

Family Empowerment Through Family Peer Supports

by Brian Huckins

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Abstract

This research paper looked at leadership empowerment through Family Peer Support services. These services were integrated with in Wraparound Services that are for children who have a serious emotional disturbance (SED) diagnosis. This paper explores peer reviewed articles, mental and public health websites, family surveys and the Wraparound Wisconsin model that all reported on the success and challenges of Family Peer Support. The survey I completed with families reported on leadership skills developed through Family Peer Supports. All families who have participated in the survey were active participants in the Wraparound process between six and nine months. After I completed my research, I hoped to track the development of family leadership through the service of Family Peer Support.

Key Words: Family Peer Supports, Mental Illness, Wraparound, Serious Emotional Disturbance

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Family Empowerment Through Family Peer Support

Introduction

Mental illness is a diagnosis that every family member fears for their children. It is a diagnosis that leads to a lifelong commitment of therapies, behavioral interventions, and advocacy for necessary supports. My research focused on the leadership skills of parents raising children who were participating in Family Peer Supports as part of the greater Wraparound process. The parents identified for this research were raising children with mental illness between the ages of six to twenty-one years of age and live in New Hampshire. With my research, I am hopeful to conclude that Family Peer Supports empower leadership skills for families.

This research is very special to me. I am the father of two children. My oldest is diagnosed with ADHD and my youngest is diagnosed with Autism Spectrum Disorder. I am also the stepfather to my stepdaughter who is diagnosed with severe anxiety. I have seen and lived the daily struggles of raising children with mental illness. I have also seen the successes of early intervention. Mental illness is so important to me and my family that I have made it my profession. I am the Director of Children and Youth Programs at the National Alliance for Mental Illness, New Hampshire. I am also concerned as a citizen of NH and the United States of America, as I have observed the mental health systems fall apart. These challenges have presented many obstacles for families to obtain services for their children. In order obtain and navigated the services needed for a child with mental illness, you must become an excellent leader.

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My research looked at one major question: Can Family Peer Supports, with in the Wraparound model, empower a family to increase their leadership skills?

Although everyone has struggled with dealing with social and emotional wellness, when it becomes concerning is when these concerns last longer than a couple of weeks and they start to interfere with daily living.

“One in Six U.S. youth aged 6-17 experience a mental health disorder each year. Fifty Percent of all lifetime mental illness begins by age 14, and 75% by age 24. Suicide is the 2nd leading cause of death among people aged 10-34” (NAMI, 2020).

Wraparound is one of the interventions for children who have mental illness and have highly intensive needs. Wraparound is a service that is comprised of a Wraparound Coordinator, a Family Peer Support Specialist, a Youth Peer Support Specialist, in home service supports, and flexible funding. To be eligible for Wraparound in New Hampshire you must have a serious emotional disturbance (SED) diagnosis, aged six or older who are transitioning out of school, foster care or state placements, Medicaid eligible, and are at risk of multi-agency involvement (includes out of placement in a residential treatment facility, psychiatric hospital, or juvenile justice facility) (NH4youth, 2020).

Wraparound is an evidenced based model that has shown in many studies that it moves funding from institutional settings to community-based services. One of the foundational goals of Wraparound is to keep children in their homes, communities and local schools. Out of district residential and long term psychiatric institutional placements are considered failures in the Wraparound process. “Practitioners also seem to perceive that wraparound is an effective

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practice; a recent survey of providers found that wraparound was the second-most frequently identified “evidence based” intervention (after cognitive behavior therapy) by service providers (Sheehan, 2007). Wraparound Services have shown reductions to hospitalizations, emergency room visits, and out of district placements, which have resulted in significant cost savings. (Smith, Nicholls, McCann, Ellis, Sitas, Waters, Jonikis, Rao, James, & Cohen, 2019).

Family Peer Support plays an integrate role in the Wraparound model. Family Peer Support plays perfectly into one of the goals of Wraparound, which is to have services based upon the family’s strengths and family lead goals.

“It operates from a value base that emphasizes building on strengths to meet needs; one family-one plan of care; cost-effective community-based alternatives to residential treatment placements, juvenile correctional placement as appropriate, and psychiatric hospitalization; increased parent choice and family independence; and care for children in the context of their family and community” (Wraparound Milwaukee, 2018).

A Family Peer Supporter is a person who has lived experience. This means, a family member has either raised or been the care giver for a child who has mental illness. A family member who has raised a child with mental illness has gone through many challenges as a parent/caregiver. They have gone the through initial concerns of early signs that there is something different about their child. The family member has gone through the devastating feeling of receiving a mental illness diagnosis for their child. They have faced the stigma that families and children go through for people who have mental illness. The family member has also faced enormous obstacles to receiving mental health services in the community they live in,

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and the school they attend. This stigma often results in delays to early intervention for their children's mental health. Finally, a Family Peer Supporter has been through the incredible difficulty of navigating emergency services for their child.

“Because children with an SED exhibit challenging behaviors, literature suggests that effectively parenting children with an SED requires increased parenting skills, capacities, and resources, which may be beyond the capabilities of parents who are high functioning” (Pickrel, 2002).

Building leadership skills for a family can be a difficult challenge for a Family Peer Supporter, because a family member may have a child who is in crisis, in and out of psychiatric hospital admissions, and/or have struggles with school districts with education strategies. Growing leadership skills can be tough when you are just trying to get through the day, forget about tomorrow or years down the road. The continued need for increased leadership skills increase when their children become of school age and need advocacy from their parents to get the proper supports for their educational and community needs.

“Participants in grassroots advocacy groups reported increased confidence and self-esteem and the ability to make personal life choices, which is significant in light of the fact that this population, due to mental illness, has typically experienced significant loss of control and self-esteem” (Hess, Clapper, Hoekstra, & Gibison, p, 265, 2001).

A Family Peer Supporter helps builds advocacy skills for families in many ways. They demonstrate to the family by leading by example, education, and shadowing. They provide families an opportunity to connect with a family member who has experienced a similar lived

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experience as to what they are going through, with their child who is having difficulty with their mental health. No amount of education can replace this lived experience. Families are more open to speaking with and connecting with someone who has gone through the same experiences they are living. This experience of the Peer Supporter can offer a family hope, at times when family member may be about to give up. A Family Peer Supporter's story can relate so closely to a family that it can show a family that they can make it through their current difficulty and see thing will get better. Ultimately, a Family Peer Supporter shows the family that they are not alone in their struggles. In the Wraparound Model, a family's ability to grow their leadership skills can be so great that they can start to share their story and leadership skills with other families. This is ultimately paying it forward. If the family member gets good enough with these leadership skills, it can lead to future employment as Family Peer Supporter too.

Literature Review

My Literature Review looked at what leadership skills Family Peer Supports provide a family who is raising a child with serious emotional disturbance (SED) diagnosis. It also looks to answer my research question: Can Family Peer Supports, with in the Wraparound model, empower a family to increase their leadership skills? My research brought me through a family's entire history of mental illness supports for their children. This review looks at the major barriers a family can face as they navigate the process of obtaining successful treatment for their child's mental illness. Some larger barriers identified families include the challenges of early intervention/stigma, successful services and interventions, upfront stabilization, self-care, and advocacy/family voice.

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Early Intervention and Stigma

A key to success with mental health treatment is to recognize the early signs and symptoms of mental illness. “People who begin to exhibit a symptom of mental illness should recognize the early signs and take prompt action to recover their own health” (Machi, Takashi, Hiroki, Suka, Yamauchi, & Sugimori, 2016, p.2). With prompt recognition of signs and symptoms of mental illness, early intervention can lead to significant improvement for a child who has mental illness.

The problem with early intervention is families face obstacles when they are noticing that their child is having social/emotional concerns. Many parents notice that something is different with their child’s behavior compared to other children they see. Many families try to resolve this behavior on their own before they seek alternative supports. One of the reasons why families don’t seek early intervention is due to the perspective of mental illness within their own culture. Some cultures are more open to receiving mental health treatment than others. “A comparative survey between Japan and the United States indicated that Japanese people exhibited greater reluctance to seek professional help” (Mojaverian, Hashimoto, & Kim, 2013).

The culture I have grown up with was one that left me with a feeling that you should just “man up” if you were having social emotional issues. It was not something you talked about openly. These types of feelings were something that you were taught to bottle up and deal with on your own. This became even more exasperated when it came to my children. It was told, “they will grow out of it”, or to take a firmer behavioral approach. When someone tells a parent, they should take a firmer behavioral approach, what they are really saying is you are not parenting correctly. “Cross-cultural comparative studies suggested that sociocultural factors influence symptom reporting in patients with depression; in particular, stigma surrounding

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mental illness increases the tendency to emphasize somatic symptoms” (Machi, Takashi, Hiroki, Suka, Yamauchi, & Sugimori, 2016, p.9).

As children and adults age, they may have an increased negative feeling about themselves. They may look at themselves as failures or not living up to what their parent’s or society says they should be. These feelings of failures can result in further isolation for a youth, and unwillingness to seek help. It can also result in unintentional negative feelings from their parents. At times parents who have children who are exhibiting signs of mental illness, have been known to question why their child is not living up to either their or society’s expectations. “A negative perception of the effectiveness of help, a lack of awareness of potential sources of help, and willingness to handle the problem by oneself were the three most frequent reasons for no help-seeking intention” (Machi, Takashi, Hiroki, Suka, Yamauchi, & Sugimori, 2016, p.9).

Stigma that is associated with mental illness is full of incorrect presumptions and false information. Because of this misleading information, families often go into isolation. Families want to keep things as close as possible to their immediate family. They don’t want to share with anyone that they are struggling to support their child who experience things like anxiety, depression or other mental health concerns. During these times, families are not in any place to advocate for themselves, because they haven’t confronted the mental health challenges their child is going through. Instead, they hope these challenges go away. They end up going through a period of hoping the issue will go away if they ignore it and/or if they just work on it harder.

The reality of mental illness is it does not get better without support. Often it gets worse without treatment. Families often play down what is going on. “Experiencing the potential hardships and setbacks of mental illness treatment of friends or family could explain the stronger

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tendency to play down one's own symptoms in order to avoid treatment and consecutive labeling as mentally ill" (Hahm, Muehlan, Stolzenburg, Tomczyk, Schmidt, & Schomerus, 2019 p.7).

The isolation these families go into can end up in crisis situations that result in the support of police or other emergencies services. It can also lead to psychiatric hospitalizations. Unfortunately, when emergency services get involved it can take away all power and leadership from a family. This is especially true if the Division of Child and Youth Services (DCYF) opens a case on family. Once DCYF becomes involved services are no longer directed by the family, they are directed by DCYF and potentially the court system.

Successful Services and Interventions

Today's publicly funded services for mental illness have the intent to be community based. One of the exciting services to help children who have mental health challenges remain in their homes and in their communities is Wraparound. Olibris, Mulvale, Carusone, Lin, Domonchuk-Whalen, & Whittaker, (2017) expressed the success of Wraparound through the research that was completed in his article. Their findings included the need for family centered approach, collaboration between all sectors, involvement of primary care, paid family peer support, and collaborative planning. This article provided evidence of successful Wraparound service, which includes family peer support. The article also discussed many aspects that make wraparound successful including working in collaboration with community partners.

Wraparound services bring a family though a process that is family and youth lead. The family and youth determine what goals they want to work on. They decide who is on and who is part of their team. They also decide where and when the family has team meetings. Leggatt, M., & Woodhead, G. (2016) shared a great discussion that talked about the struggle for clinicians look at family members who are employed as equal partners. This is a challenge that clinicians,

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school staff, and physicians are all battling with. They all come from systems that have a history of telling families what is best for their children. Professionals have a history of telling families what goals they should be work on, who should be on their team, and where meetings should be held. To have the family and child develop their own goals that they want to work on and lead the process can be very scary for a lifelong professional. It was also noted the importance of the Family Peer Supporter in the success of the overall mental health improvement for the child.

Schipke, J., Provvidenza, C., & Kingsnorth, S. (2017) discussed family peer support interventions. In the article it discusses the importance of family peer's connection with other families who are going through similar situations they have gone through with their children. This article also discusses a tool kit of best practices. "This paper describes the key activities used to develop and disseminate the Peer Support Best Practice Toolkit." Although the tool kit is a great resource for family peer supports, it is limited to focusing on the pediatric disability population.

Research also showed that when Wraparound Services and more directly Family Peer Supports are successful it will lead to a family be the leader of their child's supports and services. The family member has ultimately developed a plan that included paid professionals and natural supports to assist their child to be successful. When a family member has reached this level of leadership, the family member has learned that their lived experience can provide hope to other families. This is a full circle workforce development. This is the ultimate goal of providing Family Peer Support.

Shailer, J. L., Gammon, R. A., & de Terte, I. (2017) article investigated the fidelity of Wraparound Services in New Zealand. It evaluated 16 Wraparound teams. The study showed areas strength that included: cultural and linguistic competence, collaborative work, consistent

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service and youth and family lead delivery. The areas of improvement included the transition phase, natural supports and community-based services. However, these struggles are consistent with research completed on Wraparound.

Sather, A., & Bruns, E. (2016) looked at national trend when implementing the Wraparound process through state surveys. Their article also discussed how many of the states that reported had statewide support of Wraparound. This article updates the current progress of 25 years of work. Their research affirms that Family peer support is a key component of Wraparound (Sather & Bruns, 2016).

Upfront Stabilization

Often when families are first introduced and become eligible for Family Peer Supports, they are confronting many issues. The biggest issues are more about basic life needs. These basic needs fall right in line with Maslow's theory of basic needs. These basic needs include breathing, food, water, sex, sleep, homeostasis, and excretion. "It has long been known that housing stability, quality, safety, and affordability all affect health and that poor-quality housing is associated with negative health sequela" (Gultekin, Brush, Ginier, Cordon, & Dowdell, 2020, p.10).

Upfront stabilization for families who are supporting children with mental illness is necessary for many families. Families are presenting to Wraparound Coordinators and Family Peer Supporters in ways that show they are struggling with many social/economic issues. These concerns include stable housing, financial stability, and stable mental health services for not only the child, but for the family.

"At baseline, parent self-report and case manager ratings of family functioning found that parents affected by substance abuse fared worse in domains related to

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socioeconomics, parental trauma, parental mental health, and social supports when compared to families without parental substance abuse” (Akin, Brook & Lloyd, p.71, 2015).

Self-Care

Once a family has become stabilized social and economically, they may be able to move towards the ability to participate in Wraparound Services. One of the most important supports a Family Peer Supporter promotes is self-care. Anthony, B. J., Serkin, C., Kahn, N., Troxel, M., & Shank, J. (2019) looked at the growth and success of family peer delivered family to family supports for children who have serious emotional disturbance diagnosis. This study relates well to New Hampshire’s eligibility for Wraparound Medicaid billable services. It also looks at a similar intervention timeline of 15 months. Wraparound services are based on estimated timeline of 12 to 18 months. The greatest need noted in this study was the need for families to take care of themselves. “Caregivers were perceived as requiring significant help in taking care of themselves—recognizing their own needs, reducing stress, accessing support—and effectively dealing with crises with a coherent plan of care” (Anthony, Serkin, Kahn, Troxel, & Shank., 2019, p.395).

When Family Peer Supporters are able promote self-care to the point that families are using self-care strategies it has shown that it reduces caregiver stress. When caregiver stress is reduced, overall consumer outcomes increase. “Attending to the needs of family members could have a significant impact upon the family’s functioning, reduce caregiver stress and strain, and enhance consumer outcomes” (Acri, Hooley, Richardson, Moaba, 2017, p.248).

Advocacy/Family Voice

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Advocacy for a family and the development of family leadership so they can advocate for themselves is one of the most important components of Family Peer Support. Most families come to Family Peer Support in crisis. They have been told by family members, neighbors, friends, agencies and professionals telling them that they are doing things wrong raising their children. They have been told that they are the reason for their child's "behaviors". They have been told that there are no issues at school, "it's only a home issue". Because of these messages families often go into isolation, because of what they have been told by others. This just adds to the stigma of mental illness.

Although parent advocacy is a key component of a child receiving what they need from schools and community agencies. The goal would be to get to a place of collaboration and away from a place of constant tension. This tension would also decrease if there were a better integrated care model for children with mental illness. Like the integrated care model for patients who have cancer diagnosis. There is no hesitation in cancer care. Once diagnosed your path of integrated care is clearly defined.

If a better integrated care model was in place, everyone could work together for what is best for the child and family. They would have set aside what the barriers are for receiving services and they are figure out how to makes treatment happen as a team. "The upgrading of preventive or early intervention strategies would assist children with behavioral problems in the context of heavily strained relationships. This requires close collaboration between different services and continuity of care" (Dil, & Vuijk, 2012, p.15).

Literature Review Conclusions

A new diagnosis of mental illness for a family and a youth can be devastating. This is where some of the most important work for Family Peer Supports come into play. When a

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Family Peer Supporter shares their story, it can provide a perspective that no other professional can provide. It provides a story of hope to a family that things will get better. Research has not quantified what this means for a family at this point. “Accordingly, peer programs for families of children have either not been developed to the point that evaluations have been conducted or have been evaluated using weaker research designs” (Acri, Hooley, Richardson, Moaba, 2017, p.248).

My literature review showed that families have struggled to support mental illness for many years. Since the 1960s, there has been a gradual movement to deinstitutionalize services, to develop treatment for youth to be community-based treatment models and approaches that would result in children remaining with their family and community (Stroul, 2002). Today, parent leadership and advocacy efforts have led the way to these changes. However, upfront stabilization must be addressed before families can move towards an ability to receive interventions, and to be able to advocate for themselves. “More attention, however, must be placed on preventive services that build on child and family strengths and reduce both the incidence of homelessness and the life events that contribute to housing instability for youth and their families” (Gultekin, Brush, Ginier, Cordon, & Dowdell, 2020, p.15).

My research found many gaps in the supports that Family Peer Support services provide for a family. One of the biggest gaps in research is the lack of research on providing hope for a family who is raising a child who has mental illness. “The degree to which their children fulfill parents’ expectations of their children in adulthood affects parents’ well-being and sense of personal accomplishment” (Stein, Mann, & Hunt, 2007, p.104). Hope is the greatest piece of what a Family Peer Supporter can provide. It doesn’t matter what your educational degree is, a person cannot match a Family Peer Supporter’s lived experience, unless they have raised a child

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with mental illness. Research does not necessarily define hope. With hope being a critical component of Family Peer Supports, it needs to be defined better. I am hopeful that my personal research and family survey will shed more light on what hope Family Peer Support can provide.

In conclusion, my research has shown that Family Peer Supports with in Wraparound model leads to more community-based services when the service is completed with fidelity. My research has also helped me understand the challenges that families are facing when they are supporting a child who has mental illness. Families who receive Family Peer Supports have shown a history of developing the necessary advocacy skills that not only to lead their own family's teams, but ultimately bring change to the entire mental health system. The completion of my research into Family Peer Supports has led me to the conclusion that further research needs to be completed in order to say, Family Peer Supports, with in the Wraparound model, empowers a family to increase their leadership skills. Research assessment tools or satisfaction surveys can play key roles in this research.

Framework for Analysis

I have been a professional who has supported individuals from the ages of zero through the lifespan with mental health and developmental disability challenges for the past 20 years. I am currently the National Alliance on Mental Illness, New Hampshire Director of Children and Youth Services. I am in a situation to share my research on a local, state and national level. One area I plan to share this information is with the larger National Alliance on Mental Illness that represents mental illness on a national level. Additionally, I will share this data is the Federation for Families. These national organization advocate for families who support children who have mental illness.

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As a family member to three children who have needs mental health services. I have the personal lived experience of raising children with mental illness. I have lived through the difficulty of receiving a diagnosis for my children. I have felt the initial devastating feeling that your child will not be what you envisioned for them. I have also seen the incredible progress my children have made through the knowledge and advocacy that I have learned as a parent and a professional. Because of my professional work for the past 20 years, I have seen how important it is to be educated about your child's rights and the services they are eligible for.

I have seen families struggle to receive supports for their children, because of the parent's lack of education about the system and inability to advocate for their children. In my personal situation with my children, I, along with my partner, were able to advocate for services and supports for our children as soon as we realized their challenges were different than other children. We were able to advocate for these services, because we refused to accept anything less than what was needed for our children. We had a willingness to learn how to navigate the service systems and school special education laws. We also expanded our natural supports to work with other families who were going through similar struggles as us. Our interactions with other families gave us the greatest impact of all, hope.

This early intervention resulted in therapies, behavioral supports, educational supports, and medication that supported them to remain in their home and in their community. The ultimate plan is to share this research with families, so they can move past mental health stigma, be provided with hope, and further understand the importance of their own leadership development to increase the success of their children.

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Method

To develop solutions to concerns about the role of Family Peer Supporters and their work with families to empower leadership, I conducted a nonprobability sample, and more specifically a purposive or judgement sample. I specifically surveyed parents who have children with serious emotional disturbance. These children were between the ages of six and twenty-one and lived in New Hampshire (NH). The Families also participated in NH, Medicaid funded, State Wraparound Services for a minimum of six months. I completed the survey through the online survey platform called Survey Monkey.

I wanted to know whether families supporting children with serious emotional disturbance, that are participating with Family Peer Supports, with in the Wraparound Model, are developing the leadership skills necessary to lead their children's services. The intent of my research was to develop a nominal measure. "A level of measurement describing a variable that has attributes that are merely different, as distinguished from ordinal, interval, or ratio measure" (Babbie, 2015).

Although, I did not ask for demographic information directly from families. I was aware of their demographic situation. This could be looked at by some people as ranking people by a certain class. "Ordinal measure is a level of measurement describing a variable with attributes we can rank-order along with some dimension" (Babbie, 2015). I received permission from NAMI NH to get these participants information after they signed a release of information for NAMI NH. The release expressed that they would participate in a non-identifiable survey that would look at Family Peer Support empowerment to families who were participating in the Wraparound process.

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In total I indirectly asked 118 families to participate in the survey. All these families were part of the NH Medicaid funded Wraparound Services. This group was selected from the overall NH Medicaid funded Wraparound group that was made up over 280 families. Wraparound participants are made up of families who have received the majority of the Wraparound process. From the makeup of this group I should get a response from families who have children with serious emotional disturbance who are receiving Family Peer Supports as part of Wraparound Services.

I conducted a nonprobability sample, and more specifically a purposive or judgement sample. "A purposive or judgement sample is a type of nonprobability sample in which the units to be observed are selected based on the researcher's judgement about which ones will be the most useful or representative. Also called judgement sampling" (Babbie, 2015). I was able to eliminate families of children who experience social emotional disturbance (SED) diagnosis, who have not been through most of the Wraparound process, from the specific criteria I asked for from NAMI NH. It ensured that the survey was being filled out by parents who have children with SED, ages 6-21 years of age, and have been in Wraparound services for a minimum of 6 months.

I conducted my survey through Survey Monkey. This platform allowed me to develop my questions with answers that were selected. Survey Monkey had features that processed and sorted data in any way that I wanted to review the data. Whether I looked at each question or by the whole group of surveys. The biggest time consumption about the survey was developing a quality questions for the survey that was easy for families to respond too. I developed this survey from the information in my literature review, though researching family leadership

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questions and working directly with Granite State College's Internal Review Board (IRB) Coordinator.

Results

The survey I completed with families who were receiving Family Peer Support as part of the Wraparound process, was complete within a one-week timeframe. They also were required to have been participating in Family Peer Supports for more than 6 months. There was a total of 18 participants that completed the survey. The 18 participants completed all 20 questions. I was fortunate to get respondents of parents who had children participating in Family Peer Supports due to the daily challenges they face when raising a child who has a mental illness. I appreciated the time they set aside to complete my survey. I felt that represented a nice participant range of families I was targeting.

The survey participants were formulated through NAMI NH's data base. Once this data was shared with me, I was then able to send it to the Family Peer Supporters that were supporting these families. The Family Peer Supporters were asked to share the survey by personally sending the survey to the families they support. They shared it through email or text. In some situations, they also followed up with a phone call to further explain the reasoning for the survey. It was also clearly explained that their answers would be completely unidentifiable.

In total the survey was sent out to was sent total of 125 families by 11 Family Peer Supporters. With a total of 18 responses this was a total response rate of 14%. The highest number of families a Family Peer Supporter had on their caseload was 19 and the lowest was 3 that fit the criteria. The mean for the Family Peer Support caseload was 11.36 families. The

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median was 12. The mode was 10, 12, and 14. The range was 16. I felt that this range of families to Family Peer Supporters represented a nice participant range I was targeting.

The first question was about a family's feeling of hope for their child's mental illness when they first started Family Peer Supports with in the Wraparound Model. The response was 8 said yes (44%), 4 said no (22%), and 6 were not sure (33%). This meant that 10 of the 18 (56%) respondents were not sure or did not have hope for their child's mental health at the start of Family Peer Support services.

The second question asked about how the caregiver felt if they were a good advocate for their child when they first started Family Peer Supports with in the Wraparound Model. The response was 10 said yes (56%), 4 said no (22%), and 4 said unsure (22%). This meant that 8 out the 18 respondents were not sure or did not feel they were good advocates for their child at the start of Family Peer Support Services.

The third question asked about services that the family needed support with when they first started Family Peer Supports with in the Wraparound Model. This question had a lot to do with upfront stabilization requests from families. Respondents could check off as many items they needed support with, including an option to write in something not listed. The highest response was 11 families (61%) said they needed help successfully applying problem solving strategies. Next was 9 families (50%) needed help navigating the New Hampshire mental health system. The third biggest need was 8 families (44%) needed help utilizing self-care skills.

The middle range of this question's responses had a tie with 6 families (33%) saying they needed help with connecting with others who had similar experiences and accessing local, state, or national resources. Self-advocacy skills were the next biggest need with 4 families (22%)

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saying they needed this support. This question wrapped up with a tie with 3 families (17%) saying they needed support maintaining positive relationships with providers and accessing special education services. The least amount of support requested by families was two write in responses that required support to help the family with education about adolescents, and to help their confidence with believing there are supports available.

The fourth question looked at how families felt about being isolated as parent who had a child who had mental illness, when they first started Family Peer Supports in the Wraparound model. The responses were clear, 17 families (94%) said they felt isolated and 1 family (6%) did not feel isolated.

The fifth question asked the family members to identify places that they had trouble keeping good communication with. Respondents could check off as many items they needed support with, including an option to write in something not listed. The highest response was with 12 families (67%) said the New Hampshire Mental Health System was the most difficult resource to communicate with. The next highest was the school districts with 9 responses (50%). Psychiatrist rounded out the highest need for communication assistance with 5 responses (28%).

The lower half of the responses for this question had two responses with 3 each at (17%). The responses checked were local, state, or national resources, and physician. The lowest responses for keeping good communication were with their therapist with 2 families (11%). There were also two write ins that said getting proper heart resources and finding a therapist in their area.

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The sixth question was a yes or no question that asked, when families started Family Peer Supports with in the Wraparound model, did they have a good understanding of special education rules and laws? Families responded with 10 yes's (56%) and 8 no's at (44%).

The seventh question was also a yes or no question that asked if the family understood what self-care was when they first started with Family Peer Supports with in the Wraparound Model. The families answered yes 13 times (76%) and no 4 times (24%). The eighth question jumped related to the prior self-care question asking if family where taking time for self-care when they first started with Family Peer Supports with in the Wraparound model. Families answered with 6 yes's (33%) and 12 no's (67%).

The ninth question asked if families when they first started with Family Peer Supports with in the Wraparound model had a formal crisis plan. Families said yes 4 times (22%) and no 14 times (78%).

The 10th survey question switched from when families where first starting with Family Peer Supports with in the Wraparound model to results after receiving Family Peer Supports with in the Wraparound model. The 10th question asked if the Family Peer Supporter provided hope to the family when they shared their personal story. The results were 15 yes's (83%) and 3 not sure (17%).

The 11th question asked if the parent felt good about being an advocate for their child. The response was clear with 16 parents (94%) saying yes and 1 parent (6%) saying no.

The 12th question asked what the Family Peer Supporter helped them become more independent with. Respondents could check off as many items they needed support with, including an option to write in something not listed. The highest responses were 10 each (59%)

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with maintaining a positive working relationship with providers and successfully navigating the New Hampshire Mental Health System. The next highest responses were 9 each (53%) with accessing local, state, or national resources, and utilizing self-care skills.

The middle range of these responses for support becoming more independent with included accessing special education services with 8 families (47%) responding. Next was a tie with 7 responses (41%) with employing self-advocacy skills, and successfully applying problem solving strategies. The lowest range for this question were 5 responses (29%) said connecting with others with similar experiences. The lowest responses were two write ins saying needs for respite and resources, and the right to speak, ask, advocate for myself, and my family.

The 13th question asked the family what has the Family Peer Supporter helped them improve their communications with. The no.1 answer was increasing communication with school and special education services with 11 families (65%). The second highest answer with 7 families (41%) was the NH mental health system. The third highest answer with 6 families (35%) was local, state, or national resources. The responses then had a tie with 3 families (18%) was a therapist and psychiatrist. The responses finished up with two other responses (12%) saying help with resources not available in my area, and literature.

The 14th question asked if the family increased their knowledge around special education rules and laws since they started with Family Peer Supports. The highest response was with 10 families (59%) said yes, 3 families (18%) said no, and 4 families (24%) said not sure.

The 15th question asked for parent's current understand of what self-care is. The responses were clear with 16 families (94%) saying yes and 1 family (6%) saying no. The 16th

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question the asked if families were currently taking time for self-care. The families answered with 12 families saying yes (71%) and 5 families (29%) saying no.

The 17th question asked families if they had increased their connections with other parents since starting Family Peer Supports. The responses were tied with 6 families (35%) saying yes and no. There were also 5 families (29%) saying their connections were the same.

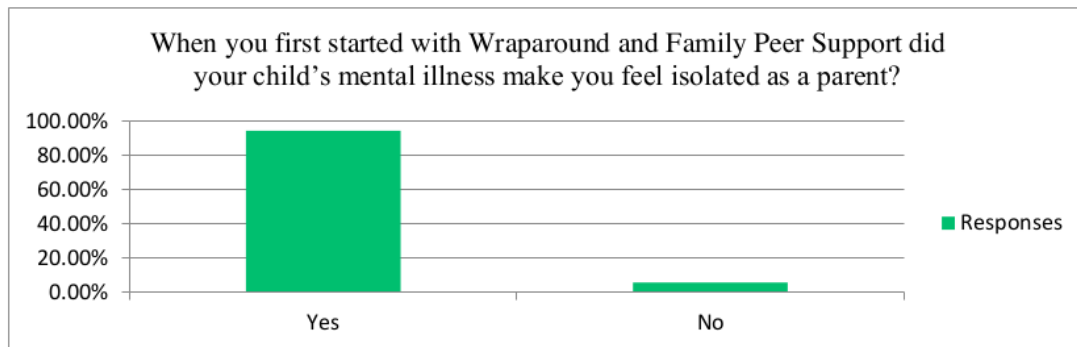
The survey finished up with the 18th through 20th questions. The 18th question asked families if they currently had a formal crisis plan. The family's answers were 10 families (59%) saying yes and 7 families (41%) saying no. The 19th question asked if families had shared their story about their child's mental illness to provide hope to another family. The families responded with 6 families (35%) saying yes, and 11 families (65%) saying no. The 20th and final question asked if families have advocated for another family since they started Family Peer Support. The families responded with 3 families (14%) saying yes and 14 families (82%) saying no.

Discussion & Analysis

The survey I completed with parents who have been receiving Family Peer Supports with in the Wraparound model and had participated a minimum of six months showed some clear results, some mixed results and room for improvement. The results showed an interesting contrast and improvement in their education, leadership and confidence before Family Peer Supports started and to where they were at the time of the survey. However overall, the results showed growth in family leadership skills.

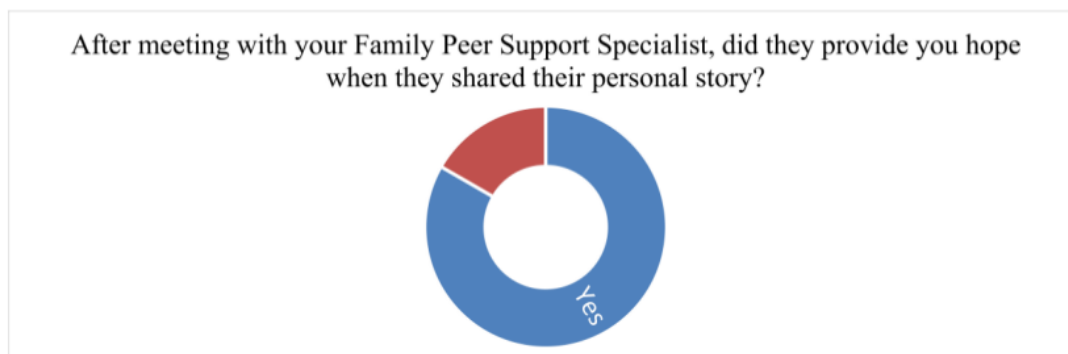
One of the clearest answers that they survey results showed was the tremendous stigma that families face. The question asking if families felt isolated because of their child's mental illness was very clear.

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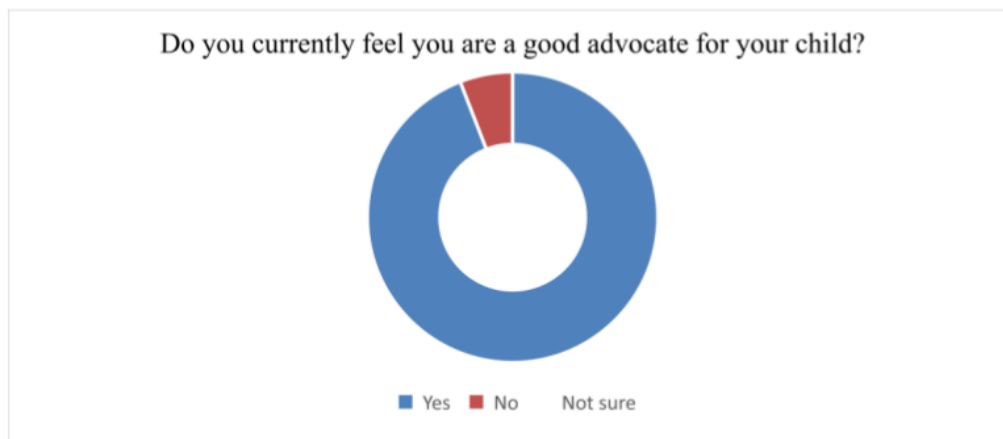
The survey also showed great growth with family's feeling of isolation after they had received Family Peer Support within the Wraparound model. The survey questioned if families had increased their connections with other families since starting Wraparound and Family Peer Supports. The responses showed that 35% of families did increase their connections with other families.

Another larger piece of Family Peer Supports was noticed by families when the questions about hope came up. When families first started Wraparound and Family Peer Supports the family's answers were mixed about their hope for their child's mental health with 55% of responses saying they weren't sure, or they did not have hope. The follow up question about hope showed a great increase in the hope after the Family Peer Supporter shared their story personal story about their child's mental health.



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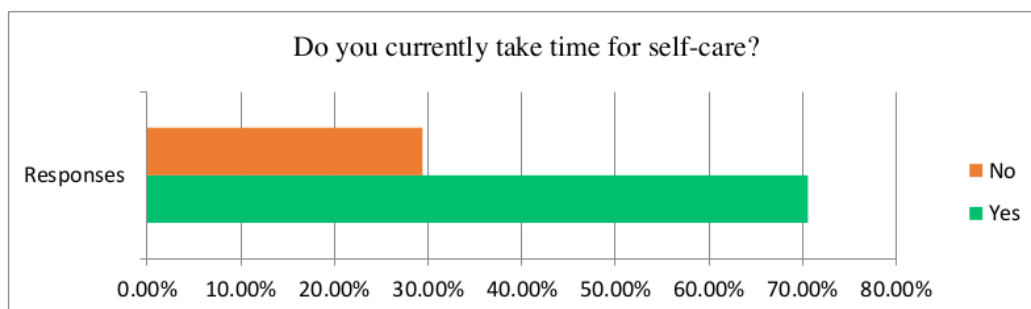
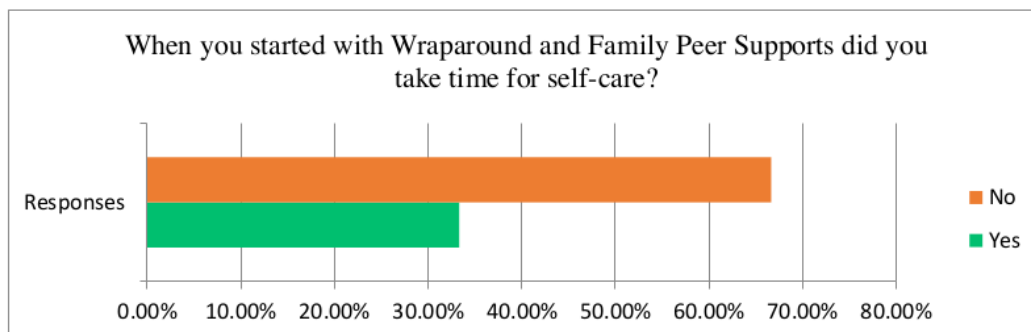
Another large leadership growth shown for families in the survey was seen through family's responses of how they felt about how they saw themselves as advocates before and after Wraparound and Family Peer Supports started. Families did see themselves as good advocates for their children, before Wraparound and Family Peer Supports started with a response of 56% of families felt they were good advocates for their child. However, there was a great increase when families responded as to how they feel today about their ability to advocate for their children currently. The response showed 38% increase as to feeling positive before and after services started.



One example that showed minimal growth was about family's education about NH special education rules and laws. This was noted in the separate survey questions of before and after Wraparound and Family Peer Support started, with family's knowledge of NH education rules and laws. Before services started 10 families (56%) said yes, and 8 families (44%) said no to their good understanding of NH education rules and laws. After Wraparound and Family Peer Supports started 10 families (59%) said yes, 3 families (18%) said no, and 4 families (24%) said same.

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A set of survey questions looked at self-care. The first question asked before Wraparound and Family Peer Support started did families understand what self-care was. The response was clear that families understood what it was with 13 families (76%) saying yes, and 4 families (24%) saying no. However, the alarming response came when families were asked if they were taking time for self-care. The families responded with 6 families (33%) saying no, and 12 families (67%) saying no. The survey continued when families answered questions about self-care after Wraparound and Family Peer Supports started. Families indicated a slight increase in understanding of self-care with 16 families (94%) saying yes, and 1 family (6%) saying no. There was a large increase came when families said they were taking time for self-care with an increase of 38% of families now saying they were taking time for self-care compared to before Wraparound and Family Peer Supports started.



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Another set of survey question looked at formal crisis plans for children. There was a question for before Wraparound and Family Peer Supports started and another question for after. The before question about whether families had a formal crisis plan for their child noted that 4 families (22%) said yes, and 14 families (78%) said no. However, when families were asked the same question after they had been receiving Wraparound and Family Peer Supports 10 families (59%) said yes and 7 families (41%) said no. This showed a 37% increase in families having formal crisis plans for their children.

The final two questions looked a family's ability to take their leadership skills they had developed in Wraparound and Family Peer Supports and share it with other families. This being the goal of Family Peer Supports, to take what you have learned and provide hope to other families experiencing the same struggles with mental illness that you have experienced. The first question asked if the family had shared their story about their child's mental illness with another family to provide them hope since they started Wraparound and Family Peer Supports. Families answered with 6 families (35%) saying yes, and 11 families (65%) saying no.

The last question asked if the family that was currently receiving Wraparound and Family Peer Supports had assisted or advocated for another family or child who has mental illness. The families answered with 3 families (18%) saying yes, and 14 families (82%) saying no. This was exciting to know that some families are advocating for another family or child. However, with only 18% saying they had offered this support this is room for growth.

Recommendations

After completing my literature review and my survey I have concluded that my capstone question was mostly supported. Family Peer Supports, with in the Wraparound model, empower

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a family to increase their leadership skills. To help with more consistent services I would recommend Family Peer Supports to help families and better integrated care. Specifically, Family Peer Support should be used by families to promote early mental health intervention, services and interventions, upfront stabilization, self-care, and advocacy/family voice, while reducing mental health stigma.

Family Peer Supporters have several non-negotiable components of their work. These non-negotiable components include engagement, self-identification and strategic sharing, self-care, collaborative, resiliency, advocacy and culturally competence. These non-negotiable components enable a Family Peer Supporters with lived experience to teach other parents to be independent and empowered as leaders to make sure their child receives the necessary supports that they need.

Critical components of being a Family Peer Supporter starts with engagement with the family. Engagement, listening, empathy and communication is the Family Peer Supporter's ability to build trust and a working partnership with the family. Well supported family engagement would lead to a family member willing to confide with the Family Peer Supporter. It also supports communication that is open, frequent, and reciprocal between the family member and the Family Peer Supporter. Unacceptable roles would include Family Peer Supporter who is directing all communication and is not open to feedback, and not responding to the family.

Self-identification and strategic sharing is the ability to build connections, trust, and relationships with peers. The Family Peer Supporter brings a level of credibility and expertise to the practice. The Family Peer Supporter will need to distinguish times when sharing elements of

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their personal story is helpful and utilizes their personal story with discretion, keeping the focus on the family they are supporting and not themselves.

Helping a family realize how important selfcare is, results in the success of their personal health and how they can continue to support their children. A Family Peer Supporter is self-aware of what contributes and what threatens one's own wellness. They help the family members follow a personal wellness plan and develop a set of strategies. The Family Peer Supporter also helps the family seek a peer group and coaching support to prevent burnout or illness when necessary.

Self-care and lived experience go a long way towards helping a family with resiliency. The Family Peer Supporter uses their strengths to empower the family to work towards self-identified goals. They model reframing to a strength-based lens when the family or others are focused on the negatives. The Family Peer Supporter shares strengths through common interests to identify or bolster the family's strengths. The Family Peer Supporter also uses strategies to assist the family to build hope.

The final component of being a Family Peer Supporter is advocacy. The Family Peer Supporter helps the family to communicate clearly and positively in different contexts so that they are heard. The Family Peer Supporter promotes various levels of advocacy (individual, family, community, school, legislative, etc.). Finally, the Family Peer Supporter teaches the family how to work collaboratively to achieve the family's goals.

Good integrative care for families and children who have mental illness will bring them early identification, quality treatment, coordinated care, resources, and consistent services. Integrated systems are challenging, because many agencies and services providers have become

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siloed. Factors include the loss of resources that they have to other agencies, limited strategies to manage protected health information through the Health Insurance Portability and Accountability Act (HIPA), and the capacity to focus on this system change while continuing to provide their current services.

Conclusion

To conclude my study, I had an opportunity to do extensive literature research on Family Peer Support. More specifically, I have had the opportunity to research mental illness stigma, early intervention, services and interventions, upfront stabilization, self-care, advocacy and family voice. I had the opportunity to survey 18 parents/caregivers from New Hampshire who have children with mental illness who are receiving Family Peer Supports with in the Wraparound Model and have been receiving services for more than 6 months. Before my survey was completed my hypothesis was that Family Peer Supports empower families to be leaders. I was hopeful that my research would help identify the need for increased research that could lead to more consistent practices of how we support families with mental health challenges in our communities, cities, states, and the nation.

My research and survey concluded parents feel isolated. It also concluded that families are being empowered to be leaders for their families. The parents identified several barriers they are seeing before they are receiving Family Peer Supports. These barriers families are seeing included accessing local, state, or national resources, successfully problem solving, navigating NH mental health system, utilizing self-care skills, and connecting with others with similar experiences. My research also concluded that Family Peer Support has assisted families to become more independent with all these barriers (see Appendix L).

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Editing the survey to ask more questions about demographic information could be a great learning opportunity for the Family Peer Supporters. If there was more demographic information specific Family Peer Supports could identify specific training opportunities. The ability to identify where people lived who filled out the survey would have also presented an opportunity to point out gaps of needed services in specific locations of the state of New Hampshire.

Overall, I would consider my hypothesis supported by my research and survey. Families identified needs before Wraparound and Family Peer Supports began. The survey also pointed out that Family Peer Supports have supported families to increase their use of self-care, confidence in the advocacy skills, completion of formal crisis plans, and increased feeling of hope. Potentially most important of all, the survey showed families are starting to share their lived experience with other parents who have children with mental illness to provide them hope, and they even starting to advocate for other families. My research concludes two things: Family Peer Supports are necessary, and they empower families to be leaders. Family Peer Supports are necessary to help families to find hope and navigate the difficult systems we have today, until more integrative care systems can be implemented.

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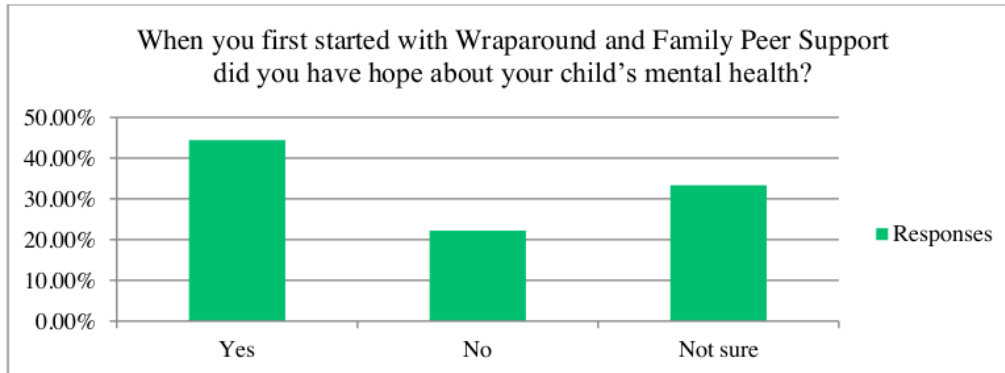
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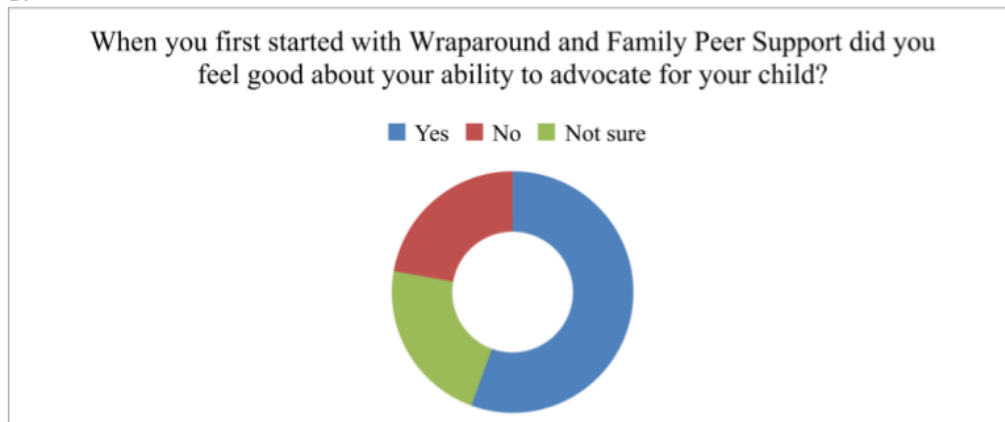
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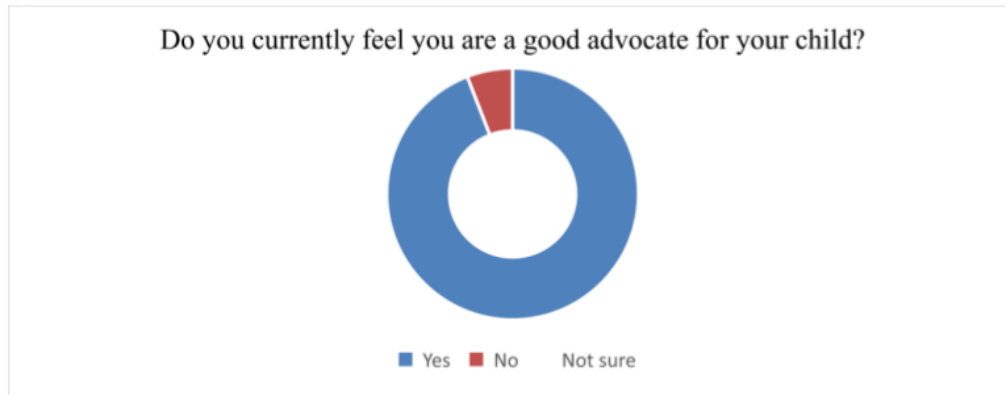
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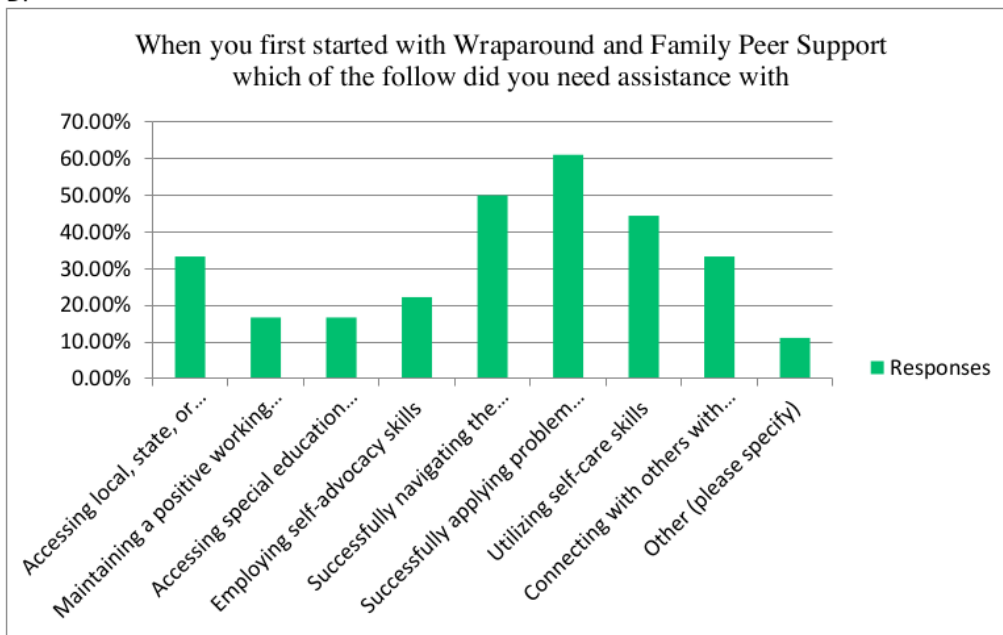


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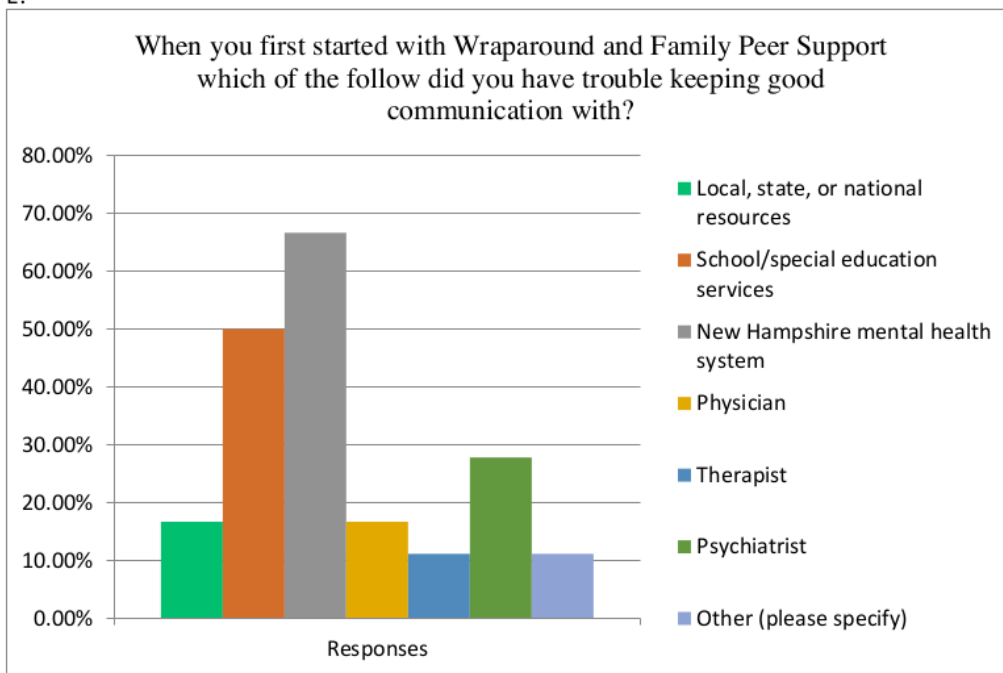


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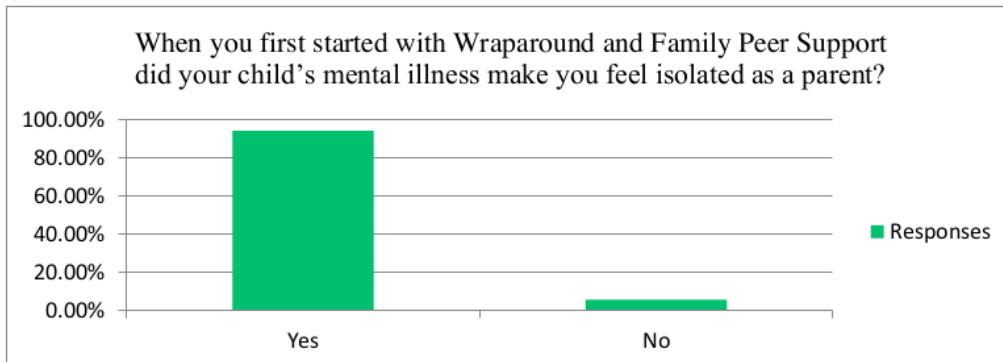


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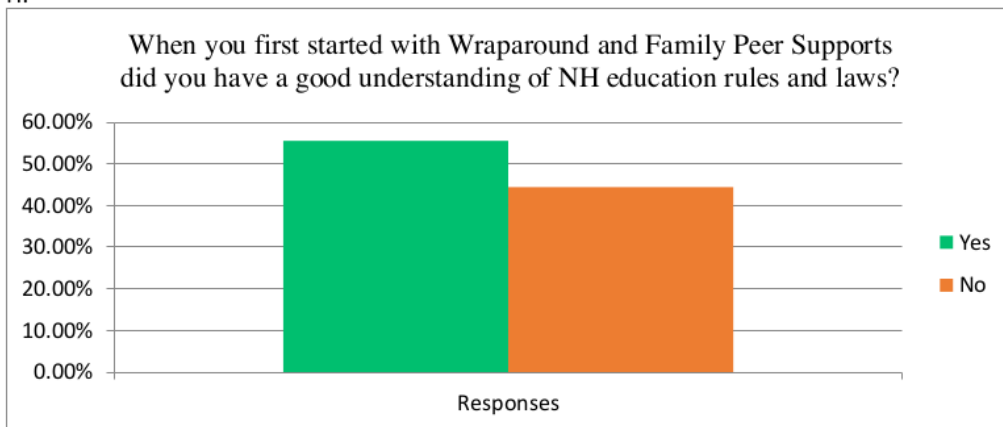


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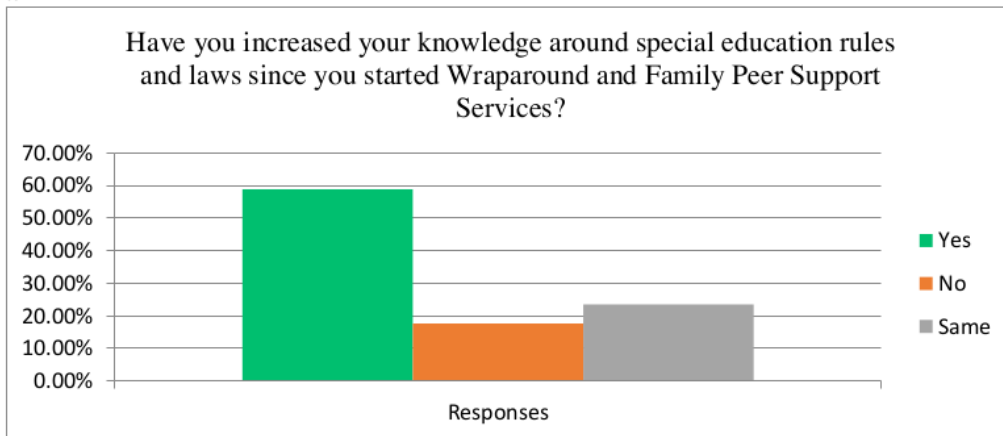
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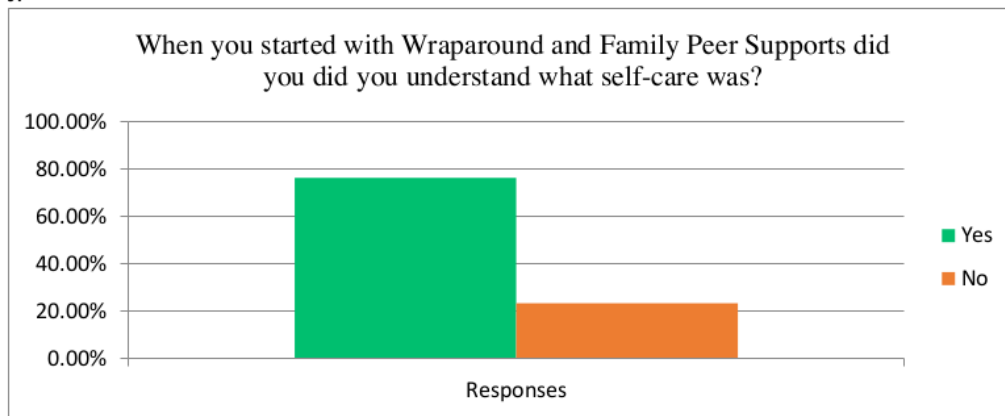


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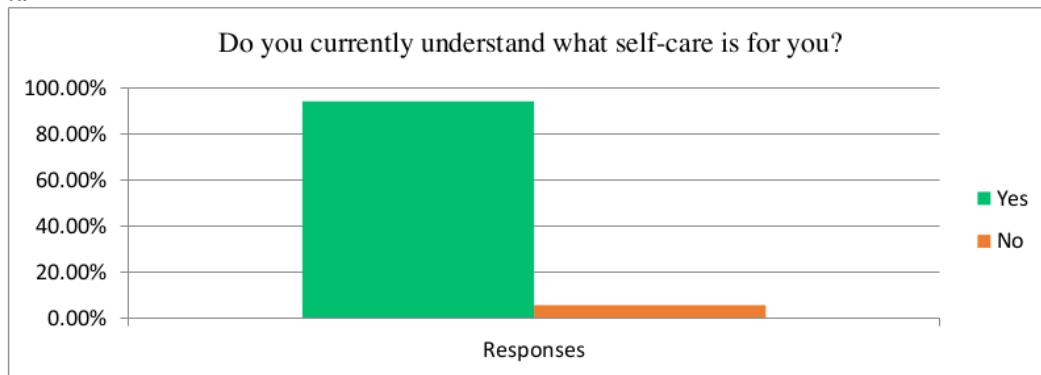


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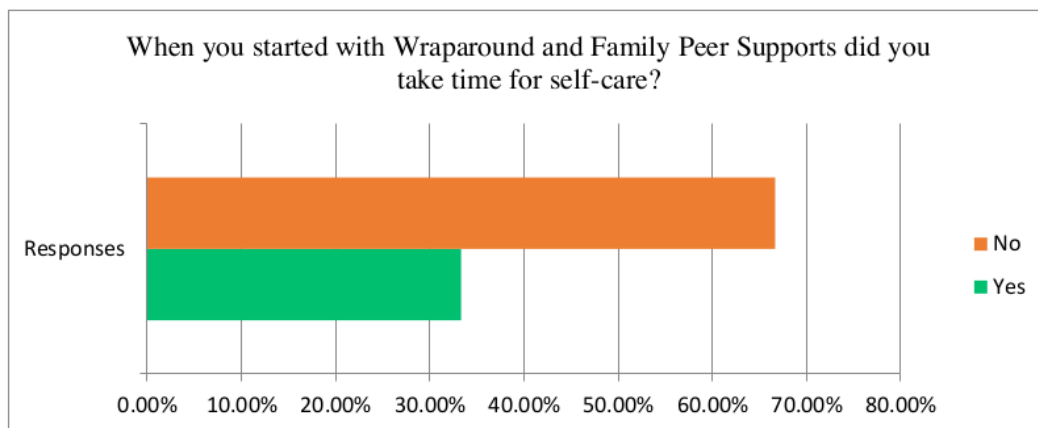
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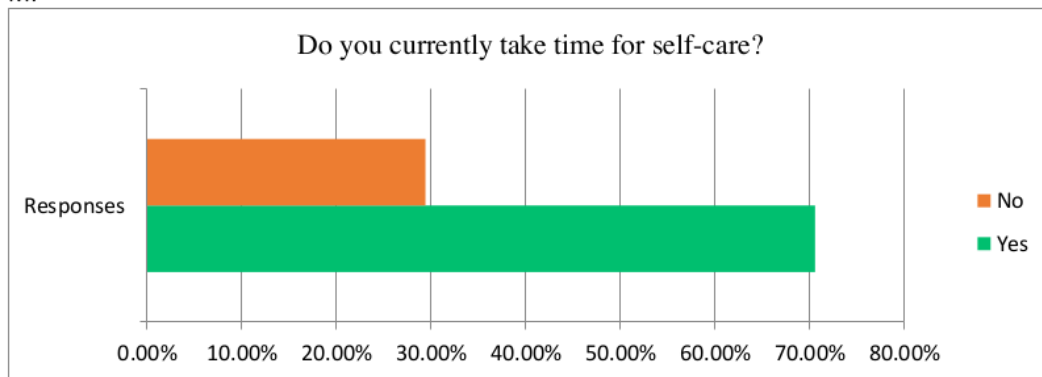


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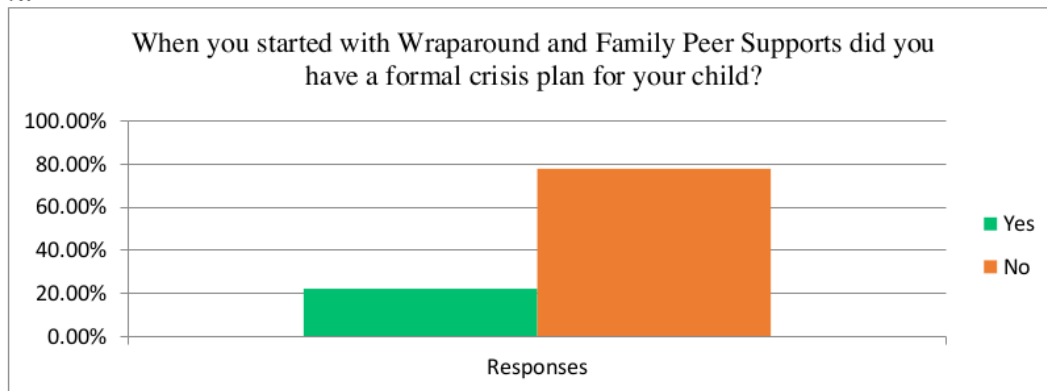


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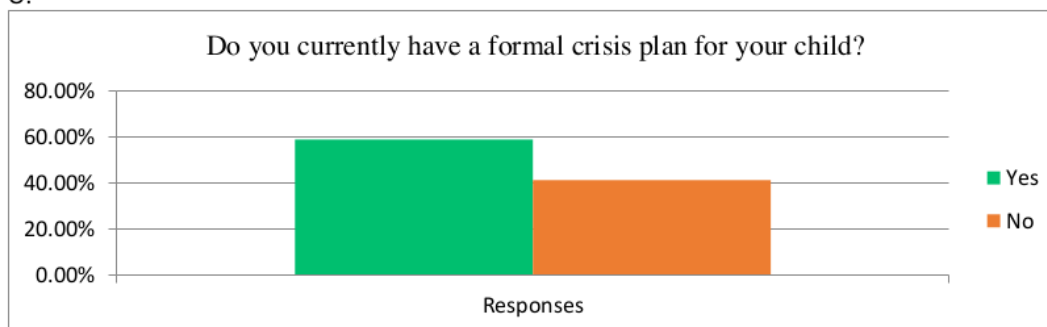
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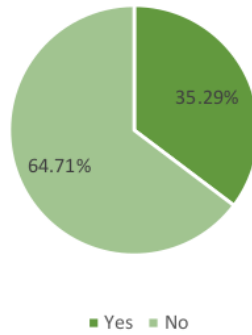
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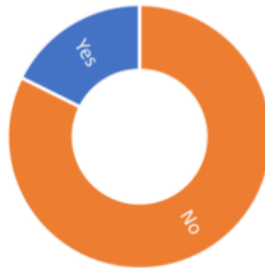
P:

Have you shared your story about your child's mental illness with another family to provide them hope since you have started Wraparound and Family Peer Supports?



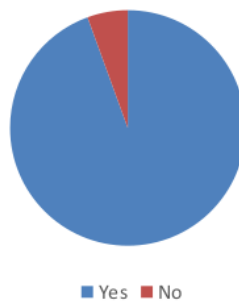
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Have you assisted or advocated for another family/child who has mental illness since you have started Wraparound and Family Peer Supports?



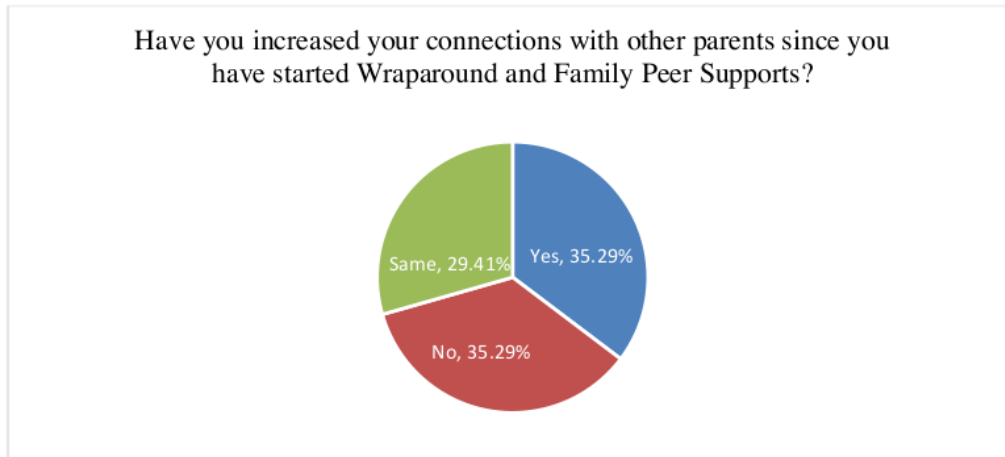
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When you first started with Wraparound and Family Peer Support did your child's mental illness make you feel isolated as a parent?

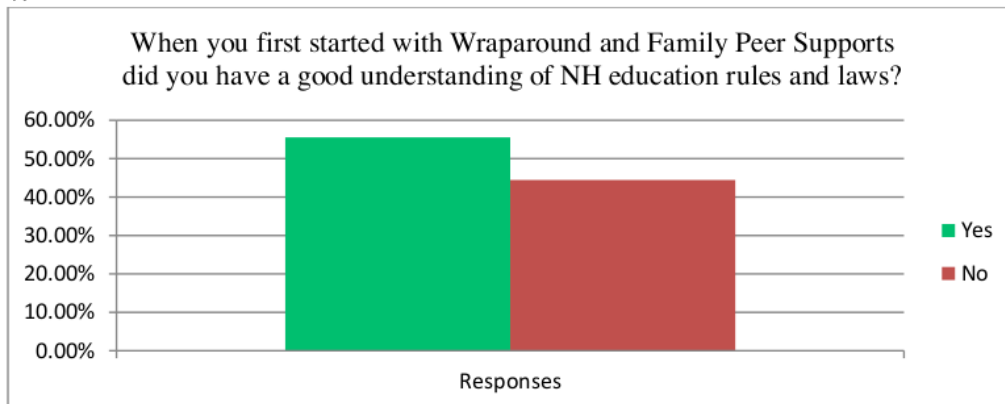


FAMILY EMPOWERMENT THROUGH FAMILY PEER SUPPORT

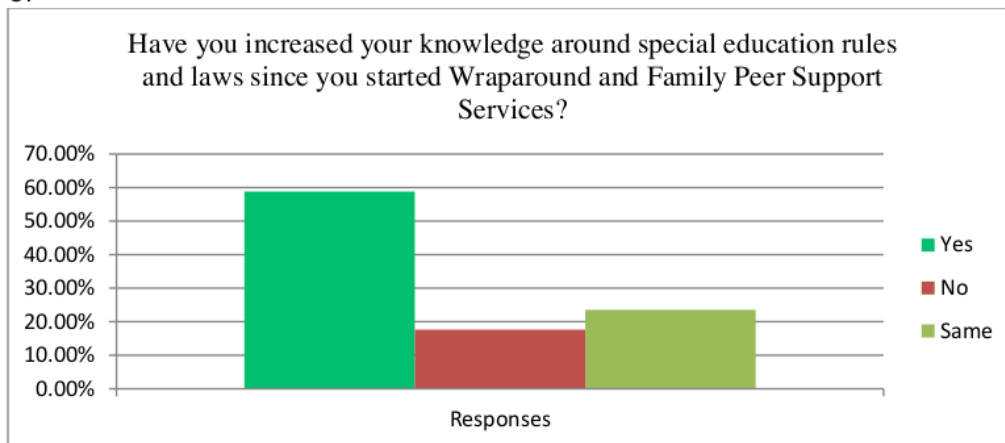
S:



T:



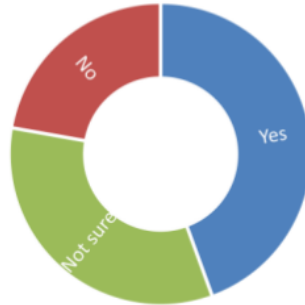
U:



FAMILY EMPOWERMENT THROUGH FAMILY PEER SUPPORT

V:

When you first started with Wraparound and Family Peer Support did you have hope about your child's mental health?



W:

After meeting with your Family Peer Support Specialist, did they provide you hope when they shared their personal story?

