

Working with the Well Sibling:
The Perspective of the Marriage and Family Therapist
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Abstract

Recent research on working with families in which one child is suffering from a developmental disability has indicated a need for more focused clinical attention on the well sibling or neurotypical sibling experience. Research has also suggested that a systemic approach to the therapeutic process would be the most beneficial to all members of the family system, including the well sibling. Although the literature supports the use of systemic interventions in supporting the well sibling, there is a gap between what the research is suggesting and the clinical application. In an effort to fill this gap, this study sought to explore how Marriage and Family therapists are working systemically with families in which one child has a disability to incorporate the needs of the well sibling. After conducting four qualitative interviews and analyzing the data, three central themes emerged: 1) stabilization; 2) involving the well sibling; and 3) methods of support. Clinical implications as well as suggestions for future research are also addressed.

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Chapter 1: Introduction

The purpose of this study was to explore how Marriage and Family therapists are currently working with families in which one child has a developmental disability, particularly in regard to the involvement of the well sibling. Marriage and Family therapists are trained to view families systemically, taking the experience of and interactions between each member of the family system into account. This skill is particularly relevant when treating this population, because the experienced stressors and emotional processing of each family member has been shown to be so interrelated that families benefit more from a systemically based intervention in which all members of the system are present, than they do when each family member is treated in isolation (Giallo & Gavidia-Payne, 2006). This is especially the case for the well siblings--neurotypical siblings--of children with developmental disabilities, who often go unnoticed during the therapeutic process (Schuntermann, 2009).

Research on well siblings has led to three types of literature: 1) empirical articles on the well sibling experience, often revealing predictors of well sibling adjustment; 2) empirically supported interventions that are highly individualized in their focus, the concentration of which remains on family subsystems rather than on the system as a whole; and 3) clinical articles, echoing the recommendations found in the empirical articles and encouraging systemically based treatment for the whole family, but remaining theoretical in nature. Thus, there is a substantial gap in research regarding how family therapists are actually working with this population. Researchers have speculated that family therapists do not typically work with families in which one child has a developmental disability (Solomon & Chung, 2012), which may account for the gap in research; however, there is little evidence to support this assertion. Thus, this study seeks to answer the following question: How are Marriage and Family therapists currently working

systemically with families in which one child has a developmental disability to incorporate the needs and experience of the well sibling?

The Problem and its Setting

A study recently released by the Center for Disease Control states that there has been a steady rise in the incidence of children with developmental disabilities in the United States over the last decade, and that, "... 15% of children aged 3 to 17 years, or nearly 10 million children in 2006-2008, had a developmental disability on the basis of parent report" (Boyle et al., 2011, p. 1037). This points to the growing need for clinicians to develop a more comprehensive understanding of the experience of each member of a family system in which one member suffers from a developmental disability. There are a variety of cognitive and physical disabilities, as well as chronic illnesses, that effect families around the world. Due to the complex nature of this topic, along with the relatively recent attention to this population, it is difficult to narrow the focus down to a particular affliction. Thus, for the purpose of this study, "A developmental disability is defined as any mental and/or physical disability that is manifested before age 22 years; that is likely to continue indefinitely; and that substantially limits one or more life activities, such as walking, seeing, speaking, breathing, or learning" (Williams et al., 2010, p. 40).

As Conway and Meyer (2008) state, the longest relationship that children with developmental disabilities will potentially have is with their siblings—longer even than with parents, caretakers, and friends. Well siblings are likely to face changing roles and expanding responsibilities as they progress through the lifespan with their developmentally disabled sibling. This makes the struggles and triumphs of the well sibling distinct from every other member of the family (Conway & Meyer, 2008). Providing support for the well sibling goes beyond

teaching tools and coping mechanisms; they need support within the family system, as well. Unfortunately, as Schuntermann (2007) points out, “More often than not, the sibling experience is marginalized in planning clinical services for developmentally challenged children” (p. 103). As a result, according to the research, well siblings are often either overlooked in the therapy room (Schuntermann, 2009), or the tools to help them cope with their unique struggles are learned independently of the family system (Conway & Meyer, 2008). Thus, in order for the family therapist to best treat the family system, the well sibling experience must be incorporated into the treatment process, and their skills and needs must be recognized (Williams, et al., 2010).

As Meyer and Vadasy (2009) state, “True ‘family-centered’ care and services will arrive when siblings are actively included in agencies’ functional definition of ‘family’ and systemic changes are made to acknowledge siblings’ contributions and concerns” (as cited in Conway & Meyer, 2008, p. 113). Much of the family treatment in the therapy room involves how best to adapt to the challenges often associated with having a child with developmental disabilities, whether it is through early intervention strategies or through day to day behavior management. As a result, the child with the disability remains the focus of treatment when working with the family in a clinical setting (Schuntermann, 2009).

Current research shows that while other members of the system are acknowledged in the clinical setting, it is not from a systemic perspective. Instead, the system is often divided, with each subset being treated separately. Parents of children with developmental disabilities have been a clinical focus for some time, as evidenced by the prevalence of services and support groups centered on providing information, encouragement, and validation (e.g. Head & Abbeduto, 2007; Hudson, Cameron, & Matthews, 2008; Ramish, Timm, Hock, & Topor, 2013). Sibling support groups, on the other hand, are less common, despite the fact that they also need

information, encouragement, and validation just as much as the parents, if not more, given the sensitive stages of development they are in (Conway & Meyer, 2008).

Parents are more likely to address the weight of the psychological implications of being a well sibling only after said well sibling is acting out in some way. However, a study conducted by Ross and Cuskelly (2006) revealed that siblings of children with autism have a higher risk of internalizing behavior problems. Internalized behaviors can include being anxious or depressed (Lougheed & Hollenstein, 2012). This suggests that the well sibling may not be overtly displaying symptoms of the stressors. Schuntermann (2007) speculates that some well siblings may suppress their need for outside support because they internalize an unspoken message from the family system that the professional focus should remain on the child with developmental disabilities. Once again, the functioning of the system overshadows the experience of the individual. This is extremely important to be aware of as a clinician, because it is our responsibility to assess all of the members of the family, even if they are not presenting overt symptoms.

Significance

While there are a number of factors that may influence adjustment in the well sibling, there is little debate that the presence of the child with developmental disabilities will have an effect on the sibling experience. A study by Williams et al. (2010) reviewed parents' descriptions of the well sibling experience as it pertains to family life, revealing negative effects in 61.1% of responses, positive effects in 37.2%, and no reported effects in only 1.7%. Examples of negative manifestations revealed included anger, resentment, loneliness, guilt, anxiety, embarrassment, and academic problems. Negative manifestations included seeking attention through unhealthy or aggressive means, and insulting the disabled sibling. Positive manifestations included early

maturation of the well child, greater sensitivity and empathy, and a closer family relationship.

Although it is crucial to recognize that these are unique circumstances that the well sibling must face and overcome, it is also important to acknowledge that this struggle can create both challenges and opportunities for the well sibling.

While parents can seek out support and resources to help them cope with the pressures of raising a child with developmental disabilities, the siblings are often left to adapt to the stress of the situation on their own. According to Schuntermann (2009), “The underlying concern is that family dynamics, including most importantly the focus on addressing the needs of the affected child, can and do interfere with addressing the needs of other siblings” (p. 297).

Current research on families in which one child is suffering from developmental disabilities demonstrates the fact that each part of the system can benefit from support given the unique stressors that each face. Research indicates that interventions have proven useful in mitigating the effects of these stressors on each part of the system separately (Conway & Meyer, 2008; McCabe, 2008; Ramish et al., 2013). However, because these interventions are highly individualized, there is little evidence documenting how they can be incorporated into the family system to promote change. Indeed, systemically based treatment of this population remains speculative at this point. This study seeks to bridge this gap by exploring if and how Marriage and Family therapists work systemically with this population, particularly in regard to the involvement of the well sibling.

Rationale

This study will employ a basic qualitative interviewing methodology (Strauss & Corbin, 1990) due to the fact that there is limited research regarding the therapeutic experience of the well sibling when one child in the family suffers from developmental disabilities. A qualitative

study will provide a more detailed understanding of the essence of the generally accepted method of practice when working with such a family in the therapy room. Additionally, by interviewing the professionals that work directly with this population, this study will provide a better understanding of the struggles faced in the therapy room, which will establish a foundation for future research regarding how best to work systemically with this population, while incorporating the well sibling into the therapeutic process. Marriage and Family therapists are uniquely qualified in the application of systems theory due to their training on relational patterns as found in the MFT Core Competencies.

Theoretical Framework

Systems theory reminds us that each individual must be considered within the context of the family, and that every family is unique (Smith, Hamon, Ingoldsby, & Miller, 2009). Each individual establishes roles within the family system, and interactional patterns develop between these roles. As time passes, these roles and interactional patterns are reinforced within the system, creating a state of equilibrium. If one role within the system shifts, the rest of the system is forced to adapt in order to regain equilibrium, which may involve one or more members taking on more responsibility. This can cause dysfunction in the individual because as one member becomes overburdened, he or she may develop unhealthy coping mechanisms in order to manage the additional stressors. Instability within the individual may also breed dysfunction in the family system as it struggles to adapt to the changing roles (Smith et al., 2009).

Smith et al. (2009) warn us that oftentimes an individual can become the focus of treatment due to the presence of more overt symptoms. This can be detrimental to the healing of the whole family system for two major reasons: first, it is not taking the fundamental family patterns of interaction into account, which are often the root of the dysfunction; second, it is

difficult to promote change in the individual without the support of the system. As such, approaching therapy from a systemic perspective releases the idea of having an identified patient (Smith et al., 2009).

This concept plays out noticeably in a family system in which one child has developmental disabilities (Williams et al., 2010). As the demands of the child with developmental disabilities increase, parents may become overburdened, leading them to lean on the well sibling as a source of support and assistance in caretaking. In addition, parents may hold the well sibling to a higher standard of expectations than a typical child whose parents do not bear the additional burdens presented by the presence of the developmentally disabled child. For example, a well sibling may not be able to be as social as some of his or her peers due to burdens of caregiving at home; or perhaps the well sibling may be treated as an adult, even though he or she is just barely reaching the adolescent years. Here we may see the dynamic interaction between each members of the system, which is struggling to maintain a normal state of functioning.

There are certain techniques that can aid the professional in the therapy room, to keep the focus of treatment on the family system. Tuerk, McCart, and Henggeler (2013) highlight some techniques that are indicative of using a systems approach in family therapies, including, "... identification of strengths across multiple systems, harnessing family supports to assist with interventions and during times of disengagement, and the maintenance of a family (versus a child) focus during treatment" (p. 177). Family centered techniques such as these focus on the reciprocal nature of the family system. As such, they provide a greater potential for success in treatment because they allow for increased communication and improved understanding between members of the system, they increase the potential for building internal supports within the

system, and they prevent one member of the system from feeling like the source of the family's dysfunction. Given that the evidence supports the benefits of a systemic approach when working with families in which one child has a developmental disability, and that this study will focus on the therapeutic process of Marriage and Family therapists working with this population, it follows that Systems Theory would provide the backdrop for this study.

Purpose of the Study

Families of children with developmental disabilities have only recently begun to be viewed from a systemic perspective, enough so to include the experience of the well sibling. Clinicians are often unaware of the systemic implications of having a sibling with developmental disabilities, and, as such, it is not uncommon for the experience of well siblings to become secondary in a clinical setting (Schuntermann, 2007). As we have seen, the well sibling may suffer the burdens and revel in the pleasures just as much as the parents do, if not more, given the length of time that they are present in the life of their developmentally disabled sibling (Conway & Meyer, 2008; Williams et al., 2010). After reviewing the research, the importance of keeping the system the focus of the treatment and including all members of the family in the treatment process is clear. Still, articles presenting the use of a systemic approach when working with this population are theoretical in nature. As a result, there is little concrete data on what is currently being done in the therapy room. It is my hope that with this study I will be able to answer the following question: How are Marriage and Family therapists currently working systemically with families in which one child has a developmental disability to incorporate the needs and experience of the well sibling?

Chapter 2: Literature Review

As previously discussed, the presence of a developmentally disabled child requires the rest of the family system to adapt and develop new family roles, which can affect the well sibling in a variety of ways. I will lay the foundation for this study by first describing the benefits of a systemic approach to the therapeutic process, followed by an outline of recent research on the experience of the well sibling, and culminating with an overview of the current treatment options when working with families in which a child has a developmental disability.

Systemic Approach

System-focused techniques can aid the professional in the therapy room to treat the family system as a whole and help utilize internal supports (Tuerk, McCart, & Henggeler, 2013). As White and Klein (2008) describe, a healthy balance is key, and family relationships must be managed so that each individual's needs are met without having a damaging effect on the needs of other members of the system.

Many researchers agree that working with families from a systemic perspective is more beneficial than working with members of the system in isolation (e.g., Nichols & Tafuri, 2013; White & Klein, 2008). Furthermore, researchers have speculated about the potential benefits of viewing families with a child with developmental disabilities through a systemic lens (Hastings et al., 2005; Williams et al., 2010). These potential benefits have remained speculative, as researchers continue to assert that the well siblings are often overlooked in the therapy room due to the more clinically pressing needs of the child with developmental disabilities (e.g., Head & Abbeduto, 2007; Schuntermann, 2009). However, due to the lack of research on the therapeutic process, it remains unclear why Marriage and Family therapists would not utilize a systemic perspective incorporating all members of the family system in the treatment process.

Although much of the current research on the families of children with developmental disabilities is highly individualized in its focus, it does provide a solid systemic foundation for the practices that would be beneficial to the well sibling when working with the family. Research on working with the systems parts provides useful information for professionals working with this population. Professionals utilizing a systemic approach when working with this population can adapt this individualized information to provide a more integrated therapeutic process.

Current research has revealed certain predictors of increased stress in parents of children with developmental disabilities, which has been shown to affect the well sibling (Giallo & Gavidia-Payne, 2006). Research has shown that increasing communication between parents helps to build internal support within the system, which will thereby help to limit the trickle down effects of stress on the well sibling (Ramish et al., 2013). Also, it is possible that parents may not be able to fully process the logistical changes that they will have to make in order to successfully adapt until they have been able to appropriately process the magnitude of the situation. Family therapists can aid in the grief process by allowing parents the space to share their pain, fears, and concerns; additionally, family therapists can normalize these feelings. Family therapists can help parents cope with feelings of self-blame, or with feeling selfish or unqualified (Head & Abbeduto, 2007; Richardson et al., 2013). This will help parents to adapt to their circumstances, and it will help therapists to mitigate the potential for parent stress or depression affecting the well sibling. Using professional judgment regarding who is in the session at a particular time, family therapists can also facilitate a conversation between the parents and the well sibling regarding any pain, confusion, or frustrations they might be feeling. Doing so may serve to unite the family and begin the process of building internal supports.

Evidence has shown that involving the family system in the therapeutic support of the child with disabilities can increase the potential for successful treatment (Boyd et al., 2011; Ferraioli, Hansford, & Harris, 2012). However, despite the benefits for the child with disabilities, it is important to take the effects of such responsibilities into account when working with the system, especially in regard to the well sibling. For example, before involving the well sibling in the treatment of the disabled child, it is essential that parents and professionals are careful to take the well siblings' age and motivation into account, along with the severity of the symptoms presented by the child with developmental disabilities. If the well sibling is emotionally unprepared for such a responsibility, or if the symptoms are too severe for sibling mediation to be successful, it may cause negative effects in the well sibling (Ferraioli et al., 2012). Furthermore, should well siblings be involved in such a manner, it is essential that they are also supported within the system, so that the potential for internalizing behaviors or parentification is minimized. Additionally, when the parents are educated in the implementation of techniques to support the child with developmental disabilities, family therapists should emphasize the risk of negative effects on the well sibling due to parental differentiation by highlighting the importance of open communication and well sibling education.

Current research on families with a child suffering from developmental disabilities indicates several predictors of healthy adjustment in well siblings that can be encouraged through systemic interventions. Perhaps one of the biggest contributors to successful family adaptation is open communication with the well sibling regarding the disability. Information about the child's disability has been found to provide the well sibling with an understanding of the nature of the family's unique situation, which can help well siblings better accept their circumstances (Kao et al., 2011). In addition to open communication, basic education within the context of the family

system can provide the well sibling with concrete tools and techniques that can be used when interacting with the developmentally disabled sibling. This can give well siblings a feeling of influence and control, which can improve their quality of life (Moyson & Roeyers, 2012). Furthermore, with open communication within the family system and knowledge regarding the disability, well siblings are more likely to feel valued and to take part in supporting the child with developmental disabilities (Conway & Meyer, 2008). As such, the well sibling can participate in creating additional internal supports, creating positive interaction cycles within the system, and potentially alleviating some of the stressors experienced by parents.

Along with open communication and education, well siblings have been found to benefit from more logistically oriented interventions. For example, an emphasis structure and routine in the household has been found to help well siblings and their families find some control in an often unpredictable family environment (Giallo & Gavidia-Payne, 2006). Family therapists can work with the family system to create a more structured environment, stressing the importance of structure in regard to the healthy adjustment of the well sibling. Furthermore, helping the well sibling to better understand their role within the family system may help them to manage their expectations and may give them a sense of influence as they learn to cope with the stresses of their unique circumstances.

Strengthening the subsystems within the larger system has also been shown to promote positive outcomes in the well sibling. As mentioned earlier, a strong parental subsystem helps alleviate stress in the parents and prevents negative effects on parenting style (Ramish et al., 2013), which may help to promote healthy adjustment in well siblings. The parent-well sibling subsystem is also an important focus of therapeutic intervention because it increases the bond between the parents and the well sibling and builds internal supports (Giallo & Gavidia-Payne,

2006). Furthermore, strengthening this subsystem may help to alleviate the presence of parental differentiation, thereby inhibiting the potential for internalizing behaviors in the well sibling.

Although current research provides a general understanding of positive interventions when working with subsets of the family system, there is little research, if any, regarding how a family therapist might take these lessons into the therapy room when the entire family system is present. Balancing the needs of the child with developmental disabilities along with the needs of the well sibling, while still managing their own stressors, is essential for parents, and it is a skill family therapists must be knowledgeable about, especially when considering the well being of the well sibling.

Well Sibling Stressors

When working with families in which one child has a developmental disability, systems theory reminds us that it is important to consider how the experience of each member of the system might impact the others (Smith et al., 2009). For example, research indicates that parent stress significantly influences well sibling adjustment (Giallo & Gavidia-Payne, 2006), which makes consideration of parent stress an essential part of the treatment process. Thus, it is important to take the functioning of the other members of the system into account, especially in regard to how they may impact the well sibling.

Parent Stress

While the presence of a child with developmental disabilities will create a long-term shift in the parents' daily life, they may experience an initial period of distress that can be emotionally demanding. Prior to diagnosis, parents may begin to notice that their child is not progressing along with his or her peers, and they may receive persistent questions from childcare providers, teachers, or family members. They may feel confused or out of control as a result. Diagnosis

may provide some relief, but along with understanding may come sadness and fear (Richardson et al., 2013). A study conducted by Richardson et al. (2013) highlights the difficulties experienced in this early phase, in which parents described characteristics most closely associated with grief, including, "... yearning, cognitions around self blame, hopelessness, guilt, avoidance, anger, disappointment, sadness, crying, numbness, worry, shock and denial" (p. 730). These feelings are typically the result of the sensation of loss that they experience as they begin to adjust their hopes for their child's future. Additionally, parents may feel a sense of loss when considering the potentials for their relationship with their child. In sum, the parent-child bond may be affected as parents struggle to reconcile their child with their child's disability. The emotional toll that parents may experience during this period of adjustment can be profound, and it is important that professionals consider this (Richardson et al.).

In addition to the initial emotional strains placed on parents of children with developmental disabilities, there are a number of logistical factors affecting their daily lives. As parents eventually adjust to their circumstances, they begin to learn how to adapt and face the new challenges presented by their developmentally disabled child. This often involves an increase in the need for external support systems and additional medical and financial requirements. However, research has shown that stress is most likely to occur during essential daily responsibilities, including meals, bedtime, and hygiene tasks, when parents are more vulnerable to the triggers presented by more challenging behaviors of the child with developmental disabilities (Plant & Sanders, 2007). There is evidence that as parents of developmentally disabled children experience an increased level of stress during basic caretaking tasks, they experience a number of additional side effects, including a decrease in sense of competence, along with an increase in stress on the partner relationship and an increase in

susceptibility to depression (Ketelaar, Volman, Gorter, & Vermeer, 2008). In other words, the stress caused by caring for a child with developmental disabilities can cause secondary stressors.

The presence of secondary stressors can have consequences of their own. Benson and Karlof (2009) studied stress proliferation and its role in the presence of anger and depression in parents of children with autism. Findings suggest that more severe symptoms in children with autism resulted in an increase in the experience of stress in other areas of life, which then resulted in an increase in the potential for depression or anger in parents. The presence of secondary stressors can also heighten difficulties experienced during the original stressors and can worsen conflict within the family system, causing additional stress for the well sibling (Giallo & Gavidia-Payne, 2006). A study on well sibling adjustment conducted by Giallo and Gavidia-Payne (2006) highlights this, finding that one of the biggest predictors of healthy adjustment in well siblings was how well the family was able to cope with the additional stressors placed on them by the presence of the child with developmental disabilities.

The influence of parental stressors on the well sibling is once again highlighted in a study conducted by Rivers and Stoneman (2003), in which marital stress and the sibling relationship was looked at through a systemic lens by questioning 50 parents of children with autism, and their well children. The study revealed that when marital stress was greater, the sibling relationship suffered. It is hypothesized in the study that the well sibling is able to pick up on the added stress on the parents, which causes them to be more sensitive to and less patient with the behavioral outburst of the developmentally disabled child. This, in turn, would negatively impact the sibling relationship (Rivers & Stoneman, 2003). Although this hypothesis appears fitting, further research is needed to establish a better understanding of the correlation between marital stress and sibling relationships.

Differential Parenting

As the parents learn adapt, the nature of their role may shift, which can alter the way that they parent other children in the family system (Fox et al., 2002). This can create parental differentiation in the household, which is when parents treat their children differently in regard to reward, punishment, and time spent with children. Fox, Vaughn, Wyatte, and Dunlap (2002) conducted a qualitative study on how the problem behaviors of the child with developmental disabilities can effect the family system, and found that parents often struggle with discipline in the household, given that the child with developmental disabilities often does not suffer the same consequences as the well sibling when misbehaving. The well sibling's experience of differential parenting can have a number of consequences, including negatively affecting the sibling relationship (Rivers & Stoneman, 2008) and feeling like less of a priority (Williams et al., 2010). A study conducted by Kao, Romero-Bosch, Plante, and Lobato (2011) notes the presence of maternal guilt because the well sibling simply does not get as much attention as the child with developmental disabilities. Moyson and Roeyers (2012) take this one step further, by elucidating the well sibling's desire not to be a sibling sometimes. The presence of a child with developmental disabilities is demanding, and as a result, the well sibling sometimes finds relief in being able to step away and be independent from the sibling; this allows other roles to step forward, like being able to be a son or a daughter. Differential parenting can make this difficult.

Well Sibling Parentification

Increased parent stress can also lead to additional pressures on the well sibling, as they may be expected to help with certain care-taking responsibilities. Parents interviewed in a study conducted by Williams et al. (2010) acknowledged the fact that the well sibling is often handed more responsibilities at a younger age, which often translates into higher expectations regarding

conduct and self care, more caretaking tasks for the sibling with developmental disabilities, and less free time for social activities. Kao et al. (2011) highlight the potential for parentification in well siblings in their qualitative study on the experience of Latino well siblings, stating that, “Siblings were actively involved in helping and supervising the child and they appeared to be integral parts of each other’s lives...” (p. 550). Kao et al. point out that it is difficult to say whether this parentification has negative effects on the adjustment of the well sibling, because the mere fact that they are often raised with these strong family beliefs at the forefront may result in a more positive experience. Still, regardless of the outcome, the fact remains that well siblings are often given greater responsibilities than siblings of typical children.

Well Sibling Behavioral Outcomes

As discussed above, families of children with developmental disabilities experience a number of additional pressures that can affect each individual differently. As a result of this, there is the potential for well siblings to avoid voicing the difficulties they may be experiencing so they don’t add to the stressors already experienced by the rest of the family (Schuntermann, 2007). A study conducted by Ross and Cuskelly (2006) revealed that siblings of children with autism are at a higher risk of internalizing behaviors and adjustment problems due to the many psychological and social outcomes that well siblings are at risk of experiencing. Well siblings may be angry and resentful for having additional pressures, or sad and depressed at the loss of their potential sibling relationship. They may be embarrassed when in social situations or at school with their developmentally disabled sibling (Williams et al., 2010).

The presence of a child with developmental disabilities has the potential to create positive outcomes in well siblings, as well, which may contribute to lowered stress in parents and increased overall functioning of the system as a whole. The stress of the presence of a child with

disabilities may bring the family closer together, and create a stronger feeling of unity within the family system. The well sibling may develop more sensitivity to the experiences of others around him or her, and may develop qualities like patience, understanding, and tolerance as a result of their struggles (Williams et al., 2010).

Although there is a mixture of potential positive and negative outcomes that can result from having a sibling with developmental disabilities, current research supports the fact that siblings are undeniably affected. Professionals should become aware of the nature of these potential outcomes so that they can best address them from a systemic approach. Understanding the dynamic interplay between members of the system will allow professionals working with this population to best acknowledge and incorporate the sibling experience into the treatment of the family system.

Current Treatment

Current research on families in which one child is suffering from developmental disabilities demonstrates the fact that each part of the system can benefit from support given the unique stressors that they each face. Research indicates that interventions have been proven useful in mitigating the effects of these stressors on each part of the system separately (Conway & Meyer, 2008; McCabe, 2008; Ramish et al., 2013). However, because these interventions are highly individualized, there is little evidence documenting how they can be incorporated into the family system to promote change. Indeed, systemically based treatment of this population remains speculative at this point.

Well Siblings

Recently, there have been more intervention programs directed towards the unique struggles of the well siblings. An article written by Conway and Meyer (2008) directly addresses

this issue, stating that sibling focused support groups are an essential part of the coping process for well siblings. The authors go on to state that sibling support groups aid in educating well siblings, provide them with a feeling of community, and help them become more aware of how to manage difficult interactions with their developmentally disabled sibling. Additionally, they can provide parents with knowledge and awareness of the needs of their neurotypical children. Still, even as sibling support groups provide well siblings with much needed support and companionship, it cannot be considered a therapeutic intervention on the family system. Any therapeutic benefits experienced fall short systemically, because they are once again focused on a single part of the system, without attention to the interactional patterns between the parts.

Parents

As parents are learning to adapt to the demands of parenting a child with developmental disabilities, they may seek out external resources for their child, and for themselves. Often, parents turn to support groups to aid in the adjustment process (Fox, Vaughn, Wyatt, & Dunlap, 2002). There are many benefits to attending support groups, including decreased feelings of isolation, emotional support, increased awareness of coping strategies, and a better understanding of what is to come (McCabe, 2008). Support groups for parents can also provide a safe space to discuss the nature of their struggles, as well as a brief period of respite from their daily stressors. Although there are many benefits to attending parent focused support groups, it is unclear whether or not they are beneficial in effecting real change in the home environment (McCabe). Therefore, although parent support groups can be useful as a separate resource, there is little evidence of what this may mean in regard to the family system.

Research has also shown that the couple relationship can be affected by the presence of a child with developmental disabilities due to the additional stressors placed on both parents. For

example, a study conducted by Hastings et al. (2005) found that depression experienced by either the mother or the father as a result of the presence of the child with disabilities increased the likelihood that the partner would experience stress. This indicates the need for additional support for the couple relationship. Ramish et al. (2013) addressed this issue by conducting a study in which Emotionally Focused Therapy was used as an intervention for three couples whose marital satisfaction was suffering due to the presence of a child with autism spectrum disorder. This intervention was found to be useful in working with couples with a child with developmental disabilities, particularly in aiding in the identification of negative interaction cycles. Additionally, Ramish et al. found that intervening with these negative patterns of interaction increased healthy communication, which made it easier for parents to navigate the weighty demands of caring for a child with disabilities. This study also indicated that these types of interventions are often sought out after conflict is present in the relationship. Ramish et al. suggest that the couple relationship would benefit from a preemptive model of intervention. Additionally, they noted that a parenting component in addition to the EFT would be useful. This again supports the need for interventions that consider the individual demands of each of the parts of the system, without ignoring the interplay between the parts and how that influences the system as a whole.

Current research has shown that parents of children with developmental disabilities can benefit from individual support, as well as from marital and parenting support. As evidenced, parents of children with developmental disabilities have access to a number of individualized resources, but without incorporating these methods into a systemic perspective. An awareness of the struggles and joys of having a child with developmental disabilities is essential for the family therapist when working with such a population (Richardson et al., 2013).

Child with Developmental Disabilities

The nature of intervention for children with developmental disabilities differs widely depending on the disability. However, it is not uncommon in the treatment of such children to see a two sided approach, using individually based therapy for the child, along with educating the family on how best to provide additional support (e.g. Boyd et al., 2011; Egilson, 2011; Ferraioli et al., 2012). Based on the research, we have seen that siblings often take on caretaking tasks (Williams et al., 2010), but recent studies have also begun to involve the well sibling in treating the child with developmental disabilities (Ferraioli et al., 2012).

Many children with developmental disabilities display particularly difficult behavioral patterns that present more complex challenges than the family system can understand without outside support. Egilson (2011) recently conducted a study on Icelandic parents' satisfaction with the support services provided to their disabled children. Using a qualitative interviewing process, Egilson found that although many parents were satisfied with the therapeutic support provided to the child with disabilities, they felt that the services were too individually focused on the child, without an enough family centered involvement on the part of the professionals. As a result, these parents felt that there was limited communication regarding clear strategies and expectations.

A review of recent research on sibling involvement by Ferraioli, Hansford, and Harris (2012) discusses the benefits of including the well sibling in supporting the child with developmental disabilities by involving them in the teaching process. By doing so, it has been shown to give the well sibling a feeling of control, and often results in increased patience with and connection to the child with developmental disabilities. However, there are potential risks to involving the well sibling in the education process. For example, the well sibling, being of a

developmental age themselves, sometimes internalizes the behaviors of the child with developmental disabilities, blaming themselves if the lesson does not go smoothly. It is important to point out that the success of an intervention such as this one relies on the assumption that siblings would want to take on the responsibilities of becoming a central part of the teaching process (Ferraioli et al., 2012).

A study by Boyd et al. (2011) discusses the involvement of the parents in supporting the child with autism by teaching them tools to help moderate repetitive behaviors in the home environment. These methods were found to be successful in treating the autistic child, showing a rise in positive behaviors and a drop in negative behaviors. This emphasizes the benefits of parent involvement, and highlights the benefits of educating the family system in regards to tools and techniques that are proven effective in the treatment of children with developmental disabilities. However, the study does not address the potential positive or negative effects that increased focus on the child with developmental disabilities may have on the well sibling.

Current research has revealed several methods for supporting children with developmental disabilities, including child centered therapeutic interventions provided by an external support group, sibling directed education, and parent guided interventions. While there are potential benefits to each of these interventions in regard to the support of the child with developmental disabilities, there is little evidence to show how each of these interventions might be modified to take a more systemically founded approach, which incorporates the experience of the well sibling.

Parent-Well Sibling Subsystem

Parent-well sibling interventions have been found to strengthen their relationship while concurrently benefitting the adjustment of the well sibling. For example, Lobato and Kao (2005)

suggested a method of intervention that centers on the education of the well sibling, while opening the lines of communication between the well sibling and his or her parents. Utilizing group workshops for the well siblings overlapping with group workshops with the parents, the intervention encourages communication regarding the nature of the disability. Additionally, it gives parents a clearer understanding of the well sibling's experience of having a sibling with developmental disabilities.

Full System Speculation

Several researchers have suggested that systemically based interventions should be the next stage of research on supporting this community. For example, Head and Abbeduto (2007) suggest a model of systemically based assessment in which the well being of all members is considered, as is their ability to adapt to the stressors faced by having a child with a disability within the system. Schuntermann (2009) also discusses the benefits of moving towards a systemic approach, suggesting a more integrative treatment plan in which the well sibling's interrelationships and personal struggles are moderated through the process of mentalizing. Unfortunately, current research on family based systemic interventions falls short due to the fact that it is theoretical in nature. Current systemic interventions remain speculative, based on previous research and on family report. As of yet, there has been no research exploring what clinicians working with these communities are actually doing in the therapy room to support the whole system, including the well sibling.

Summary

As evidenced, research identifies the presence of unique stressors throughout the family system when one child has a developmental disability. The benefit of a family systems approach has been detailed, along with specific predictors of successful well sibling adaptation. Although

much evidence encourages the support of the family system, particularly in regard to the adjustment of the well sibling, there is little research indicating if and how practitioners are currently working with these families. Thus, it is the goal of this study to explore the following question: How are Marriage and Family therapists currently working systemically with families in which one child has a developmental disability to incorporate the needs and experience of the well sibling?

Chapter 3: Methods

Design of the Study

The goal of this study was to develop an understanding of how Marriage and Family therapists are currently working with well siblings in the therapy room when treating families in which one child is suffering from a developmental disability. General Systems Theory guided this study. According to von Bertalanffy (1968), General Systems Theory presents the idea of generalized systems, which are made up of parts that influence one another. Von Bertalanffy (1968) continues on to state that as these parts interact and affect one another, they impact the organization of the system as a whole. This is especially relevant in the therapy room as one part begins to change, because there is inevitably a response from the rest of the system.

Using General Systems Theory as a foundation, a qualitative interviewing process allowed me to develop a better understanding of how Marriage and Family therapists take these interactional patterns into account when working with families in which one child is suffering from a developmental disability. As Creswell (2007) describes, the purpose of qualitative research is to increase understanding of the experience of specific populations so that we can develop generally applicable theories (p. 40). As previously stated, there is little information regarding how and when to best involve the well sibling in the therapeutic process when working with families with a developmentally disabled child. Therefore, qualitative interviewing was used to explore the methods of current MFT's in regard to the treatment of such families and to the handling of the presence of the well sibling in the therapy room.

Study Participants

Due to limited research guiding the therapeutic practice of Marriage and Family therapists working with families in which one child is suffering from a developmental disability,

this study focused on the point of view of the therapists rather than on the experience of the well siblings. The researcher interviewed four licensed Marriage and Family therapists that have treated at least one family in which one child had a developmental disability and in which at least one well sibling was living in the home during the time of treatment. Due to the fact that this study used systems theory as a foundation, particularly focusing on the interactional patterns involved in the well sibling's development and adjustment, it was essential that at least one well sibling was living in the home at the time of treatment. As Licensed MFT's, each interviewee was trained from an MFT perspective, and thus, focused on family interactions in their treatment. As MFT's, they had the MFT Core Competencies as defined by the AAMFT guiding their treatment process. For example, the MFT's ability to, "Develop hypotheses regarding relationship patterns, their bearing on the presenting problem, and the influence of extra-therapeutic factors on client systems" (p. 3), and to, "Empower clients and their relational systems to establish effective relationships with each other and larger systems" (p. 5) makes their therapeutic skillset distinctively systemic on a foundational level.

Procedures

Prior to beginning data collection, IRB approval was obtained. Once approval was granted, the researcher began the recruitment process by posting a flyer on the MFT listserv. The flyer listed the researcher's phone number and email address so that potential participants could contact the researcher to be screened for suitability. The researcher was contacted by four MFT's. As previously discussed, the two main criteria for involvement in this study were, first, that the participant be a licensed Marriage and Family therapist, and, second, that, since getting licensed, the participant had experience working with at least one family in which one child had from a developmental disability with at least one well sibling living in the home during the time

of treatment. After any potential participant was screened, the researcher scheduled an appointment with the participant to conduct the interview. Interviews were in person and over the phone. Prior to beginning the interview, each participant was given an informed consent form, and was offered the opportunity to ask questions so that any concerns could be addressed appropriately. Once the consent form was obtained, the interview began. All interviews were audio recorded, so that they could be transcribed and analyzed. At the start of the interview, the researcher informed the participants of the nature of the study, and reminded them that they are free to stop at any point if they so desire.

Instruments

For the purpose of this study, each participant was given a brief demographic questionnaire as follows:

- What is your age?
- What is your gender?
- What is your ethnicity?
- What state are you licensed in?
- How long have you been a licensed MFT?

In addition to the demographic questionnaire, the researcher conducted a 60-minute, one on one qualitative interview with each therapist participant. The interview was semi-structured, with the option for probing questions. The interview protocol was as follows:

- Please tell me about a family you have worked with that had a child with a developmental disability and at least one well sibling. What was the disability? Who were the members of the family system?

- Why did they come in and what was their presenting issue? Did they come in for the child with developmental disabilities, or for the well sibling?
- Tell me about who was usually present in the therapy room.
- When every member was present in the therapy room, where did the focus of the therapy often fall, and why?
- Were subsystems ever the focus of therapy? For example, the parental subsystem, or the parent-well sibling subsystem?
- Did you sometimes focus on the well sibling without meeting them or having them in the therapy room? Why or why not? If so, what did this entail?
- During therapy, did you do anything specific to support and/or involve the well sibling?
 - If yes, can you provide me with examples? What were the goals of these interventions? From where did you take those ideas?
 - If no, what held you back from doing so?
- Was educating the well sibling on the nature of the child's disability brought into the therapy room at any point? Why or why not? If so, how?
- Was there any discussion about the nature of the communication between the parents and the well sibling? Why or why not? What did this look like?
- Did you find a need to address the family's daily routine and structure? How did you come to this decision?
- Did you ever work with the well sibling individually? Why or why not? What was the nature of the therapy?

- Was there ever any involvement with other types of support services concurrently? What did that look like?
 - How did the family's involvement with these services affect therapy?
 - How did the family respond to these services?
- In your experience, how do families typically address the well sibling experience prior to family therapy?
- Is there anything I have not asked you that you feel is important?

Validity was established throughout the interview through probing questions in order to get the best, most complete descriptions. Additionally, the researcher established validity by utilizing reflective listening as a manner of member checking during each interview.

Data Analysis

Each interview was audio recorded, and the data was sent out for professional transcription. The researcher then double-checked the completed transcriptions for accuracy. The researcher then began the process of analysis using techniques described by Strauss (1987). Through the method of open-coding, the interviews were read and reread to see what patterns emerged. As the data were reviewed, memos were made and consistent themes became more apparent. Additionally, the researcher bracketed any assumptions and biases that may have influenced the analysis of the data. Throughout this process, the researcher used the co-researcher to help cross-code the data in order to ensure credibility and trustworthiness.

Chapter 4: Manuscript

Abstract

Recent research on working with families in which one child is suffering from a developmental disability has indicated a need for more focused clinical attention on the well sibling or neurotypical sibling experience. Research has also suggested that a systemic approach to the therapeutic process would be the most beneficial to all members of the family system, including the well sibling. Although the literature supports the use of systemic interventions in supporting the well sibling, there is a gap between what the research is suggesting and the clinical application of these suggestions. In an effort to fill this gap, this study sought to explore how Marriage and Family therapists are working systemically with families in which one child has a disability to incorporate the needs of the well sibling. After conducting four qualitative interviews and analyzing the data, three central themes emerged: 1) stabilization; 2) involving the well sibling; and 3) methods of support. Clinical implications as well as suggestions for future research are also addressed.

Working with the Well Sibling:
The Perspective of the Marriage and Family Therapist

Christina Bonenberger

Introduction

The purpose of this study was to explore how Marriage and Family therapists are currently working with families in which one child has a developmental disability with particular regard to the involvement of the well sibling. Marriage and Family therapists are trained to view families systemically by taking into account the experience of and interactions between each member of the family system. This skill is particularly relevant when treating this population because the experienced stressors and emotional processing of each family member have been shown to be so interrelated that families would benefit more from a systemically based intervention in which all members of the system are present than they do when each family member is treated in isolation (Giallo & Gavidia-Payne, 2006). This is especially the case for the well siblings--neurotypical siblings--of children with developmental disabilities who often go unnoticed during the therapeutic process (Schuntermann, 2009).

Research on well siblings has led to three types of literature: 1) empirical articles on the well sibling experience, often revealing predictors of well sibling adjustment; 2) empirically supported interventions that are highly individualized in their focus, the concentration of which remains on family subsystems rather than on the system as a whole; and 3) clinical articles, echoing the recommendations found in the empirical articles and encouraging systemically based treatment for the whole family, but remaining theoretical in nature. Thus, there is a substantial gap in research regarding how family therapists are actually working with this population. Researchers have speculated that family therapists do not typically work with families in which

one child has a developmental disability (Solomon & Chung, 2012), which may account for the gap in research; however, there is little evidence to support this assertion. This study seeks to answer the following question: How are Marriage and Family therapists currently working systemically with families in which one child has a developmental disability to incorporate the needs and experience of the well sibling?

A recent study by the Center for Disease Control shows a steady rise in the incidence of children with developmental disabilities in the United States over the last decade (Boyle et al., 2011). This points to the growing need for clinicians to develop a more comprehensive understanding of the treatment of a family system in which one member has a developmental disability. There are a variety of cognitive and physical disabilities, as well as chronic illnesses, that affect families around the world. Due to the complex nature of this topic, along with the relatively recent attention to this population, it is difficult to narrow the focus down to a particular affliction. For the purpose of this study, “A developmental disability is defined as any mental and/or physical disability that is manifested before age 22 years; that is likely to continue indefinitely; and that substantially limits one or more life activities, such as walking, seeing, speaking, breathing, or learning” (Williams et al., 2010, p. 40).

As Conway and Meyer (2008) state, the longest relationship that children with developmental disabilities will potentially have is with their siblings—longer even than with parents, caretakers, and friends. Well siblings are likely to face changing roles and expanding responsibilities as they progress through the lifespan with their developmentally disabled sibling. This makes the struggles and triumphs of the well sibling distinct from every other member of the family (Conway & Meyer). Providing support for the well sibling goes beyond teaching tools and coping mechanisms; they need support within the family system, as well. Unfortunately, as

Schuntermann (2007) points out, “More often than not, the sibling experience is marginalized in planning clinical services for developmentally challenged children” (p. 103). As a result, well siblings are often either overlooked in the therapy room (Schuntermann, 2009), or the tools to help them cope with their unique struggles are learned independently of the family system (Conway & Meyer). In order for the family therapist to best treat the family system, the well sibling experience must be incorporated into the treatment process and their skills and needs must be recognized (Williams, et al., 2010).

Systems Theory

Systems theory reminds us that each individual must be considered within the context of the family and that every family is unique (Smith, Hamon, Ingoldsby, & Miller, 2009). Each individual establishes roles within the family system and interactional patterns develop between these roles. As time passes, these roles and interactional patterns are reinforced within the system, creating a state of equilibrium. If one role within the system shifts, the rest of the system is forced to adapt in order to regain equilibrium, which may involve one or more members taking on more responsibility. This can cause dysfunction in the individual because as one member becomes overburdened, he or she may develop unhealthy coping mechanisms in order to manage the additional stressors. Instability within the individual may also breed dysfunction in the family system as it struggles to adapt to the changing roles (Smith et al.).

Smith et al. (2009) warns us that oftentimes an individual can become the focus of treatment due to the presence of more overt symptoms. This can be detrimental to the healing of the whole family system for two major reasons: first, it is not taking the fundamental family patterns of interaction into account, which are often the root of the dysfunction; second, it is difficult to promote change in the individual without the support of the system. As such,

approaching therapy from a systemic perspective releases the idea of having an identified patient (Smith et al.).

System-focused techniques can aid the professional in the therapy room to treat the family system as a whole and help utilize internal supports (Tuerk, McCart, & Henggeler, 2013). As White and Klein (2008) describe, a healthy balance is key, and family relationships must be managed so that each individual's needs are met without having a damaging effect on the needs of other members of the system. Marriage and Family therapists are uniquely qualified in the application of systems theory due to their training on relational patterns as found in the MFT Core Competencies.

Many researchers agree that working with families from a systemic perspective is more beneficial than working with members of the system in isolation (e.g., Nichols & Tafuri, 2013; White & Klein, 2008). Furthermore, researchers have speculated about the potential benefits of viewing families with a child with developmental disabilities through a systemic lens (Hastings et al., 2005; Williams et al., 2010). These potential benefits have remained speculative, as researchers continue to assert that the well siblings are often overlooked in the therapy room due to the more clinically pressing needs of the child with developmental disabilities (e.g., Head & Abbeduto, 2007; Schuntermann, 2009). However, due to the lack of research on the therapeutic process, it remains unclear why Marriage and Family therapists would not utilize a systemic perspective incorporating all members of the family system in the treatment process.

The Well Sibling in Research

Well Sibling Experience

When working with families in which one child has a developmental disability, systems theory reminds us that it is important to consider how the experience of each member of the

system might impact the others (Smith et al., 2009). For example, research indicates that parent stress significantly influences well sibling adjustment (Giallo & Gavidia-Payne, 2006), which makes consideration of parent stress an essential part of the treatment process. Parents of children with disabilities experience several types of stress. Parents may experience an initial period of confusion and fear, followed by a grieving period as they begin to process and accept the loss of their neurotypical child (Fox, Vaughn, Wyatte, & Dunlap, 2002; Richardson, Cobham, McDermott, & Murray, 2013). The emotional toll for parents during this period of adjustment can be profound.

Adapting to the challenges presented by their disabled child can be another source of stress for parents. This often involves an increase in the need for external support systems and additional medical and financial requirements (Richardson et al., 2013). However, research has shown that stress is most likely to occur during essential daily responsibilities, including meals, bedtime, and hygiene tasks, when parents are more vulnerable to the triggers presented by more challenging behaviors of the child with developmental disabilities (Plant & Sanders, 2007). There is also evidence that as parents of developmentally disabled children experience an increased level of stress during basic caretaking tasks, they experience a number of additional side effects, including a decrease in sense of competence, along with an increase in stress on the partner relationship and an increase in susceptibility to depression (Ketelaar, Volman, Gorter, & Vermeer, 2008).

As the parents learn to adapt, the nature of their role may shift, which can alter the way they parent other children in the family system (Fox et al., 2002). This can create parental differentiation in the household. Concepts such as reward, punishment, and time spent with each child can no longer be separated equally; instead, out of necessity, parents are often forced to

prioritize the needs and behaviors of the child with the developmental disabilities (Fox et al., 2002; Rivers & Stoneman, 2008). The well sibling's perception of differential parenting can have a number of consequences, including negatively affecting the sibling relationship (Rivers & Stoneman) and feeling like less of a priority (Williams et al., 2010).

Parents interviewed in a study conducted by Williams et al. (2010) acknowledged the fact that the well sibling is often handed more responsibilities at a younger age, which often translates into higher expectations regarding conduct and self care, more caretaking tasks for the sibling with developmental disabilities, and less free time for social activities. Kao, Lobato, Plante, and Romero-Bosch (2011) point out that it is difficult to say whether this parentification has negative effects on the adjustment of the well sibling because the mere fact that they are often raised with these strong family beliefs at the forefront may result in a more positive experience. Regardless of the outcome, the fact remains that well siblings are often given greater responsibilities than siblings of typical children.

Well Sibling Behavioral Outcomes

While there are a number of factors that may influence adjustment in the well sibling, there is little debate that the presence of the child with developmental disabilities will have an effect on the sibling experience. A study by Williams et al. (2010) asked parents to describe the experience of the well sibling as it pertains to family life, revealing negative effects in 61.1% of responses, positive effects in 37.2%, and no reported effects in only 1.7%. Examples of negative manifestations revealed included anger, resentment, loneliness, guilt, anxiety, embarrassment, and academic problems. Negative manifestations included seeking attention through unhealthy or aggressive means and insulting the disabled sibling. These negative manifestations are more overt, and are more likely to result in parents seeking outside support for the well sibling.

However, the well sibling may not be overtly displaying symptoms of the stressors. A study conducted by Ross and Cuskelly (2006) revealed that siblings of children with autism have a higher risk of internalizing behavior problems. Internalized behaviors can include being anxious or depressed (Lougheed & Hollenstein, 2012). Schuntermann (2007) speculates that some well siblings may suppress their need for outside support because they internalize an unspoken message from the family system that the professional focus should remain on the child with developmental disabilities. The potential for internalized behaviors is important for clinicians working with this community to be aware of because the symptoms are not always apparent.

The presence of a child with developmental disabilities has the potential to create positive outcomes in well siblings, as well, which may contribute to lowered stress in parents and increased overall functioning of the system as a whole. The presence of a child with disabilities may bring the family closer together and create a stronger feeling of unity within the family system. The well sibling may develop more sensitivity to the experiences of others around him or her, and may develop qualities such as patience, understanding, and tolerance as a result of their experience (Williams et al., 2010). Although there is a mixture of potential positive and negative outcomes that can result from having a sibling with developmental disabilities, recent research supports the fact that siblings are undeniably affected.

Current research on families with a child suffering from developmental disabilities indicates several predictors of healthy adjustment in well siblings. Perhaps one of the biggest contributors to successful family adaptation is open communication with the well sibling regarding the disability (Kao et al., 2011). In addition, basic education within the context of the family system can provide the well sibling with concrete tools and techniques that can be used when interacting with the developmentally disabled sibling (Moyson & Roeyers, 2012). With

open communication within the family system and knowledge regarding the disability, well siblings are more likely to feel valued and to take part in supporting the disabled sibling (Conway & Meyer, 2008). The well sibling can then participate in creating additional internal supports, creating positive interaction cycles within the system, and potentially alleviating some of the stressors experienced by parents.

Along with open communication and education, well siblings have been found to benefit from more logistically oriented interventions. For example, an emphasis on structure and routine in the household has been found to help well siblings and their families find some control in an often unpredictable family environment (Giallo & Gavidia-Payne, 2006). Furthermore, helping well siblings to better understand their role within the family system may help them to manage their expectations and give them a sense of influence as they learn to cope with the stresses of their unique circumstances.

Current Treatment

Current research on families in which one child is suffering from developmental disabilities demonstrates that each part of the system can benefit from support given the unique stressors that each face. Research indicates that interventions have proven useful in mitigating the effects of these stressors on each part of the system separately (Conway & Meyer, 2008; McCabe, 2008; Ramish, Timm, Hock, & Topor, 2013). However, because these interventions are highly individualized, there is little evidence documenting how they can be incorporated into the family system to promote change. Indeed, systemically based treatment of this population remains speculative at this point.

Well Siblings

Recently, there have been more intervention programs directed towards the unique struggles of the well siblings. An article written by Conway and Meyer (2008) directly addresses this issue, stating that sibling focused support groups are an essential part of the coping process for well siblings. The authors go on to state that sibling support groups aid in educating well siblings, provide them with a feeling of community, and help them become more aware of how to handle difficult interactions with their developmentally disabled sibling. Additionally, they can provide parents with an awareness of the needs of their neurotypical children.

Parents

Often, parents turn to support groups to aid in the adjustment process (Fox et al., 2002). There are many benefits to attending support groups, including decreased feelings of isolation, emotional support, increased awareness of coping strategies, and a better understanding of what is to come (McCabe, 2008). Support groups for parents can also provide a safe space to discuss the nature of their struggles, as well as a brief period of respite from their daily stressors.

Research has also shown that the couple relationship can be affected by the presence of a child with developmental disabilities. Depression experienced by one parent increased the likelihood that the partner would experience stress (Hastings et al., 2005). This indicates the need for additional support for the couple relationship. Research reveals that Emotionally Focused Therapy is a useful intervention for parents of disabled children, because it increases healthy communication and internal supports, which has shown to aid parents in navigating the weighty demands of caring for a child with disabilities (Ramish et al., 2013).

Child with Developmental Disabilities

The nature of intervention for children with developmental disabilities differs widely depending on the disability. However, it is not uncommon in the treatment of such children to

see a two-fold approach, using individually based therapy for the child, along with educating the family on how best to provide additional support (e.g. Boyd et al., 2011; Egilson, 2011; Ferraioli, Hansford, & Harris, 2012). Outside support services for the child with developmental disabilities have been helpful in managing symptoms for more difficult behavior; however, there is also evidence that these services can be too individually focused on the child, without enough family centered involvement on the part of the professionals (Egilson).

Parent-Well Sibling Subsystem

Parent-well sibling interventions have strengthened relationships while concurrently benefitting the adjustment of the well sibling. For example, Lobato and Kao (2005) suggested a method of intervention that centers on the education of the well sibling, while opening the lines of communication between the well sibling and his or her parents. Utilizing group workshops for the well siblings overlapping with group workshops with the parents, the intervention encourages communication regarding the nature of the disability. Additionally, it gave parents a clearer understanding of the well sibling's experience of having a sibling with developmental disabilities.

Full System Speculation

Several researchers have suggested that systemically based interventions should be the next stage of research on supporting this community. For example, Head and Abbeduto (2007) suggest a model of systemically based assessment in which the well being of all members is considered, as is their ability to adapt to the stressors faced by having a child with a disability within the system. Schuntermann (2009) also discusses the benefits of moving towards a systemic approach, suggesting a more integrative treatment plan in which the well sibling's interrelationships and personal struggles are moderated through the process of mentalizing.

Unfortunately, current research on family based systemic interventions falls short due to the fact that it is theoretical in nature. Current systemic interventions remain speculative, based on previous research and on family report. As of yet, there has been no research exploring what clinicians working with these communities are actually doing in the therapy room to support the whole system, including the well sibling.

Summary

As evidenced, research identifies the presence of unique stressors throughout the family system when one child has a developmental disability. The benefit of a family systems approach has been detailed, along with specific predictors of successful well sibling adaptation. Although much evidence encourages the support of the family system, particularly in regard to the adjustment of the well sibling, there is little research indicating if and how practitioners are currently working with these families. Thus, it is the goal of this study to explore the following question: How are Marriage and Family therapists currently working systemically with families in which one child has a developmental disability to incorporate the needs and experience of the well sibling?

Methods

Due to limited research informing the therapeutic practice of Marriage and Family therapists working with families in which one child is suffering from a developmental disability, this study focused on the point of view of the therapists rather than on the experience of the well siblings. Marriage and Family therapists were chosen due to their systems training as described in the MFT Core Competencies, which makes their therapeutic skillset distinctively systemic on a foundational level. Prior to beginning data collection, IRB approval was obtained. Participants for this study were recruited through the Virginia Tech MFT listserv, and through word of

mouth. Interested participants contacted the researcher and were screened for eligibility. In order to qualify for this study, participants had to be a currently licensed Marriage and Family therapist with experience working with at least one family in which one child had a developmental disability with at least one well sibling living in the household at the time of treatment. Four Marriage and Family therapists contacted the researcher and all four qualified for participation in the study. A mutually agreed upon time and location were set up to conduct the interviews and an informed consent form was sent to the participant to review and sign.

The four individual interviews were in person or over the phone, beginning with a demographic questionnaire. The researcher then conducted a 45-minute semi-structured qualitative interview, with the option for probing questions in order to develop a thorough understanding of the participant's therapeutic process when working with these families. Validity was established throughout the interview through probing questions in order to get the best, most complete descriptions. Additionally, the researcher established validity by utilizing reflective listening as a manner of member checking during each interview. Each interview was audio recorded, and the data was sent out for professional transcription. The researcher then reviewed the completed transcriptions for accuracy.

The researcher then began the process of analysis using techniques described by Strauss (1987). Through the method of open-coding, the interviews were read and reread to see what patterns emerged. As the data were reviewed, memos were made and consistent themes became more apparent. Throughout this process, the researcher used the co-researcher to help cross-code the data in order to ensure credibility and trustworthiness.

Results

Participants

All participants were licensed Marriage and Family therapists, with time of licensed experience ranging from about 4 to 11 years. All participants were licensed in Virginia and practicing in the Northern Virginia area in a private practice setting. All participants had worked with at least one family with a child with a developmental disability and with at least one well sibling living in the home during the time of treatment. All participants were female, ranging from age 28 to 57. Participants were randomly assigned numbers in order to ensure confidentiality during the process of data collection and analysis.

During the interview, participants were asked a series of questions about their process of treating these families. They were encouraged to reference a specific family if possible; these included children on the autism spectrum, ADHD, and an anxiety disorder. The ages of well siblings discussed during the interview process ranged from about 5 years old to about 18 years old. The data revealed three major themes in the MFT's process when working with families in which one child has a developmental disability: 1) stabilization; 2) involving the well sibling; 3) methods of support.

Theme 1: Stabilization

Participants reported that families often enter the therapy room in crisis, in need of more focused support. Thus, out of necessity, members of the family without overt signs of crisis were not targeted during this initial phase of treatment. Participants identified three presenting issues in need of immediate attention: the child with the developmental disability, the couple relationship, and parenting/co-parenting support.

Child with Developmental Disability

According to participant report, families may enter the therapy in need of additional assistance for the child with developmental disabilities. Participants indicated that the disabled child may draw a lot of the family focus due to the complications created by his or her disability, which the family therapist may need to concentrate on initially to create better balance within the system in the long term. One participant stated: “The focus was definitely on the [child with disabilities] and his treatment. In the beginning, it was more about figuring out what treatment plan would be most helpful,” (Participant 3).

Couple Relationship

Participant report indicated that stress experienced by the parent subsystem can manifest in a few ways, one of which is placing strains on the couple relationship. Parents may need external support in learning how best to support each other as they adapt to the struggles of raising a child with disabilities.

These families were so overwhelmed, some of them, with getting through day-to-day, and some of them, the couples were on the verge of divorce so that we had to focus on keeping the couple together or not. There were a few other families where the couples were on the brink or getting divorced, they weren't speaking, where the focus was on the couple. –Participant 2

Parenting/Co-parenting Support

Participants reported that stress within the parental subsystem may also influence their experience as parents, and may influence the manner in which they parent. Participants indicated that the weight of the emotional stressors presented by the child with developmental disabilities would often motivate parents to seek additional support. One participant remarked:

I'd say those 6 to 8 sessions were all about co-parenting... They were often tearful. 'We're losing our [developmentally disabled] son. What is happening to him?' The kind of typical: try this med, take him off; try this med, take him off. Watching him becoming erratic and then himself, and then erratic and then himself is very sad. I did a lot of grief work with them in that first 6 to 8 sessions, and just basically helped them contain and vent, and have a safe place to learn their new normal. –Participant 1

Theme 2: Involving the Well Sibling

According to participants, once the initial phase of stabilization was complete, they were able to view the family system with a wider lens. Participant 3 stated, "Then as he went through it was more about the relationship and family issues, but that was more farther down the line in the treatment after he got stabilized." Participant report indicated a transition in the therapeutic process as treatment shifted from stabilization to a broader consideration of systemic influences, which was often when the well sibling experience would enter the therapy room.

Systemic Training as Primary Influence

Participants stated that after stabilization, they were able to focus more on the interactions between family subsystems and they were able to inquire about those members of the system that were not exhibiting identifiable problems. Most participants credited their training for their systems focus. One participant stated:

Really, because I'm kind of a true systems therapist, it's always about the relationships... The entire time, I was focused on the productivity, promoting basically healthy family functioning between the relationships of each individual within the system... My goal as a family therapist is to have no IP in the room. That's my goal, number one. –Participant 1

Participants reported that in thinking systemically, they seek opportunities to at least query about subsystem impacts resulting from the presence of a child with developmental disabilities in the family system. In regard to well sibling inquiries, one participant stated:

When I check in with these other families and they say: ‘Our kids are fine,’ to myself I say: ‘How do you know?’ So I start to ask some questions: ‘How are these kids? What do they do? What behaviors are you seeing when there’s a struggle with the child with needs?’ It’s like the whole family, the kids have to accommodate to the child with needs.

–Participant 2

Parent Motivators for Well Sibling Involvement

Although participants reported the importance of making an effort to investigate sibling well being, participants also indicated that the extent and nature of the well sibling’s involvement in therapy was primarily dependent upon the parents. Participants indicated that parents have several motivations for well sibling involvement in the therapeutic process, including concerns about differential treatment, concerns about well sibling adjustment, feeling inadequate as an emotional resource for the well sibling, and wanting assistance in educating the well sibling. Participants reported that when these factors were present, parents often actively sought out additional supports for the well sibling through the therapeutic process:

[The parents] said: ‘Can [the well sibling] please come in and use this resource? It has helped us. It gives us words. We’re using words with her, and we’re not therapists,’ – basically– ‘we don’t know what to do with her sadness and fear.’ –Participant 1

Data reported by participants revealed another significant factor influencing the nature of the well sibling involvement in the therapeutic process: parent need for the well sibling to be

“okay”. According to participant report, the need for the parents to feel like the well sibling is doing well can be a major motivator for parents to bring the well sibling into the therapy room.

Then when I worked with the well sibling or what we call the ‘neurotypical sibling’, that I was just able [to get] eyes on him, which I think the mom was about. ‘Can you just see him? Can you just make sure he’s okay?’... She needed that reassurance. –Participant 2

Parent Deterrents for Well Sibling Involvement

Participant report indicated several factors that may prevent parents from involving the well sibling. For example, the need for parents to feel like the well sibling is doing all right can be a major deterrent for parents to bring the well sibling into the therapy room.

They didn’t actually follow through with therapy for her which I think probably is kind of interesting because the child with autism, they have her in all different kinds of speech, OT, play therapy, things like that... Obviously, they have a lot on their plate too and they go to a lot of appointments every week, but I also wondered if a piece of it was they wanted to see her as kind of the kid who was doing well in the family. –Participant 4

Participants reported several additional factors that might prevent parents from directly involving the sibling in the therapeutic process, including feeling overwhelmed and lacking time, money, and/or resources. Participants suggested that these factors might also place unspoken pressures on well siblings, who then attempt to internalize their own struggles to limit the stresses experienced by the parents. Participant 4 highlighted this possibility, stating, “I think [well siblings] also learn that their [developmentally disabled] sibling is struggling so much that they have to keep themselves more together.” Thus, some parents may not seek out additional support for their well children due to a perceived absence of problematic symptoms.

Participants reported that when these deterrents were present, parents were more dismissive when discussing the needs of the well sibling:

I noticed, I have parents that often tell me: ‘Oh, you guys offer a sibling support group, that’s so nice. I wish we could do that.’ But I think... only a few families I feel like really do it because I think they are just expending so much energy and I’m sure money too on the child with struggles that the other child really gets left behind in many ways. –

Participant 4

Participants indicated that when these constraints were present, families were less open to direct support for the well sibling. It is in this way that parents become the unofficial gatekeepers of the therapy room. However, participants indicated that there were ways of providing indirect support for the well sibling, which will be discussed later.

Theme 3: Methods of Support

Direct Support

Once the level of sibling involvement in the therapeutic process has been established, participants reported several methods of providing support for the well sibling. Methods of direct support included: helping the well sibling with problem solving skills in regard to the sibling relationship; helping the well sibling process his or her experience, including feelings of grief, loss, shame, and embarrassment; educating the well sibling on the nature of the disability; helping well sibling and parent communication; assisting the family in finding balance in the system so that everyone is getting their needs met; and assessing the nature of the attachment between the sibling and his or her parents. One participant commented on the importance of considering the well sibling experience, stating,

Yeah, there's the risk for these siblings to feel either abandoned by, and/or neglected, and/or angry with their parents. I think repair work about being the outside child and/or the 'better than' child, depending on the nature of that family, is really important because it can create wounds that people don't even know they have a lot of times. Each of those has their own grief and loss process. –Participant 1

Indirect Support

As previously mentioned, participant report indicated that there were ways to support well siblings indirectly even when they were not actually present in the therapy room. Participants reported that they were able to provide indirect support for the well sibling by: educating parents with tools and language that the well sibling can also benefit from; educating parents on the well sibling experience, including the importance of boundaries and allowing the well sibling to “be a kid”; encouraging focused alone time with the well sibling; and providing parent support to limit the potential for parental stress impacting the well sibling's experience. One participant highlighted this process, stating,

I definitely encouraged them to have that individual time with [the well sibling] to touch base about what was going on for him. I thought it was really important that they were keeping his needs in mind and just maintaining a relationship with him even though he kind of flew under the radar, just wanting to check in to make sure there was nothing that they weren't seeing or that [he] was experiencing, and just trying to keep quiet so that he wasn't causing problems or stirring up trouble. I definitely thought it was important they were checking in about his well being on a regular basis. –Participant 3

Discussion

Although it is necessary to utilize the same terminology that is present in previous research, it is also important to recognize that the use of the term “well sibling” may not be appropriate for this population. The implication of running this study is that the siblings of children with developmental disabilities are in need of assistance much like the rest of the family, and by that logic are not “well”. It is also important to note that by using the label “well sibling”, parents and professionals may place pressure on siblings to remain in that category, which may promote the potential for internalized behaviors in the sibling. Additionally, use of the term “well sibling” by clinicians may inadvertently deter parents from seeking out the very supports that Marriage and Family therapists are encouraging because the implication is that the sibling is “well” and thus is not in need of services. Therefore, it is important to acknowledge that there is a need for a shift in the language used to study and work with this population.

Results of our study reveal that the interviewed Marriage and Family therapists working with this population do adapt a systemic approach to the work. However, they were careful to note that this approach was evidenced in their clinical practice at different times and in different ways depending on the needs of the family. For example, participants stated that system stabilization was of primary importance in the beginning phase of working with families in which one child has a developmental disability. According to participant report, the initial phase of treatment tends to focus on the child with developmental disabilities, the parental subsystem, or the couple relationship because this is the particular subsystem that is creating the most distress- the issue that actually compelled the family to seek therapy. Given this, the sibling experience is often not initially a primary concern. This scenario is consistent with previous research, which suggests that the sibling experience is likely to be overlooked in the therapy

room due to the presence of more apparent clinical concerns (Schuntermann, 2009; Williams et al., 2010).

Of note however is that Marriage and Family therapists in this study reported an *intentional transition* in the treatment process *after* the system has been stabilized to focus on members of the system that had previously been overlooked. This is of interest given that previous research only highlights a general lack of sibling attention in the clinical setting (e.g., Head & Abbeduto, 2007; Schuntermann, 2009), making no mention of a transition point during which professionals are able to reassess their treatment goals.

Indeed, several participants in the present study cited their systemic training as the source of their motivation to keep the sibling experience in mind when working with families in which one child is suffering from a developmental disability. Participants in this study stressed the importance of finding a healthier balance within the system, in which every member of the system is getting his or her needs met. This practice is consistent with research on the benefits of a systemic approach to the therapeutic process, which emphasizes the importance of attending to the interaction of the system's parts and how that effects the needs of each individual (White & Klein, 2008).

Despite the intentional focus on the family system, participants noted potential obstacles in the clinical setting that can prevent them from working directly with the entire family system. In the current study, participants indicated that Marriage and Family therapists are sometimes limited in their capacity to work systemically based on the ability and willingness of the family to involve the well sibling in the therapeutic process. According to participant report, the most significant factors deterring the family from seeking out additional support for the well sibling are limitations on time, money, and resources, which is consistent with the research (Richardson

et al., 2013). Another significant deterrent for parents seeking additional support for the well sibling was a feeling of generally being overwhelmed and overburdened (Fox et al., 2002). Participants reported several motivators for parents to seek out additional support for the well sibling, including parental concerns about the effects of differential treatment (Kao et al., 2011) and concerns regarding well sibling adjustment (Branstetter et al., 2008), parent feelings of inadequacy (Ketelaar et al., 2008), and the desire to educate the well sibling (Branstetter et al., 2008). Reported aspects of the parent experience are consistent with what researchers in recent studies have described as notable considerations for parents.

However, these considerations are discussed in the research solely as motivators for clinicians to incorporate systemic interventions into the therapeutic process when working with these families (Branstetter et al., 2008); they are not discussed in regard to their potential to influence a family's decision to include the well sibling in the treatment process at all. According to participant report, not only do these factors represent why these families should be treated systemically, they also represent some of the very reasons that families may feel motivated or deterred from involving the well sibling in the therapeutic process.

One aspect of the parent experience that was described in participant report but was not as present in the research was the need for the well sibling to be "okay". According to participant report, this need can motivate parents to bring the well sibling into the therapy room, just as quickly as it can deter parents, either to confirm their hope that the well sibling is progressing as he or she should, or to prevent the opportunity for a clinician to inform them that the well sibling is also developing an affliction. In either case, it emphasizes an underlying parent need for the well sibling to remain just that.

Parent desire for the well sibling to remain “low-maintenance” (Safer, 2002, p. 62) may become internalized by the well sibling, which can cause other problems within the well sibling. Safer (2002) beautifully articulates this delicate balance and its effects on the well sibling, stating that siblings, “... feel tormented by the compulsion to compensate for their parents’ disappointments by having no problems and making no demands, and they are often unaware of the massive external and internal pressure to pretend that nothing is amiss” (p. xviii). Indeed, research on the potential for internalized behaviors indicates that the well siblings might try to hide their experience to avoid putting any additional pressures on their parents (Schuntermann, 2007). As a result, parent need for the well sibling to be “okay” has the potential to influence the well sibling’s willingness to openly ask for help (Schuntermann). Therefore, parents may not bring the well sibling in for treatment because of the lack of any overt problems displayed by the well sibling. Thus, it is important to recognize that the absence of overt symptoms does not necessarily translate into healthy adjustment for the well sibling. Unfortunately, this belief may be the very reason that parents do not seek out additional support for the well sibling.

Given their intentional systemic focus on the well sibling, and the very real obstacles to including them in the actual therapy process, participants reported a number of direct and indirect methods of supporting the well sibling—depending on the level that the well sibling was involved in the therapeutic process. Reported methods of direct support (i.e. well sibling was part of therapy session) include working on problem solving skills regarding how to address the difficulties they might face in having a sibling with developmental disabilities (Branstetter et al., 2008); helping the well sibling process the weighty emotions that come along with having a sibling with disabilities, including grief, loss, shame, and embarrassment (Schuntermann, 2009; Williams et al., 2010); educating the well sibling on the nature of the disability (Lobato & Kao,

2005); increasing healthy communication between the well sibling and the parents (Branstetter et al., 2008); and helping the family find better balance so that each member is getting his or her needs met (Schuntermann, 2007). Participants also highlighted the benefit of assessing the nature of the attachment between the well sibling and his or her parents, which is not mentioned in the research as a potential method of direct well sibling support.

Reported methods of indirect support (i.e. the well sibling was not part of the therapy session) include educating the parents with tools and language that the family, including the well sibling, can use to manage the child's disability and increase harmony within the household (Moyson & Roeyers, 2012); educating the parents on the well sibling experience, particularly in regard to boundaries and parentification (Branstetter et al., 2008; Kao et al., 2011); encouraging one on one time with the well sibling (Kao et al.); and providing the parental subsystem with emotional support to limit the influence of stress or the resulting relationship discord on the parenting of the well sibling (Richardson et al., 2013; Rivers & Stoneman, 2003). Interestingly, research has indicated that consistent routine can be a facilitator of healthy adjustment in well siblings (Giallo & Gavidia-Payne, 2006); however, participants made no mention of educating the parents on the importance of structure for the benefit of the well sibling. Thus, it is possible that this could be considered another method of indirect support for the well sibling.

According to participant reports, each of these methods of supporting the well sibling, both directly and indirectly, can be part of a larger systemically influenced therapeutic process. Participant report indicated that MFT's will read the needs of each individual family and each individual well sibling and utilize the methods of support that are most appropriate in the context of a larger goal of supporting the system as a whole. Even without the well sibling present in the therapy room, MFT's are able to utilize their knowledge of the concept of interactional parts

within a system as described in General Systems Theory (von Bertalanffy, 1968) to guide their work and to help with indirect methods of supporting the well sibling.

Limitations

There are several limitations in this study that should be addressed. First, this study was open only to Marriage and Family therapists due to their systemic training. There are a variety of other professionals working with families in which one child has a developmental disability. This study provides no indication of what other therapists are doing to support or involve the well sibling in the therapy room. Future studies should seek to understand how other professionals are working with this community, particularly in regard to the use of a systemic approach. Furthermore, all participants in this study were working in a private practice setting. Families seeking support through agencies may not have access to the same resources, which may result in additional limitations on parent willingness or ability to seek out additional supports for the well sibling. Further research should seek to understand the potential differences in practice versus agency setting.

It is also important to note that the influence of family demographics on the therapeutic process was not factored into the qualitative interviewing process. Possible therapeutic implications resulting from the number of siblings, as well as the age or gender of the well sibling and/or the child with developmental disabilities were not a focus of this study. Further studies should consider family demographics in regard to the therapeutic process as they may influence the timing and nature of systemic interventions.

Clinical Implications

There are several clinical implications resulting from this study. Based on participant report, families do not often enter the therapy room aware of well sibling needs, so it is essential

that clinicians have a basic understanding of the well sibling experience so they can properly inquire about well sibling well being. This is especially the case for those families that are overwhelmed or overburdened, in which the parents might be unwilling or unable to actively involve the well sibling in the treatment process. In these cases, it is important that clinicians are able to provide indirect support for the well sibling through parent education and by working with those subsystems that are present from a systemic perspective.

Another major clinical implication resulting from this study involves a greater awareness of the risk for well sibling internalized behavior. As previously mentioned, it is evident in both this study and in previous research that well siblings will often bottle their emotions in an effort to avoid adding stress or pressure on their parents (Schuntermann, 2007). This can have a variety of negative consequences on well siblings and their relationships. Although participants appeared to be aware of the risk of internalized behaviors in well siblings, their reports indicate that they often fall into the trap of assuming that the lack of any overt issues is an indication that the well sibling is not suffering at all. Therefore, it is important that clinicians consider the potential for internalized behavior and help to educate the parents and open the lines of communication so that these issues can come to the forefront.

Conclusion

Treatment of families with children that have developmental disabilities continues to be a topic of debate among practitioners, and consideration of well sibling needs and experience is no exception. Participants in this study have shared details about their therapeutic process and interventions in an effort to contribute to the limited body of research regarding the clinical support of the well sibling. The information gathered from their clinical considerations can provide a foundation for future research and more informed interventions. Additionally, the

therapeutic experiences described by participants will contribute to the growing number of resources that practitioners can reference when working with this community so that all the members of each family system is fully supported during the therapeutic process.

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Appendix A: Informational Flyer

Are you a Marriage and Family therapist? Have you worked with families with a child with a developmental disability?



For my thesis, I am recruiting Marriage and Family therapists to participate in a research study focusing on the treatment of families with a child with developmental disabilities with at least one sibling.

What is the study about?

This study seeks to understand the perspective of the MFT working with families with one child with a developmental disability and with at least one sibling. For the purpose of this study, developmental disability is defined as any mental or physical disability that substantially limits the child's daily activities, learning, or general functioning and is revealed before the age of 22. This can include Autism and ADHD.

What will the study entail?

You will be asked to complete a 60-minute interview in which you discuss your therapy process while working with these families.



Am eligible to participate?

Contact me at 203-996-8083 or at ebchri8@vt.edu and I will ask you some questions to see if you qualify.

Qualifications:

- Over the age of 18
- A currently licensed MFT
- Experience treating at least one family in which one child suffered from a developmental disability *with at least one sibling living in the home at the time of treatment*
- Specialization in the treatment of children with developmental disabilities and their families is *not necessary*.

Interested participants should contact:

Christina Bonenberger
ebchri8@vt.edu

Appendix B: Online Advertisements

Text for MFT listserv:

Hello!

My name is Christina Bonenberger and I am a graduate student from Virginia Tech's Marriage and Family Therapy Program. I am pleased to announce that I am currently recruiting participants for my research study exploring how Marriage and Family therapists are working with well siblings in the therapy room when treating families in which one child is suffering from a developmental disability.

I am reaching out in the hopes that you may know of Marriage and Family therapists that would be a good fit for this study and would be willing to participate!

Some basic information about my study:

- In families in which one child is suffering from a developmental disability, the well sibling faces stressors unique to every other member of the family system. This study seeks to understand how Marriage and Family therapists are currently addressing these issues in the therapy room.
- For the purpose of this study, developmental disability will be defined as, "... any mental and/or physical disability that is manifested before age 22 years; that is likely to continue indefinitely; and that substantially limits one or more life activities, such as walking, seeing, speaking, breathing, or learning" (Williams et al., 2010, p. 40).
- Participants will be asked to complete a 60-minute interview in which they discuss their therapy process while working with well siblings and their families.
- Interviews will be held at a mutually agreed upon location, or may be conducted via telephone or Skype.
- There will be no compensation for participation in this study.
- Any identifying information will be kept confidential.

Eligibility:

- Potential participants will complete a brief phone screening to ensure that they are an appropriate fit for this study.
- To be eligible, participants must:
 - Be over the age of 18.
 - Be a currently licensed MFT.
 - Have experience treating at least one family in which one child suffered from a developmental disability *with at least one sibling living in the home at the time of treatment.*
- Specialization in the treatment of children with developmental disabilities and their families not required.

Attached is a flyer with the above information to pass on to any MFT's you think would be a good fit for this research study. Thank you for your time and consideration! If you or potential participants have any questions, please feel free to contact me at 203-996-8083, or ebchri8@vt.edu.

Sincerely,
Christina Bonenberger
M.S. Candidate, Virginia Tech

Text to use along with image of flyer on Facebook:

I am pleased to announce that I am currently recruiting participants for my research study exploring how Marriage and Family therapists are currently working with well siblings in the therapy room when treating families in which one child is suffering from a developmental disability.

I am reaching out in the hopes that you may know of Marriage and Family therapists that would be a good fit for this study and would be willing to participate!

Follow up email to MFT Listserv:

Hello everyone!

I recently sent out an email requesting participation in my research study on the MFT's experience working with families when one child in the family is suffering from a developmental disability. I have received some follow up questions, so I wanted to clarify that Autism and ADHD can be included in the criteria for this study. Also, the MFT does not need to specialize in the treatment of families in which one child is suffering from a developmental disability.

For my thesis I am interested in learning more about the Marriage and Family therapist's perspective on working with families in which one child has a developmental disability with at least one sibling living in the household at the time of treatment. Participation in this study may provide MFT's with a more well rounded understanding of their treatment process when working with this community.

Please pass this information along to anyone that might be interested in participating!

The requirements for participating are as follows:

- Over the age of 18.
- A currently licensed MFT.
- Have experience treating at least one family in which one child suffered from a developmental disability with at least one sibling living in the home at the time of treatment.

Please see the attached flyer for additional information, and feel free to contact me with any questions.

Regards,
Christina Bonenberger
M.S. Candidate, Virginia Tech

Appendix C: Telephone Screening Script

When potential participants called the co-investigator, Christina Bonenberger, they were provided the following information:

We are interested in studying the process of working with the well sibling when one child is suffering from a developmental disability from the perspective of the Marriage and Family therapist. I will ask you some questions regarding your therapy process when working with this community. This study is confidential, which means that no identifiable information will be linked to your responses. I would only break confidentiality if you were to threaten harm to yourself or others, in which case I would try to protect you by notifying the appropriate authorities or by providing you with a treatment referral. If you qualify for the study, you will be asked to first complete a brief demographic questionnaire, followed by a 60-minute interview that can be conducted face-to-face, over the phone, or via online Internet chat. There are minimal risks to participating in this study. As you reflect on your experience working with this community, it is possible that you will reconsider your treatment plans for previous cases, which may leave you with a feeling of regret. I am available to process this with you if needed.

The benefits of participating in this study include a chance to contribute to the body of research on working with this community, which may aid other professionals in the field. Additionally, participating in this study may provide you with a better understanding of your own therapeutic process through professional reflection. It is our hope that you will be able to participate in the entirety of this study; however, there will be no penalty should you choose to withdraw.

Do you have any questions about the nature of this study or the participation requirements? Would you like to begin the first step of the process of participating in this study by answering a few questions to help me determine eligibility? If the answer is yes, then let's begin with the questions.

The participant was then be asked the following screening questions to determine their eligibility:

1. Are you over the age of 18?
2. Are you currently a licensed MFT?
3. Do you have experience treating at least one family in which one child was suffering from a developmental disability, and in which at least one well sibling was living in the home at the time of treatment?

If any potential participants were ineligible for participation in the study, or if they chose to opt out of participating, they were thanked for their time and interest. Those participants that were eligible to participate and chose to continue on with the study then set a time and location convenient to both the participant and the researcher to provide consent for continued participation in the remaining portion of the study.

Appendix D: Informed Consent

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY Informed Consent for Participants in Research Projects Involving Human Subjects

Title of Project: Working with the Well Sibling: The Perspective of the Marriage and Family Therapist.

Principle Investigator: Angela J. Huebner, Ph.D.

Co-Investigator: Christina Bonenberger, B.S.

I. Purpose of Research

This study will explore how Marriage and Family therapists work with the well sibling while treating families in which one child is suffering from a developmental disability. For the purpose of this study, developmental disability will be defined as any mental or physical disability that greatly limits the child's everyday functioning and is discovered before the age of 22. We are interested in learning what is currently happening in the therapy room when Marriage and Family therapists treat this community.

II. Procedures

You will be asked to complete a brief demographic questionnaire. You will then participate in an interview with the co-investigator. This interview will be conducted in person, over the phone, or via online video chat. The interview will last about 60-minutes and will be audio-recorded.

III. Risks

Risks of participating in this study are minimal. You may rethink your treatment plans for previous cases, which could leave you with a feeling of regret. I am available to process this with you if needed.

IV. Benefits

Participation in this study may give you a chance to contribute to the body of research on working with this community. This contribution may aid other professionals in the field. Participating in this study may provide you a better understanding of your own therapeutic process through professional reflection.

V. Extent of Anonymity and Confidentiality

We will adhere to strict confidentiality of information throughout this study. Your interview will be assigned an identification number by the co-investigator. Your interview will be transcribed using the identification number. The identification number along with this information sheet will be kept separate from the transcribed interview, and both will be stored in separate locked files that only the research team has access to. The audio recording of your interview will be destroyed once all interviews have been transcribed and checked for accuracy. The only exception to confidentiality is if you have expressed a desire to harm yourself or others, at which point we would notify the appropriate authorities and would refer you for treatment. It is possible

that the Institutional Review Board (IRB) may view this study's data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

VI. Compensation

You will not be provided any compensation for participation in this study.

VII. Freedom to Withdraw

You are not required to participate in this research study. If you agree to participate, you can withdraw from the study at any time without penalty.

VIII. Participant's Responsibilities

I voluntarily agree to participate in this study. I have the following responsibilities:

1. Prior to or at the start of the interview appointment, I will complete a brief demographic questionnaire.
2. I will meet with the co-investigator for an interview at a mutually agreed upon time and location, or I will be available for a phone call or online chat at a mutually agreed upon time.

IX. Participant's Consent

I have read the Informed Consent and the conditions of this project, and I have received answers to all my questions. I hereby acknowledge the above and give my voluntary consent.

Participant's Signature

Date

Participant's Name (please print)

If you have any questions about this research study or its conduct, and research subjects' rights, and whom to contact in the event of a research-related injury to the subject, I may contact:

Angela J. Huebner, Ph.D

Principal Investigator

Christina Bonenberger, B.S.

Co-Investigator

David M. Moore

Chair, Virginia Tech Institutional Review
Board for the Protection of Human Services

703-538-8491/ahuebner@vt.edu

Telephone/e-mail

203-996-8083/ebchri8@vt.edu

Telephone/e-mail

540-231-4991/moored@vt.edu

Telephone/e-mail

Appendix E: Demographic Questionnaire

Participant Number _____

DEMOGRAPHIC QUESTIONNAIRE

Date completed: _____

Gender: _____

Age: _____

Ethnicity: _____

Licensure History

State of Licensure: _____

Years as a Licensed MFT: _____

THANK YOU FOR YOUR PARTICIPATION!

Appendix F: Interview Protocol

- Please tell me about a family you have worked with that had a child with a developmental disability and at least one well sibling. What was the disability? Who were the members of the family system?
 - Why did they come in and what was their presenting issue? Did they come in for the child with developmental disabilities, or for the well sibling?
 - Tell me about who was usually present in the therapy room.
 - When every member was present in the therapy room, where did the focus of the therapy often fall, and why?
 - Were subsystems ever the focus of therapy? For example, the parental subsystem, or the parent-well sibling subsystem? What did this look like, and what was the goal?
 - Did you sometimes focus on the well sibling without meeting them or having them in the therapy room? Why or why not? If so, what did this entail?
 - During therapy, did you do anything specific to support and/or involve the well sibling?
 - If yes, can you provide me with examples? What were the goals of these interventions? From where did you take those ideas?
 - If no, what held you back from doing so?
 - Was educating the well sibling on the nature of the child's disability brought into the therapy room at any point? Why or why not? If so, how?
 - Was there any discussion about the nature of the communication between the parents and the well sibling? Why or why not? What did this look like?

- Did you find a need to address the family's daily routine and structure? How did you come to this decision?
- Did you ever work with the well sibling individually? Why or why not? What was the nature of the therapy?
- Was there ever any involvement with other types of support services concurrently? What did that look like?
 - How did the family's involvement with these services affect therapy?
 - How did the family respond to these services?
- In your experience, how do families typically address the well sibling experience prior to family therapy?
- Is there anything I have not asked you that you feel is important?

Appendix G: Confidentiality Agreement for Hired Transcriptionist**Confidentially Agreement for Interview Data**

I, _____ agree to safeguard the identity of participants enrolled in the *Working with the Well-Sibling: The Perspective of the Marriage and Family Therapist* research study. I will not disclose or discuss participant related material outside of meetings with the research team. I will protect the confidentiality of all participants by safeguarding participant related materials, which includes identifiable information disclosed in participants' interviews.

Print Name: _____

Signature: _____ Date: _____

Appendix H: IRB Approval Letter



Office of Research Compliance
 Institutional Review Board
 North End Center, Suite 4120, Virginia Tech
 300 Turner Street NW
 Blacksburg, Virginia 24061
 540/231-4606 Fax 540/231-0959
 email irb@vt.edu
 website <http://www.irb.vt.edu>

MEMORANDUM

DATE: February 11, 2014
TO: Angela J Huebner, Christina Elizabeth Bonenberger
FROM: Virginia Tech Institutional Review Board (FWA00000572, expires April 25, 2018)
PROTOCOL TITLE: Working with the Well Sibling: The Perspective of the Marriage and Family Therapist
IRB NUMBER: 14-142

Effective February 11, 2014, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

<http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As: **Expedited, under 45 CFR 46.110 category(ies) 6,7**
 Protocol Approval Date: **February 11, 2014**
 Protocol Expiration Date: **February 10, 2015**
 Continuing Review Due Date*: **January 27, 2015**

*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

Invent the Future