2022

Caregiver Experience of Voice and Choice in Wraparound Systems of Care

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CAREGIVER EXPERIENCE OF VOICE AND CHOICE

IN WRAPAROUND SYSTEMS OF CARE

A Dissertation

Presented to the Faculty of

Antioch University New England

In partial fulfillment for the degree of

DOCTOR OF PSYCHOLOGY

by

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April 2021

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Antioch University New England
in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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ABSTRACT

CAREGIVER EXPERIENCE OF VOICE AND CHOICE

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The following is a qualitative study of the caregiver's experience of having voice and choice in the New Hampshire wraparound program, conducted through Keene State College's Behavioral Health Improvement Institute (BHII). Wraparound systems of care emphasize the family's role in directing the generation of a network of supports for intervening with a youth with Severe Emotional Disturbances (SED). Indeed, caregiver voice and choice are key principles of this service delivery model. There are many established benefits to encouraging family involvement in systems of care, but little research to date on the subjective caregiver experience. A review of literature covers the development and program features of wraparound with established outcomes for youth and caregiver, as well as the current knowledge base with regard to family involvement. The BHII team conducted interviews with 15 caregivers who had recently terminated from wraparound. Those interviews were analyzed using Thematic Analysis (TA) to understand the caregiver experience of voice and choice with a pragmatic lens for program evaluation purposes. Results are compiled and explained here with a discussion on implications for the program. This dissertation is available in open access at AURA (https://aura.antioch.edu) and OhioLINK ETD Center (https://etd.ohiolink.edu).

Keywords: wraparound, Thematic Analysis, family voice and choice, qualitative research, systems of care

Acknowledgements

The past four years have been deeply painful and also transformative, as most painful things are. I arrive at the end of this program by the grace of the people who walked with me through it. Profound gratitude goes to my committee: my advisor, Marti Straus, who is simultaneously the most loving and most brutal editor; to Gina Pasquale, my perpetual supervisor, who taught me to take up space; and to Kate Evarts Rice, the wearer of most hats, and the most nurturing ProSem leader. My thanks to Jim Fauth, George Tremblay, and Johanna Wilson-White of BHII, for letting an ambitious first-year student jump on the research bandwagon. My large and loving family held me together in more ways than one; my parents, Mary and Bill O'Neil, encouraged me to put my work and my life together like a quilt, piece by piece; and my siblings: Dan, Meredith, Cullen, Grace, and Linnae—I hope to one day be as brave, brilliant, and beautiful as you all. Thanks to my friend Rae Torres, for her graphic design expertise and spiritual consultation. Finally, I want to acknowledge my gratitude to the families who were willing to offer their experience—and their voices—to this study. Thank you.

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Caregiver Experience of Voice and Choice in Wraparound Systems of Care

Wraparound has emerged as an effective intervention model that puts child trauma and healing in the context of family and community. The goal of wraparound is to build a stronger support network around children and families enabling them to recover from crisis with the ambitious long-term goal of creating lasting positive change on individual, family, and community levels. One key principle of wraparound is the engagement of the family as participants in the evaluation team, granting them "voice and choice" in their own program (Suter & Bruns, 2009, p. 337). Interventions are thus individualized to the family and their culture; as a result, caregivers can be more engaged and empowered. The emphasis on including family members in their program development and evaluation is a unique characteristic of wraparound among available treatment modalities; however, little research is available regarding the caregivers' experience of this added level of involvement. It is notable that while proponents of wraparound believe that caregivers are empowered through participation, they still have much to learn about how caregivers experience the benefits and challenges of voice and choice—or if they experience it at all.

Wraparound has come into the spotlight as one treatment option available for intervening on behalf of children with severe emotional disturbances (SED). SED is defined as a condition in which a child meets the criteria for a disorder as indicated in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) causing significant functional impairment substantially limiting the child's participation in family, school, or community activities (*DSM-5 Changes: Implications for Child Serious Emotional Disturbance*, 2016). Risk factors for SED include exposure to chronic and persistent early childhood adversity including, for example, abuse, neglect, poverty, developmental disabilities, and family dysfunction (Grundle, 2002). In 2016, the Center for Disease Control and Prevention (CDC) recorded 676,000 cases of child abuse and neglect reported to Child Protective Services (*Preventing child abuse and neglect*, 2019); children at risk for SEDs comprise a

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significant population, with profound personal, social and economic costs. In fact, one recent study estimated the US population economic burden of child maltreatment at 428 billion dollars for substantiated cases only due to associated risks; these include costs of short- and long-term healthcare, child welfare, criminal justice, and special education (Peterson et al., 2018). This estimate does not include the intangible costs of trauma to the victim and the community, but notably refers to taxpayer-funded services. One can thus broadly conclude that this is a problem that affects the entire country on a massive scale.

While childhood trauma is undoubtedly problematic and costly, few effective interventions have emerged. Previous models for addressing the disorders associated with traumatic exposure essentially comprised of increasingly restrictive settings, beginning with outpatient care—for example, individual and family therapy, or in-home support, and, when that proved insufficient, out-of-home placement—usually psychiatric hospitalization, residential treatment, or entry into the juvenile justice system. When children and teens exhibited behaviors that seemed too challenging or unsafe for outpatient care, they had to be removed from the home.

Before wraparound was introduced in the 1980s there was no middle ground for treating children with severe emotional disturbances in their home communities; systems were forced to over-rely on the most restrictive and costly settings, usually residential treatment (Bruns et al., 2014; Suter & Bruns, 2009). While residential treatment centers (RTCs) have been the necessary choice in many cases over the years, there remains a certain irony that children with behaviors likely connected to trauma and insecure attachment are then made subject to further trauma from separation inherent in removing a child from the home to live with strangers.

In fact, children with SEDs attendant to complex trauma demonstrate an increased fear of separation and difficulty adjusting to new routines, suggesting that these children suffer greater psychological harm than would a typical child when separated from caregivers—even abusive ones

(Drewes, 2015; Schaefer & Swanson, 1988). A study by Adam et al. found that such traumatic separation registered similarly to an unresolved loss or abuse on a subscale of the Adult Attachment Interview in 49% of adolescents who had been removed from their home. Eighty-two percent of all adolescents interviewed reported already experiencing at least one other incident of traumatic loss, separation or abuse from a caregiver (Adam et al., 1995). Care coordination, like wraparound, presents a more inclusive option to keep children and families together, and a less expensive option for mental health service providers in contrast to RTCs (Snyder et al., 2017).

The focus of wraparound has been the target child within the family. However, while research on the benefit to caregivers is limited, wraparound appears also to ease caregiver burden, relative to other in-home supports. For example, several studies found that wraparound services significantly decreased reported caregiver strain (e.g., Cook & Kilmer, 2010; Painter, 2012; Schreier et al., 2019). Painter found that these benefits persisted at the 24-month follow-up point after terminating from the program. Schreier et al. found that this relative strain was mediated both by the number of meetings and the delay from enrollment to the first meeting. With fewer meetings and a shorter delay, caregiver strain decreased. Interestingly, the caregiver's desire for support was associated with increased strain—wanting help and not getting it made their situation even more stressful. As the caregiver established more connection with resources, the experience of support diminished strain (Cook & Kilmer, 2010). While these studies are useful for generally observing wraparound's benefits to the family, they provide little detail on how caregivers experience support specifically. Notably, too, these studies explore the effect of wraparound on caregiver strain over time; we don't know whether alternative programs or residential placement offer similar alleviation of strain for caregivers.

Wraparound has been determined to be an effective, evidence-based treatment modality for youth with Severe Emotional Disturbances and their families (Anderson et al., 2008; Bruns et al.,

1995; Jivanjee & Robinson, 2007; McCarthy et al., 2016; Painter, 2012). Outcomes of previous studies have generally been positive in terms of mental health benefits to children and reduced cost to the mental health system, although efficacy varies and appears to be contingent on the fidelity of the specific wraparound program to the model and a region's access to a range of family supports and community resources (Bruns et al., 2015; Graves & Shelton, 2007; Suter & Bruns, 2009).

The Case for Wraparound

Defining and Justifying Wraparound

Historically, social service systems working with children and families have relied on institutional placements for children with severe emotional disturbances. These programs are costly and cause additional family stress through fragmentation of services and the separation of children from their parents. There's also very little evidence of any long-term benefits of residential treatment (Knorth et al., 2008). Despite this, a large proportion of children are still being placed in residential programs. One study concluded that, over a two year period, thirty percent of youth identified as having SEDs had been referred for out-of-home placement (Farmer et al., 2008).

In order to address the problem of intervening with SEDs in a cost-effective and family-centric manner, congress funded an initiative in 1984 through the National Institute of Mental Health (NIMH) to establish the Child and Adolescent Service System Program (CASSP). This agency was formed to address the complex, multi-systemic challenges faced by families with a child identified as SED. Children with SEDs often require a range of services including, for example, mental health, special education, healthcare, and social and legal services. On its own, each supporting system may form their own plan of intervention for the child that can be redundant, inconsistent, insufficient and undermining of the other systems—while also further overwhelming already maxed-out caregivers with additional requirements. While well intentioned, such fragmented care typically resulted in poorer mental health outcomes, increased costs, reliance on prescription

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medications, over-use of hospitalizations, competition among agencies, and conflicting information from different providers (Bruns et al., 2014).

Wraparound was developed to address some of the most vexing systemic problems faced by SED children and their families. Mindful of varying regional needs and values, CASSP grants were awarded to the states as a localized, multisystem approach to providing care for youth and families with complex needs. Wraparound particularly emphasizes a strengths-based approach to working with the youth and families, and incorporates family voice and choice to provide individualized, need-based and culturally competent care across multiple agencies (Grundle, 2002). These wraparound principles were developed based on systems and social-ecological theories, focusing on family-centered and strengths-based approaches to healthcare. As such, the implied mechanism of change is the empowerment of families and the strengthening of their connection to various systems. Emphasis on caregiver voice and choice was meant to increase family engagement and commitment to the program, as well as create ongoing communication to create and maintain a coherent plan with a shared vision for all stakeholders (Walker & Matarese, 2011).

Ideally, in an effective wraparound program, children receive all the necessary care from different community systems, including both formal supports (e.g., mental health services) and informal supports (e.g., quality time with a neighbor). The treatment plan is oriented to address the needs of caregivers and the whole family, not only the child with an SED (Bruns et al., 2014). Because it is an intensive program, a trained wraparound coordinator spends time getting to know the family in order to identify priorities and create a tailored action plan designed to integrate services and coordinate communication among helpers. The progress of the plan is tracked and the plan modified over time as necessary (Bruns et al., 2014). One unique attribute of wraparound is the intention to create sustainable systems of support, including natural community resources, that continue following termination of the program in order to put positive change in motion for the long

term. One study found medium to large effect sizes for positive changes to mental health and overall functioning at the 24-month mark following termination from wraparound (Painter, 2012).

The process of wraparound thus creates an individualized network of formal and natural supports for the family which enables the youth to stay in their home community (Mendenhall et al., 2013). The ten core principles of wraparound, or philosophical points which guide practice, are as follows: (a) family voice and choice, (b) a team-driven process, (c) community-based services, (d) cultural competence, (e) individualized and strengths-based services, (f) inclusion of natural supports, (g) continuation of care, (h) collaboration, (i) flexibility in provision of services and funding, and (j) outcome-based services (Mendenhall et al., 2013).

Outcomes

Children involved in wraparound programs have shown improvements with regard to behavioral functioning, school functioning and quality of life (Mendenhall et al., 2013). A meta-analysis of seven studies showed that wraparound has better outcomes than conventional means of service delivery when directly compared, demonstrating significant improvements in living situations, mental health outcomes, youth functioning, reduced recidivism rates, more successful permanency outcomes, and increased academic achievement and attendance (Suter & Bruns, 2009). In a similar vein, a longitudinal study by Anderson, Wright, Kelley, and Kooreman showed that the average youth's strengths rating using the Behavioral and Emotional Rating Scale (BERS), a measure of behavioral and emotional strengths, had increased from below average to average by six months; the average level of functional impairment associated with SED improved from clinical to borderline by 36 months, demonstrating steady improvement over time irrespective of age, gender, or race (Anderson et al., 2008). Another longitudinal study with slightly different results, concluded that no significant gains were made *until* the 12–18 month marks, but following that point all measures

showed improvement in youth behavioral and emotional strengths, mental health symptoms, and caregiver stress (Painter, 2012).

Despite these positive results, measuring outcomes of wraparound programs has continued to present a challenge for several reasons. First, we cannot establish that encouraging outcomes can reasonably be attributed to the entire wraparound process and not just to individual interventions within the process. Second, in part by intention, there is no universal protocol for implementation of wraparound, nor single method of assessing fidelity to the program's guidelines; thus, variability inevitably exists among programs even within states. Third, wraparound programs serve broad populations of youth and families with a vast spectrum of complex needs and challenges. As such, the variability among wraparound families makes generalization about outcomes extremely difficult. With these qualifiers in mind, additional research is needed to better understand outcomes from wraparound and the precise qualities of the program that contribute to positive outcomes.

Community Benefits

In addition to the individual benefits of wraparound for families and youth, this and similar systems of community-based care presented a more cost-effective option than residential care for treating youth with SEDs who typically require services from multiple agencies. For example, one study found that the nine percent of youth categorized as SED were utilizing 48% of all state mental health resources (Bruns et al., 2014). Wraparound's coordinated care services also reduce the rate of hospitalization for youth, and decrease patient spending for up to a year after participation, according to Snyder et al. (2017). Additional research and support of wraparound may contribute to increased use of the intervention in communities as it gets recognized as a more effective intervention with a lesser financial burden than other intervention strategies.

Wraparound can also potentially have positive impacts for communities in the long term. In a study by Stroul and Manteuffel (2007) of communities that were as much as five years past the

completion of federal funding for wraparound programs, services for SED youth had actually increased in availability. Local behavioral aide services, transition services from residential treatment to the community, medication monitoring, and substance abuse treatment all had increased their capacity to serve the community from the grant period—although some supportive services decreased in capacity without the federal funds that came with wraparound services (Stroul & Manteuffel, 2007).

In addition, these communities reported a sustained ability to implement components of the wraparound philosophy, particularly around involving families in treatment decisions and greater cultural competence in service delivery. Following the grant period, local services were able to maintain focus on goals of keeping care within the community and children in the least restrictive environment. While there were numerous challenges to sustaining strong systems of care, including, for example, broader economic concerns and changes to elected officials, aspects of the program left lasting benefits (Stroul & Manteuffel, 2007).

Fidelity

Studying outcomes and comparing wraparound programs has proved challenging as, despite the establishment of core principles, a wide variability exists in implementation across programs. The integration of support systems varies with the region, the local organizations, and available resources. Wraparound is thus necessarily interpreted within the context of local communities rather than adhering to the national model. As such, making outcome attributions to the overall wraparound program becomes very difficult (Mendenhall et al., 2013). Studies show that establishing treatment fidelity while maintaining a flexible localized approach is difficult, but ultimately the standardization of training and ongoing assessment of the local program can help maintain that fidelity (Mendenhall et al., 2013). Poor fidelity to a particular program is actually associated with poorer outcomes for the

youth; it is thus important that states and communities attend to issues of local standardization (Bruns et al., 2015).

The Importance of Family Involvement

Rationale and Outcomes

Active family involvement and the elicitation of feedback from youth and caregivers is a core principle of wraparound that sets it apart from other service delivery models. A number of studies have supported the many ways in which family involvement is necessary for an effective wraparound program. For example, in one study, a strengths-based approach incorporating family input was found to reduce subjective caregiver strain (McCarthy et al., 2016). Empowering families in a similar high-fidelity program predicted positive change in the youth's mental health outcomes (Graves & Shelton, 2007), while a program focused on the child's strengths encouraged cultural responsivity, family collaboration, and positive mental health outcomes (Fallon & Mueller, 2017). Finally, Painter, Allen, and Perry also found that good rapport between the family and wrap coordinator was a necessary precondition for program efficacy (Painter et al., 2011). The wrap coordinator's ability to facilitate a positive working relationship with the family thus encourages their participation and engagement and enhances the overall quality of the program, which is reflected in positive outcomes for the target child as well as the family as a whole.

Family Roles in Wraparound

Incorporating the family voice in service delivery represents a shift from directive models in which the individuals served take a passive role and are simply recipients of care. In moving toward a family-centered approach, wraparound team members each strive to assume an articulated role that reflects the particular family's and community's needs (Jivanjee & Robinson, 2007). Indeed, the results of one study found that engaging families as articulated and valuable members of that team in collaboration with coordinators served as an investment to improve the structures, processes,

relationships and value of the wraparound system (Ferreira, 2011). In this exploration caregivers were included at multiple levels, from decision-making with the wrap coordinator to membership on a governing board for the organization where the caregiver members served as equal contributors. In some cases, individuals filled paid positions to do so. Walter and Petr (2011) argue that, in the absence of such administrative positions, family members should receive sufficient training to become their own resource coordinators following termination of wraparound services, in order to sustain progress over the long term. As a result of such training, for example, caregivers in wraparound learn how to become better educational advocates for their children; they begin to see themselves as partners with the school. They become more involved in their child's education and begin to bridge the power gap between schools and families (Walter & Petr, 2011).

The quality of relationships among families, schools, and other involved services hinges in no small part on the degree of caregiver engagement (Stefanski et al., 2016). These researchers explored the continuum of family involvement ranging from passive service delivery at one end, to the inclusion and engagement of parents in the process, to the empowerment of parents to become active in community development roles at the other end. They noted, too, the potential burden that greater engagement may place on families and the systems that encourage it. In general, however, creating trusting, engaged partnerships with families ultimately led broadly to positive outcomes with regard both to student learning and family empowerment (Stefanski et al., 2016).

Family Feedback on Process

Family involvement in systems of care has been established as a critical component and precondition for progress in youth with SED. The purpose of caregiver involvement at the evaluation level serves to increase the relevance and cultural appropriateness of the intervention, to improve the quality of the data, and create more generalizable findings that may then be applied in other contexts (Jivanjee & Robinson, 2007).

Since 2003, systems of care have been required to include family partners in the development and evaluation of programs (Jivanjee & Robinson, 2007). A study which surveyed 37 different sites found that family participation in the evaluation process was perceived by stakeholders to improve the quality of data and services provided. Some studies have even included parent partners as interviewers in the evaluation process (Osher et al., 2001). However, studies have largely focused on caregiver perceptions of relative strengths and weaknesses of the program, rather than the qualitative experience of receiving services. In particular, no available studies seem to have explored the caregiver experience of voice and choice, and whether the principle has in practice served its intended purpose of higher quality care or the empowerment of the caregiver.

Defining the Problem

Evaluation has demonstrated wraparound to be a promising and effective system for addressing severe emotional disturbances in youth. Though caregivers are key stakeholders, they do not typically play a central part in the program evaluation. Given the intentional and effortful inclusion of caregivers in the wraparound process, remarkably little research exists to understand the specific benefits of their contribution, both their contribution to the family and to the program as a whole. If caregiver voices are valued in the shaping of a local program, they should similarly be valued in the evaluation of that program.

Significance

Currently, there is little research directly exploring caregivers' perceived experience of voice and choice and its benefits to the process or caregiver. Although interventions in wraparound include services for all of the family members, outcome research to date focuses largely on its impact on participating youth. However, wraparound is meant to support the whole family—not only the youth—to create a more stable and healing context for all. Exploring the impact of wraparound on the caregivers seems particularly fruitful considering the fact that they are in a unique position as

both the beneficiaries of, and participants, in the intervention.

A qualitative study is well-suited for tapping into the complexity of a family's experience in the context of socioeconomic and systemic challenges, mental illness, the range of family stressors and presentations, and myriad other factors that might be salient to understanding a particular family's view of wraparound. In investigating the experiences of caregivers, who are simultaneously participants and beneficiaries of the program, program evaluators gain a rich source of information on the specific components of the wraparound that were most effective for them. In focusing program development on these components, wrap coordinators may make the greatest long-term difference in assisting a family to co-create lasting change. The purpose of this research was to explore, via semi-structured interviews and qualitative analysis, the caregiver's experience of voice and choice in wraparound, to better understand their lived experience of it, as well as to gain perspective on its benefits and drawbacks.

Research

Research Questions

As a component of a larger program evaluation engaging caregivers in open-ended interviews about their experiences, this study sought to answer the following research questions:
(a) How did caregivers experience voice and choice in the wraparound process? (b) What do wrap coordinators specifically do to allow caregivers voice and choice in the process? (c) What challenges did caregivers experience with regard to having voice and choice? and (d) How might eliciting feedback from the caregivers about their experiences in wraparound benefit them?

Researcher's Perspective

I approached this dissertation with a background in special education and nearly a decade of working with youth and families in school settings using a team-based approach. Conceptually, I am oriented toward family systems and attachment theories with regard to understanding how symptoms

manifest in children and adolescents. From this perspective, I believe that traumatic experience is like a ghost that haunts the entire family, leading to rippling repercussions in the mother–child attachment and the overall family dynamic, and the likely creation of new traumatic experience in the children. I believe that treating the child in isolation and seeking to understand only the impact of an intervention on the child independent of the family dynamic is insufficient to address the greater problem. The family trauma remains toxic to its members until the system as a whole is treated.

Wraparound is a more comprehensive approach to treating and healing the whole family system in a manner that teaches family members the skills and community to address future problems. I imagine that the family learns, through the community support built through wraparound, that they are not alone and have adequate resources to harness their own dynamic, patch holes in damaged relationships in the family system, and strengthen attachments as investments in overall family wellbeing, embedded in community and culture. I have a particular interest in wraparound as a model of intervention that seeks to address the core of an issue by conceptualizing a problem in the context of overall family wellbeing. As such, I have a strong bias toward wraparound as an alternative to approaches currently in practice. I tried to bracket this bias during analysis in order to be more objective in my interpretation of the data.

Methodology

Research Methodology

For this study, I approached the research questions using Thematic Analysis (TA) as a qualitative manner of understanding caregivers' unique experiences of voice and choice in the wraparound process. While "thematic analysis" as a term has been broadly applied to a range of different approaches, Braun and Clarke (2006) argue for TA as a method in its own right without strict commitment to a particular ideology. Rather, one of the method's strengths is in its flexibility as an active approach to identifying patterns and providing a rich and detailed narrative of the data

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compatible with multiple paradigms. For the purposes of this research, TA was used to provide a nuanced account of a particular theme within the data set: *the caregiver's experience of having voice and choice in their wraparound program.*

Analysis came from an inductive essentialist perspective in order to understand the experience, motivations, and meaning of the participants, allowing their responses to shape the themes. While I hoped that participant responses would speak for themselves, I searched in part for latent themes to understand underlying ideas or significance. Data analysis incorporated a recursive process of moving back and forth between data items and data set to create a consistent and coherent extraction of themes that generate a rich narrative of caregiver experience. In this case, analysis was guided by a pragmatic paradigm, as the results of this study were used for evaluation of the wraparound program. As such, data were interpreted and research decisions made in such a way as to be most useful to stakeholders (Mertens, 2020).

Research Setting

This study was conducted in the context of the Behavioral Health Improvement Institute (BHII) based at Keene State College. BHII conducts program evaluation and consultation within the local communities to improve behavioral health for underserved populations. BHII formerly operated through Antioch University New England as the Center for Behavioral Health Innovation. I was a research assistant on this team for two academic years, and participated in the first round of data collection in that role. In the second round of interviews, occurring in the spring of 2020, I assisted by recruiting participants, completing the informed consent process with those participants, and conducting 50% of the interviews as a volunteer intern with BHII. While the interviews will be qualitatively analyzed separately by the BHII team, I conducted my own analysis of the feedback related specifically to voice and choice for the purposes of program evaluation and for this dissertation project.

Participants

This study recruited individuals who had recently terminated participation in the wraparound program through the Monadnock Region Systems of Care as caregivers of children with Serious Emotional Disturbances. In this case, *recent termination* was defined as "within one year," and pertained to families who had engaged in at least five wraparound meetings to ensure adequate exposure to the program. Reasons for termination may include successful completion of the program, long-term out-of-home placement, or early termination due to dissatisfaction, as well as other unforeseen issues. While approximately 100 families enrolled in the New Hampshire wraparound program, 33 families transitioned out of the program during the research period. Of those, the team elected not to contact eight families due to one of three reasons: (a) several families had siblings in the program, some of which were still participating; (b) several families had not attended enough meetings, thereby not meeting threshold for an adequate "dose" of Wraparound; and (c) three cases transitioned out of wraparound after the data collection period had ended. BHII ultimately reached out to 25 families in the southern New Hampshire area. We were able to interview 15 caregivers for this study, for a response rate of 60%.

For the study conducted by BHII, demographic data were collected primarily to understand the Wraparound experience of the youth, rather than that of the caregivers. Of the 15 caregivers interviewed, three were adoptive parents and two were custodial grandparents. Six children were cared for by their biological mothers in a single-parent household. Four households contained two parents with at least one biological parent. Eighty percent of the youth in the program were white-identifying with 13% identifying as mixed-race and one participant declining to respond. At the time of the interview, youth age ranged from 10 to 19 years, with a mean of 13.9 years. Attention Deficit/Hyperactivity Disorder (ADHD) was the most common diagnosis for youth in the wraparound program, occurring in 10 cases. Other common diagnoses include Oppositional Defiant

Disorder and Depression (four cases each), as well as Anxiety, Post-Traumatic Stress Disorder (PTSD), and Disruptive Mood Dysregulation Disorder (DMDD) (three cases each). Other diagnoses included Reactive Attachment Disorder, Bipolar Disorder, Borderline Personality Disorder, Autism Spectrum Disorder, Intellectual Disability, and Adjustment Disorder. Twelve of the youth had more than one diagnosis. Reported family income was greater than $50,000 per year in seven of the caregiver's households (47%). The remaining seven (47%) who chose to report indicated a yearly income of less than $25,000, with three families reporting less than $15,000 per year. One family chose not to report their income.

Procedure

Following termination of the program, caregivers received a letter informing them of the study (see Appendix A). A member of BHII contacted those caregivers by phone to invite participation and undergo the informed consent process in order for them to fully understand their participation in the study (see Appendix B). If caregivers agreed to participate, they had the opportunity to arrange a phone interview at a time convenient for them. This second phone call began with confirmation of verbal consent and consisted of a semi-structured interview (see Appendix C). Questions for the interview were crafted by the BHII team and edited by a family partner—a caregiver who had previously experienced the wraparound program for her own child and family. Interview questions inquired about a range of topics regarding the caregiver's experience of the benefits and drawbacks of wraparound. For the purpose of this dissertation, however, two interview questions were most salient to my project:

1. "Family voice and choice is key to wraparound. What was your experience of voice and choice in the program?" This includes a sub-question: "How much did you feel valued and supported?"

2. "What prompted you to interview today?" This includes a sub-question: "What was it like to discuss your experience of wraparound in this interview?"

These questions were standardized across interviews; caregiver responses provided the data for the thematic analysis to address my research questions. Interviews took between 7 and 75 minutes each. They were conducted by doctoral students—including me—who have been trained in human subjects' research and clinical interviewing. Interviews were audio recorded using external recorders and stored using HIPAA-compliant practices on a secure database. While the above questions were specifically designed to evoke responses related to the research questions, the entire interview was analyzed for themes relating to the family's experience of voice and choice, self-advocacy, and decision-making. Themes and the analytical process were reviewed and validated by a peer also trained in thematic analysis at both the code and theme levels. The resulting themes were compiled to provide a broad contextual picture of caregiver experience.

Data Analysis

For this study, I used a Thematic Analysis (TA) approach to analyze the resulting qualitative data from interviews and to determine common themes of caregivers' lived experience. While this process can be flexible in response to the questions and the researcher, I analyzed the transcribed interviews following steps in the order described by Braun and Clark (2006): (1) Familiarization with data, (2) Generate initial codes, (3) Search for themes, (4) Review themes, (5) Define and name themes, and (6) Produce report.

Throughout this process I also kept a journal of my thinking in order to bracket biases and maintain a level of interpretation that remained true to the caregivers' voices while uncovering latent themes as well. I had considered including interviewing behaviors as an in vivo source of data regarding caregivers' experience of voice, but ultimately opted not to code beyond the transcribed interview in order to focus the scope of the analysis. I was also concerned about establishing a fair

and useful system of coding for interviewing behaviors that would not essentially become a judgment of personality traits or communication skills from a very limited sample of behavior. This additional layer of data collection may well present an opportunity for future research, however.

Familiarization with data refers to researchers immersing themselves in the data in order to gain an understanding of both the depth and breadth of the responses. This can begin with transcription of audio material, reading and re-reading text information, and taking notes on initial interpretations. In this case, I had conducted many of the interviews and had some beginning familiarity. I then listened to all of the interviews and took some general notes on points of interest. I then transcribed each of the interviews verbatim and took notes on the transcription. In particular, I was looking for commonalities across interviews, outlying experiences, and how caregivers defined "voice and choice" to describe their own experiences. When caregivers in this study were asked about their experience of voice and choice, they generally described one or more of the following components: feeling heard and understood, playing an active role in a team process, and personal empowerment. As a result, I prioritized those portions of the interviews that discussed these ideas. I then checked in with the BHII team to inform them of my direction and thinking, and to validate the degree to which I was interpreting caregiver words.

Generating initial codes involves identifying interesting features of the data in either semantic or latent content. The initial codes represent the most basic element of data analysis. In order to generate basic codes, I reviewed the transcription and highlighted the portions that were relevant to my research questions and the definitions generated by caregivers. I then used my notes to create codes that captured the essence of each separate comment. I stopped here to allow a peer, also trained in thematic analysis, to review my codes for dependability, credibility, and confirmability.

Searching for themes requires codes to be reviewed broadly for common themes in which to "house" the codes. This process is complete with an initial collection of candidate themes and sub-

themes. *Reviewing the themes* exercises the recursive nature of the analysis process, in which themes and codes are refined both at the level of coded extracts and in relation to the entire data set. The goal is to make sure the themes can accurately represent the meaning of the interview responses as related to the interview questions and redistribute or re-write themes as necessary. For my purposes, I printed and cut out each separate code to physically group them by common theme and sub-theme, resulting in 4–10 codes per theme. I also kept outlying codes that nonetheless seemed to represent a significant experience. While using a concrete method to sort codes allowed me to see them all at once and move them freely for easier grouping, I compiled sorted codes and themes into a color-coded document to be reviewed by a peer researcher, again for dependability, credibility, and confirmability.

At this point, the *themes are "defined and refined"* in step five, in which the researcher identifies the essence of each theme and determines which aspect of the data each theme is capturing (Braun & Clarke, 2006). This process allows the researcher to understand the story of each theme and how it integrates into the broader story of the interviewee's experience. I grouped my themes according to research question and shifted groupings based on peer feedback and in order to most effectively provide information back to the program.

According to Braun and Clarke (2006), the story generated by these themes should be *compiled into a final report*, resulting in a multidimensional representation of how the caregivers interpreted their experience. This serves to deepen our understanding of the elements of wraparound that were most meaningful or, alternatively, where support was particularly needed, in order to channel resources and time where they might be better utilized. In addition to this dissertation, I created a series of idea maps, a two-page concise report (see Appendix E), an infographic (see Appendix F), and a virtual presentation of my findings. These were offered both to the BHII team and the team at Monadnock Region Systems of Care in order to capture and communicate the

experience of caregivers, affirm the work of wrap coordinators, and offer feedback to more effectively support voice and choice in their work with families.

Considerations for Data Quality

While qualitative research presents many natural advantages to this study, the constructivist nature of the process necessitates some consideration to ensure the quality of the data collected, even with a pragmatic paradigm. This approach stands in opposition to that of the postpositivist which dwells in the realm of the observable, the knowable, and the objective. Rather, a constructivist approach assumes that an individual's reality is socially constructed and therefore highly contextual and subject to change. Thus, in order to draw reasonable conclusions about the common and disparate experiences of caregivers in wraparound, I considered three standards with regard to both data collection and analysis: dependability, credibility, and confirmability; these standards essentially mirror the quantitative qualities of reliability, validity, and objectivity (Mertens, 2020).

Dependability. This standard refers to the qualitative equivalent of reliability, in which change is expected, tracked and documented by the researcher. While consistency and standardization are the mainstays of a postpositivist value of reliability, these qualities are limiting in qualitative research in terms of how subjects are able to present their experience. Rather, data might be considered more dependable when interpretations are conducted by individuals immersed and collaborating within the context, when interpretations themselves are grounded in that context, and when data are integrated to create a more holistic picture of experience (Mertens, 2020).

In order to ensure dependable interpretations, I fully immersed myself in the pool of data prior to beginning thematic analysis of interviews. As a research assistant previously, I had the opportunity to perform evaluative tasks for wraparound in other capacities which might be considered an advantage here, as it created a foundation for understanding the context in which wraparound occurs. Following immersion, I analyzed data with attention to how each case might

inform another, in order to create themes across cases and find common and disparate elements of experience from a holistic perspective. I also collaborated and discussed themes with peers and supervisors in order to ensure the integrity of my interpretations.

      Credibility. This refers to possible gaps between the ways in which a subject perceives social constructs and the way a researcher presents their viewpoint (Mertens, 2020). In other words, it refers to whether the reader can reasonably trust the researcher's interpretation. Credibility can be compared to the postpositivist quality of validity, and might be strengthened in qualitative research through prolonged and substantial engagement, persistent observation, peer debriefing, negative case analysis, progressive subjectivity, member checks, or triangulation (Mertens, 2020, p. 426). Given that this research was with archival data and in tandem with an existing study, several of these options were not available for the purposes of this study. However, I used peer debriefing and progressive subjectivity checks in order to develop distance from my own assumptions and biases. In addition, I included several cases in which the participant was not satisfied with the outcomes of wraparound. This negative case analysis presents an opportunity to provide a counterbalance and additional rich context to the overall interpretations.

      Confirmability. The qualitative equivalent of objectivity, confirmability seeks to ensure that the interpretations are not a reflection of the researcher's assumptions, but can be confirmed by similar research. While strict quality standards are considered limiting and perhaps impossible, each researcher is left to make their best judgment as to what constitutes appropriate validation of interpretation. This might be accomplished in collaboration with peers or through an audit of interpreted themes. In this case, immersion in, and connection to, the data are considered a strength which yields more accurate information than the alternative.

      With the understanding that all research and its conclusions are, in some capacity, a reflection of the researcher's beliefs, several measures were taken to increase confirmability. For one, I enlisted

the help of an external auditor to review my interpretations of the data. Secondly, I engaged in a self-reflective process of bracketing biases, as described in Smith et al. (2009), in which assumptions or biases are consciously set aside so that the researcher might interpret data with greater openness. One method for recognizing and bracketing assumptions is through reflection via journaling during the interpretive process. Another is the exercise of comparing part to whole and vice versa, in a hermeneutic circle of interpretation. Each subject represents a component of the holistic experience of being a caregiver in wraparound. By flexing between the individual and the group perspectives, and between the researcher's broad assumptions and the respondent's individual experience, the researcher is better able to create confirmable interpretations (Smith et al., 2009).

Ethical Considerations

This study was designed with deep respect for the caregivers willing to participate, as well as the experience they were able and willing to share. In order to best protect our respondents, a number of safeguards were put in place. Overall, each member of the research team that conducted interviews was trained in research with human subjects and clinical interviewing skills in order to manage any distress that might arise and to allow the subjects to discontinue if they felt it was appropriate. Other ethical considerations are described in greater detail below.

Confidentiality

As is standard in research with human subjects, each of our respondents' identities were protected using multiple measures. Each family in the wraparound system was given an identifying number to use in lieu of names. All personally identifiable information was stored in a HIPAA-compliant cloud-based system. Interviewers on this project were trained in privacy practices for research on human subjects and take precautions to protect the identities of those interviewed, including conducting the interview in a private location. Interviews were stored on external audio recorders and uploaded to the secure database. All interviews were deleted following data analysis.

Information taken from interviews was then subject to thematic analysis which was reported in aggregate. As a result, no specific or identifiable information was reported in the final product for BHII or for this dissertation, including direct quotes, providing an additional measure of privacy to the participants.

Informed Consent

Each participant in this study underwent an informed consent process prior to engaging in the interview (see "Appendix B"). Following termination from wraparound, caregivers were contacted via phone to gauge interest and obtain consent. Caregivers were informed as to the purpose of the study, the intended results of the study, what would be required of them, and the possible risks and benefits. These included possible distress resulting from discussing their family's experience, but a possible benefit of having an opportunity to reflect on and share their experience. Candidates then gave verbal consent over the phone and a consent form was signed on their behalf by the research assistant. Consent was then additionally confirmed in the second phone call prior to beginning the interview. Verbal consent was deemed appropriate and sufficient for this case, given minimal risk of harm and in order to prevent additional inconvenience to the caregiver.

Results

Overview

For this project, and consistent with my qualitative methodology, I allowed caregivers to define "voice and choice" in their own terms and I analyzed the data accordingly. Thus, for this study, *voice and choice* was understood as the processes in wraparound that (a) allowed caregivers to feel heard and understood, (b) included caregivers as an active member of the team, and (c) prioritized caregiver empowerment. Results are organized to answer the research questions. Data are reported here in terms of themes and sub-themes. In order to protect caregiver privacy, and in accordance with the informed consent agreed to by caregivers for the original study, I did not report

direct quotes from caregivers. Rather, I used the analysis to tell a story, in aggregate, of caregiver experience with support from codes.

RQ1: How did caregivers experience voice and choice in the wraparound process?

When asked this purposefully broad question, caregivers responded in a variety of ways. Many responded with stories of specific events that allowed them to experience voice and choice; these responses generated our working definition of the term while contributing to the second research question. For the purposes of this study, "voice and choice" was defined as the experience of being heard and understood, of being a part of a team, and/or being empowered in wraparound. Some caregivers discussed how they experienced voice and choice at the time of the program, while others described the lasting impact those experiences had on them and their families. See Appendix D for the entire table of themes.

Having Voice and Choice was a New Experience

This theme did not contain any subthemes. Five caregivers reported that having voice and choice was a new experience for them, which could be challenging to adjust to. In particular, they reported that having an empowered voice in meetings and being given choices felt unfamiliar to them.

Positive Experiences

Voice and choice was a positive experience. Caregivers overwhelmingly reported positive experiences of having voice and choice, even given challenges that arose. Caregivers described examples of positive experiences such as feeling heard and understood and being treated as an active member of the team.

Voice and choice felt empowering. Several caregivers described feeling empowered in the wraparound program. Caregivers noted that the program allowed them to clarify their priorities and

gave them the tools to act on them, putting the caregiver in a role to effectively manage difficult situations.

Negative Experiences

Voice and choice created additional burden in some circumstances. This is the only sub-theme in this category. For this series of interviews, participants reported several ways in which voice and choice could be experienced as burdensome, particularly with regard to feeling overwhelmed, worrying about maintaining family roles and boundaries as a caregiver, and the challenge of articulating painful life events. While common experiences include the challenge of making decisions when overwhelmed, many of the negative experiences were notably the result of individual circumstances and represented unique views in this study.

For example, a few participants described ways in which the wraparound program was not a good fit for their family's unique circumstances. Some described negative experiences when the community did not have supports available that the family expected or needed at the time of intervention, and/or a family needed more intensive intervention than wraparound was able to provide.

Empathy and Acceptance

Feeling heard and understood allowed caregivers to experience voice and choice. Caregivers primarily described their experience of voice and choice as feeling heard and understood by team members. A majority of caregivers responded to the interview question speaking about the empathic responses they received from their wrap coordinator, family peer support, and team as a whole. This perspective further enriched the working definition of voice and choice. Several noted that this experience of feeling heard and understood was unique to wraparound, and that they had not experienced this with other services, such as case management or school programs. Conversely, sometimes caregivers expected to be heard in order to support their role in the team and did not, as

with one code, "Caregiver felt they did not get voice and choice when the team did not hear and understand them." It is important to note in this divergent finding that "the team" refers to team members other than their wrap coordinator.

Caregivers felt connected to others when their voices were received without judgment. In addition to feeling understood, caregivers also reported feeling a sense of community through their experience of voice and choice. This experience stands in opposition to a reported feeling of isolation resulting from their circumstances prior to wraparound in which they were tasked with managing family crisis alone. For some, the opportunity to share their experience with the team facilitated feelings of both empathy and community. Sample codes include, "Caregiver felt less isolated when they felt valued by the team" and "Caregiver felt as though they were able to speak openly and without judgment."

Team Process

Caregivers experienced voice and choice when able to take an active role as a part of the team's collaborative problem-solving process. The caregiver's inclusion as an active member of the team process was experienced by all of the participants as an important component of having voice and choice. Caregivers spoke to the shift in their participation in service delivery from passive to active as they were expected to speak up and share their opinions, and have their perspectives taken seriously. Caregivers described experiencing a sense of agency and a faith that the team would work together to address challenges that arose. They spoke to the benefits of hearing a variety of perspectives on the team and having multiple people to whom they could bring concerns.

Caregivers experienced voice and choice as allowing them to take on an advocacy role for their child. Caregivers described opportunities to participate as an active team member as allowing them to advocate for their child. In some cases, this advocacy further allowed them to

overcome challenges with the wraparound program. One caregiver indicated that they had not previously had opportunities to advocate as they did in the program.

Flexible scheduling allows family to feel their needs are respected. Scheduling meetings came up as a challenge and also as a concrete way for wrap coordinators to respect caregiver time and contributions to the team. Four caregivers reported that scheduling meetings according to their needs allowed them an experience of voice and choice. In interviews, some caregivers described needing to reschedule as a result of family crisis or overwhelming responsibilities, so flexibility in this regard represented the program's ability to prioritize and adapt to family needs.

Caregivers felt their experience of voice and choice was enhanced when the youth's voice and choice was also prioritized. Finally, several caregivers spoke to wraparound's inclusion of youth voice and choice as a key element of the program and an important part of their own voice and choice experience. One caregiver noted that they experienced their needs as being met when their youth felt heard. Several caregivers felt that the enhanced communication in their family facilitated by shared voice and choice led to observable progress toward their family's goals. However, this was not universally experienced as positive. One caregiver remarked on their experience that sharing voice and choice with their child was actually detrimental to clear roles in the family; they worried that the coordinator would prioritize the youth's voice over the caregiver's voice, leading to a minimization of the parental role.

Decision Making

Decision making can be overwhelming, especially with limited choices available. The opportunity to help make decisions represented another clear element of caregivers' experience of voice and choice, in line with their role as an active team member. Notably, however, many caregivers felt that needing to make decisions on behalf of their family was overwhelming at times, especially when choices were limited or confusing.

Caregivers experienced voice and choice when they could make decisions without feeling pressured. Caregivers described how team members were able to help them think through possible choices without judgment or pressure. As a result, caregivers felt empowered to have the final say on what their families needed.

Empowerment

Caregivers experience voice and choice as having lasting impact in terms of personal empowerment. While many of these themes speak to the caregivers' experience of voice and choice at the time of the program, the five sub-themes included here also describe longer-term effects of voice and choice following termination.

Caregivers felt that voice and choice helped them become more effective advocates for their children. Caregivers felt that this process allowed them to become more effective advocates for their child, particularly in school meetings or with outside agencies. Caregivers described feeling more confident in voicing their needs outside of wraparound meetings. Caregivers felt that their ability to better articulate their needs led to more positive outcomes for their child, and described feeling more confident in challenging the opinions of professionals in those meetings in order to get their child's needs met. In some cases, caregivers described feeling more comfortable serving as their own coordinators following termination, as they became better able to evaluate resources in their community and ask for help.

Caregivers felt more confident and able to trust their judgment. Caregivers described voice and choice as providing them with opportunities to build confidence in themselves, both individually and as parents. Wrap coordinators and family peer supports encouraged them to trust their knowledge and judgment, which became a lasting benefit of the program for several participants.

Voice and choice led to caregiver's personal growth. Three caregivers reported that their experience of wraparound contributed to their own personal growth. They describe making changes in their career trajectory and personal choices, as well as adopting a more positive mindset as a direct result of the program.

Caregivers associated voice and choice with improved family communication. Several caregivers reported that having voice and choice in wraparound directly contributed to enhanced family communication and relationships. Caregivers described ongoing benefits to their communication patterns as a family, which allows them to better understand one another. Several named the strengths exercise, a task facilitated by wrap coordinators fairly early in the process, as a powerful activity that strengthened their relationships as a family. This represents a skill that follows caregivers and families long after wraparound had ended.

RQ2: What do wrap coordinators specifically do to allow caregivers voice and choice in the process?

Wrap coordinators undergo rigorous training in order to best support families in the wraparound program, with emphasis on the ten key principles (Mendenhall et al., 2013). However, there is little specific instruction on how to provide an experience of voice and choice, particularly in light of the context-specific challenges that caregivers face when given a more active role in the program. The following three themes describe the activities that caregivers perceived to be most helpful in granting them an experience of voice and choice.

Responsiveness to Caregiver Needs

While team members were often helpful in managing a variety of challenges, caregivers spoke to the ways in which their wrap coordinators and family supports were able to read and respond to unique family needs in a particularly skillful manner as making a larger impact on their

progress. This theme includes six sub-themes that outline how team members were able to accomplish this.

Wrap coordinators support caregiver choice by creating an atmosphere of nonjudgment. Skillful wrap coordinators were able to shape a process conducive to meeting caregiver needs by first creating an atmosphere of nonjudgment that allowed caregivers to feel comfortable sharing information and engaging meaningfully in the process.

Caregivers trusted wrap coordinators who went out of their way to respond to caregiver requests and respect family culture. Wrap coordinators demonstrated respect for family culture by following caregiver rules and house norms, such as removing shoes before entering the house, and by making a point to respond to caregiver messages or phone calls. These habits arguably set a foundation for an effective wraparound process that allow caregivers to feel valued and welcome as a part of the team and facilitated effective engagement.

Wrap coordinators respect caregiver time and experience by allowing them to set priorities. Caregivers reported that they felt heard and respected as a team member when they were given license to shape the priorities of the team and to set the pace of the process. Some caregivers noted that they appreciated input from the team regarding issues to address as their own concerns were prioritized.

Wrap coordinators set the stage for caregiver voice and choice by shaping team and meeting structure. Wrap coordinators were able to take more concrete steps that created experiences of voice and choice when they assisted in shaping a team and meeting structure that reflected the discussions that needed to occur. Caregivers described the ways that wrap coordinators were able to alter the length or structure of the meeting to suit family needs.

Wrap coordinators and team make decision-making more manageable by employing specific support strategies. Wrap coordinators were able to assist with the difficulty of decision

making by offering structure and support in that process. Caregivers reported that their coordinators assisted by offering smaller choices, by offering more time to make bigger choices, by thinking through outcomes together, and offering the caregiver access to families who were facing similar challenges.

Wrap coordinators help caregivers engage more effectively in decision making by offering information on relevant topics. Caregivers also reported that they were better able to engage and make decisions when they had access to relevant information, such as parenting classes or information on addiction or the special education process. The majority of participants reported that they appreciated the fact that wrap coordinators gave caregivers the final word on those decisions.

Building Trust

Many caregivers expressed negative experiences with other services or systems, and struggling with shame and mistrust as they attempted to obtain help from the wraparound program. As a result, they reported difficulty sharing personal information with team members at first, or believing that this program could create positive change. This theme contains two sub-themes that address how coordinators were able to build trust to work with caregivers.

Caregivers felt more comfortable engaging in the process and opening up when they shared a personal connection with the wrap coordinator. Caregivers reported that they were better able to trust coordinators with whom they shared a personal. Some caregivers described a shared experience or hobby that allowed them to feel a personal connection, as an example.

Families felt heard when wrap coordinators engaged in deep listening to understand caregiver concerns. Caregivers described team members who made a point to put down their phones and remain focused and present without distractions. Skilled team members also demonstrated active listening skills, such as asking clarifying questions and validating caregiver experience.

Creating Room for Voice

Given the relative unfamiliarity of having voice and choice, caregivers noted the means by which skilled wrap coordinators were able to facilitate opportunities for the caregiver to feel comfortable communicating their needs and opinions. This theme includes five sub-themes that describe how the coordinators accomplished this.

Caregivers valued frequent invitations to voice via questions, texts, check-ins, or advance notice of questions to answer. Coordinators were able to create many small opportunities for the caregiver to voice their needs and preferences. This was accomplished via text messages, asking them questions in meetings, and performing routine check-ins to offer opportunities to speak. Several caregivers expressed wishing for more frequent check-ins as a means of expressing themselves without the time commitment of a full meeting.

Wrap coordinators strengthen caregiver voice by helping them to find the right words to articulate their concerns. When caregivers were given opportunities to speak, they also experienced support for voice and choice as coordinators sought to help them articulate their needs more precisely. Coordinators asked clarifying questions and explored concerns with caregivers. This not only facilitated communication in the moment but prepared caregivers to better communicate in other settings as well.

Wrap coordinators balanced support with challenge in order to facilitate the development of caregiver voice. Skilled coordinators were able to balance support for the caregiver's needs with challenge in order to push their growing edges in the development of voice. In some cases, caregivers described coordinators' encouraging them to adopt self-care practices and regularly check in with their own emotional state. In others, coordinators pressed caregivers to speak up for themselves despite their anxiety.

The team supported caregiver's role in the family. In the process of teaching caregivers to care for themselves and to advocate for their child, coordinators emphasized and affirmed caregivers' role in the family as parent. Many caregivers noted that this process allowed them to balance asserting their leadership with nurturing their children.

Additional support with advocacy in meeting with outside agencies strengthened caregiver experience of voice. Coordinators and family supports were instrumental in assisting caregivers with engaging meaningfully in meetings with outside agencies. The principal way by which team members were able to do this was by offering additional advocacy in these meetings. Caregivers reported that simply having a supportive person in those meetings with them allowed them to feel stronger and more confident. They also described ways in which their team members had coached them to speak up, in one instance using a "secret signal" to indicate when a parent had an opportunity to disagree or voice concerns in those meetings. Of note is that these strategies were aimed at allowing the caregiver to have the final word and speak up on behalf of their own families; team members didn't just speak for them.

RQ3: What challenges did caregivers experience with regard to having voice and choice?

Caregivers noted a number of challenges with regard to having voice and choice for the first time. Some of these were related to caregiver adjustment as they sought to take an active role, while others were challenges related to the wraparound program's process. While each family was unique and faced distinct hurdles, caregiver responses reflect both overarching concerns and particular experiences that may provide useful information to wraparound team members.

Caregiver Challenges

Caregivers struggle to engage in the team process, ask for help, and make decisions when overwhelmed. Caregivers struggle to participate in the process when emotionally or cognitively overwhelmed. For example, caregivers described difficulty slowing down, asking for

help, considering decisions, and participating in various preparatory exercises necessary to the wraparound process while they were experiencing family crisis. Several caregivers spoke to their frustration with regard to the pace of the program; they wished for quicker solutions when their burden felt like too much. For those who were able to maintain engagement in the program, they described a number of ways that coordinators helped manage caregiver overwhelm to allow them to participate in the process, even if change came more slowly than they had wished for.

Past circumstances created shame, self-doubt, and difficulty trusting others, which were barriers to engaging with the team process. Caregivers described previously experiencing isolation and alienation in their communities as a direct result of trying to parent a child with dangerous behaviors or a family history of addiction. They reported that these experiences made it difficult for them to trust the program and the individuals who expressed a desire to help. Caregivers reported having developed rigid boundaries in response to previous struggles and challenges that were at odds with the wraparound process of building trust and communication.

Process Challenges

While caregivers brought their own challenges to engaging fully, the structure and process of wraparound itself also limited at times the full expression of caregiver voice and choice. Two sub-themes describe these challenges.

Some caregivers experienced the collaborative process as inhibiting their ability to take quick action. This first challenge is related to the slow pace of setting up a tailored program which, in tandem with caregiver's overwhelming burden and the nature of the family crisis, limited how much support families received in the early days of wraparound as the team developed, began to establish trust, and co-created a family mission. Other times, caregivers perceived their voice as being limited or unheard when the assembled team was not able to provide answers right away.

Caregivers reported some frustration with needing and expecting a quick response to a family crisis and feeling disappointed when they didn't get immediate help.

Limited available resources were a barrier to choice. Caregivers felt that their voice and choice was limited by whatever resources were available in their mostly rural communities. Bound by wraparound budget constraints and few established programs for providing supports in their communities, caregivers experienced disappointing limitations to their options for choosing services and interventions.

Outlying Challenges

Other concerns that came up in the interviews were represented by singular reporters, but present relevant challenges to the program. No sub-themes were noted for these individual perspectives. One caregiver, as noted, reported their experience that voice and choice was not balanced among family members, which they felt threatened their role and voice as a parent. This caregiver spoke to the challenge of competing agendas; they discussed how attention to their child's needs sometimes took priority over their own.

Another caregiver reported frustration with the overconfidence of some professionals who viewed their challenges as less daunting than they did (e.g., in school meetings); this sunnier assessment led them to doubt their judgment as a parent. Consequently, this caregiver described struggling to assert their perspective in meetings.

Other caregivers noted challenges to the very intention of wraparound. For example, one caregiver stated that the interventions offered by their team were not suitable or sufficient to match the family's needs. Another reported that their team struggled with poor communication throughout the course of engagement; this level of misunderstanding ultimately limited their experience of voice and choice in their program.

RQ4: How might eliciting feedback from the caregiver about their experiences in wraparound benefit them?

Following the initial eight semi-structured questions in the interview, caregivers were asked "What prompted you to interview today?" and "What was it like to discuss your experiences of wraparound with me?" Most caregivers responded briefly and in positive terms. Several described the process by which BHII researchers had contacted them (e.g., receiving the letter and phone call). Caregivers generally reflected on their reasons for agreeing to interview.

Motivations for Interviewing

Interviewing allowed caregivers to feel their experiences could support other families and create positive change for the community. Most caregivers reported that they were motivated to interview in order to offer support to others. They reported hoping that researchers might be able to use their experiences to support families in similar circumstances and to offer hope to others who might need it.

Caregivers interviewed to help the program grow and develop. Some participants hoped to give back to the program through sharing their experience. Others were motivated to correct process issues they had encountered with the program so it would be more effective in the future.

Interviewing allowed caregivers to express gratitude for those who helped them. Several caregivers reported a desire to interview in order to express their gratitude for the wraparound program and for those who had helped them. One caregiver indicated, in particular, that the team had been a support to them when they felt hopeless; interviewing allowed them to offer their appreciation to the team.

Caregiver interviewed for personal gain. One caregiver reported interviewing in order to obtain the proffered gift card, available to each participant.

Positive Experiences of Interviewing

Most caregivers had a positive experience of interviewing, although for some it brought back disappointment and frustration. Most caregivers reported experiencing discussing their time in wraparound as positive. One caregiver noted that the interview had brought back the frustration and disappointment of the program.

Interviewing allowed caregivers to reflect on personal growth. Several caregivers reported that the process of interviewing allowed them to reflect on how far they had come in their process. One remarked that the interview felt like an important step in their personal growth to close out a significant period of their life.

Discussion

Wraparound programs are unique for their focus on treating the whole family, rather than the child alone, with an emphasis on voice and choice as one of the ten key programmatic principles (Bruns et al., 2014). Family voice and choice is a value that is intended to create a family-centric and strengths-based approach to service delivery; personal empowerment is a mechanism of change in wraparound programs. Walker and Matarese (2011) suggest that—at least theoretically—voice and choice should lead to increased family engagement and commitment to the program, better communication, a more coherent plan and a shared vision among the team. While there are no previous studies evaluating whether these benefits might be true in practice, the current study provided a unique and rich insight into the caregivers' experience of family treatment and affirmed many of those goals.

The demographics of those interviewed suggest additional questions. We had predicted that most respondents would fall under the poverty line, which the U.S. Census Bureau defines as $26,246 or less for a family of four ("Poverty Thresholds for 2020 by Size of Family and Number of Related Children Under 18 Years," 2020). In fact, seven of the 15 participating families reported

incomes of greater than $50,000 per year. Is it possible that the families who were able to stick with the program and engage sufficiently were those who tended to have sufficient resources to do so? On the other hand, perhaps this speaks to the breadth of mental illness across the socioeconomic divide, particularly in rural areas with few community resources. Otherwise, demographics represented a fairly predictable mix of single-parent and mixed-family households, predominately white and caring for children with complex diagnostic profiles.

Research Question 1: How did caregivers experience voice and choice?

Caregivers tended to respond to the purposely-broad question about their experience in one of three ways: they told stories in which they experienced having voice and choice; they described how voice and choice felt at the time; or they described the lasting benefits of having had voice and choice.

Story-telling

With regard to the first type of response, caregivers described experiencing voice and choice in three salient ways: when they felt personally empowered, when they felt heard and understood, and when they were actively engaged in the team process. These three components provided a useful working definition of the term "voice and choice" in the initial immersion stages of this study. Once this definition of voice and choice was established, the data were subsequently analyzed to prioritize themes describing these experiences. Notably, then, this finding offers a practical explanation of what caregivers perceive to be the three key elements of voice and choice.

Positive Experiences

Caregivers described feeling empowered and more connected to others, and spoke to their previous isolation and stress of raising a challenging child alone. The empathy and acceptance experienced by caregivers particularly from their wraparound care coordinators stands in stark contrast to their previous disappointment and frustration with getting help. By the time a family

receives wraparound services, they usually have a long and disappointing history seeking family support. For many, this was the first time they have been met with some measure of understanding or sense of community. Similarly, caregivers entering wraparound had previously felt as though their struggles in parenting somehow disqualified them from making decisions on their own. The simple act of engaging empathically was, across caregivers, perceived as an essential component of their healing, allowing the caregiver to build trust, feel connected, and come to value themselves—and their own expertise—as well.

Negative Experiences

While those with a negative experience were outliers in this group, several caregivers also described challenges related to having voice and choice. In some cases, the challenges were manageable and ultimately caregivers continued to feel positively about their experiences. For example, some found voicing their experience painful, or struggled to assert their place in the team process at first. For a few caregivers, the additional expectation of active engagement felt like one more burden, particularly when they felt overwhelmed or in the midst of a crisis. In these cases, the situation improved when wrap coordinators were able to offer empathy and concrete support; the challenges then became growth opportunities. While we cannot assume why caregivers may have left the program, we might conclude that they found challenges such as these insurmountable.

Lasting Benefits of Voice and Choice

Finally, caregivers discussed the ongoing impacts that they experienced from having had voice and choice, suggesting areas in which voice and choice has real mileage. While some caregivers appreciated developing better skills for helping their family members communicate better, their overall greater sense of empowerment constitutes the most significant and enduring change they reported. For example, caregivers described feeling more confident about their role as a parent and

their ability to make decisions, to become their child's best advocate, and to assess their community connections for resources and ask for help.

Caregiver empowerment is perhaps the most important legacy of voice and choice in wraparound programs. By teaching parents to become their own care coordinators, as recommended by Walter and Petr (2011), caregivers rely less on formal and sometimes-unreliable systems of support and become more adept at accessing their natural communities for care. We evolved not to live and parent alone but in community. This legacy of successful wraparound, in effect creating a self-sufficient support system, is at its best the enactment of the African proverb, "it takes a village to raise a child." This is also supported by Fonagy's (2017) work creating systems of attachment to support children with mental health difficulties and their caregivers. When individuals become effective advocates and have sufficient natural community, they will rely less on agencies and out-of-home care and contribute support back to their community. Moreover, in healing from trauma, families are essentially breaking the cycle of intergenerational trauma for future generations.

Research Question 2: What did wrap coordinators specifically do to allow caregivers voice and choice in the process?

Caregivers offered a range of examples of situations in which they particularly felt as though they had voice and choice in their program; for example, caregivers appreciated coordinator responsivity to caregiver needs, ability to build trust, opportunities for education on relevant topics, and creating room for the caregiver's voice. These findings are consistent with the scant research literature on the benefits of effective case-coordination and collaboration. For example, Stefanski et al. (2016) found that creating trusting, engaged partnerships with parents led to positive outcomes in terms of family empowerment. Many of the examples mentioned by caregivers affirm the efficacy of wrap coordinators' current practices. These findings may also serve to help case-coordinators to focus on those practices that are most helpful in facilitating voice and choice (outlined in Appendix

E). Given the in-depth work conducted by wrap coordinators typically faced with a dauntingly-long list of tasks to accomplish, the results presented here may serve as a roadmap to help them better budget time and energy. Notably, for example, an intangible element of care like deep listening appears to have a deep and enduring impact.

In a similar vein, Painter et al. (2011) also found that good rapport was a necessary precondition for program efficacy. In essence we are asking wrap coordinators not only to perform the cognitive tasks of collecting information and managing services, but to connect personally and authentically with caregivers in a sort of emotional labor not often recognized or operationalized. Given that these connections seem to mediate the success of the more logistical components of the program, skills related to empathy and building meaningful relationships with caregivers are essential both to training of future coordinators, and to the appropriate recognition and compensation for this deeper empathic connection provided by current care providers.

Research Question 3: What challenges did caregivers experience with regard to voice and choice?

Most caregivers reported appreciating the opportunity to take an active role in problem-solving and making decisions for their family. In the ongoing and uphill efforts to connect vulnerable families with necessary resources and reduce the need for future services, the idea of empowering caregivers seems essential. However, as hypothesized by Stefanski et al. (2016), and confirmed by these interviews, such active engagement in a family-centric program also required additional skills and energy from some caregivers that exceeded personal resources while in the midst of crisis.

Wrap coordinators were often able to scaffold and offer support in order to help the caregiver adjust and ease the burden sufficient to allow participation. However, for some caregivers, it felt as though they were expected to acquire skills for fire prevention when their proverbial house was ablaze and they just wanted the fire department to come with the water. In other words, some

caregivers didn't think the expectation for engagement in the program as a whole was a good fit for families already in crisis. Similarly, several caregivers reported that they had declined to sign up for wraparound services right away, because they were already exhausted and didn't feel as though they could manage the demands of the program. Many additionally remarked broadly on the slow pace of service delivery; some, holding on by their fingertips, struggled to trust the process. They needed greater reassurance and evidence that the methodology of wraparound was, indeed, going to put out the fire and repair the home, so to speak.

These findings are supported by previous research. For example, Schreier et al. (2019) noted that wraparound has the potential to ease caregiver burden; however, if caregivers do not receive the sort of help they were expecting, their relative strain actually increases. The path to the empowered experience of voice and choice takes time. Interventions cannot be implemented and fine-tuned overnight. Family systems are complex and there are few shortcuts to building trust, generating support networks, and developing and coordinating a menu of wraparound services.

However, many families contending with a multitude of issues along with the stress of raising a youth with SED need options for immediate relief in order to meaningfully participate in wraparound. In other words, they hope the fire department will quell the blaze first. One alternative, of course, is prevention. It is not hard to identify high-need children and families. Perhaps wraparound programs would be more immediately effective if initiated sometime prior to imminent crisis, before caregivers are this overwhelmed, terrified, and depleted.

Several caregivers addressed their challenge to trust others. They described negative past experiences with service systems and family workers, as well as a history of shame and stigma in the community related to family struggles including, for example, addiction, poverty, mental illness, and/or the distressing behaviors of the target child outside of the home. Given those past challenges,

caregivers described difficulty in agreeing to the in-depth work of wraparound and allowing multiple

strangers into their home, despite knowing that they needed the support.

Many, if not all, of the caregivers, had also struggled with their own traumas. Though beyond

the scope of this inquiry, it is important to understand their difficulty trusting in the context of such

traumatic exposure—including the chronic stress they face living with a volatile and sometimes

dangerous child. Effective wraparound requires attention to the trauma of the caregiver in the context

of the whole family system. Overwhelmed caregivers with insufficient resources face unique

challenges in a culture that blames parents—particularly mothers—for their children's problems and

stigmatizes and alienates those with serious mental illness. Wraparound is, of course, made to

address the needs of the entire family while working on the behaviors of the targeted child. However,

it is important to suggest that the caregiver holds the key to the family system: attending to caregiver

trauma provides a path forward for healing the trauma of the whole family.

Some additional challenges, for example, limited resources or poor communication inhibiting

the process, are commonly found in complex systems of intervention. Other challenges identified

were more specific to individual families. For example, one caregiver reported feeling pressured to

agree to decisions they were not comfortable with when school officials were overly optimistic and

confident. Wraparound thus became an opportunity for this caregiver to build a sense of confidence

in their knowledge as a parent and express their opinions in school meetings. Another individual

example was a caregiver who expressed concern that family voice and choice was unevenly balanced

among family members at wrap meetings, leading to a fear that they would lose their ability to parent

effectively when their child became accustomed to making their own choices. This challenge may

suggest some important cultural differences between the caregiver's beliefs in parental authority and

the collaborative nature of wrapround. When this underlying concern was not addressed, this

caregiver ultimately left the program relatively early on. Consequently, this caregiver did not have

much opportunity to experience voice and choice relative to the others interviewed. As this concern contributed to the choice to terminate, it may offer insight into other caregivers' struggle to maintain cultural family roles in the face of wraparound's mission and culture of empowerment.

Research Question 4: How might eliciting feedback from the caregiver about their experiences in wraparound benefit them?

This research question served as a kind of meta-inquiry into voice and choice; I was interested in whether the provision of feedback itself might also be empowering. My intention was to investigate an in vivo experience of voice and choice as caregivers were asked to share their perspectives on having an active role in their team process. The results offer some interesting insights into the caregivers' experiences of interviewing and suggest a number of topics for reflection.

Perhaps most striking is that caregivers overwhelmingly hoped to use the interview as a means to offer gratitude or otherwise give back to the program. Even those with negative experiences hoped to see the program develop in order to help other families. Others wanted to use their experience to offer hope to caregivers in similar circumstances. This points to the caregivers' emotional investment in the program and belief in its potential to facilitate growth in the community. It also points to a spirit of generosity in connection with the program, that caregivers were willing to give their limited time and energy to this process.

A few caregivers responded that the interview itself contributed to their personal growth, providing an opportunity for consolidation and closure. Wraparound is designed for complex, high-need families with histories of mental illness and trauma so any feedback suggesting avenues for healing are worth exploring. From a therapeutic standpoint, the question asks caregivers to self-reflect and put their entire wraparound experience in perspective in a way that they perhaps had not done before. The task of creating a coherent narrative of experience can be empowering for trauma victims (Siegel, 2020). In fact, D'Cruz et al., (2020) found that sharing a personal story for altruistic

purposes may contribute to positive identity growth. At the end of wraparound, it makes great sense for a question like this to be included, offering caregivers the opportunity to create coherent narrative, reflect on their own growth and recognize the value of their expertise about their experience.

Interestingly, some caregivers seemed surprised to be asked about their reasons for interviewing; though wraparound had worked to empower them, several seemed not to know that they had a choice. In addition, those caregivers who opted not to participate, rarely gave an explicit 'no,' but rather declined to return researchers' calls. In a few cases, caregivers first deferred by asking researchers to call them at another time. They then did not pick up the phone when called at the hour they had requested. Though this is all surmise, the combination of surprise about choice from some and avoidance of interview by others might suggest that caregivers did not perceive this voluntary interview as truly voluntary. As a small sliver of data helping us to understand caregivers' empowerment and status as part of the team—in the context of a study on voice and choice—this constellation of responses is, at very least, thought-provoking and noteworthy.

Soliciting family feedback is an important element of intervention. Previous research (e.g., Jivanjee & Robinson, 2007; Osher et al., 2001) examines the importance of eliciting family feedback at the evaluation level, citing improvements to the quality of data and services provided. Jivanjee and Robinson (2007) also touches on how such feedback can improve the cultural appropriateness and relevance of intervention. Results from this study have already been reported back to BHII for program evaluation purposes and to the staff of the Monadnock Region Systems of Care; whether the results serve to inform their practices remains to be seen. However, these findings constitute a unique contribution to the field; there does not appear to be any existing prior research on benefits to the caregiver from offering feedback on the process in terms of engagement, empowerment, or

investment in the process. The results gathered here may suggest personal growth as a possible outcome of involvement at this level, creating room for research on this topic in the future.

Implications

This study provides rich feedback for wrap coordinators who continue to work with families, both in terms of affirming what caregivers perceive to be valuable contributions and in terms of strategies to better support a family's experience of voice and choice. Indeed, this study was intended to serve as a program evaluation for BHII. However, the findings contained here have implications for any clinician or support person working with complex family systems seeking to empower and engage actively with individuals in such a system.

- Clinicians or wrap coordinators should focus on first building trust, by using active listening skills, offering empathy and nonjudgment, and making personal connections.

- Individuals should practice reading and responding to family members' needs and style by scheduling flexibly or offering a different approach, such as incorporating visuals or prioritizing different goals.

- Clinicians would do well to emphasize the ways in which they can be a reliable presence, by responding to phone calls or messages promptly, and offer information that will inform and empower the client to make their own decisions—though they should not have to make them alone.

- Clinicians should teach and encourage the development of advocacy skills, while affirming that the parent is in charge and has the final say.

- Clinicians can make the decision-making process more manageable by breaking choices down into smaller elements, allowing caregivers time to process bigger decisions, and thinking through outcomes of possible choices together.

- For caregivers who struggle with voicing concerns, clinicians should try making space for them to speak in meetings, or through check-ins over the phone or email.

- Clinicians should reflect on and develop sensitivity to cultural and power differentials among professionals, teams, and the members of complex families, working to offer the support most appropriate to the particular family system

Finally, this study has implications for the power of family voice and choice in wraparound and beyond. By creating a structure in which family voices are valued, caregivers may begin to feel re-connected to their communities and empowered in their roles; they may even become their own care coordinators, easing away from their reliance on wraparound services. Some caregivers took their new expertise a step further and became community members with roles supporting similar families, In terms of program efficacy, this is the dream—to create a dynamic network of community support and informed individuals who know how to access it. While more research is needed, the experiences of the caregivers interviewed here illustrate the promise of the best that wraparound has to offer to families and communities.

Limitations

This study was naturally limited by the self-selection of caregivers that agreed to interview. It seems probable that these are the caregivers who had a more positive experience with wraparound and voice and choice, although there certainly were many reasons that a caregiver would choose to decline to be interviewed or neglect to call back. BHII ultimately contacted 25 families and interviewed 15. A response rate of 60% is higher than expected, but conclusions cannot necessarily be generalized to all families, particularly if we want to understand the experiences of those who declined to participate.

The families who agreed to interview were also those who had had sufficient engagement with the program in order to offer an informed perspective on their experience as they had already attended five or more meetings. This limits the data in the study to those families for whom wraparound was more clearly an appropriate fit; we do not know much about the kinds of challenges that led families to drop out of the program earlier than the required cutoff. Wrap coordinators have anecdotally informed me of their struggle to engage those families in the wraparound process. Thus, this sample included only caregivers who both stayed with wraparound a while and agreed to be interviewed about their experience. The study is limited regarding the challenges of the program and fitness of approach for struggling families that qualified for wraparound but whose voices and choices are not part of the data collected.

Topics for Future Research

Exploration of family voice and choice in wraparound reveals the dearth of available research and suggests five additional questions for future inquiry. Perhaps most notably, there appeared to be a number of challenges to engaging families in an active role on the team. Future research should continue to explore these challenges and, particularly, seek to understand reasons families struggle to engage or choose to leave the program. This study explored the challenges to voice and choice, but ultimately those reflections were limited to participants who were sufficiently engaged to meet criteria for the study. A first suggestion for future research might explore a family's decision to terminate involvement with exit interviews or even interviews with prospective families about their concerns upon entering the program.

Next, I was struck by the significance of the match between caregiver need and wrap coordinator style. I noted that some caregivers seemed naturally to advocate while others needed more support to find their voice in the process. Future research might follow caregivers through the program to better understand the development of a trusting attachment relationship between

caregiver and wrap coordinator. One possible avenue could be the evaluation of fit between a caregiver's natural propensity to voice their needs and the level of support provided by the wraparound team. The wrap coordinator's natural ability to assess and respond to family needs could determine whether the caregiver received the supports suited to their unique circumstances. Assessing and judging caregivers needs and responding accordingly may serve to provide the right degree of challenge to empower without overwhelming.

Third, caregiver trauma arose as a relevant topic, particularly with regard to engagement and need for support. This leads to another question about how trauma presents in the process and how caregivers might be supported using the existing support structure of wraparound. While there is some relevant research available regarding the benefits to the *program* of eliciting caregiver feedback, there is little regarding benefits to the *caregiver* in reflecting on their time in wraparound or the value to them of contributing to further program development. In fact, one might speculate that voice and choice offers an avenue for relief from the immobilizing and voiceless nature of trauma. Initial inquiry here suggests that these may support the caregiver's process of healing from trauma.

Fourth, given an operationalized definition of voice and choice, one might explore interviewing behaviors as a measure of voice and choice. This might include the caregiver's choice to interview or not, the length of their responses, their assertiveness in tone or volume, and the pacing of the interview. This avenue may require the creation of a measurement device correlating to behaviors indicating empowerment and advocacy.

Finally, I believe there is more to be explored regarding the idea of empowering the chronically disempowered and often overwhelmed. Caregivers reported struggling with the responsibility of making their own decisions when they were hoping for quick relief from burden. Given my sense that caregivers did not seem to recognize the voluntary nature of the interview, I wonder about the extent to which a caregiver in wraparound is truly empowered rather than trained in

specific advocacy skills. Is it, for example, still empowerment if the value is imposed upon them by a program that grants access to resources? In this context, a family that terminates wraparound is, in fact, exercising their power, albeit the power to forgo those resources. Future studies may examine the nature of power and empowerment when bridging gaps between the under-resourced and historically-disempowered families and the systems that serve them.

Reflection

I would like to acknowledge the irony of seeking and then blurring caregiver voices through codes and my own interpretation. Due to the language of the informed consent for the original BHII study, I was not able to use direct caregiver quotes, which might potentially identify individuals within the study. Several years have elapsed since the study began and caregivers are often busy, difficult to reach, and many have moved or changed phone numbers in that time. As a result, I was not able to obtain a second informed consent with permission to use direct quotes. I am aware that in interpreting caregiver words into codes, my own voice is taking the place of caregivers' in a study on the importance of caregiver voices. The coding process was, consequently, difficult philosophically, as no degree of interpretation felt quite right.

With deserved humility, I relied then on a more pragmatic lens to compile codes and themes in terms of what I judged to be most helpful for the program and the wrap coordinators. Without using their words, I instead focused on the essence of the caregiver experience to inform future practice and for the benefit of other families in the community. That said, I continue to have a deep respect for each of the caregivers who chose to speak on behalf of their experience as well as for the power of their original words.

To that end, in addition to coding caregiver words, I would like to offer some observations regarding interviewing behaviors as a means of understanding their experiences in developing stronger voices through the wraparound approach. As an example, one caregiver described the

process of finding their voice through the wraparound program, developing confidence and personal empowerment; their manner of interviewing essentially echoed their story. That is, the caregiver began the interview quietly and answering with few words and long pauses, but throughout the interview became more talkative, offered more spontaneous comments, and presented as increasingly assertive in tone and volume, ending the interview with an impassioned statement about their personal journey. Similarly, caregivers who had expressed difficulty opening up to strangers in the past demonstrated great vulnerability in sharing their experience in the interview. On the other hand, some had difficulty articulating their experience, while others over-articulated or indulged in tangential dialogue.

Throughout the project I worked to bracket my own biases about the program. I have a personal interest in wraparound as a means to support families with trauma and I had high hopes for the project to clarify the precise mechanisms of change in order to streamline the wraparound process. Mostly, I hoped that the program would be life-changing. For some caregivers, it was; I was admittedly moved to tears by some stories of hope and empowerment. For others, it was disappointing, or only a stepping-stone on the way to more intensive intervention. However, the information garnered from situations in which the program did not go smoothly was perhaps some of the most valuable feedback reported here. As such, I took particular care to include outlying opinions and explore negative experiences to inform conclusions and suggest additional courses for research.

In conclusion, the study offered rich insights into the caregiver experience of taking an active role in their own service delivery. In particular, it highlighted the delicate balance between the urgency of family need and the time it takes to develop experiences of trust and self-confidence sufficient for caregivers to become more effective self- and family-advocates. The beauty of wraparound evokes notions of attachment and healthy interdependence within a more traditional collective framework; a strategy of care somewhat foreign to our cultural values of independence and

autonomy. At its best, wraparound represents a return to the proverbial village necessary for raising healthy children and supporting—not alienating—the overburdened adults who care for them.

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Appendix A

Wraparound Recruitment Letter (Original)

Dear

We would like to talk with you about your family's experience with wraparound and the NH/MR System of Care. What worked for you and what did not work for you? What was your overall experience of wraparound?

We are researchers based at the Center for Behavioral Health Innovation at Antioch University New England in Keene. Our job is to help NH/MR System of Care learn about how wraparound is working and how to make it better.

We will contact you by phone to see if you are willing to talk with us. If you are, we would set up another time to talk to you for about 30 minutes. Whether you talk with us or not is your choice. If you do complete an interview, we will send you a $20 Visa Gift card by mail afterwards as a thank you. We value your time and experience.

If you have any questions, please contact [BHI director]. He can be reached either by email at [email] or by phone at [phone number].

Sincerely,

Verbal Consent to Interview

Who we are
We are researchers from the Behavioral Health Improvement Institute at Keene State College. Our job is to help NH/MR System of Care learn about how wraparound is working and how to make it better.

What we seek
We would like to set up a time to talk with you about your family's experience with wraparound. We'd like to ask questions like: What worked for you and what did not work for you? What was your overall experience of wraparound? The phone interview would take about 20-30 minutes. We would record and store the interview file on a secure website. We offer a $20 visa gift card for completed interviews to recognize your time and experience.

Key consent information:
- Whether you talk with us or not is completely your choice.
- If you don't feel comfortable with a question, please tell the interviewer, and the interviewer will move to the next question.
- You may end the interview and/or your participation at any time.
- One possible risk is that it might be painful to speak about your experience in the interview
- It could also be a possible benefit to be able to reflect on your experiences
- We don't share individual interviews with anyone beyond our research team. Anything that we share with others contains themes that are taken from all the interviews taken together. You cannot be identified.
- Interview tapes are stored on a secure website while we are analyzing them and then destroyed at the end of our work.

To get your consent, I will read a statement and then ask you to give verbal consent to me, then I sign and date this document.

"I have been given a chance to ask questions. I agree to be interviewed and I have gone through the process of verbal assent."

If you do not feel comfortable agreeing with these statements, that is entirely your choice and I will respect it. Do you provide consent?

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

_____

Appendix C

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 prompted your family to enter this wraparound program?

2. What has been your experience with [insert coordinator's name] and the rest of your wraparound team?
    a. In what ways, if any, did you feel listened to and understood by those on your team?

3. Family voice and choice is key to Wraparound. What was your experience of voice and choice in the program?
    a. How much did you feel valued and supported?

4. How much did this program focus 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?

5. What was most memorable or surprising for you about this process?
    a. What were some good things?
    b. What were some hard things?
    c. If you could change just one thing, what would it be and why?

6. What was the biggest change for you and your family since beginning the program?

7. Was there anything that you were able to get through Wraparound that you could not get before?

8. What else should we know about your experience with this program?

9. What prompted you to interview today?
    a. What was it like to discuss your experience of Wraparound in this interview?

Appendix D

Sample Themes

RQ 1	Themes	Sub-Themes	Sample Codes
	Having voice and choice was a new experience	Having voice and choice was a new experience that sometimes required adjustment	Having an empowered voice in meetings was a new experience for caregiver
			Caregiver was actively discouraged from making choices in other situations
			Having choices was a new experience and took some getting used to
	Positive Experiences	Voice and choice felt empowering	The process gave caregiver a sense of power and control to effectively manage a difficult situation
			Process clarified caregiver's priorities and empowered caregiver to act on them
		Voice and choice was a positive experience	Despite challenges, caregiver had a positive experience of voice and choice
			Caregiver reports a positive

			experience of V+C
	Negative Experiences		Caregiver experienced shared family V+C as detrimental to clear boundaries in family roles
		Voice and choice created additional burden in some circumstances	Caregiver experienced disappointing limits to V+C
			Voicing experience was painful, but lead to personal growth
			Caregiver experienced an added burden of needing to facilitate communication and services to compensate for program barriers
	Empathy and Acceptance		Caregiver experienced V+C when they felt heard by the team
		Feeling heard and understood allowed caregivers to experience voice and choice	Having a voice was experienced by feeling understood by the team
			Caregiver felt they didn't get voice and choice when the team did not hear and understand them
		Caregivers felt connected to others	Caregiver felt they were able to speak openly and listened to

		when their voices were received without judgment	without judgment
			Caregiver felt less isolated when they felt valued by team
	Team Process	Voice and choice was experienced when caregiver was able to take an active role as a part of the team's collaborative problem-solving process	Caregiver experienced V+C as collaborative work to solve problems and support family
			Caregiver felt a sense of agency when they were able to work as a team, even when things got hard
			Choice was experienced when deciding how to target issues
		Caregivers experienced voice and choice as allowing them to take on an advocacy role for their child	Caregiver felt that their ability to advocate was critical to overcoming challenges in W program
			Caregivers' ability to advocate was limited before the program
		Flexible scheduling allows family to feel their needs are respected	Caregiver was given choice around scheduling meetings
			Caregiver experienced flexible scheduling as respectful of family needs

		Caregiver felt their experience of V+C was enhanced when the youth's V+C was also prioritized	Caregiver experienced their needs as being met in tandem with the facilitation of youth voice and choice
			Caregiver valued the ways that youth developed voice
	Decision Making	Decision making can be overwhelming, especially with limited choices available	Decision making was a challenge
			Caregiver experienced choices as limited and confusing
		Caregivers experienced voice and choice when they could make decisions without feeling pressured	Team supported caregiver's choices without pressure
			Caregiver valued the chance to make decisions
	Empowerment	Caregivers felt that voice and choice helped them become more effective advocates for their children	The program helped caregiver take on an advocacy role for their child
			The process allowed caregiver to experience a greater voice when advocating for child
			Caregiver was empowered to

			challenge outside agencies
		Caregivers feel more confident and able to trust their own judgment	Caregiver now feels more confident in taking others' opinions into account while valuing own judgement
			Wraparound contributed to increased self-esteem for caregiver
		V+C led to caregiver's personal growth	Having voice valued in the program led caregiver to seek a job helping others
			Caregiver experienced V+C as an opportunity to take a proactive mindset in their life
		Caregivers associated voice and choice with improved family communication	The process facilitated more effective communication in the family
			Having V+C for youth and caregiver increased communication skills as a family.
		Caregivers feel more empowered to seek	Caregiver feels empowered to continue asking for help as

		resources in community and ask for help.	needed.
			The wraparound process has empowered caregiver to evaluate available resources and ask for help.
RQ2	Responsiveness to caregiver needs	Wrap coordinators set the stage for caregiver voice and choice by shaping meeting structure and team	The team adapted to demonstrate respect and patience for caregiver's disabilities
			Coordinator assembled a team that reflected the discussions that needed to occur
			Team allowed for caregiver choice by modifying the structure of the meeting
		WCs support caregiver choice by creating an atmosphere of nonjudgment	An atmosphere of nonjudgment and safety allowed caregiver to feel comfortable opening up
			Caregiver's choices were supported without judgment or pressure
		WCs and team make decision-making more	Caregiver experienced having choice with multiple, smaller

		manageable by employing specific support strategies	choices
			Caregiver was better able to make choices when they had time to process them
			FSP helped caregiver understand available choices and think through outcomes.
		WCs help caregivers engage more effectively in decision making by offering information on relevant topics	Understanding the W process better would have allowed caregiver to engage more effectively
			Parenting classes strengthened caregiver's ability to advocate for their child
			Learning more about addiction helped caregiver make better choices
		Caregivers trusted WCs who went out of their way to respond to caregiver requests and respect family culture	Having someone reliable to ask for help was empowering to caregiver
			Invitations to ask for help with a consistent response to requests made caregiver feel supported

		WCs respect caregiver time and experience by allowing them to set priorities	Team allowed the family to set the pace, which created a sense of agency
			WC invited caregiver to choose priorities while highlighting others that the caregiver was less attentive to
	Building Trust	Caregivers felt more comfortable engaging in the process and opening up when they shared a personal connection with WC	A personal approach and relationship made the caregiver feel more comfortable to engage in W process and open up about family history
			WC knowing youth's likes and dislikes helped caregiver feel understood
		Families felt heard when WCs engaged in deep listening to understand caregiver concerns	Caregiver felt heard and valued when team members were focused and present, without distractions
			Caregiver was able to trust team when they listened and validated their experience
	Creating room for	Caregivers valued	Frequent communication with

	voice	frequent invitations to voice via questions, texts, check-ins or advance notice of questions to answer	team made caregiver feel supported and heard
			WC consistently gave caregiver opportunities to share concerns and ask for help
		WCs strengthen caregiver voice by helping them to find the right words to articulate their concerns	WC helped caregiver find the right words to voice concerns
			FSP facilitated communication with other agencies by helping caregivers better articulate their concerns
		Additional support with advocacy in meeting with outside agencies strengthened caregiver experience of voice	Family support's advocacy at school enhanced the youth's IEP
			WC's efforts in facilitating work with other agencies allowed caregiver to have a voice in the system
		WCs balanced support with challenge to facilitate the development of caregiver voice	Support with self-care allowed caregiver to more effectively engage in meetings
			WC challenged and empowered caregiver to speak up, even when it was hard.

		Team supported caregiver's role in the family	FSP supported caregiver's responsibility as a parent
			WC supported caregiver to trust their knowledge as a parent.
RQ3	Caregiver Challenges	Caregivers struggle to engage in the team process, ask for help, and make decisions when overwhelmed	The experience of being overwhelmed negatively affects caregiver's ability to adopt a broader perspective and make effective decisions
			Caregiver distress and burden negatively affect their ability to ask for help.
		Past circumstances created shame, self-doubt, and difficulty trusting others, which were barriers to engaging with the team process	Caregiver struggles to balance need to ask for help with difficulty trusting others
			The shame and stigma of addiction is a barrier to family involvement in support services.
	Process Challenges	Some caregivers experienced the collaborative process as inhibiting their	Caregiver found the collaborative team process frustrating when they sought immediate help

		ability to take quick action	Caregiver felt frustrated voicing their concerns when the team was not able to provide effective solutions
		Limited available resources were a barrier to choice	Caregiver experienced limited choice with regard to team members
			Limited available resources created fewer choices for the team.
	Outlying perspectives		The overconfidence of other professionals pressured caregiver to discount their own experience and give up their voice.
			V+C was not experienced as balanced among family members, which threatened caregiver's voice and choice.
			Caregiver felt that the interventions offered did not match their family's experience
			Poor communication was a

RQ4	Motivations for Interviewing	Interviewing allowed caregivers to feel their experiences could support similar families and create positive change for the community	Interview allowed caregiver to feel as though they could give hope to other families to help them feel less alone
			barrier to family voice and choice *(above this section)*
			Caregiver hoped her challenges could be experience that helps others.
		Interviewing allowed caregiver to express gratitude for those who helped them	Caregiver interviewed in order to express gratitude for those who helped them when they felt hopeless
			Caregiver interviewed to express gratitude for the program
		Caregivers interviewed to help the program grow and develop	Caregiver felt interview was an opportunity to share information back to the program.
			Caregiver experienced the interview as an opportunity to correct the problems they experienced in the program.

		Caregiver interviewed for personal gain	Caregiver was motivated to interview for the giftcard
	The interview was experienced as mostly positive	Most caregivers had a positive experience of interviewing, although for some it brought back disappointment and frustration	Discussing experience in the interview revivified disappointment and frustration
			Caregiver expressed a positive experience of discussing W in the interview
		Interviewing allowed caregiver to reflect on personal growth	Interviewing felt like an important step in the caregiver's growth
			Reflecting on the process allowed caregiver to see how far they've come.

Summary of Results

Caregiver's Experience of Voice and Choice in Monadnock Region Systems of Care
Kate O'Neil, M.S., Doctoral Candidate
Antioch University New England

How did caregivers experience voice and choice?
In 15 semi-structured interviews done after families completed or left the wraparound program, caregivers overwhelmingly felt that voice and choice was a positive part of their experience. While voice and choice was difficult in some ways, caregivers felt that being heard by their team and being a part of the decision-making process was empowering for them as a parent.

What were some of the challenges with voice and choice?
Professional supports had rarely invited caregivers to make decisions before wraparound. Assuming this responsibility could be overwhelming at first, especially when they wanted quick relief from stress. They described struggling with shame, self-doubt, and trust, which made it hard for them to participate in the team process right away. In some cases, strong opinions from outside professionals left caregivers doubting their own judgment. In addition, while most caregivers valued youth voice and choice, some worried about maintaining appropriate parental roles and boundaries with shared family voice.

How did the wraparound team support caregiver voice and choice?
Building trust. Caregivers were more likely to feel comfortable with the team process when they felt heard and understood, when their coordinators were able to make a personal connection, within an atmosphere of empathy and nonjudgment. Caregivers trusted team members who made efforts to be fully present and listen deeply to what caregivers were saying, checking to make sure they understood.

Teaching advocacy. Caregivers felt empowered to speak up for their children when they had a team behind them, especially in school meetings. Caregivers appreciated being coached on how systems work, the vocabulary used in those systems, and how and when to disagree to get their needs met.

Responding to caregiver needs. Caregivers knew their voices were valued when their phone calls were returned consistently and the team made changes based on caregiver preference. These changes included scheduling meetings and setting group priorities, as well as respecting family culture and house rules.

Inviting caregiver voice. Caregivers appreciated when coordinators created space for them to speak up for themselves. This space was created with frequent check-ins, text messages, and questions from coordinators. The team often helped caregivers find the right words to voice their concerns more clearly.

Making decisions manageable. Team members supported overwhelmed caregivers by breaking decisions down into smaller choices, giving extra time to process bigger decisions, and thinking

through the consequences of different decisions together. Importantly, this was done without judgment or pressure, so that the caregiver could make the final decision.

In order to best voice and choice, team members are encouraged to…

Focus first on building trust with caregivers. Using active listening skills, offer empathy and nonjudgment, and form a personal connection rooted in common interests when possible. Validate the caregiver experience, understanding that they have done what they needed to do to survive a difficult situation.

Get to know family members in order to actively read and adjust to the family's needs and style. For example, some families may need more visuals, a shorter meeting time, more movement during meetings, or a different way of breaking up the discussion. Some families may expect quick action and need help slowing down.

Maintain a reliable presence – answer phone calls or return them as quickly as possible, attend meetings at the school, and be willing to listen to whatever the family is going through. Offer information on topics relevant to the family's needs. These include how wraparound works, how school systems and the IEP process works, and even information on mental health and addiction.

Teach advocacy skills – affirm that the parent is in charge and has the final say, and encourage them to disagree or to ask for more time or more information. Prepare for school meetings in advance and consider thinking of a signal to quietly communicate important prepared points in those meetings. For example, a gesture to encourage the parent to ask for more time to consider a decision.

Find ways to make choices easier. Discuss all the options together and think through the consequences of each one without judgment. Let caregivers know that big decisions are coming up so that they have time to think about them. Break bigger decisions into smaller ones when possible. When in doubt, with big choices or small, give the caregiver the final word. Take care to offer choices that are available in the community.

Create space for the caregiver to speak, at wraparound meetings and out in the world. This includes asking caregivers what they think or echoing their perspective in school meetings, asking questions, and checking in frequently with texts or phone calls. Take care not to speak for caregivers unless they've agreed to it in advance. Recognize that sharing family voice may be uncomfortable, and take care to balance voices accordingly or ease into a shared conversation where each member might be heard without overshadowing the others. Affirm the importance of each voice while reinforcing family roles.

Appendix F

Voice and Choice Infographic
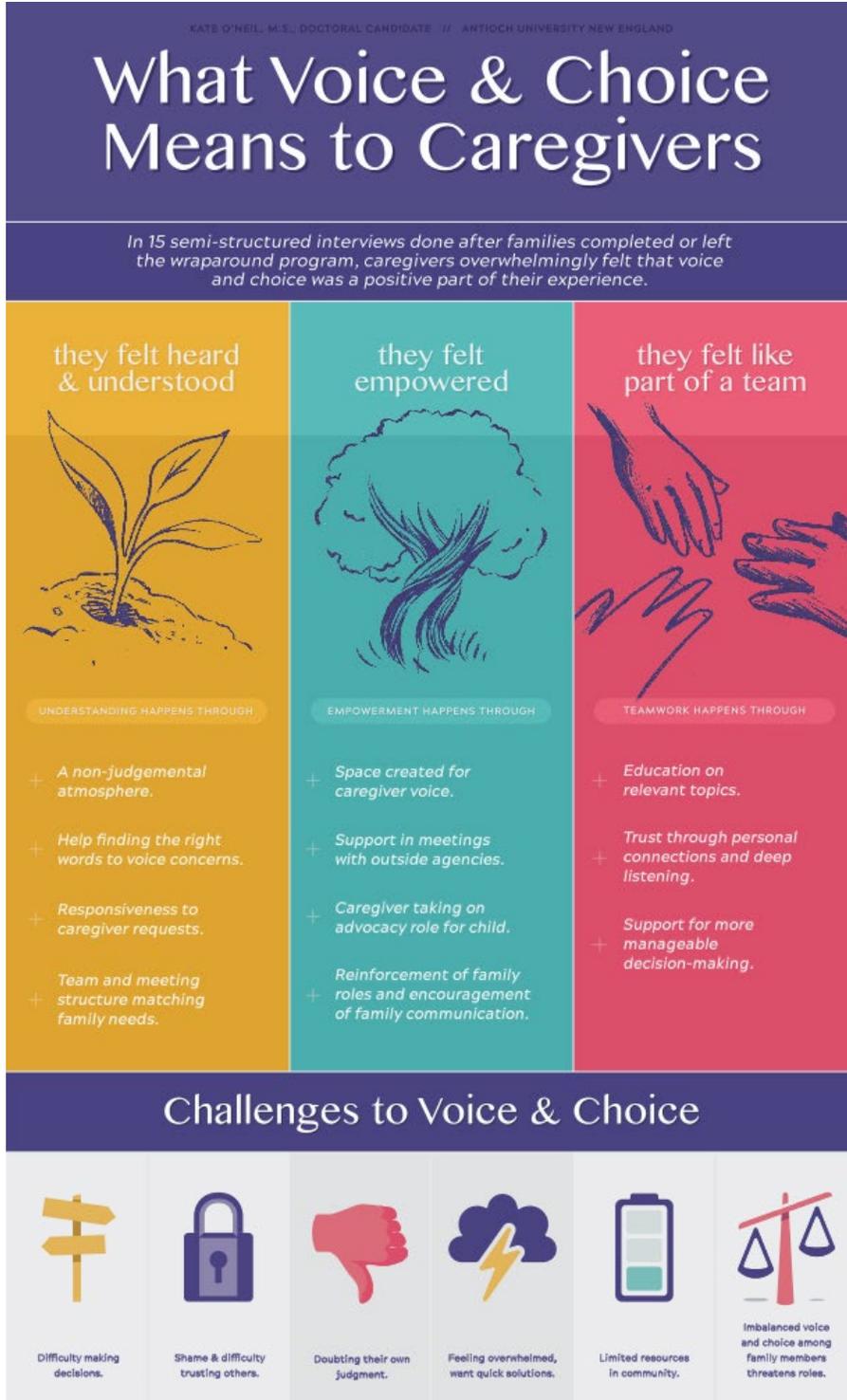
Appendix G

Written Permission for Use of BHII Interview Protocol

Fauth, James   Wed, May 26, 7:39 PM (14 hours ago)   ☆   ↰   ⋮

to me, Johanna ▾

The interview protocol used in this study was developed by the BHII team. As director of BHII, I grant permission for this protocol to be published as a part of Kathryn O'Neil's dissertation and reproduced in the AURA, OhioLINK and ProQuest databases as an appendix in that dissertation.

Jim Fauth

Jim Fauth, PhD
Director
Behavioral Health Improvement Institute
Keene State College

Appendix H

Written Permission for Use of Infographic Design Content

Rae Torres   12:17 PM (35 minutes ago)   ☆   ↩   ⋮
to me ▾

I, Rae Torres, designed the infographic for this study including layout, icons and illustrations. Using open-source Adobe fonts.

I grant permission for this graphic to be published as part of Kathryn O'Neil's dissertation in print or digitally. Everywhere the dissertation is published or presented. Globally and in perpetuity.

Sincerely,
Rae Torres
—

Content Creator
Ink & Flame Studio