under “real world” conditions, and outcomes results are less likely to demonstrate unequivocal results. Due to the local nature of wraparound programs, it is more likely that outcome studies of the program examine the *effectiveness* of the intervention, and more specifically particular components of the intervention. As a result, there has been a recent shift in the research from identifying outcomes to identifying the components of a wraparound program that contribute to its success; to date the most salient component appears to be the faithful application of wraparound principles.

Wraparound Uses a Backward Mapping Approach

Wraparound, informed primarily by the voices and needs of youth and caregivers, is an unusual, bottom-up approach to care. In traditional social delivery systems, services are typically made with a top-down approach where “higher” levels (e.g., federal, state, agency, provider) assume the client’s needs and determine the remedy to these needs (Walker, Koroloff, & Bruns, 2010). A top-down approach means that those at higher implementation levels typically

determine what services can be provided for those at “lower” levels (e.g., consumers). By contrast, in wraparound, those in the lower levels of the implementation drive the intervention.

Another name for this bottom-up approach is *backward mapping*. The concept of backward mapping brings the focus of problem solving first to the “lowest” levels of the intervention. Backward mapping, in contrast to the traditional top-down approaches, does not make assumptions about problems located at lower levels of implementation. To explain further, Elmore (1979) states that backward mapping considers the following:

The closer one is to the source of the problem, the greater is one’s ability to influence it; and the problem-solving ability of complex systems depends not on hierarchical control but on maximizing discretion at the point where the problem is most immediate. (p. 605)

Backward mapping suggests that youth and caregivers will have the most influence in addressing problems in a wraparound program. The major tenet of backward mapping parallels the wraparound principle that problem solving should be youth- and family-focused and driven.

At this lowest level of implementation, the wraparound team is responsible for creating a plan of care that individually responds to the needs of a specific youth and their family. The team then has to determine higher-level policies and practices to bring the resources and interventions to the family to support them. Walker and Koroloff (2007) provide an example of this strategy: “If a team identifies a need for respite and a neighbor who can provide respite at low cost, there is still a need for resources to pay the neighbor and for policy that allows for this to happen” (p. 446). In backward mapping, the consumers are considered the “experts” on what they need and policy makers are to help get those needs met by putting the proper systems in place.

Backward mapping also allows for the variation and differences to be highlighted in a national intervention that is applied across diverse swaths of the country. Each state is faced with

unique resources and challenges; for this study, backward mapping provides a framework in which to describe the specific service needs and interventions for the particular families in the New Hampshire program. The framework of backward mapping emphasizes the importance of caregiver voices to determine needs, barriers, and outcomes of the current system in order to continue to find ways to improve it.

Wraparound is a Philosophy and a Care Coordination Intervention

Wraparound is both a philosophy and intervention approach that integrates services and supports for youth struggling with mental health difficulties. Though different states' programs operate under various names, individuals and organizations that follow the wraparound philosophy are committed to providing individualized, comprehensive, community-based care for children and their families (Walker et al., 2011). Wraparound originated from the need to serve complex children and families in their communities.

Wraparound can be viewed at three different levels. As a philosophy, it aims to provide services to youth with SED and their families. At an administrative level, it describes a systems change approach designed to coordinate services. Finally, at the child and family level, it is a care-management process that integrates services and promotes wraparound principles. The actual process of wraparound, as described within the child and family level, is the focus of this study.

Wraparound has Ten Key Principles

Bruns, Walker, and The National Wraparound Initiative Advisory Group (2008) outline 10 elements that provide the foundation for successful wraparound:

1. Family member and youth's perspectives are prioritized in the wraparound process. This principle recognizes that those closest to the youth have the deepest connections to

him/her/them and are most committed to his/her/their well-being. The team aims to provide the family with options; the plan should reflect the family's preferences. This first principle recognizes the unique position and influence that the family members and the youth have in the process and its outcomes. It also acknowledges that success hinges on the buy-in of these individuals, and that the team must make intentional efforts to ensure that the family and youth's voices are heard. Due to frustrating prior experiences—perhaps a feeling of stigma about needing help—families with SED children may demonstrate some reluctance to buy-in or have little hope for the process. Therefore, the team must put forth an additional and explicit effort to make the family preferences and values the priority.

2. Wraparound is a team-based approach. To the extent it is possible, the family decides upon the team's make-up. Individuals invited to join the team are committed to the family's well-being and can be comprised of natural and formal supports.
3. Natural supports—or individuals/organizations who are connected to the family but not part of formal service systems—are an essential component of the wraparound process. The wraparound plan uses these natural supports for interventions and activities to help the youth and family. Examples of natural supports include friends, extended family, neighbors, members of worship communities, and members of sports teams. Professionals and paraprofessionals, including, for example, teachers, classroom aides, and coaches, can also be considered natural supports when their relationship with the family or youth exceeds the expectations of their formal roles.
4. Collaboration of team members is an important aspect wraparound. The wraparound plan represents the cooperation and coordination of the team members' work. Team members

must be open minded to others' perspectives but also willing to provide their own opinions. In order to have a collaborative plan, each team member needs to be committed to the team's goals and the wraparound plan.

5. Wraparound plans should implement services and supports that are based in the community. This principle promotes the wraparound value that children should be placed in the least restrictive setting and be integrated into the community as much as possible.
6. The wraparound process should be culturally competent, demonstrating respect for and building on the values and identity of the youth and his/her/their family. This principle recognizes that a family's traditions and values are a source of strength. As such, the plan will attempt to include strategies that place an emphasis on these values.
7. Every wraparound plan is individualized for every youth and family involved in the wraparound process. The process will differ for each family based their unique set of experiences. This principles challenges the team to be collaborative and innovative in its brainstorming process to create a plan that will work best based on the individual strengths and resources available to each individual family.
8. The wraparound process identifies, builds on, and enhances the strengths of the youth, family, and members of the team. The wraparound plan utilizes strengths in two ways. First, goals are based on increasing assets, rather than decreasing deficits. Second, the plan utilizes strengths of every team member to increase the likelihood of achieving goals.
9. The wraparound team provides unconditional care for the youth and his/her/their family, even when faced with challenges or setbacks. Achieving goals can be a long process and requires persistent, unconditional support. Adverse events or problematic behaviors

should be seen as a need to revisit the plan and determine whether adjustments are needed, not as deficits of the youth and family.

10. The wraparound plan needs to be based on observable and measurable goals and outcomes that can be monitored throughout the wraparound process. Every member of the wraparound team is responsible for achieving the goals described in the wraparound plan.

Wraparound Unfolds over Several Phases

Wraparound programs require a team process through which families, providers, and key members of the family's support system work together to make a plan and monitor progress towards meeting the needs of every member in the family. The team meets frequently to monitor and adjust the plan's objectives and strategies as goals are being met or outcomes are not being achieved. Programs provide youth and their families with an individual who is trained to manage the process of developing and overseeing care coordination. This individual is called a *wraparound facilitator*.

The wraparound facilitator guides the team through four phases of the process: (a) engagement and team preparation, (b) initial plan development, (c) plan implementation and monitoring, and (d) transition. Walker, Bruns, and The National Wraparound Initiative Advisory Group (2008) describe each of the phases and activities associated with them:

1. During the *engagement and team preparation* phase, a shared vision of wellness is created between the family and the wraparound team allowing the team to come together to create a collaborative wraparound plan. The facilitator also sets the tone of the experience by informing the team about wraparound principles. During initial conversations, the facilitator strives to discover the needs, strengths, and culture of the youth and his/her/their family members. These conversations also highlight a major

difference between wraparound and other care program by emphasizing the focus on the needs and experiences of the youth and family.

2. An initial plan of care is created during the *initial plan development* phase. This is a youth and family-driven process where family members choose needs they want to focus on and select among available strategies to help meet those needs.
3. During the *implementation* phase, the strategies developed by the team are put into place and growth is monitored as the youth and family progress towards reaching goals. This phase continues for varying lengths of time—typically between 12–18 months—until formal wraparound services are no longer needed because the family's services and supports are able to function independently of the wraparound facilitator.
4. The final phase, *transition*, occurs when plans are made to transition the youth and family out of formal wraparound. At this point, the youth and family are supported by formal and natural supports in their community, but no longer need the coordination of care by the wraparound facilitator.

Wraparound Is Proven to be Effective When Faithful to its Mission

Walker and Koroloff (2007) explain that specificity about the practice model being evaluated is important because there are a number of contextual factors that have an impact on whether wraparound programs can be implemented successfully. In particular, fidelity of implementation is critical. Fidelity, the extent to which a program is implemented in a way that's faithful to the conceptual model, plays a significant role in an intervention's outcome. As a result, national organizations, such as the National Wraparound Initiative (NWI) and Wraparound Evaluation and Research Team (WERT), have emerged to set forth national

standards for wraparound programs by providing implementation trainings and fidelity and outcome measures.

In addition to research looking at the importance of wraparound fidelity, a growing consensus of evaluators suggests that quantitative measures alone are insufficient to capture the idiosyncratic and regional challenges faced by families and providers on the ground level (Painter et al., 2011; Walker et al., 2011; Walker & Koroloff, 2007). Thus, in recent years, evaluators have begun to include qualitative data in their evaluations, examining stakeholders' views and experiences of wraparound, to help assess various aspects of the program.

Providers and Administrators Have Taught Us Much About Wraparound

Need for a qualitative approach. The use of qualitative methods in wraparound programs is a more recent approach. For example, Hodges, Hernandez, Pinto, and Uzzell (2007) reviewed 100 qualitative studies presented between 1988 and 2009 at the annual research conference by the Research and Training Center for Children's Mental Health at the University of South Florida. This conference focuses on systems that provide services to children with serious emotional challenges and their families. The authors wanted to understand the impact that qualitative methods had in the research of wraparound programs and determine the focus and frequency of qualitative research. They found that, "Although the number of qualitative studies generally have been increasing (1988, N=1; 2003, N=11), there were never more than 16 qualitative studies identified in a single year" (p. 363). Given the relatively small number of studies, the range of inquiry has been limited. The primary topics of these studies included: (a) gaining understanding of stakeholder/service provider's perspectives on service delivery, (b) system of care, (c) service and system financing, and (d) the process of team collaboration.

Qualitative approaches on the systems/service-level. The use of service providers to gain the “on the ground” perspective is relatively common in the qualitative literature of wraparound (Hodges et al., 2007). For example, Mendenhall and Fraunholtz (2014) captured the stakeholder experience of a wraparound program in its early implementation phases through semi-structured qualitative interviews. In this study, participants included directors of community mental health centers, members of the program’s steering committee, and members of the intensive staffing team. The interview questions explored the current situation for children’s mental health services in the particular state where the program was being carried out, program implementation of wraparound principles, and potential outcomes for the program.

Mendenhall and Fraunholtz (2014) identified four critical areas of focus when implementing a wraparound program. First, it is essential that all stakeholders have a shared vision that can “facilitate the adoption of system changes” (p. 162). Researchers found that those who did not share the vision of the need for improvements in the children’s mental health system often were a source of resistance and created barriers to implementing this new approach. Second, the study concluded that it was essential to develop policies to guide the new wraparound system. Different approaches significantly threatened fidelity of implementation. Stakeholders also described the challenge inherent in concurrently following general guidelines while maintaining the primary program principles of delivering flexible and individualized services for the family. Third, stakeholders voiced concern about wraparound sustainability. Many of them noted the need for a consistent, long-term funding source, which had not yet been identified. They also noted that funding limitations affected the availability of certain services for the families, highlighting a call for higher-level policy changes. Finally, the findings highlighted the importance of collaboration in implementing a system of care for children. Stakeholders

found that bringing service providers together under a system of care was challenging but rewarding. One interviewee reflected on one program's initial challenge with care coordination noting, "communication difficulties sometimes result from 'lack of understanding about how each of our systems work.'" Once coordination started to occur, however, the interviewee recognized "more familiarity, trust, willingness—even desire—to help out" among the coordinating services (p. 165). The results of this study were shared with the stakeholders in an effort to illuminate what aided or hindered implementation of the program.

Related qualitative program evaluation studies highlighted similar phenomena when interviewing stakeholder/service providers. For example, Walker and Koroloff (2007) interviewed 35 expert team members from wraparound sites in 12 states, including eight caregivers. Participants were asked to share their views of the factors that supported success or failure of wraparound teams. After analyzing the data, they found that in order for effective wraparound team process, it was necessary to have supportive systems in place at the organizational and systems levels.

A theme that emerged in Walker and Koroloff (2007) study was uncoordinated plans of care for the youth created multiple, at times conflicting, services across helping systems. In order for agencies to consolidate actions and documentation, organizational/system-level strategies need to put into place systems for disparate providers to better communicate through the use of comparable and consistent paperwork, data collection, and billing requirements (Walker & Koroloff, 2007). While the consolidation of data sharing systems used by so many diverse agencies would require monumental effort to put into place, the current fragmented system poses a huge barrier to the delivery of an optimally effective system of care.

The importance of backward mapping for stakeholders is further illustrated when higher level implementation strategies fail. For example, Walker and Koroloff (2007) further described stakeholders' perception that strategies originating at higher levels of program implementation to support lower levels of implementation rarely came to fruition. Indeed, on an organizational level, it is a primary wraparound principle that community members and natural supports are part of the wraparound team. However, there is no mechanism to hold teams accountable to this standard and it is quite possible to have wraparound teams made up entirely of professionals from different agencies who may come and go as they please, or no wraparound team at all. Furthermore, those working more remotely at higher implementation levels are also not held accountable to aid in the creation of these supports. This often leaves many families without the necessary community and natural supports that are, at least theoretically, essential wraparound principles.

The issues raised by Walker and Koroloff (2007) have been echoed in other qualitative studies exploring the perspectives of those working at the systems/service-level role of wraparound. For example, Sather and Bruns (2016) found that stakeholders similarly stressed (a) the importance of the collaboration of services, (b) concern about of state-level leadership on the program, (c) a focus on funding issues/sustainability, and (d) barriers to adhering to the model. These overarching themes, repeated throughout the qualitative literature, are noteworthy both for their consistency across studies and for the absence of the voices of perhaps the most important stakeholders of all: caregivers.

We Still Have Much to Learn About Wraparound from the Caregiver Perspective

Research gap. Most of the qualitative research of wraparound focuses on the perspectives of service providers and those involved in the systems-level implementation of the

program (e.g., Hodges et al., 2007; Mendenhall & Frauenholtz, 2014; Walker & Koroloff, 2007). However, there is notably less research exploring the perspectives of the youth and caregivers served by wraparound programs. The absence of the youth and caregiver voice in the literature is a significant research gap as youth and caregivers often have very different perspective about their needs—from one another and from service providers; they also may have diverging opinions about strategies that might best meet these needs (Walker & Koroloff, 2007). For example, although over 100 studies were presented at the annual research conference hosted by the Research and Training Center for Children's Mental Health at the University of South Florida, very few utilized caregivers as the sole participants. Indeed, when their perspectives were included, they were usually combined with those of other stakeholders.

Neglecting the voices of youth and caregiver stakeholders in research undermines a major tenet of wraparound and the mandates of SAMSHA and CCMHS: participants should have an equal voice in their mental health care (Jivanjee & Robinson, 2007; Painter et al., 2011). While it would be logical and consistent with the principles of wraparound to include youth and caregivers in the evaluation of programs, their voices are remarkably scarce in the current literature. As Aarons et al. (2010) state succinctly, "Consumer and family member perspectives about mental health services are little understood and often poorly described" (p. 459).

Traditionally, youth and caregiver perspectives have been limited to responses to surveys and questionnaires that are used to track outcomes or consumer satisfaction. However, these surveys are of questionable value. For example, Young, Nicholson, and Davis (1995) found that participants' responses appear to be influenced by bias toward social desirability, impacting the accuracy of the accounts. Further, survey data also may have little in common with interview data. For example, in another study that paired surveys with qualitative interviews, the research

found that negative consumer experiences obtained through interviews were not reflected in negative satisfaction ratings on quantitative measures (Williams, Coyle, & Healy, 1998). This research suggests that quantitative measures do not provide the scope needed to understand the full range of a consumer's experience. It is important to appreciate and understand the experience of youth and caregivers who participate in the mental health service system: their perceptions can affect their participation in treatment and whether they remain fully engaged in the process. Therefore, "the use of open-ended qualitative measures is often considered essential to elicit a full range of values and experiences that might otherwise elude capture" (Aarons et al., 2010, p. 460).

Reasons for limited consumer voice in the literature. Jivanjee and Robinson (2007) suggest that evaluators are more likely to utilize systems/service-level participants for interviews as opposed to interviewing youth and caregiver both to maintain professional distance from the program and out of fear that evaluator involvement with participants could compromise the rigor of the research. The authors also expressed the possibility of concern about illuminating power imbalances between the family and the evaluators that run so contrary to the philosophical structure of wraparound. Other explanations for low consumer participation in evaluation may include the additional time and resources necessary to engage participants in the evaluation process and the additional layers of protection required for conducting research on vulnerable participants, including going through an Institutional Review Board (IRB).

However, the wraparound philosophy also urges that these barriers between evaluator and family be broken down, reducing the power within research and evaluation. It is necessary for evaluators to understand backward mapping as an evaluation tool, too, recognizing caregivers as "experts" in the field of implementation. Further, despite concerns that family involvement can

have negative effects on research methods, several studies have shown that family participation in evaluation can actually increase the quality and accuracy of data, allowing results to be utilized more effectively (e.g., Burke, 1998; Turnbull, Friesen, & Ramirez, 1998). In fact, SAMSHA and the CCMHS explicitly require communities that receive grants to partner with families in the development, implementation, and evaluation of system of care.

Despite this mandate, Jivanjee and Robinson (2007) point out the lack of guidelines for how communities and evaluators should best include consumers, specifically throughout the evaluation process. To gain an understanding of how youth and caregivers currently participate in evaluation, Jivanjee and Robinson created a qualitative study to ask youth and caregivers who participated in evaluation about their roles and activities. Answers varied across communities, but interviewees noted they were interested in being part of the research too. Indeed, in some projects, youth and caregivers actively engaged with research interviews, and even helped to analyze the data. This study highlighted the need to train evaluators to find opportunities for consumer involvement.

Caregiver voice in the literature. Only a few evaluators have made an effort to shine a spotlight on the caregiver experience of wraparound. In a thesis from Texas, for example, England (2013) worked with a wraparound Community Evaluation Team (CET) to create a qualitative evaluation that could capture caregiver perspectives on their experience. The CET is a group of stakeholders that functions separately—but in conjunction with expert evaluators. This CET consisted solely of caregivers who had been involved in the wraparound program for at least six months. The CET expressed dissatisfaction with quantitative measures that were used in evaluation, sensing that the data did not adequately capture caregiver experience. The CET provided additional feedback to create a qualitative element of the evaluation that they believed

would more appropriately explore the caregiver perspective of wraparound. They eventually developed three interviews that focused on three different phases of the wraparound program; the follow-up phase interview protocol was the focus of England's thesis. The follow-up interview protocol consisted of five multi-part questions about the following topics: (a) program outcomes, (b) rapport with the wraparound facilitator and make-up of the wraparound team, (c) utilization of resources, (d) utilization of family mentors, and (e) unexpected skills gained.

The interview was administered to 24 caregivers via snowball sampling. Qualitative analysis identified seven major themes: (a) benefits caregivers experience from the program, (b) characteristics of the facilitator, (c) wraparound implementation, (d) barriers to implementation, (e) program limitations, (f) appreciation of the program despite its perception of being ineffective, and (g) other resources desired by the family members. The interview protocol created by this study stands as a template for future caregiver interviews.

In a similar vein, Painter et al. (2011) conducted a study to elicit the experiences of caregivers who that are not typically captured by quantitative measures. Similar to England (2013), this study was conceived and carried out by caregivers who received wraparound services. Caregivers in that wraparound program were also aware of the lack of evaluation measures or quantitative measures that adequately reflected the caregiver voice. The CET for this program, which consisted of 15 caregivers, developed open-ended questions based on their experience across the wraparound stages (i.e., referral, engagement, ongoing process, and transition). Members of the CET were also trained by evaluators to conduct face-to-face interviews. The CET members believed that caregivers would feel more comfortable sharing their story with other caregivers rather than professionals.

Through the data analysis, common themes were identified in each of the four stages. Themes found in the *referral and intake process* included common circumstances that led the families to wraparound: (a) recurring school problems, (b) financial difficulties, (c) family violence, and (d) lack of social support. Common themes also emerged when caregivers reflected on their experience during the *engagement* phase of wraparound, including the facilitator's ability to connect with both the child and the caregiver and the importance of home visits. Themes that emerged from the *ongoing process* stage included: (a) the caregiver feeling empowered, learning new skills, and feeling supported/not alone; and (b) wraparound's approach to addressing the needs of the whole family rather than just the child. Finally, common themes that emerged from caregivers' reflection on their experience of the *transition out of wraparound* included: (a) caregivers acknowledging their lack of natural supports, and (b) experiencing the transition as premature due to unexpected staff turnover (Painter et al., 2011).

The studies mentioned above helped set the stage for caregivers to have an important part in the evaluation of wraparound programs. Of equal importance, the studies also allow for backward mapping—evaluators can get a sense of whether wraparound principles are being carried out at the lowest implementation level. Wraparound programs may look different in how they tailor interventions; however, they should be implemented with fidelity to carry out the work most effectively, keeping the wraparound principles in mind at every level.

Exploring and Honoring the Experiences of Caregivers Involved in Wraparound

The purpose of the study was to better understand wraparound services from the perspective of caregivers, thus continuing to fill a significant gap in the current wraparound literature. Specifically, an aim of this study was to underscore the need to include the caregiver voice not only in the literature, but in the program evaluation process. Aarons et al. (2010)

described that the family member's perspectives of mental health services—including wraparound—are not fully understood and often inaccurately represented. Furthermore, quantitative measures do not adequately allow for the deeper understanding of what is important to this group of individuals. To address these two concerns, this study used a qualitative research design, using semi-structure interviews, to explore caregivers' experience of the fidelity and efficacy a wraparound program.

Research questions. Through a series of open-ended interview questions, this qualitative study addressed the following questions:

1. What is the experience of a caregivers involved in wraparound?
 - a. What aspects of the program do they find most beneficial?
 - b. What do they view as the barriers to successful outcomes?
2. How does wraparound differ from the previous models of care to which the caregiver has been exposed?
 - a. Are components that caregiver identifies different or the same components that are identified in the wraparound literature?
 - b. What is the caregiver's experience of elements that differ from past models of care?
3. Can qualitative interviews adequately capture elements and quality of program implementation in order to supplement fidelity measures?
 - a. Will caregiver responses to semi-structured interviews reflect essential components of wraparound?
 - b. Can caregiver interviews adequately identify gaps in the program implementation or unique, local challenges that reduce program fidelity?

Methodology

Research Methodology

This study used a qualitative methodology of Interpretive Phenomenological Analysis (IPA) to explore the subjective experiences of caregivers who took part in a wraparound program. IPA is a qualitative research approach that aims to examine how people make sense of an experience (Smith, Flowers, & Larkin, 2009). It is a bottom-up approach, thus paralleling the backward mapping framework of this study. IPA attempts to “understand a phenomenon prior to and independent of scientific knowledge” (Mertens, 2015, p. 247), so themes are created from the data, instead of interpreting the data with a set of themes already in mind (Pietkiewicz & Smith, 2014). Smith et al. describes this further stating “IPA also recognizes that access to experience is always dependent on what the participant tells us about that experience, and that the researcher then needs to interpret that account from the participant in order to understand their experience” (p. 3). This method of analysis was chosen because the study’s primary aim was to understand caregivers’ experience of being enrolled in the wraparound program.

Research setting. The data used in this qualitative study were collected by the Center for Behavioral Health Innovation (BHI) at Antioch University New England as part of a larger mixed methods evaluation of a statewide wraparound program in New Hampshire called FAST Forward (Families and Systems Together). FAST Forward is a system of care values-based program that was designed to serve youth and families across the state. BHI works with community partners such as FAST Forward to improve behavioral health practices and outcomes.

During my four years of graduate school, I was part of the BHI evaluation team. In recognition of the research gap, BHI created a qualitative study to capture the voice of youth and

caregivers enrolled in FAST Forward. The results from this study were used to complement other quantitative and qualitative explorations of fidelity and implementation efforts of the program. Taken together, BHI hoped stakeholders could use these data to help improve the overall quality of the wraparound program. The original study sought to enrich the other quantitative and qualitative information.

Participants. Eight caregivers² consented to participate in the study. In order to meet inclusion criteria, the caregiver's child had to be enrolled in the wraparound program for at least two months. We attempted to gain cross-sectional, rather than longitudinal data, in order to gain the caregiver perspective across different phases of wraparound.

Participant recruitment. Participants were recruited for about a year on an ongoing basis using two recruitment strategies. Initially, the Evaluation Coordinator randomly selected six families using the database that was maintained by the evaluation team to track family enrollment for the program. There was an attempt to stratify by phase and across the three wraparound facilitators. The Evaluation Coordinator then asked each family's designated facilitator to send a Recruitment Letter (see Appendix A) and Informed Consent and Assent Documentation (see Appendices B and C), inviting the caregiver to participate in the interview. Caregivers were asked to contact the Evaluation Coordinator if they wished to participate. If they did not contact the Evaluation Coordinator within a week of the initial invitation, they were sent a reminder invitation (see Appendix D). If there was no response to that letter within a week, another caregiver was randomly selected.

² The original study also captured one youth interview; however, the current study only focused on information captured in the caregiver interviews due to the limited number of youth participants.

After initial recruitment efforts yielded few participants, the evaluation team consulted with the wraparound facilitators to determine a more successful recruitment strategy. The facilitators informed the evaluation team that the level of initiative and organization required to pursue participation in the research interviews was a barrier to participation for families with very busy lives. As a result of this feedback, the recruitment protocol was revised so that the Evaluation Coordinator followed up directly with a phone call to invite the caregivers to participate. At that time, the Evaluation Coordinator responded to any questions, reviewed the consent and assent documents provided by the service coordinator, and offered to schedule an interview. This second strategy was effective in recruiting caregiver participants.

Data Source

Following training in interviewing and human subject ethics, four doctoral student members of the evaluation team conducted interviews. The interviews followed an interview introduction protocol (see Appendix E), reviewing whether the respondent had any questions, confirming consent/assent, and then proceeding to the questions. As is common with qualitative methods, interviews were conducted in a conversational style allowing for some freedom to elicit further discussion as needed (Patton, 2003); however, the interview followed a general outline of six questions and sub-questions (see Appendix F), which were created in consultation with wraparound stakeholders.

Interviews were audio-recorded using both a phone recorder and a secondary recorder as back up. They ranged between 10–30 minutes. Upon completion of the interview, caregivers were mailed a \$20 Visa gift card as compensation for their time.

Data Analysis

I employed Interpretive Phenomenological Analysis (IPA) to understand and describe the experiences of the participants by assessing and identifying themes found within and across interviews. The IPA analysis proceeded as follows: I reviewed the interview transcripts a number of times as IPA researchers “immerse themselves in the data” (Pietkiewicz & Smith, 2014, p. 11). I made notes about the interview content and process, specifying striking quotes and noting thoughts on language, significance, and emotionality. Once thoroughly reviewed, I recorded emerging themes. This process of capturing themes is described as a “dual interpretation process” (Pietkiewicz & Smith, 2014, p. 8). During the process, I made meaning of the participant’s interpretation of their experience. Themes consisted of a representation of important details of the data with my own conceptualization and interpretation of the participant’s meaning (Pietkiewicz & Smith, 2014). Themes that emerged from the first interview data informed analysis of later interviews. Once all of the themes emerged across interviews, they were compiled for further analysis. Themes were reviewed for potential connections or similarities, which were then clustered under a descriptive label that summarizes the meanings (Pietkiewicz & Smith, 2014). Participant quotes were provided to demonstrate specific examples in the data. The original interview transcripts were referenced throughout the analysis to ensure the themes and clusters are an accurate representation of the raw data. A table was created to graphically organize the clusters and themes (see Appendix G).

Issues of Trustworthiness

As part of the analysis process, several strategies were used to ensure the integrity of the study.

Credibility. Credibility in qualitative research is equivalent to the concept of internal validity in quantitative research (Mertens, 2015). Because I used archival data, my avenues for ensuring credibility were more limited than is often the case in IPA research (Mertens, 2015). For example, I could not employ member checks to consult with caregivers about my interpretations. However, I was able to employ other strategies. First, I utilized *peer debriefing* by engaging in extended discussions about the process and the findings of the analysis with a peer who had familiarity with wraparound (Mertens, 2015). This process was essential as I invested extended time emerged in the data in order to gain an understanding of the phenomenon. I was able to accomplish this through various parts of the study, including engaging in open-ended, in depth interviews with participants and immersing myself in the audio of interviews I did not conduct myself.

Confirmability. Confirmability, or objectivity, is the degree to which others can confirm my findings. In this study, I sought out the consultation of an external auditor to confirm that the themes and cluster effectively represented the data (Mertens, 2015). This auditor reviewed the data analysis, which included all the raw data, themes, and clusters. She provided both written and verbal feedback and posed questions to ensure I remained true to the raw data. I also present the data table, which includes original text segments, to allow readers to review my data for themselves.

Another way confirmability was enhanced was through the use of bracketing biases. *Bracketing biases* helps the researcher identify and become aware of any personal biases they hold in the process of analyzing the data and the content of the data itself (Mertens, 2015). I served as an auditor when these data were originally analyzed for the purpose of providing feedback to stakeholders, so I already had previously immersed myself in this set of data. I also

created qualitative data visualizations to represent the analyzed data. Even though I analyzed the same data, it was important to remain grounded in this particular analysis; I approached it with fresh eyes with a different set of questions and a study that had a different purpose. Time between the two analyses significantly diminished my memory about findings from the previous analysis, which I did not review prior to my thematic coding for this study. I also wrote down my biases prior to the analysis and throughout the analysis process (see below).

Journaling. First, I noted my knowledge that there were factors that decreased wraparound fidelity. Examples of this are the difficulty engaging natural supports and a lack of state-wide infrastructure (i.e., available mental health services, community knowledge and understanding of the need for a wraparound program) to support the implementation of the program. At the time of the interviews, this program was in its infancy in New Hampshire, which I anticipated would also result in lower fidelity. Another belief I brought to the study was with regard to the FAST Forward staff. In my role as an evaluator, I developed a deep appreciation and respect for the wraparound facilitators. I analyzed interviews they participated in and analyzed videotaped team meetings they facilitated. I had an intimate knowledge of some of their difficulties and accomplishments throughout program implementation; however, I never engaged with them one-on-one to collect the data to be analyzed.

I expected that caregivers would experience some of the challenges to fidelity I had noticed, but I was uncertain to the degree they would be able to identify the source as service gaps and newness of the program. I was not certain what to expect in terms of their perceptions about wraparound facilitators. On one hand, I expected a positive disposition, but on the other hand, I worried that the facilitators would carry the blame and burden for system-level challenges.

Ethical Considerations

There were two primary ethical considerations addressed in this study: (a) confidentiality, and (a) informed consent.

Confidentiality. Efforts to maintain confidentiality were an important part of this study. Information regarding study participants was maintained on a password protected, HIPPA compliant, web-based storage system called Box. Once interviews took place, the digital recordings were placed into Box and deleted off of the recording devices (e.g., computers, cell phones). The recording was given a coded ID number. The audio files were only accessible to leadership members of the evaluation team who were given the password for the system in order to minimize access to the data. Those who interviewed or had access to the raw data were instructed to not take notes during the process. All the audio files were permanently deleted after transcription.

All physical (e.g., handwritten notes) and electronic (e.g., transcripts, data analysis) were secured, either in a locked file case or with password protection. Only deidentified quotes and aggregated data were shared to minimize identifiability. To protect individuals named in the interviews, shared quotes only identify the individuals by their role in the wraparound program (e.g., caregiver, facilitator, family support, youth, natural support). Although there were a number of different types of caregivers who participated in the interview process (e.g., grandparents, biological parents, foster parents), I referred to them all simply as caregivers; to further protect their confidentiality, I opted not to identify them by caregiver type.

Informed consent. Prior to participation, all participants signed informed consent/assent forms. The study recognized the vulnerability of those who are part of this population. Risks for taking part in the study including the following: (a) harm to the relationship between the program

staff and participant if the staff learned and took offense to the caregiver's perception of the program, (b) emotional discomfort from the experience of answering the study's interview questions, (c) and harm to the participant's reputation if the information regarding their SED experience was shared outside of the evaluation team. In addition to the strategies mentioned above to maintain confidentiality, in order to minimize potential risks, the follow procedures were put in place:

- Participants were informed that participation in the study was voluntary, that they did not have to answer any questions they did not wish to, and that they could stop or take a break whenever they wished.
- Participants were reassured that participation in the study would not impact their participation in the wraparound program.
- There was an emphasis that there were no "right answers" to the questions and that we were just interested in the perspective of the respondent.
- To address emotional discomfort, interviews were conducted by doctoral students in a clinical psychology program who were trained and sensitive to emotional distress and well prepared to recognize and respond to it. Licensed clinical psychologists supervised these students.

Results

Demographic Information

The current study was conducted using archival data so the demographic information is limited. Two males and six females were interviewed for this study. Caregivers included two adoptive parents, one grandparent, and five biological parents. The FAST Forward model was set

up so that FFCs provided services based on region. All three FFCs were represented in the data, so caregivers also represented several regions of New Hampshire, both rural and urban.

Overview

Several themes emerged from the qualitative analysis. While the caregivers interviewed for this study all participated in the same FAST Forward program, the individualized nature of the wraparound suggests that each caregiver experienced the program as tailored to the specific needs of his or her family. As a result, the interviews reflected individualized experiences.

Although caregivers received tailored interventions, I wanted to learn about the similarities caregivers described in their experience with the wraparound program. I did not want to lose individual voices so I also explored themes that were shared by just a couple of caregivers. This process helped to maintain more individualized data points that might have otherwise been consolidated or undervalued in the analysis process. During the analysis, I also kept notes and reflections about parts of the process that were striking to me.

Themes were organized within six clusters: (a) Initiating Wraparound Services, (b) FAST Forward Coordinator (FFC) and Family Support Specialist (FSS), (c) Wraparound Team, (d) Supports and Services, (e) Family Engagement, and (f) Program Outcomes. A reference table has been provided in Appendix G.

Cluster 1: Initiating Wraparound Services

All caregivers reflected on starting wraparound and their experience of the initial phase of receiving services. Four themes emerged relating to this topic: (a) Child's difficulties with severe and complex mental illness led family to wraparound, (b) caregivers felt helpless prior to the start of wraparound, (c) experiences varied accessing FAST Forward to initiate services, and (d) the initial phase of FAST Forward was slow.

Child's difficulties with severe and complex mental illness. Six caregivers responded to the first interview question "What was going on in your family's life that prompted you to enter this wraparound program?" by discussing their child's severe and complex mental illness. They discussed their child's symptomology including explosive behaviors, suicidal ideation and attempts, and psychotic features. For example, one caregiver reported, "I have a child with a number of mental illness diagnoses. His is largely explosive and he becomes explosive at school" (Caregiver 1).

Caregivers felt helpless prior to the start of wraparound. Two caregivers noted their feelings of helplessness managing their child's mental illness and working to receive services for their children. Though initially mentioned in response to the first question, this theme often carried throughout the interview. One caregiver reflected, "Because having to wait, just because I was so broken...I waited until I was broken basically to even try to get help" (Caregiver 4). This helplessness created a sense of urgency to receive help. As the caregiver stated as he or she continued to reflect on the experience, "I needed help yesterday."

Experiences varied accessing FAST Forward to initiate services. Caregivers had varied experiences initially accessing wraparound services. While FAST Forward was readily accessible to some families, other families struggled to find a suitable program after their child experienced a mental health crisis. Those who found FAST Forward most accessible made their first contact with the program through the psychiatric hospital. For example, one caregiver explained, "We went down for a family night while he was admitted and FAST Forward was there. Wraparound was there. They had [the Family Support Specialist] from NAMI, which I thought was really neat" (Caregiver 7). Two caregivers stated that they called the New Hampshire division of the National Alliance on Mental Illness (NAMI) looking for resources,

one of whom was quickly linked to FAST Forward while the other called several times over several months before he or she was referred to the program.

The initial phase of FAST Forward was slow. Four caregivers remarked on the perceived slow initial phase of FAST Forward services and discussed how it sometimes took a crisis to turn plans into action. One caregiver compared the initial phase of the program to the length of time it had taken to get services in the past with other agencies. This caregiver believed that this repetitive intake process prevented their child from receiving services in a timely manner. In a similar vein, Caregiver 3 described the following:

I mean she had been hospitalized at the point that she entered the program probably five times. So for us to have the same exercises and the same sort of discussion over and over again—it was almost a barrier to getting services.

One caregiver further described this initial phase as an extended needs assessment that needed to be streamlined; another wondered whether the FAST Forward staff understood the magnitude of the problem at hand.

Caregivers noted that it took some kind of family crisis for FAST Forward to take real action. Crises included events such as hospitalization due to suicide attempts, police intervention due to a child's severely dysregulated behavior, and an increase in psychotic symptoms. Once FAST Forward was more fully engaged, Caregiver 8 felt that the action steps and the response to his or her child's crisis were adequate:

That's the most important thing. But they came out—they came out for 8 months before anything really traumatic happened. They started a holding mode—they held, because there's not much they could do. But when it happened they were there and so I thank the people involved. I really do.

However, other caregivers were frustrated that more efforts to meet immediate needs were not made earlier, before a crisis. One caregiver even referred to their crisis point as a “wake-up call” to FAST Forward staff.

Cluster 2: FAST Forward Coordinator and Family Support Specialist

The second cluster described relationships with FAST Forward staff with whom the caregivers had the most contact: the FAST Forward Coordinator (FFC) and Family Support Specialist (FSS). Three themes emerged around this topic: (a) Characteristics of FFC and FFS, (b) FFC's and FFS's personal experience helped connect with caregivers' current challenges, and (c) FFC and FSS availability and responsiveness varies. It should be noted that there were three FFCs and two FSSs who staffed this particular wraparound program. All FAST Forward staff were represented across respondents.

Characteristics of FAST Forward coordinator (FFC) and family support specialist (FSS). Seven caregivers responded to the second question, “How has your experience with [insert coordinator's name] and the rest of your wraparound team been so far?” by discussing their overall positive experience with their FFC and FSS. Many of the caregivers reflected on characteristics of their FFCs and FSSs. Adjectives used to describe FAST Forward staff included, but were not limited to, the following: (a) Phenomenal, (b) compassionate, (c) dedicated, (d) caring, (e) sensitive, (f) understanding, (g) calm, and (h) uplifting. Caregiver 3 reported, “Well, we had [FFC] who, [FFC] was the sweetest, nicest, totally caring individual who you would ever want to meet.” Five of the seven caregivers specifically focused on their FAST Forward staff being strengths-based. They discussed how the staff always made them feel supported and focused on strengths. Caregiver 5 spoke about this experience:

Yeah, sometimes just getting reassured. Having someone come into the house and reassure that what I tried to do, what I want to do, is okay—that I was not a bad [caregiver], or someone who makes all the mistakes. It was nice to know that.

Even for a caregiver who did not believe they were successful in the program, he or she responded to the final question “What else is important for us to understand about your experience with this program” by stating, “Only again that I can’t say enough good things about [FFC] and [FSS]. I’m grateful for what they tried to do” (Caregiver 1).

FFC’s and FSS’s personal experience helped connect them with caregivers’ current challenges. Two caregivers discussed the importance of FAST Forward staff’s sharing their personal experience as part of developing a relationship. For example, Caregiver 7 described, “And it was really helpful that they both have children. And I know [FSS] had difficulties and stuff. So it really helps them relate.”

FFC and FSS availability and responsiveness varied. All eight caregivers discussed how available and responsive they found FAST Forward staff to be. Despite overall positive feelings about the FFC and FSS, caregivers had varied experiences with staff availability based on the family’s schedule and needs. Some caregivers reported that their FFC and FSS were very responsive, while others found them to be less so. To illustrate the latter, one caregiver described waiting to hear back about a service the FFC was supposed to contact on their behalf: “So we see each other once a month. I could call and say, “Hey, did you hear back?” But I haven’t. So that’s partially...I know it’s not my fault because it’s their job” (Caregiver 4).

Similarly, caregivers reported varied experiences with how much they felt understood by their FFC and FSS. The overall message from many of the caregivers suggested that the FAST

Forward staff were generally attuned to the caregivers' needs; however, there were also times that the caregivers noticed they were not on the same page.

Cluster 3: Wraparound Team

Another cluster referred to experiences of being a part of the wraparound team. Ideally, the team's make-up consists of invited individuals who are committed to the family's well-being as well as the family members themselves. These individuals can be both natural (e.g., family friends, coaches, pastors) and formal (e.g., therapists, school personnel, and other "paid to care" individuals) supports.

Many caregivers did not speak about their wraparound teams. In the instances when the wraparound team was mentioned, it was most often done so to report that the team did not exist or was minimally part of the process. Themes about the wraparound team emerged from the interview question, "How has your experience with [insert coordinator's name] and the rest of your wraparound team been so far?" Many caregivers responded by only discussing their experience with their coordinator; they required a prompt of "and how about your wraparound team?" Furthermore, some caregivers needed clarification on the term "wraparound team." For those caregivers who elaborated on their responses, two themes emerged around this topic: (a) Formation of the wraparound team, and (b) team process.

Formation of the wraparound team. Three caregivers discussed their varied experiences of constructing their wraparound teams. Some caregivers were able to talk about the formation of their team as bringing people together from different specialties to get them on the same page. One caregiver emphasized the choice they were given in selecting members who would be part of the wraparound team. However, caregivers also reflected on how difficult it was to find people to be part of their team; some noted they had a very small team or no team at all.

For example, one caregiver reported, “So my quote unquote ‘team’ really didn’t exist of anybody because there was nobody” (Caregiver 1).

Team process. Five caregivers ultimately acknowledge that a team had been assembled. However, experiences varied with how involved and committed the team was to the wraparound process. Few caregivers reflected on their wraparound team being a positive aspect of their FAST Forward experience. Caregiver 8 reported an overall positive experience stating the following:

And it’s really then profitable. A lot less spinning the wheels—I don’t know if that’s a good analogy. So I think it works in that manner. Meeting at school, community partners are there, wraparound’s there, so it’s productive, yes.

However, other caregivers found that, despite the fact they were able to form a wraparound team, their team members were not committed to the wraparound process. One caregiver illustrated this point by describing the behavior of a particular team member, “But one of them comes once in a while to a team meeting but really he doesn’t care about it. He’s just doing it to check it off. And the other therapist, she’ll talk but she can’t come to meetings” (Caregiver 4).

Cluster 4: Supports and Services

The next cluster depicts caregivers’ experiences with available supports and services. Four themes were identified: (a) Lack of services in New Hampshire, (b) accessing services and supports, (c) helpful supports and services, and (d) experience with school system.

Lack of services in New Hampshire. Four caregivers discussed their belief that New Hampshire lacked the mental health service infrastructure for a program like FAST Forward to be successful. Some caregivers reflected that necessary services simply do not exist in some areas of the state. One caregiver hypothesized that this absence of services was a result of the

state government not prioritizing mental health, specifically children's mental health. Caregiver 1 stated the following:

In many other states there is someone who is dedicated at the state level to being the, you know, child mental health—child mental wellness “czar,” for lack of a better word. So it's just not a state priority. So there is no funding.

Those who had similar reflections discussed how they had to look elsewhere for mental health services for their child. One caregiver expressed frustration as he or she talked about having to go through the juvenile justice system instead of having his or her child treated for his or her mental illness. “Except for um CHINS [Children in Need of Services]...there's nothing. There's nothing. My child, she's mentally ill. Going through the court system isn't going to change her behavior. It isn't going to change her problem” (Caregiver 3). It is important to note that there was likely a difference in availability of services related to home region. Caregivers in more populated and urban regions were able to access resources through wraparound, while those in rural regions continued to struggle to access resources because of the service gaps in the immediate area.

Accessing services and supports. Three caregivers acknowledged that services and supports existed in their region, but they varied in being able to access them. A few caregivers found that barriers (i.e., limited hours, limited services providers) continued to block them from getting the help they needed. For example, Caregiver 3 noted the following:

You know [FCC] was very good at saying, ‘We can get whatever it is that you need.’ But then when [FCC] went to go and find what we needed, there wasn't a provider that did that or provide those types of services.

By contrast, other caregivers found that being part of FAST Forward suddenly allowed them to have resources they previously did not know existed or had been unable to access. One caregiver stated, “But once I got connected with [FFC], jeez I had access to all of these resources” (Caregiver 5).

Helpful supports and services. Three caregivers responded to the question “What’s been most different for you and your family since beginning the program?” and the prompt “Is there anything that has been made available to you through FAST Forward that you did not have access to before?” by discussing specific services that they found particularly helpful. Caregiver 7 reflected on the following:

But they have kind of an outreach program. They have a lady that comes twice a week, that wraparound set that up, she comes twice a week to take him out and do some community socialization and integration. And they work on some of his coping skills, and I feel like that has helped dramatically.

Caregivers did not specify the exact services other than respite, but found ones that were community- and home-based to be the most helpful in feeling successful in the program.

Experience with school system. School personnel are an essential part of any wraparound team. School can provide services and resources for children, especially if other services are lacking in the community. Three caregivers discussed their experiences with the school system once they were involved in wraparound. On the positive side, one caregiver described a school representative who was an asset in helping the caregiver’s child access services and supports within the school. On the other hand, caregivers described school personnel that could not meet the needs of their children. One caregiver noted, “Nothing was happening in school—they tried to teach her stuff but [he or she] was fainting and pseudo

fainting. They couldn't help [youth]—they tried” (Caregiver 8). This caregiver later discussed how his or her child was subsequently placed in a school that could better fit the child's mental health needs; although the previous school was not sufficient, school personnel were able to help the family find a more suitable school for the child.

Cluster 5: Family Engagement

Another cluster of themes reflected how families engaged in the FAST Forward process. Three themes were identified in this cluster: (a) Family member's impacted by child's mental health needs, (b) FAST Forward supported the entire family, and (c) family participation in the decision-making process.

Family members impacted by child's mental health needs. Two caregivers responded to the first interview question: “What was going on in your family's life that prompted you to enter this wraparound program?” by discussing the impact their child's severe and complex mental illness had on them and other members of their families. They spoke about the strain of figuring out how to care for their children and the impact it had on their own mental and physical health. For example, Caregiver 4 remarked on the experience of putting his/her child's needs first:

And people can say, “You've got to feed yourself.” But then who is going to take care of the kids? You know? And that's what's so frustrating because people say, “Well you got to.” I know...so who is going to watch my child while I go for a walk?

FAST Forward supported the entire family. Six caregivers recognized that FAST Forward addressed the needs and provided services and support to the entire family, rather than just the identified youth. This theme came up in almost all interviews. Caregiver 2 summarized, “They worked with us, worked with my [child], worked with other family members.” Caregivers

reported that the supports offered allowed them to address some of their own mental health needs and support their children with renewed energy. Noticeably, caregivers also discussed different ways that their needs were addressed, even specifying the individualization of their services. For example, they discussed the felt benefits of in-home services, someone to talk to in times of great stress, and help getting their own mental health care.

Family participation in the decision-making process. Five caregivers discussed the ways in which they were encouraged to make decisions. Caregiver 5 remarked, “Yeah [FFC] always made sure that we had as much say as possible.” One caregiver reflected to how he or she was looked at as an expert of his or her experience. Another discussed how wraparound intentionally encouraged family participation by family members who had previously been absent from the decision-making process. Caregivers also reported it was not just the adults who were encouraged to participate. Another caregiver stated, “Not just me as a parent. The way they went above and beyond to include [child] in it as well and say ‘Hey! This is your thing...let’s see what you want to work on’” (Caregiver 7).

Cluster 6: Program Outcomes

The final cluster related to program outcomes. Three themes were identified in this cluster: (a) Termination of services due to unmet needs, (b) successful program outcomes, and (c) attitudes about the FAST Forward process.

Termination of services due to unmet needs. Five caregivers discussed their decision to withdraw from the program when they determined that, despite a significant amount of time receiving wraparound services, their family continued to be in distress. In some cases, caregivers wanted to continue but had no option other than to end services because their child was placed in residential care. One caregiver responded, “But soon after that my [child] was placed in a

residential placement and those services stopped as soon as [child] was moved out of state. But we are a family that is still in crisis” (Caregiver 3).

Positive program outcomes. Five caregivers also noted positive outcomes they experienced from the program. Notably, some of the caregivers who offered examples of positive outcomes were those who also terminated from the program early due to unmet needs. Most caregivers were able to describe some positive outcomes in the program, no matter how long they were part of the wraparound or whether they would call their FAST Forward experience “successful” overall.

Caregivers identified positive program outcomes for both the child and the caregiver. In particular for the child, caregivers identified the benefits of receiving treatment in the community without having to be placed elsewhere to get needed help. For example, one caregiver noted, “Oh they were a wonderful help with organizing everything and helping us get everything to be able to keep [child] at home, in the community, and in school” (Caregiver 6). Some caregivers identified several caregiver-related outcomes including: (a) increased knowledge of mental illness, (b) a better understanding about accessing community- and school-based supports, (c) increased caregiver wellness, and (d) increased hope and confidence. Caregiver 7 reflected on his/her gains:

And that we can cope, and we just need some extra skills. They brought all of that together. I had the skills there, but bringing it all together and finding me more resources and showing me how to better advocate for him was really a huge thing.

Attitudes about the FAST Forward process. Despite varied successes resulting from participation in the program, six caregivers shared generally positive attitudes in retrospect about their time with FAST Forward. One caregiver even went so far as to recommend the service to a

friend, “I have a friend who has a daughter with mental health issues and I told her to give [FAST Forward program manager] a call or NAMI a call” (Caregiver 5).

However, two caregivers also noted specific areas of dissatisfaction. These caregivers felt the “needs assessment” phase took too long and felt repetitive, and were frustrated that FAST Forward was not covered by (their) insurance, and with termination of services upon child entry into residential care.

Discussion

Summary

This study was conducted in an effort to better understand wraparound services from the perspective of the caregivers enrolled in a wraparound program in the state of New Hampshire called FAST Forward. Eight caregivers volunteered to participate in the study. All caregivers were enrolled in the program for at least two months; however, those interviewed generally represented perspectives of across different phases of wraparound.

Caregivers engaged in semi-structured interviews with doctoral student members of the Center for Behavioral Health Innovation (BHI) at Antioch University New England. The interview consisted of six basic questions with some scripted prompts to encourage more descriptive information from the caregivers about their experience with FAST Forward. However, interviewers—clinical psychology graduate students—were able to devise prompts outside of the script as well in order to encourage deeper caregiver discussion about their experiences.

Interview data were analyzed using Interpretative Phenomenological Analysis (IPA). IPA is a qualitative research approach that aims to examine how people make sense of their experiences (Smith et al., 2009). In at “dual interpretation process” (Pietkiewicz & Smith, 2014,

p. 8), I aimed to make sense of the experiences shared by the caregivers in the interviews.

Common themes among interviews were identified and then these themes were grouped into clusters based on a summarizing label. Themes were ultimately grouped into six clusters that represented different phases and aspects of the wraparound program: (a) Initiating Wraparound Services, (b) FAST Forward Coordinator (FFC) and Family Support Specialist (FSS), (c) Wraparound Team, (d) Supports and Services, (e) Family Engagement, and (f) Program Outcomes.

Finding and Implications of the Study

Cluster 1: Initiation of the process. All caregivers reflected on starting wraparound and their experience of the initial phase of receiving services. Caregivers in this current study focused more on the difficulties faced by the child, while Painter et al. (2011) described a broader swath of social and familial concerns such as recurring school problems, financial difficulties, family violence, and lack of social support. One possible explanation for this difference could be the interviewer. In the Painter et al. study, caregivers were trained to interview other caregivers. It is possible that there was a sense of comfort from sharing experiences with the individual who conducted the interview, resulting in more openness about stigmatizing experiences.

Further, in spite of early efforts to orient families to the wraparound model, caregivers still appeared to lack an understanding of how it operated. Their frustration with the slow start up—and indeed with other elements of the program all the way through termination—seemed to stem, at least in part, from some persistent misunderstandings about what wraparound was and wasn't. It seems likely that families were either not provided, or were not in an emotional and psychological place to take in, the information about the process of FAST Forward.

This finding mirrors similar concerns raised in previous research. For example, England (2013) noted that information about their wraparound program was delivered through a resource called a family guide. However, in interviews with families caregivers reported that they had only given it cursory attention or bypassed it altogether during the initial phase.

The lack of a shared understanding about wraparound is a significant problem. Indeed, the first element of a wraparound program outlined by Bruns et al. (2008) maintains that the family member and youth's perspectives are prioritized in the wraparound process, yielding a collaborative intervention. Results from this study, and others (e.g., Painter et al., 2011), depict that most families are in crisis upon entering any wraparound program; they have the need and expectation for immediate intervention and little resource for other conversation.

By contrast, in design, the initial phase of the wraparound process is supposed to focus on establishing a broader context for the services that follow—creating a vision of wellness, discovering needs, strengths, and culture, and highlighting differences of the wraparound program from other care programs (Walker et al., 2008). It is notable, therefore, that what the initial phase does not explicitly do is address the immediate needs of the family in crisis even as it purports to prioritize their needs.

Even though addressing an immediate crisis does not permanently fix all the family's problems, it would likely create the space and ability for caregivers and youth to then more fully participate in the engagement and team preparation phase. Part of this engagement *must* include an explicit conversation about the wraparound process. For example, families need to know from the beginning that transition will occur when they can be supported by their team, without wraparound case management, and services can be withdrawn upon a child's removal from the home.

Cluster 2: Foundational relationships. The second cluster described relationships with FAST Forward staff with whom the caregivers had the most contact: the FAST Forward Coordinator (FFC) and Family Support Specialist (FSS). Results from this study mirrored results of other studies. The wraparound coordinator/facilitator appears to matter greatly, particularly as he or she is able to connect with the child and the caregiver (England, 2013; Painter et al., 2011). Similar to my study, England found that caregivers viewed the bond with the wraparound facilitator to be a significant benefit of the program.

Successful facilitators with FAST Forward, as well as in other wraparound programs, have positive characteristics including being available, effective communicators, competent in their knowledge of the issue, and the ability to keep the family's perspective and interest in mind. In my study, the Family Support Specialist (FSS) was particularly important to successful wraparound. In FAST Forward, every family was assigned a FFS; most caregivers positively spoke about them during the interviews. By contrast, in England (2013), the caregivers noted they found FSSs to be helpful, but had limited interaction with them during the program.

These results are not particularly surprising with regard to wraparound in a rural state like New Hampshire. Due to the lack of resources for youth with SED, the burden of care falls on the family systems. This burden can be financial, physical, and emotional, and impacts the nature and extent of social relationships caregivers can maintain. With regard to formal supports, individual outpatient therapists working with older children and teens typically provide limited support to caregivers. As such, caregivers navigating the larger mental health system for their children often do so in isolation. The establishment of relationships with case coordinators and support specialists are critical to successful wraparound process.

Cluster 3: Creation and expansion of the wraparound team. Another cluster of themes referred to caregivers' experience of being part of the wraparound team. Most surprisingly, however, given the prompts and inquiries (and the fact that the team is so fundamental to the concept of wraparound), many caregivers did not speak about their wraparound teams *at all*. In the couple instances when the wraparound team was mentioned, it was most often done so to report that the team did not exist or was minimally part of the process.

Although I was surprised to find out how rare it was to have caregivers understand they were supposed to be part of a team, the difficulty others described identifying and maintaining an effective team is consistent with previous findings. For example, England (2013) found that difficulties with the team process were a barrier to implementation for many caregivers. The study noted that it typically took between six and 12 months for many teams to come together. Once teams were formed, the inconsistent involvement and variable commitment impeded the implementation of the plan of care to help the child and family members reach measurable goals and objectives. Without sufficient engagement and collaboration of an interdisciplinary team, one of the key elements of wraparound is missing.

Indeed, the second element of a wraparound program outlined by Bruns et al. (2008) states that wraparound is a team-based approach. But having a team is not sufficient in itself, the team must also be committed to the family's well-being. This element of wraparound was notably lacking among the FAST Forward participants interviewed.

In particular, the development of natural supports are another key element of a wraparound program (Bruns et al., 2008) that creates scaffolding for high-risk families when the formal wraparound ends. Notably, in this study, no caregivers mentioned natural supports. In fact, BHI's final report, which summarized the outcome and process data from the program,

found that, on average, families who had consistent teams had one natural support for every two formal supports in attendance at team meetings (Fauth, Wilson-White, Erdmann, & Roberts, 2017, p. 7). This finding contrasted with England's (2013) study that found that wraparound teams primarily consisted of family, friends, and the facilitator, with fewer formal supports mentioned.

This finding is particularly concerning as the stress of caring for a child with SED can have such an isolating impact on caregivers; the lack of real community can contribute to the marginalization of a struggling family. Caregivers must invest their time and energy into meeting their children's needs, which likely prevents them from building and maintaining social relationships. Moreover, the cultural ethos of New Hampshire, with its 'Live Free or Die' motto, reinforces a certain "pick yourself up by your bootstraps" mentality. Struggling caregivers may feel they should be able to do things on their own and don't have much experience with asking for help. Rugged New England individualism can contribute to a sense of having to go it alone.

Thus, for a variety of reasons, the caregivers in FAST Forward were significantly more reliant on formal supports than on natural ones. However, the availability of formal supports was also uneven for families depending on where they lived in the state. The challenges of developing a robust wraparound team comprised of both professional and community supports have also been described by other evaluations in other states. For example, several wraparound studies similarly identified the barriers in locating or persuading services to be part of a wraparound team (e.g., Mendenhall & Frauenholtz, 2014; Sather & Bruns, 2016; Walker & Koroloff, 2007), which suggests that building wraparound teams is likely a common difficulty even in regions with more people and more resources.

However, the formation of a diverse and engaged team should be fundamental and essential to the success of any wraparound intervention. Ideally, the community participants of the team need to function in a sufficiently supportive manner so that when the wraparound facilitator ends their involvement with the family, the family doesn't return to a state of social isolation and crisis. In theory, the approach should provide the range of multifaceted, complex, and timely interventions needed to stabilize and treat youth with SED over a longer period of time.

There are challenges to both forming and sustaining team engagement that are worth noting. Even if FAST Forward had been more effective in convening a team, there is no guarantee people would have stayed committed to it. Thus, when a team is able to form, it needs to be tended and managed so it can sustain its purpose. For example, in noting the difficulty with team engagement over time, England (2013) cites suggestions for overcoming obstacles (i.e., scheduling conflicts) by keeping the team small and pushing for changes at the state-level to allow for agency personnel to seek reimbursement to attend meetings. It is probably useful to view the findings from this current study through the eyes of caregivers experiencing such limited and marginal team functioning. The reliance on—and at times, frustration with—case managers and support workers is better understood in light of the fact that these formal supports essentially *were* the wraparound team for most of the caregivers interviewed.

Cluster 4: Program implementation with insufficient infrastructure. Caregivers also spoke about their uneven experiences with available supports and services. Themes about variable access, lack of infrastructure, and lack of collaboration between services are commonly found themes in stakeholder interviews (Mendenhall & Frauenholtz, 2014; Sather & Bruns, 2016; Walker & Koroloff, 2007). In other caregiver studies, the topic is discussed with regard to

the felt impact it has on the construction and utility of the wraparound team (England, 2013; Painter et al., 2011). From these reports, it is reasonable to assume that this problem is not unique to New Hampshire, but common to wraparound programs across the United States. Uneven, insufficient, and unavailable services comprise a significant barrier to wraparound implementation. Families cannot carry out an effective plan of care without access to relevant, high-quality services.

Prior to the start of FAST Forward, BHI conducted a Community Readiness Assessment (Wilson-White, Fauth, Evarts, Moniz, & Erdmann, 2014) that looked at whether the communities in New Hampshire were ready to provide services and supports needed to implement a wraparound program. The report stated, “the success of FAST Forward hinges on the availability, utilization, and provision of well-coordinated, high quality professional services, natural supports, and community resources in the home communities of youth with SED and their families” (p. 4). The assessment looked at six dimensions of readiness: (a) Existing efforts, (b) knowledge of the efforts, (c) leadership, (d) climate, (e) knowledge about the issue, and (f) resources. Results of the assessment found that New Hampshire was in the “preplanning stage.” The report explained, “Preplanning means that there is clear recognition of the importance of the issue, but attempts to address it are nascent, not easily accessible, and/or ineffective” (p. 10). Thus, it is perhaps not surprising to learn that caregivers experienced implementation obstacles given the preplanning level of available services in New Hampshire.

A closer look at the vision for wraparound compared to the current reality of mental health services both in New Hampshire and across the United States makes true, high-fidelity implementation feel even more ambitious—even in areas where there are ample resources. For example, VanDenBerg and Rast (2006) suggest that siloed systems need to extend beyond

coordination and become *integrated*. Integration goes beyond coordination in that it is a more uniform approach to care through documentation and funding. Improved connectivity and communication are only a step towards actual integration.

Ultimately, FAST Forward was implemented despite the disadvantageous conditions, perhaps as an initial step to build a more coherent system of care for youth with SED in New Hampshire. Recommendations from the Community Readiness Assessment report suggested that the first step was to build “awareness, effectiveness, coordination, and connectivity among and between *existing* programs” (Wilson-White et al., 2014, p. 15). However, the larger target of change was building up regional leadership and connecting local efforts to statewide efforts.

The final FAST Forward practice report summary (Fauth et al., 2017) highlights that staff interviewed from the system/practice level continued to experience difficulty engaging systems and services as a barrier to change. They noted that some providers encountered enduring reluctance from administrators of community agencies “to modify their work for only a few families and differentiate financial reimbursement” (p. 16). FAST Forward staff also suggest that there may need to be a larger “systematic change in order for providers to buy into wraparound values and ideals” (p. 16).

BHI further completed an interpreted evaluation (Fauth, Wilson-White, & Erdmann, 2016), integrating all the data collect from the program evaluations to understand whether changes occurred across three different domains: (a) Environment and Infrastructure, Leadership, Policies; (b) Practice; and (c) Collaboration. Across all three domains, the most progress occurred in areas that were most immediately influenced by the FAST Forward project. For example, stakeholder agencies, those who were closest to the implementation efforts, were more likely to adapt wraparound ideals and commit to delivering the services with high fidelity.

However, as each domain got further from the professional source and closer to the community (i.e., toward community-based services and supports, facilitative structures within the community, and community climate/support), data showed minimal gains.

This current study, along with others, calls attention to the need for intervention at all levels; it is essential for shifts in leadership and legislature on the local, state, and national level that can facilitate coordination—and ultimately—integration of services. However, without more localized services and community engagement, families will be unlikely to benefit from the sustained promise of wraparound.

Cluster 5: Family engagement is critical. The next cluster that emerged reflected how families described their engagement in FAST Forward. The findings from this study closely match the experience of caregivers from other studies. Painter et al. (2011) found that caregivers discussed the following themes when asked about the *ongoing process* stage: the caregiver felt empowered and wraparound's approach addressed the needs of the whole family rather than just the child. These findings are likely linked to the positive responses about the wraparound facilitators and family support specialists (or family mentors/parent peer supports in other studies), as they were responsible for delivering these more immediate in-home elements of the intervention.

Previous research similarly highlights the importance of facilitators and family support specialists. For example, Gopalan et al. (2017) interviewed caregivers who reflected that the Parent Peer Support services “provided emotional support (e.g., building a support system, creating friendships, being comforted)” and “were instrumental in relieving overall stress” (pp. 1929-1930). Wraparound staff are uniquely positioned as an ally for caregivers and offer emotional as well as instrumental support. For example, the care coordinator offers everything

from words of hope and encouragement to a parent to taking charge of pursuing a new resource for a child.

Results such as these highlight the importance of building and maintaining a robust staff in wraparound programs in order to support family engagement over a period of time. Staff turnover is an ongoing problem for mental health organizations (Aarons & Sawitzky, 2006). Typical turnover rates of wraparound coordinators and supervisors range between 20–30%, with burnout cited as the most common reason, and “just under half of the turnover...accounted for by care coordinators leaving in their first year” (Walker, 2017). Wraparound staff believe turnover is a significant problem because children and families suffered when care coordinators changed (Walker, 2017). When staff become burned out, they may offer fewer of the qualities of investment and engagement caregivers find so essential to making them feel supported.

Reducing turnover would seem to be an essential goal of successful wraparound implementation. It is necessary for wraparound programs to select, train, and reward high-quality personnel and to provide ongoing training and support to help staff maintain their own emotional well-being so that families can reap the benefits noted by caregivers in this study.

FAST Forward evidently succeeded notably in selection and support of case managers. Indeed, caregivers' descriptions of FFCs and FSSs describe compassionate and empathic staff who did not display signs of burnout. There are several reasons why FAST Forward's staff may have avoided burnout and turnover. FAST Forward was a two-year pilot program, which meant that it was intentionally small-scale, also resulting in smaller caseloads than those of most wraparound programs. FAST Forward staff may also have benefitted from significant support and training during program implementation that was offered by various stakeholder agencies. The time-limited nature of the pilot may also have helped FAST Forward staff push beyond that

initial year, with an end soon in sight. Following the pilot, FAST Forward received more funding to expand throughout the state. As this expansion occurs, it will be essential to maintain this high level of training and support of the FFC and FFS.

Because direct-care staff are so important to the families they serve, this research also highlights a limitation of the wraparound model for children whose crisis point leads to out of home placement. Although the whole family is a focus of the intervention, once a child is placed in alternative care, services are discontinued. In fact, one caregiver specifically spoke of their distress over services stopping once their child was placed in residential care. While this programmatic decision was likely based in funding streams that require the child to be part of the care plan, it left family members in crisis and, once again, without desperately-needed resources.

If wraparound intends to be a strategy that wraps care around the entire family, a programmatic commitment to that whole system should be honored. In successful wraparound, the “identified patient” has got to be the whole family. Viewing complex family problems through such a systemic lens constitutes a paradigm shift away from the medical model and its funding streams. Treating the family as the client ultimately requires policy and rule changes so wraparound programs can stay in place even when identified youth are, themselves, temporarily not receiving wraparound services.

Cluster 6: A reflection on outcomes. The final cluster that emerged from the thematic analysis addressed program outcomes. This study did not include a specific question about, or aim to capture, specific program outcomes. The measurement of outcomes is an important element of a wraparound program outlined by Bruns et al. (2008). These authors specify that outcomes should be monitored throughout the wraparound process through observable and measurable goals towards that outcome. It would have been useful to our understanding of FAST

Forward effectiveness had this study included more specific inquiry about targeted behavioral changes of the child as observed by the caregiver.

In the FAST Forward final practice report, Fauth et al. (2017) stated that youth and families who persistently engaged in FAST Forward demonstrated improved well-being. Despite positive outcomes overall, it is still notable that the subset of caregivers of this study had positive feelings about the intervention but reported that, nonetheless, they remained in distress. In fact, this finding brings voice to the lived experience of outcome data in the final report.

One of the measures used to monitor youth and caregiver well-being was the Outcome Rating Scale (ORS). The report explained that “ORS scores range from 1 to 10...and respondents who score below 7 are considered psychologically distressed” (p. 13). Although the improvement in well-being for caregivers was statistically significant, the final score was still 6.68, which suggests that many caregivers continued to experience psychological distress even at termination (Fauth et al., 2017).

While the data from the final report also suggest positive gains for youth enrolled in the study, the caregivers in my study expressed more muted appreciation of the gains in their child's behavior and well-being. Many continued to feel challenged and stressed by their children's needs when wraparound ended. It is likely that SED children and their distressed, crisis-prone families need a larger array of both acute and ongoing supports for lasting change; even when the scaffolding of case management helped, caregivers did not feel prepared to lose it.

Implications for practice. As findings from related research have suggested, it may be useful to consider not just behavioral outcomes but also other wraparound components that may contribute to success. For example, in this study, caregivers had a voice; their thoughtful engagement was noteworthy in itself. Caregivers successfully identified the presence or absence

of the essential components of wraparound in their interviews. Their ability to do so is important as wraparound should be informed by the voice and needs of youth and caregivers, utilizing the unique bottom-up approach to care. This study highlighted that the lived-experiences of caregivers enrolled in FAST Forward were captured by some parts of the evaluation, while other measures did not adequately capture their voice.

It is essential that the evaluation of wraparound mirrors the implementation philosophy, prioritizing consumer voice in the evaluation tools and process. While the final evaluation report (Fauth et al., 2017) found that fidelity of the program met national wraparound benchmarks, these caregiver interviews highlighted some of the challenges to fidelity in New Hampshire. This difference was also present within the interrater scoring differences on the Wraparound Fidelity Index-EZ (WFI-EZ), one of the fidelity tools used by the BHI evaluation. Fauth et al. (2017) reported that FFC's scores on the measure were generally higher than caregiver's scores, which became more prominent over time (p. 8). This finding underscores the difference of perceptions of the delivery of services between the consumer and the individual delivering the intervention, perhaps suggesting a change that may need to occur at a programmatic level. It is possible that much more time needs to be devoted—both initially and over the course of services—to discussing with caregivers some of the essential elements of the wraparound program so these elements will be recognized during implementation.

Limitations

Archival data. This study, utilizing archival data, differed from the original BHI study in a couple of ways. BHI originally sought to inform stakeholders about the caregiver experience in FAST Forward. Although the question of exploring the family experience of wraparound was consistent between the two studies, the purpose differed. In the original BHI study, the purpose

was, ultimately, to inform implementation practice of wraparound across the state. The purpose of this study was to explore an evaluation method, more congruent with program philosophy, to increase consumer voice in the literature.

Ultimately, archival data was used to fulfill the purposes of the second study, limiting any shifts in follow-up kinds of questions that might have been adapted with the shift of an audience in mind. There are several ways using archival data was limiting. First, this study failed to capture a more in-depth profile of the caregivers interviewed. Traditionally in IPA studies, the researcher adds more information about the participants of the study to inform readers so that they can make decisions about the generalizability of the results (Heppner & Heppner, 2004). Some of the information that would have been included in these profiles was gathered informally or through the interview process, resulting in varied amounts of demographic information provided. For example, I would have been interested in gaining more information such as which region of the state the caregivers and their families lived, the phase(s) of the program the family experienced or the length of time they spent in the wraparound program, and household composition (i.e., single or multiple caregiver household). Because I used data that had already been collected, I was also not be able to ask clarifying questions or have participants look over their responses and amend them with member checks as is commonly done in IPA (Pietkiewicz & Smith, 2014).

The research questions also focused narrowly on programmatic elements which may have led participants to provide more concrete and less reflective answers. The closely matched cluster categories mirror the leading nature of the questions selected. For example, although question four, "What's been most memorable or surprising for you about this process so far?" and question six, "What else is important for us to understand about your experience with this

program?” promote opportunities for the caregivers to choose aspects of the program to discuss, they are outliers in the protocol. These more open-ended opportunities are preceded by very specific questions aimed to gain information about the staff, the team, and services and resources. Even with these structural limitations, it is noteworthy that this exploration still yielded some interesting and unexpected results.

Limited generalizability. Recruitment for this study posed unexpected challenges. Two rounds of recruitment were necessary to gain access to an adequate number of participants to be interviewed. The initial strategy attempted to use random sampling in an effort to minimize potential sampling biases on the part of the evaluation coordinator and FAST Forward staff who aided in the recruitment process. The original sampling method also aimed to eliminate bias for families who were in the program longer, thus having a different—and perhaps more successful—course of intervention than others with less time in the program. In the original methodology, researchers attempted stratification by phase (including interviewing both caregivers still receiving services and who had terminated or graduated from the program) and more evenly across the three wraparound facilitators. While such precautions are not required for qualitative research, the fact that it was difficult to get even a small sample of willing participants raises questions about who decided ultimately to be interviewed.

I have no way of knowing, for example, if the sample of caregivers that finally participated was skewed in some way. It is possible that caregivers with extremely negative experiences were more likely to offer feedback than others with more complex or neutral feelings. It is also quite possible that ongoing stress and crisis limited—and skewed—the engagement of available caregivers. It could well have been difficult for families in survival

mode, barely keeping their heads above water, to find the time and space to discuss their experiences in wraparound.

It is also a possibility that some caregivers chose not to participate in fear of potential negative repercussions. Despite the promise of anonymity and reassurance that participation would not impact their access to the wraparound program, families receiving wraparound are particularly vulnerable and stressed. Caregivers may well have worried about losing resources if they shared a negative view of parts of the program, disappointed their FFC or FSS, or criticized the program as a whole. Many of these caregivers likely had extended histories of working with agencies, programs, and schools during which the caregivers themselves were viewed as antagonistic and in which they experienced stigma and disempowerment. The group of caregivers who chose to participate may have been further limited by how many actually felt comfortable enough to do so.

Caregivers were also only sampled from a single wraparound program, which may limit generalizability to wraparound programs in other states, and even the next iteration of FAST Forward that is now being implemented in New Hampshire. Though wraparound programs across the United States evidently face some similar challenges, there are likely also unique aspects to the program run in New Hampshire. For example, the FAST Forward program was the first of its kind in the state of New Hampshire. Many of the challenges noted, specifically with regard to limited infrastructure for resources and services, do not necessarily pertain to the wraparound program itself but reflect how New Hampshire is addressing—or not addressing—children's mental health as a whole.

Varying levels of interviewer experience and different interview techniques. Though I was the primary researcher of this study, interviews were conducted by four different student

members of BHI. Patton (1999) describes ways in which the credibility and validity of qualitative research is affected by the researcher: "The researcher is the instrument of qualitative inquiry, a qualitative report must include information about the researcher" (p. 1198). Indeed, different techniques of inquiry among interviewees became evident to me during the analysis process and merit acknowledgement.

Four student members of the evaluation team conducted interviews for the study, each with different interview styles. All four of the students were female. Two of the students were in their first year of the doctoral program which focuses on students learning and understanding the theoretical underpinnings of psychology and therapy. While students who enter the program tend to demonstrate certain attributes and potential that gain them entrance to the profession, these skills are honed once they enter their clinical practicums in their second year. The two first-year students also had less knowledge and experience with evaluating this wraparound program. They received information in lectures and readings to learn more about wraparound. They also participated as researchers in other aspects of the evaluation. Though all four student members received training in conducting semi-structured interviews, the two first-year students made fewer inquiries and generated less conversation through follow-up questions over the course of the interviews. Their interviews were shorter in length and followed closely to the interview protocol.

The third interviewer was a fourth-year student in the doctoral program; she had been engaged in the therapeutic enterprise for three years at that point in her training. However, she had been working at BHI as an evaluation coordinator and only filled in to do one interview. Despite her additional years of clinical training, her interview was also more perfunctory. That interview was short in length and did not stray from the interview protocol.

I was the final interviewer. At the time of the interviews, I was in my second year of the doctoral program, my first year of training in therapy. I was assigned as the student lead on the study, so I was responsible for training the two first-year students. I had developed mastery of many of the evaluation methods of the project and had a good understanding of the wraparound program. Notably, I also had an interest in potentially using the data for my dissertation. Though I followed the questions and prompts of the interviews, I also offered reflective comments or asked follow-up questions to the interviewee's responses. Reflective comments are a restatement or paraphrasing of what an interviewee says. Reflections are a common therapy technique and often a focus of early training for practitioners. The caregivers I interviewed often went into further detail or added new details to their answers. My interview protocols were significantly longer than that of my colleagues. Consequently, there were numerous instances during data analysis that I wished I had been able to ask follow-up questions in interviews conducted by my colleagues, particularly with responses that seemed to diverge so significantly from what I expected to learn.

Directions for Future Research

Future research should continue to explore the perspective of caregivers—and give voice to the reluctant youth—enrolled in wraparound programs. The consumer plays an essential role in program evaluation and improvement. With a complex and tailored set of possible interventions across agencies, those receiving support are best qualified to speak to what services they are receiving, the quality of the support, and the actual—as opposed to imagined—experience of their engagement. Notably, they are also uniquely equipped to speak about the localized challenges that they encounter that may not be recognized or well understood by those

at higher levels of implementation (i.e., funding groups, steering committees, state representatives).

However, research that generates such feedback is only the first step; there also needs to be a systematic plan for addressing the programmatic changes called for by participants. As stated by Walker and Koroloff (2007), the goal is to develop a mechanism for “upwards accountability” that reaches into the higher levels of the system where funding gets established and administrative decisions are made. It is essential that research includes how noted changes can be incorporated and whether they can actually improve implementation practice.

For example—and although this important change did not actually occur as a result of these findings—the second implementation phase of FAST Forward has begun managing wraparound programming at a more local, community-based level. When this study gets replicated the next phase of FAST Forward, it will be useful to explore if more local staffing improves some of the infrastructure problems that have been identified.

Conclusion

This dissertation described a qualitative study that used a semi-structured interview to explore eight caregivers' experience of fidelity and efficacy in a wraparound program in New Hampshire. Results from this study highlighted successes and challenges in the localized implementation of wraparound in New Hampshire. From their initial introduction into the program, caregivers miss a fundamental part of the program—introduction to the process. This gap could possibly be explained by the state of crisis in which most caregivers enter wraparound. The study highlighted the need for the initial phase to address the crisis, at least temporarily, so the caregiver and youth can have a fuller understanding of the program process in addition to its elements. The study also emphasized the importance of building and maintaining both a

professional and natural workforce who can provide immediate and ongoing support for caregivers through this difficult experience. With wraparound's unique strength-based, individualized, and consumer-driven philosophy, staff who work for the program can dramatically impact the perception of positive outcomes—even in the face of enduring difficulty and dropout. Indeed, a surprising finding of this study suggests that it may not be the constellation of services that matters for caregiver satisfaction/well-being as much as an invested and responsive wraparound facilitator.

Results also highlighted the impact of insufficient community readiness. Caregivers felt and reported the reality of the unevenness of access of resources for children's mental health needs in their communities. This finding is not just an experienced challenge for the state of New Hampshire, but for many other states as well. For programs like wraparound to be successfully implemented with fidelity, sufficient infrastructure and potential for agency coordination must be in place, even in more remote areas of a rural state. Without sufficient natural supports and formal services, wraparound faces challenges to the creation of one of its more fundamental elements: the wraparound team.

The lack of a dedicated and functional team to sustain families led to some terminations marked by rupture and crisis. Without a team to support families both during and at the end of the intervention, the temporary nature of wraparound becomes a liability; in these instances, such programs may not offer much more to families than more traditional home-based interventions. Finally, the feedback of caregivers, fundamental to maintaining program fidelity, should also inform what kind of wraparound New Hampshire families need going forward. As a program that already emphasizes consumer voice and choice, it is necessary and fruitful to also include consumer voice in the evaluation of wraparound.

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Appendix A

Family Experience of Wraparound Recruitment Letter

Dear [Participant Name],

FAST Forward wants to learn what it's like for families to be part of the program. We're asking for your help.

FAST Forward has teamed up with researchers at Antioch University, in Keene, NH, who will help us learn about your experience. If you decide to participate, the researchers will call you at a time that is convenient for you. They will wish to speak with one parent/caregiver for approximately 30 minutes. If the youth who participates in the FAST Forward project is 12 years or older, they would also like to set up a time to speak with that youth (with your permission).

In appreciation of your time, the research team will offer the parent/caregiver a \$20 Visa Gift card, and the youth a \$10 VISA gift card.

The attached Informed Consent Document provides more details about the project, to help you decide whether you would like to participate.

If you would like to consider participating in this project, please contact the Antioch research team's project coordinator, [REDACTED]. Her phone number is [REDACTED], and her email address is [REDACTED]. [REDACTED] will answer any questions you may have, guide you (and your youth, if 12 or older) through the Consent and Assent documents, and talk with you about next steps, if you wish to proceed. *Please keep all of those documents until after you've spoken with [REDACTED].*

If you decide not to participate, that will not affect your access to FAST Forward services in any way.

Thanks for considering our request!

Sincerely,

[Coordinator]

FAST Forward System of Care

[contact info]

Appendix B

Consent to Participate in Research

You are being asked to take part in a research study. What you decide is completely up to you. Participation in the research is voluntary.

You (and your child, if age 12 or older) are being invited to take part in this study because you have participated in the FAST Forward program, which aims to improve New Hampshire's system of care for emotionally disturbed youth and their families. Your decision whether to take part in the study will have no effect on your access to the FAST Forward program.

Before you decide to take part in this study, read this form carefully. Feel free to ask one of the researchers about what the study is all about. Feel free to take the time to talk about it with a family member or friend. Please ask questions if there is anything you do not understand.

What is the purpose of this study?

We are a team of researchers from Antioch University New England, in Keene NH. Our job is to help FAST Forward learn what it's like for families to be part of this program.

Here are some of the things we'd like to ask you about:

What was going on in your family's life that prompted you to enter this wraparound program?

What it has been like to work with your facilitator and your wraparound team?

Have you notice and differences in your family's experience since working with your facilitator and your wraparound team?

How much has your wraparound team respected your family's lifestyle and customs?

Are there any benefits from being in this study?

You may not benefit from participating in this study. You may find the interview rewarding. You may enjoy having the chance to reflect on your accomplishments.

We also hope that the information you share may help FAST Forward improve the program for future participating families.

What does this study involve?**If you decide to participate**

- We will arrange an appointment for a 30 minute phone conversation with you. We would like to speak with one parent/caregiver who participated on the wraparound team.

If you permit your child age 12 or older to participate, and she or he chooses to do so

- We will schedule a separate phone conversation with your child, asking the same questions we asked you. It's normal for parents and children to have somewhat different views about events in the family, and we would like to hear both of your perspectives.

What will happen differently if you are not in this research?

If you do not take part in this study, you will not be interviewed about your experience in FAST Forward. Nothing else about your involvement with FAST Forward will be affected by your decision whether or not to take part in this study.

What are the risks involved with being in this study?

We know that some of the experiences we want to ask you about have been hard for your family. It's possible that you would still feel some stress talking about these experiences.

It's quite likely that two family members participating in separate interviews would answer our questions differently. If you talk to each other about your conversations with us, you could become aware of disagreements, and this may trouble you in some way. We don't think it's important for you to agree on an answer – we just want to hear from both of you.

Other important items you should know:

- Whether or not you decide to take part in this study, or stop participating in the middle of it, you will not lose any benefits to which you are entitled. You will not be penalized in any way.

• To withdraw from the study at any time:

You may choose to stop taking part in this study at any time. If you decide to stop, it will not affect your access to the FAST Forward program.

- To withdraw before your interview has taken place, please call [REDACTED], at [REDACTED].
- To withdraw during the interview, just tell the interviewer that you would like to stop.
- To withdraw after the interview, please call [REDACTED], at [REDACTED].

- **Funding:** This study is funded by the federal Substance Abuse and Mental Health Services Administration, which provided a grant to the State of NH to launch the FAST Forward project.

- **Number of people in this study:** We hope to speak with 20-25 families as part of this project.

How will your information be protected?

The information we will collect in this study includes your answers to our interview questions. We will record our phone conversation with you. Later, we will type all that was said in that conversation into a document called a transcript. The transcript will not have your names in it. We will review the transcript carefully to identify what seems most important about your experience. Then, we will erase the recordings. We will keep the transcripts until the end of the study around December of 2016, then destroy them.

We respect and will protect your privacy

Only the Antioch team will listen to your recordings, and we will not tell anyone else which families told us which stories. We will keep your data labeled with only a number, not your name. The name-number code will be kept locked up. This way no one outside the research team can look up your information. We will keep information that identifies you in a separate place

from your interview information. Both will be kept in locked filing cabinets. We will not use your name in any reports written from this study.

Some study data will be kept on computers. These files will be password-protected. They will be kept on computers used only by the research team.

No FAST Forward staff, including your facilitator, will hear the recordings (the Antioch research team works more than 50 miles away from the FAST Forward staff). In any report we write about this project, we will be describing what we learn from *all* of the families together. If we want to use any of your exact words in our reports, we will ask for permission from both the youth and adult first.

Please be aware that all members of the research team are legally required to report suspicion of child abuse or neglect. If anything you tell us during the interview leads us to suspect that a child is being abused or neglected, we are required by law to make a report to the NH Division of Children, Youth, and Families. If you have questions about what would require us to file a report, please ask at any time.

Who may use or see your data?

By signing this form, you are letting certain people use or see your data until the study is done. This means the research team can listen to our recording of your interview, and read the transcript. The research team includes the researcher directing this study plus the Study Coordinator and interviewers, all working on this study at Antioch University New England.

If you wish to have a copy of your study data, you may request a copy of the audio recording before we delete it.

During this study, we may have to give information that identifies you to other agencies. These agencies may not have a legal duty to keep it private. These agencies may use it or give it away for other purposes.

This study is reviewed every year by a group that watches out for the safety of people in research studies. They also watch out to make sure the study is done right. These groups are allowed by law to look at your study data so that they can do their job. Also, any agency that has given the money to do the study can look at your study data. For this study, those groups and agencies are:

- The New Hampshire DHHS Committee for the Protection of Human Subjects at the Mental Health Center of Greater Manchester
- The Federal Substance Abuse and Mental Health Services Administration

There is no guarantee that your data cannot be obtained by a court order or other legal process.

Do I have to let you use my data?

Yes. If you do not let us use your data, you cannot be in this study.

If you choose to stop taking part in this study, you may also tell us not to use your data anymore. You should let us know this in writing. If you want, you can ask the researchers to help you write your request down. The request should be sent to:

██████████
 Antioch University New England
 40 Avon Street
 Keene, NH 03431

We will keep using data we already gathered. We will not gather any more data about you after you make this request.

Whom should you call with questions about this study?

If you have questions about this study, you may ask the study coordinator, ██████████, at ██████████, or the researcher in charge of the study, ██████████, at ██████████.

If you have any questions or concerns about your rights as a research participant, you may call:

- The New Hampshire DHHS Committee for the Protection of Human Subjects at the Mental Health Center of Greater Manchester
- (603) 668-4111 x5301
- 8 am – 5 pm, Mon - Fri.

What about the costs of this study?

There will be no cost to you from taking part in the study.

Will you be paid to participate in this study?

Yes, you will be paid for doing the research interviews. If the parent/caregiver participates in the interview, we will mail you a \$20 VISA gift card. You can use this card anywhere VISA is accepted.

If a youth aged 12 or older participates in the separate youth interview, we will provide her or him a \$10 VISA gift card.

CONSENT

When we speak with you by phone, we will ask whether you feel comfortable agreeing to the following statement:

I have read the above information about the Family Experience of Wraparound study.
 I have been given a chance to ask questions. I agree to be interviewed for this study and I have been given a copy of this consent document for my own records.

If you decide that you do not feel comfortable agreeing with these statements, that is entirely your choice, and we will respect it and thank you for your time on the phone with us.

Verbal Consent received on _____ [insert date] at _____ [time] by

Appendix C

Assent to Participate in Research

You are being asked to participate in a research study. You do not have to be in the study if you do not want to.

This study is to learn what it is like for families to be part of the FAST Forward program.

We would like to speak with you by phone, for about 20 minutes, to ask you some questions about what it was like for you to be part of the FAST Forward program. Some of the things we would like to ask you about are:

What was going on in your family's life that prompted you to enter this wraparound program?

What it has been like to work with your facilitator and your wraparound team?

What has been different for your family since working with your facilitator and your wraparound team?

How much your wraparound team has respected your family's lifestyle and customs?

We will do our best to keep your records private. We won't give any information about you to anyone unless you and your (legal representative) give us permission.

Are there any benefits from participating in this study?

You may not benefit from being a part of the study. You may enjoy telling the interviewer about your experience.

We will send you a \$10 VISA gift card, which you can use at any store that accepts VISA cards.

We hope to gather information that may help other families like yours.

What are the risks involved with being enrolled in this study?

We know that families enter the FAST Forward program because they're having some hard times. Asking you to talk about those times may feel stressful. You don't have to answer any questions you don't want to – just say, "I don't want to answer that."

Your parent said it was OK for you to be in the study, but we also want to know it is OK with you. You can ask questions any time you want to. Do you have any questions?

If you have any questions, you can ask us when we speak with you about this form, or you can call the study coordinator, [REDACTED], at [REDACTED], or the researcher in charge of the study, [REDACTED], at [REDACTED].

Verbal Assent received on _____ [insert date] at _____ [time] by



Appendix D

Interview Invitation Reminder

Dear [Participant Name],

We sent the invitation below a week or so ago. We know these sorts of things sometimes fall through the cracks, so we're sending one reminder. If you want to take part in the interview, please call this week. If you don't want to take part, no need to do anything – we won't trouble you with another invitation.

Thanks!

FAST Forward wants to learn what it's like for families to be part of the program. We're asking for your help.

FAST Forward has teamed up with researchers at Antioch University, in Keene, NH, who will help us learn about your experience. If you decide to participate, the researchers will call you at a time that is convenient for you. They will wish to speak with one parent/caregiver for approximately 30 minutes. If the youth who participates in the FAST Forward project is 12 years or older, they would also like to set up a time to speak with that youth (with your permission).

In appreciation of your time, the research team will offer the parent/caregiver a \$20 Visa Gift card, and the youth a \$10 VISA gift card.

The attached Informed Consent Document provides more details about the project, to help you decide whether you would like to participate.

If you would like to consider participating in this project, please contact the Antioch research team's project coordinator, [REDACTED]. Her phone number is [REDACTED], and her email address is [REDACTED]. [REDACTED] will answer any questions you may have, guide you (and your youth, if 12 or older) through the Consent and Assent documents, and talk with you about next steps, if you wish to proceed. *Please keep all of those documents until after you've spoken with [REDACTED].*

If you decide not to participate, that will not affect your access to FAST Forward services in any way.

Thanks for considering our request!

Sincerely,

[Coordinator]
FAST Forward System of Care
[contact info]

Appendix E

Family Experience of Wraparound Interview Introduction

Hi, I'm [name] calling from Antioch University New England! You scheduled this time for an interview about your experience with wraparound. Are you expecting my call?

Wait for response.

Thank you so much for agreeing to talk with me!

Just to give you a quick reminder, we are doing these interviews so that we can learn from the experience of youth and caregivers involved in wraparound so we can make it better.

During the interview, we will be asking different members of your family the same questions and you may have different perspectives as you answer. It may feel uncomfortable to disagree but know that we don't need you to agree; we just want to hear your perspectives.

During the interview, answer the questions as best as you can. There are no right answers.

You may experience some stress while talking about some of the hard stuff your family has been through. It is important for you to know that you can ask to stop at any time and have your interview withdrawn from the study. This will not affect your access to FAST Forward.

Do you have any questions for me before we get started?

Okay, great! Before we begin the interview, would you confirm that you gave consent/assent for the interview in your conversation with [REDACTED], and that you feel comfortable starting the interview?

Wait for response.

Again, please let me know if you need to stop at any time.

Appendix F

Family Experience with Wraparound Interview Questions

[Begin with numbered questions; use alphabetically labeled prompts beneath each question only to elicit elaboration, as needed]

1. What was going on in your family's life that prompted you to enter this wraparound program?
2. How has your experience with [insert coordinator's name] and the rest of your wraparound team been so far?
 - a. How much have you felt listened to and understood by those on your team?
3. How much has this program focused on the things that are most important to you?
 - a. How much has your team respected and considered your family, your lifestyle, and how much time you have available?
4. What's been most memorable or surprising for you about this process so far?
 - a. Have there been good things that have happened?
 - b. Have there been bad things that have happened?
 - c. If you could change just one thing, what would it be and why?
5. What's been most different for you and your family since beginning the program?
 - a. Is there anything that has been made available to you through FAST Forward, that you did not have access to before?
6. What else is important for us to understand about your experience with this program?

Appendix G

Table 1

Qualitative Data Table

Cluster	Theme	Quote
Initiating Wraparound Services	Child's difficulties with severe and complex mental illness led family to wraparound	I have a child with a number of mental illness diagnoses. He is largely an explosive child and he became explosive at school. Caregiver 1 My oldest daughter had had multiple suicide attempts. Caregiver 3
	Caregivers felt helpless prior to the start of wraparound	Because having to wait, just because I was so broken...I waited until I was broken basically to even try to get help. Caregiver 4
	Experiences varied accessing FAST Forward to initiate services	Actually yeah. We went down for a family night while he was admitted and Fast Forward was there. Wraparound was there. They had [FSS] from NAMI, which I thought was really neat. Caregiver 7 I spent five days at the phone trying to find some help. And I finally got to them. Basically every time I called someone they would be like, "Oh yeah," and I'd end up in the same place. Caregiver 4
FAST Forward Coordinator (FFC) and Family Support Staff (FSS)	The initial phase of FAST Forward was slow	Well no, nothing happened. We had meetings with [FFC] over and over and over and over again. But nothing happened. So nothing changed. Caregiver 1 Maybe a month ago, so they got a really good dose of what was happening. A wake-up call that this is a problem. I think now they have a better outlook on what is going on and is happening and what we are looking at. Caregiver 2
	Characteristics about FFC and FFS	Well, we had [FFC] who, [FFC] was the sweetest, nicest, totally caring individual who you would ever want to meet. Caregiver 3 Yeah, sometimes just getting reassured. Having someone come into the house and reassure that what I tried to do, what I want to do, is okay—that I was not a bad [Caregiver], or someone who makes all the

		<p>the programs that were available were cost-prohibited to the grant. So what good is it if you can't spend so much money on something? Caregiver 3</p> <p>The resource being made available to us. They have resources we can use. Say you're going through a problem. They can help you obtain advice or anything you need. They have another group that comes in that, again, has many valuable resources. Caregiver 2</p>
	Helpful supports and services	<p>But they have kind of an outreach program. They have a lady that comes twice a week, that wraparound set that up, she comes twice a week to take him out and do some community socialization and integration. And they work on some of his coping skills, and I feel like that has helped dramatically. Caregiver 7</p> <p>I think it's most helpful to have them, to have a home-based service where they come into the home. Caregiver 2</p>
	Experience with school system	<p>Nothing was happening in school—they tried to teach her stuff but she was fainting and pseudo fainting. They couldn't help her—they tried. Caregiver 8</p> <p>And her school counselor is wonderful too. The person who was on board—she is—was—another aspect...she's no longer there because we went to a different school. But she's one who also helped her get into the other school. We received a lot of help and it's showing. Caregiver 6</p>
Family Engagement	Family member's impacted by child's mental health needs	<p>It's tough on an old man too, I'll tell ya. Caregiver 8</p> <p>And so our family, my husband, was very stretched for a very long time. Caregiver 4</p>
	FAST Forward supported the entire family	<p>They worked with us, worked with my son, worked with other family members. Caregiver 2</p> <p>So for instance, I have wrap services where I have a therapist in my house five days per week. And I also have a psychiatrist and I have a therapist for me and I have a social worker. Caregiver 1</p>

<p>Program Outcomes</p>	<p>Family participation in the decision making process</p>	<p>Not just parent, parent and child. Not just me as a parent. The way they went above and beyond to include [child] in it as well and say “Hey! This if your thing...let’s see what you want to work on.” So I thought that was really fantastic. Caregiver 7</p>
	<p>Termination of services due to unmet needs</p>	<p>Nothing has happened. Nothing. I ended up terminating the relationship because I’m receiving wrap services somewhere else. Caregiver 1 But soon after that my daughter was placed in a residential placement and those services stopped as soon as she moved out of state. But we are a family that is still in crisis. Caregiver 3</p>
	<p>Successful program outcomes</p>	<p>Oh they were a wonderful help with organizing everything and helping us get everything together to be able to keep [child] at home, in the community, and in school. Caregiver 6</p>
	<p>Attitudes about FAST Forward process</p>	<p>I can’t say I would change anything, honestly. It’s all been good, it’s all been helpful to us. I’ll associate the question toward the FF program, I have to say right off the top of my head. I don’t think there is anything I want to change. Caregiver 2</p>
