

Support Group Design for Parents of Children with Severe Developmental Disabilities

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## Abstract

Parents of children with severe developmental disabilities face a variety of unique circumstances as they raise a child who requires specialized care. Accessing the support of other parents of children with developmental disabilities can be a valuable external resource for managing the stress associated with raising a child with special needs. The literature on support groups for parents of children with disabilities predominantly focuses on evaluating existing support groups rather than designing support groups based on the recommendations of the population that would utilize them. The purpose of this study was to determine the perceived value of support groups and identify recommendations for support group design based on the experiences and feedback of 19 interviews with parents of children with severe or profound developmental disabilities. Despite varied experiences with support groups, most participants indicated the value of support groups is in providing a place where parents can feel understood, share information, and gather information. There was a high degree of variability among parents' recommendations for support group design, with the preferences of some parents being in direct contrast to the preferences of others; the summary recommendations for support group design address a wide range of preferences: a qualified group leader to organize groups that are highly flexible in structure, composed of parents with a high degree of similarity, and that offer a wide variety of content in various formats.

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## General Audience Abstract

Parents of children with severe developmental disabilities (any type of impairment that is chronic and affects functioning) are often confronted with unique challenges because of the extra care their child may require. Having a child that requires full-time care, while in some ways rewarding, is also often difficult for parents, and may affect many different areas of their lives. As a result, parents may seek additional support, including seeking support from other parents of children with severe developmental disabilities. Support groups are groups of people with a shared interest or need—in this case, parents of children with severe developmental disabilities—who meet in a variety of possible formats. The purpose of this research study was to get a better understanding of the value parents perceive support groups to have, and the specific formats they recommend to facilitate what they would most like to get out of support groups. The results of this research study provide recommendations that can be used by parents or by professionals to design support groups to best meet the needs of parents of children with severe developmental disabilities.

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## Table of Contents

Chapter 1: Introduction .....	1
Statement of the Problem.....	1
Significance.....	2
Rationale .....	3
Theoretical Framework.....	3
Family systems theory. ....	3
Family stress theory .....	4
Purpose of the Study .....	4
Research Questions .....	5
Chapter 2: Literature Review .....	6
Introduction.....	6
Definitions and Prevalence .....	6
Family Stress: The Double ABCX Model of Adjustment and Adaptation .....	8
Challenges of Parenting .....	10
Resources and Appraisal.....	12
Social Support.....	14
Support Groups .....	15
Support Groups for Parents of Children with Disabilities .....	17
Group structure .....	18
Group composition.....	19
Session content.....	19
Facilitation .....	20
Peer-to-peer support groups.....	21
Professionally facilitated support groups.....	22
Summary.....	23
Chapter 3: Methods.....	25
Design of the Study.....	25
Study Participants and Procedures .....	25
Instruments.....	29

Data Analysis .....	30
Data assessment .....	30
Content analysis .....	32
Verification .....	33
Chapter 4: Results .....	35
Assessment of Value .....	35
Reasons support groups were perceived as valuable .....	38
Feeling understood.....	39
Helping others.....	40
Positive experience .....	40
Creating connections.....	40
Taking Action .....	41
Reasons support groups were not perceived as valuable .....	41
Poor fit .....	41
Does not help .....	42
Comparison to others .....	42
Negative experience.....	43
Support from other sources.....	43
Support Group Design .....	44
Group structure .....	44
Meeting length and frequency .....	45
Group duration and type .....	46
Meeting accessibility .....	47
Concurrent services.....	47
Group composition.....	48
Group size .....	49
Degree of Sameness .....	50

Meeting content .....	54
Sharing emotions .....	56
Sharing information .....	57
Formal psychoeducation .....	59
Direction for advocacy.....	59
Group leadership.....	60
Member Recruitment .....	61
Chapter 5: Discussion .....	63
Summary.....	63
Clinical Implications.....	66
Group structure recommendations .....	68
Group membership composition recommendations .....	70
Meeting content recommendations .....	73
Meeting leadership and facilitation.....	77
Member outreach .....	78
Limitations .....	78
Directions for Future Research .....	80
References.....	81
Appendices.....	97
Appendix A: Confidentiality Agreement.....	97
Appendix B: Interview Questions.....	98



**List of Figures**

Figure 1. The Double ABCX Model..... 9

## List of Tables

Table 1: Participant Household Demographics .....	27
Table 2: Participant Demographics.....	28
Table 3: Child with Developmental Disabilities Demographic Information.....	29
Table 4: Support Group Participation and Assessment of Value .....	36
Table 5: Support Group Participation and Assessment of Value by Gender.....	37
Table 6: Perceived Value of Support Groups .....	39
Table 7: Support Group Structure Preferences .....	45
Table 8: Support Group Composition and Membership Preferences .....	49
Table 9: Support Group Meeting Content Preferences.....	55
Table 10: Support Group Meeting Facilitation Preferences .....	61
Table 11: Support Group Member Recruitment Preferences .....	62
Table 12: Support Group Design Recommendations .....	67
Table 13: Support Group Meeting Agenda Options: Sample.....	75

## **Chapter 1: Introduction**

### **Statement of the Problem**

Approximately one in six children in the United States have been diagnosed with a developmental disability (Boyle et al., 2011). About 1 in 100 children are severely affected by a developmental disability meaning that they are significantly limited in their ability to care for themselves and participate in everyday activities (Kennedy et al., 2007; Murphy & Christian, 2007). Having a child with severe developmental disabilities can result in a variety of impacts to family unit (Rolland & Walsh, 2006). Impacts to the family unit can be perceived as both positive and negative (Hastings & Taunt, 2002; Pozo, Sarriá, & Brioso, 2014). For example, parents of children with developmental disabilities report that caring for their child is fulfilling and is a source of happiness (Hastings, Beck, & Hill, 2005). Conversely, caring for a child with severe or profound disabilities (who generally require full-time attention) can be a source of stress (Beckman, 1991; Beresford, 1996; Dyson, 1993; Kennedy et al., 2007). The severity of child's disability is significantly related to the parental stress (Jones & Passey, 2004) as well as the likelihood that parents will place their child in out-of-home care (Blacher, 1990; Friedman, Kalichman, & Council on Children with Disabilities, 2014). Families may utilize a variety of coping resources to increase positive impacts and decrease negative impacts (Weihs, Fisher, & Baird, 2002). A resource that is often employed by parents is social support. Specifically, the level of social support, or the support received from others, is closely tied to parent wellbeing and adaptation in families of children with severe disabilities (Saloviita, Itälina, & Leinonen, 2003; White & Hastings, 2004). One of the ways that parents access social support is through participation in formal groups with other parents of children with disabilities.

Support groups, which are a specific modality of group therapy, are widely used by parents of children with disabilities and are reported to be beneficial (Diehl, Moffitt, & Wade, 1991; Mandell & Salzer, 2007). However, there is little research to understand how parents access support groups, what they want in support groups, and how support groups can be best designed to meet parent needs. With support groups having the potential to be a powerful and accessible resource for parents of children with disabilities, research on the topic is of significant relevance.

### **Significance**

Families of children with disabilities are more likely to experience financial strain, relationship stress, and emotional distress (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Murphy & Christian, 2007). And historically, the research on families of children with disabilities has focused on understanding those additional stressors and challenges associated with raising a child full time care needs (Olkin, 1999). However, more recent research has begun to focus on understanding how to promote wellness and adjustment rather than how to manage specific stressors (Dykens, 2005; McConnell, Savage, & Breitzkreuz, 2014; Weber, 2011). As the number of children with developmental disabilities continues to rise, more families will need resources to cope and promote adjustment as they face the very real challenges of raising a child that requires extra care (Boyle et al., 2011; Dunn et al., 2001). The use of social support from both informal (family and friends) and formal (professionals and service providers) sources is associated with positive outcomes for families of children with disabilities (Canary, 2008; Shilling et al., 2013). The results of this study contribute to an understanding of the ways in which support, provided in the form of support groups, can be designed to best meet the needs parents of children with severe disabilities and promote family adaptation.

## **Rationale**

I conducted a secondary data analysis of transcripts from interviews with parents of children with severe or profound disabilities who had made the decision to place their children in out-of-home care. The results of this study were intended to address the needs of parents of children with severe disabilities whether or not they have placed a child in out-of-home care, as the parents in the sample who had attended support groups typically did so prior to placing their child with disabilities. By using interviews from parents about their experience with support services, the results of the study privilege their voices within the literature and within clinical practice.

In addition to the appropriateness of the dataset to study support groups for parents of children with severe or profound disabilities, there are several advantages to using data that have already been collected. One of the primary reasons to use existing data is to avoid the need to collect more (or redundant) data and to fully utilize data that already exist (Heaton, 2004). The data for the present study had already been collected, but had not yet been analyzed.

## **Theoretical Framework**

**Family systems theory.** The fundamental basis of any family systems theory is that families are a collective whole made up of interconnected individuals; as such changes in one individual, or in one relationship, can affect the functioning of the whole (Boss, 2002). In addition, the stresses that affect the system (or family) affect the individual, and vice versa. The ways in which a family reacts to stress is an indication of the family's functionality (Minuchin, 1974). The conceptualization of the family as a whole serves as the basis for the present study because the birth of a child with severe or profound disabilities often affects family functioning as a whole, as well as the individual experience of the parent (Crnic, Friedrich, & Greenberg,

1983; Weihs et al., 2002) . Furthermore, based on family systems, addressing the needs of a parent will promote positive change within the family and positive interactions among family members (Gehart, 2014).

**Family stress theory.** Though several family stress and adaptation models have been developed to understand the differences in family responses to stressful circumstances (Weber, 2011), the double ABCX model developed by McCubbin and Patterson (1983) as an expansion on the ABCX model developed by Hill (1958) serves as the framework for the present study. In the original ABCX model, the interplay between the stressor event, the family's resources, and the family's perception of the stressor all contribute to either the presence of family crisis or to its absence (Boss, 2002; Hill, 1958). The double ABCX Model expands the framework to include components that explain the actual process over time of family stress, crisis response, and adaptation (McCubbin & Patterson, 1983). The double ABCX model has been used in previous research to understand the stress and adaptation process for families of children with disabilities because the model addresses post-crisis adjustment (e.g., stressors occurring subsequent to the initial crisis of a child's diagnosis) and highlights the possibility of healthy family adaptation (Bristol, 1987; Jones & Passey, 2004; Nachshen & Minnes, 2005; Pozo et al., 2014; Saloviita et al., 2003). Based on the double ABCX model, support groups can be defined as a resource as well as a mechanism to reappraise the situation, play a role in the ongoing adaptation process (Beresford, 1994; Boss, 2002; Hannemann & Blacher, 1998; Saloviita et al., 2003).

### **Purpose of the Study**

One of the primary benefits of participation in support groups for parents of children with disabilities is an increased sense of empowerment (Lam, Wang, Singer, & Kim, 2016; Law,

King, Stewart, & King, 2002; Solomon, Pistrang, & Barker, 2001). And yet, parents of children with disabilities often report being dissatisfied and disempowered by formal support providers (Cunningham & Davis, 1985; Hartman, Radin, & McConnell, 1992; Robert, Leblanc, & Boyer, 2015). This study used secondary data analysis to better understand (a) what the elements of an ideal support group are according to parents, and (b) how parents, professionals, or both, can best design support groups to satisfy and promote adjustment in parents of children with disabilities.

### **Research Questions**

1. How valuable do parents of children with severe or profound disabilities perceive support groups to be?
2. What do parents recommend in terms of support group design (e.g. frequency of meetings, duration of participation, number of members)?
  - a. What aspects of support groups do parents believe would be beneficial?
  - b. What aspects of support groups do parents believe would not be beneficial?

## **Chapter 2: Literature Review**

### **Introduction**

The number of children diagnosed with a developmental disability or showing signs of a development disability is rapidly growing with the prevalence increasing 17% (accounting for an additional 1.8 million children) in a 12-year period (Boyle et al., 2011). The families, and parents or caregivers of children with severe developmental disabilities often experience high levels of stress as they struggle to meet the child's wide ranging special needs (Beresford, 1996; Murphy & Christian, 2007). Although there are a variety of support services for parents and their children with developmental disabilities (respite care, occupational therapy, out-of-home placement), parents report that receiving social support, specifically in the form of support groups, is particularly beneficial for coping with the stress of meeting a child with developmental disabilities' special needs (Beresford, 1994, 1996; Diehl et al., 1991). Whereas there is a vast amount of research on the effectiveness of support groups and group treatment (McRoberts, Burlingame, & Hoag, 1998; Yalom & Leszcz, 2005), there is limited research on how professionals can design support groups for parents of children with severe disabilities, as well as what elements make these groups beneficial specifically for parents of children with developmental disabilities (Shilling et al., 2013; Solomon et al., 2001).

### **Definitions and Prevalence**

Developmental disabilities vary in type and degree, can include both mental and physical impairments and, in general, are characterized as inhibiting one's ability to independently complete everyday activities. Developmental disabilities are distinct from other types of disabilities in that they are chronic impairments that appear before adulthood (thus affecting development) and are lifelong (National Center on Birth Defects and Developmental Disabilities



& Centers for Disease Control and Prevention, 2015). The severity (assessed as mild, moderate, severe or profound) of any disability, including a developmental disability, is determined by the number of domains of functioning that are affected and the degree to which those domains are impaired. The domains vary in the research, and generally include considerations of the person's ability to engage in self-care and daily life activities, impairments affecting communication or social skills, learning ability, mobility, and degrees of independent living, self-sufficiency and financial management (American Psychiatric Association, 2013; Jackson & Roper, 2014; U.S. Census Bureau, 2008). A severe or profound disability is one that impairs most or even all domains of functioning. Examples of developmental disabilities that can range in severity include autism spectrum disorders, Down syndrome, epilepsy, cerebral palsy and intellectual disabilities (Jackson & Roper, 2014; Kennedy et al., 2007).

The limitations that inherently define a severe or profound developmental disability often require that parents or caregivers make extra efforts to meet the needs of their children. Though approximately 15% of school aged children have a developmental disability based on parent report (Boyle et al., 2011), only 1%-2% of children have a severe developmental disability that requires ongoing support from care givers (Kennedy et al., 2007). The impacts of meeting the needs of a child that requires ongoing care are wide ranging and include increased stress levels and changes to family dynamics (Crnic et al., 1983). Families that pursue placement in out-of-home care for their children with disabilities are more likely to do so if their child has severe limitations, if the level of stress in the family limits the parent's ability to cope, and if they lack adequate support (Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999; Nankervis, Rosewarne, & Vassos, 2011).

### **Family Stress: The Double ABCX Model of Adjustment and Adaptation**

There are several stress theories that have been developed to understand the ways in which individuals and families respond to and cope with stress. The basis of many of those theories, including the double ABCX model (Figure 1), is that when faced with a stressor, family strengths and perceptions influence the coping and adaptation process (Weber, 2011). The original ABCX model provides a framework to understand the ways in which families address a stressor (factor *a*) by using their resources (factor *b*) and appraisals (factor *c*) to either prevent or facilitate a family crisis (factor *x*; Hill, 1958). The double ABCX model expands Hill's ABCX model and provides a framework to understand post-crisis adjustment over time. Specifically, the model suggests that a family's ability to manage or adapt (factor *xX*) when faced with a crisis is based on the interplay between the presence of ongoing stressors, new stressors, or both (factor *aA*), the family's ability to identify and utilize emotional and tangible resources (factor *bB*), and the meaning (factor *cC*) that the family ascribes to the stressors (Boss, 2002; Lazarus & Folkman, 1984; McCubbin & Patterson, 1983).

The double ABCX model is an appropriate model to understand the adaptation process in families of children with disabilities because it considers *pile-up* stressors (those stressors that are either chronic or created as a result of the initial crisis) that continue to be mediated by family resources and family appraisals over time (Nachshen & Minnes, 2005; Patterson, 1988; Paynter, Riley, Beamish, Davies, & Milford, 2013). The family adaptation outcomes range from balanced (bonadaptation) to continued imbalance (maladaptation) in the family system. The process of coping is the interaction between the double ABCX factors as the family system strives to achieve or restore balance (Saloviita et al., 2003, p. 301).

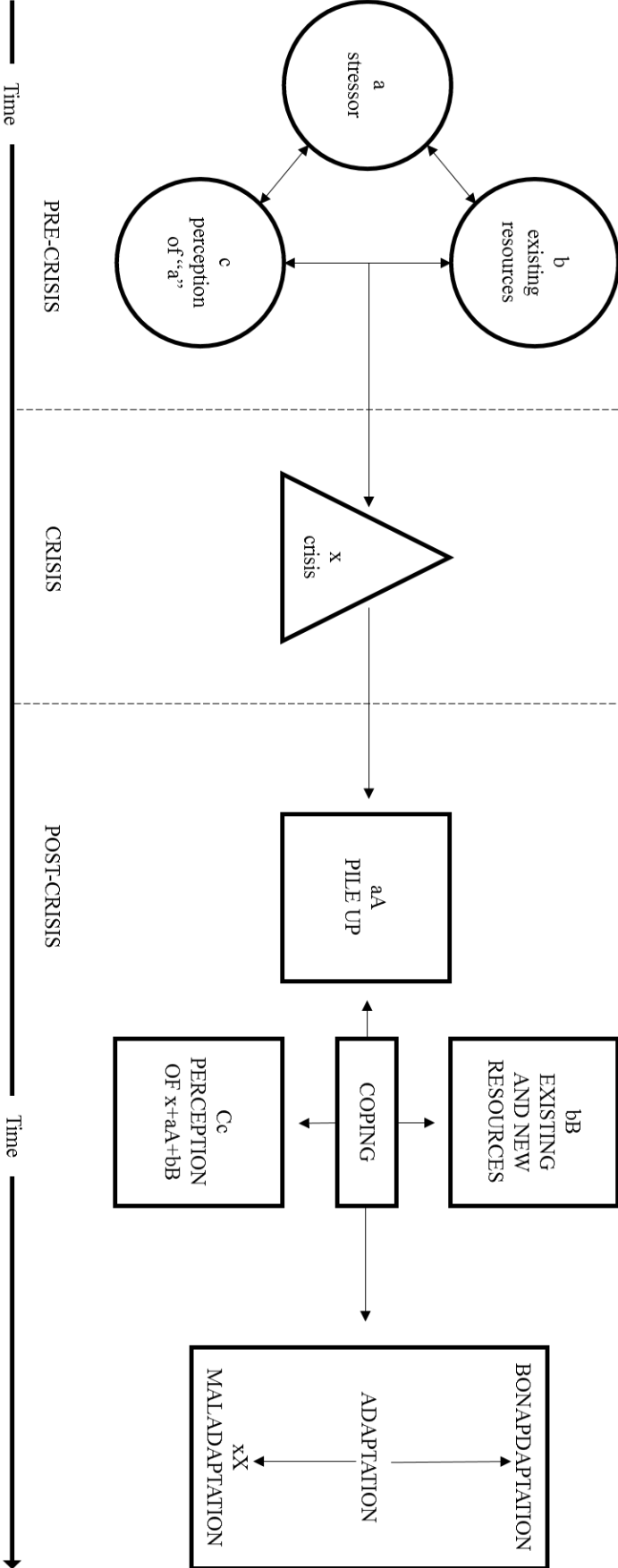


Figure 1: The double ABCX model  
Source: McCubbin & Patterson (1983).

In order to clarify the application of the double ABCX model, take for example the stressor of a child's disability diagnosis: a family may experience additional stressors (aA) that result from the initial diagnosis or that continue to emerge over time (e.g., severity of the disability; Bristol, 1987). In an effort to cope, a family will identify and utilize internal and external resources (bB) to manage that additional stressor (e.g., seeking support from others, considering out-of-home placement), and the family will develop a perception (cC) of the situation (e.g., believing that the circumstance is manageable; Pozo et al., 2014; Saloviita et al., 2003). The family's adaptation (xX) as either positive or negative (e.g., level of well-being) will be predicted by this process of coping (Nachshen & Minnes, 2005).

### **Challenges of Parenting**

Parents of children with severe developmental disabilities report high levels of stress that are "wide-ranging, unrelenting and sometimes overwhelming" (Beresford, 1996, p. 34). These parents report more stress than parents of children without developmental disabilities (Beckman, 1991; Dyson, 1993). Parents are rarely only dealing with one stressor and, as such, factor aA as described in the double ABCX model of stress and coping, accounts for the pile-up of the multiple stressors that become apparent after initial crisis of the birth of a child with severe disabilities (McCubbin & Patterson, 1983; Pozo et al., 2014). The causes of this added stress are related to: (a) functional challenges (challenges directly associated with caregiving, and the nature of the disability or its symptoms), (b) emotional challenges (challenges related to uncomfortable or negative feelings), and (c) interpersonal challenges (challenges associated with changes in relationships).

In terms of functional challenges, parents must get used to addressing unique medical needs, which include integrating masses of new information and managing and complex care for

their child (Cunningham & Davis, 1985; Hartman et al., 1992). In addition, children with developmental disabilities may exhibit more behavioral issues that require extra care from parents (Beresford, 1996; Kennedy et al., 2007; Wang & Singer, 2016; Witt, Riley, & Coiro, 2003). Families may also experience financial stress because of the cost associated with medical or other types of care, as well as the loss of income or employment due to the time associated with extra care (Goudie, Narcisse, Hall, & Kuo, 2014; Kuhlthau, Hill, Yucel, & Perrin, 2005; Parish, Rose, Swaine, Dababnah, & Mayra, 2012; Parish, Seltzer, Greenberg, & Floyd, 2004).

In terms of emotional challenges, parents of children with developmental disabilities often face a variety of unexpected and often uncomfortable feelings related to their child's disability. Often the initial diagnosis after the birth of a child with disabilities is accompanied by feels of loss, lower self-esteem and disappointment as parents adjust their expectations for their child and the role they will play in their child's life (Waisbren, 1980). Throughout the child's development, parents frequently report feelings of sadness, anger, frustration, guilt, helplessness and loneliness as they are faced with the ongoing stressors associated with caring for a child with disabilities (Cunningham & Davis, 1985; Florian & Krulik, 1991; Jackson & Roper, 2014; Waisbren, 1980).

Functional and emotional stress can impact interpersonal relationships, particularly within the family unit. Though parents of children with developmental disabilities tend to experience greater challenges overall, the research is mixed regarding how marital satisfaction is affected. Some studies suggest parents of children with developmental disabilities do not experience significant changes in marital satisfaction or rates of divorce (Freedman, Kalb, Zablotsky, & Stuart, 2012; Urbano & Hodapp, 2007) whereas other studies suggest that parents may experience decreased levels of marital satisfaction or are more likely to divorce (Crnic et al.,

1983; Hartley et al., 2010; Wymbs et al., 2008). Sibling relationships can also become strained as siblings may experience jealousy or embarrassment of the child with a developmental disability (Diehl et al., 1991). Family conflict and a deterioration of family cohesion are also common concerns reported by parents of children with complex care needs (Crnic et al., 1983; Cunningham & Davis, 1985; Diehl et al., 1991; Freedman et al., 2012; Nihira, Meyers, & Mink, 1980).

Although parents of children with severe developmental disabilities face many pile-up stressors and higher levels of stress, they do not necessarily experience an increase in distress or family dysfunction (Beckman, 1991). Many families find caring for family members with disabilities to be a source of satisfaction and, in some cases, a source of increased family cohesion (Hastings et al., 2005; Wang & Singer, 2016). The distinctions in how a family responds to a child with severe disabilities, (xX) is associated with the resources available (bB) and the meaning they ascribe (cC) to the added challenges (aA) that they may face (McCubbin & Patterson, 1983; Wang & Singer, 2016; Zeitlin, Williamson, & Rosenblatt, 1987).

### **Resources and Appraisal**

In the double ABCX model, factor bB expands the definition of family resources to include emotional and tangible resources that the family already possesses as well as those resources that a family or its members begin to identify because of a crisis (McCubbin & Patterson, 1983). Emotional and tangible resources may be characterized in several ways, one of which is based upon the confluence of context and degree of control. As an example, external contextual resources are those over which the family may not have control, such as access to money, their age, or their culture; internal contextual or emotional resources are those that the family can change, such as their roles within the family, behaviors, and the appraisal of the

stressor event (Boss, 2002; Crnic et al., 1983). Another way to conceptualize the idea of resources is the way in which they function for the family. Utilitarian resources, for example, would include finances, mobility, or access to care; whereas personal resources, may include physical health, competence and problem solving skills (Cunningham & Davis, 1985).

There are also social-ecological resources such as those found in relationships inside and outside of the family (Beresford, 1994; Lazarus & Folkman, 1984). Social supports such as community, family, friends, neighbors, other parents, and care providers, and medical professionals provide families with emotional support, tangible support and informational support. When emotional, tangible, and informational support comes from a social support network parents are healthier and better able to cope with stressful events (Schaefer, Coyne, & Lazarus, 1981). Conversely, parents of children with severe disabilities are more likely to place their child in out-of-home care if they do not feel adequately support from family or friends (Llewellyn et al., 1999).

In addition to the identification of resources, the family's appraisal of a stressor also plays a significant role in the family's adaptation process per the double ABCX model. Factor cC is the family's redefinition of the stressor to give the crisis new meaning (McCubbin & Patterson, 1983). The new meaning (or reappraisal) can in turn make the situation more manageable and decreases emotional intensity for the family. Parents of children with disabilities may reappraise the situation with either a focus on the burdens and stresses of caretaking, or on their resilience and the opportunity for increased family cohesion that having a child with special needs presents (Saloviita et al., 2003). A significant factor in promoting positive reappraisal (and positive family adaptation as a result) for parents of children with severe disabilities is the level of social support they receive from others (McConnell et al., 2014).

## **Social Support**

Parents of children with disabilities often use social supports as both a means to understand the situation and as a coping resource. Furthermore, within the double ABCX model, social support is one of the most significant resources a family can utilize to recover from a crisis (McCubbin & Patterson, 1983, p. 15). Although the definition of social support can be broad, it can be understood as “individuals, groups or institutions that provide assistance of varying degrees and forms to help another individual combat stresses that tax her or his personal resources” (Schilling, Gilchrist, & Schinke, 1984, p. 47). Engaging social support systems can effectively mediate family stress (Beresford, 1994; Hammarberg, Sartore, Cann, & Fisher, 2014; Hannemann & Blacher, 1998; Schilling et al., 1984), increase family congruence (McConnell et al., 2014), and play a role in maintaining physical and mental health (Nichols & Jenkinson, 2006). Though not always clearly delineated, social support can generally be grouped into two, sometimes overlapping, categories of (a) formal social supports and (b) informal social supports.

Formal social support is generally provided by organizations, professionals, or trained individuals who are paid for their services and function beyond the scope of a specific person’s needs. Examples of some formal supports include institutions such as hospitals, agencies and schools, and qualified service providers such as medical doctors, trainers, respite care workers, and mental health clinicians (Blacher, 1994; Bristol, 1987; Canary, 2008; Florian & Krulik, 1991). The research is mixed on the effectiveness of formal support as a mediating resource for parental stress in parents of children with disabilities; some research suggests that formal supports such as respite care, home services, and parent training provide a buffer against stress (Beresford, 1996; Birenbaum & Cohen, 1993; Hannemann & Blacher, 1998), whereas other studies suggest that formal supports are not associated significantly with lower levels of parental



stress or stress reduction (Saloviita et al., 2003; White & Hastings, 2004) and may even be a source of stress itself (Beresford, 1994; Knoll & Bedford, 1989).

Alternatively, informal social support is generally provided independently of formal organizations by groups or individuals who are not paid for their assistance and may maintain a personal relationship with the person to whom they provide support. Examples of some informal supports include relatives, friends, neighbors, or members of a shared community (Blacher, 1994; Bristol, 1987; Canary, 2008; Florian & Krulik, 1991). The amount of stress that the parents of children with disabilities report is closely related to the level of informal support they receive. An increase in informal support is associated with higher levels of wellbeing and decreased levels of stress among both mothers and fathers of children with disabilities (Beckman, 1991; Saloviita et al., 2003; White & Hastings, 2004). The ability of families to adapt to the disability of a child is also predicted by the levels of informal social support they received (Bristol, 1987).

Although categorizing social supports as either formal or informal provides a general framework for understanding the types of social support that parents of children with disabilities may utilize, these categories are neither distinct nor mutually exclusive (Tétreault et al., 2014). For example, group therapy may include elements of formal social support (e.g., professional facilitation, participation costs, and ongoing scheduled meeting) or informal support (e.g., self-organized, member facilitated, and based on personal relationships) depending on group structure.

### **Support Groups**

Research suggests group therapy is both as effective as individual therapy and has curative factors that individual therapy lacks. Some unique curative factors include an enhanced

opportunity for interpersonal learning, information sharing, and increased opportunity for normalization (McRoberts et al., 1998; Yalom & Leszcz, 2005). Groups can be structured in a variety of different ways in order to best meet the needs and goals of group members. Support groups, which are the focus of this present study, are groups designed specifically to offer members a means of social support to enhance coping. The primary difference between support groups and other types of groups is that the support itself comes from the members and their contributions rather than from the expert (Lakin, 1985; Nichols & Jenkinson, 2006).

The natural tendency of people in need to seek support from those with similar needs serves as the basis for the contemporary support group. Historically marginalized, stigmatized, and isolated groups of people formed communal networks to help one another because formal institutions failed to meet and acknowledge their unique needs. Mutual aid, which was once viewed as a social phenomenon, has been adopted by professional disciplines as an effective treatment modality with several hundred support groups existing in the US alone (Katz & Bender, 1976; Lakin, 1985).

Like any treatment modality, the design and composition of a support group is based on the goals of the members (Yalom & Leszcz, 2005). Members that participate together in a support group typically share a common identified need and are capable of both giving support to other members as well as receiving support from other members (Katz & Bender, 1976). Groups that are led by the members (often called self-help groups, peer support groups, or mutual help groups) are characterized by the power of the members to help one another without professional leadership or facilitation (Law et al., 2002). Alternatively, support groups with a facilitator create an environment in which group members give and receive informal support to one another while also being a part of a formal group structure led by a professional who gives

guidance, serves as a model, and fosters an environment of safety (Nichols & Jenkinson, 2006). In either case, support groups are unique because they provide an opportunity for members to share information, and both give and receive emotional support. It is the bi-directionality and reciprocity of support between groups members that makes support groups effective (Maton, 1988).

Participation in support groups reduces member isolation, provides an opportunity for emotional expression and discussion with others, and encourages member growth through the group interaction (Lakin, 1985; Nichols & Jenkinson, 2006). The interactions that occur within support groups offer members social support to cope with stress and affect the appraisal of stressor events (Beresford, 1994; Sloper, 1999). The combination of these curative factors makes support groups a powerful modality for working with people struggling with stressor events, including those experienced by parents of children with disabilities.

### **Support Groups for Parents of Children with Disabilities**

Parent support groups help to battle isolation, normalize the parental experience and validate emotions (Louv, 1993). Parents of children with special and complex needs almost universally report support groups to be helpful (Diehl et al., 1991). However, much of the data on groups for parents of children with disabilities focuses on the use of training and psychoeducation groups rather than support groups (Lam et al., 2016; Wang, Kim, Detar-Smith, & Singer, 2016). Furthermore, much of the research on support groups for parents of children with disabilities describes pre-existing support groups and their outcomes rather than providing recommendations for support group design that will predict those specific outcomes (Solomon et al., 2001).

**Group structure.** In the context of group design, structure generally refers to the frequency and duration of meetings, location in which groups take place, and other logistical considerations (Nichols & Jenkinson, 2006). A *closed* group does not accept new members and only meets for a limited and predetermined number of sessions. Conversely, an *open* group may either meet for a preset number of sessions or be ongoing, but retains its size by allowing new members to join as other members leave (Yalom & Leszcz, 2005).

In terms of frequency and duration of support group meetings, the research suggests that a variety of different structures can be used, though the rationales and effects of those structures on outcomes is not as clear. Studies that evaluate multiple groups for parents of children with disabilities found similar outcomes among all surveyed members despite the differences in group structure (Law et al., 2002; Solomon et al., 2001). Alternatively, several research studies suggest that closed groups, many of which met 6-15 times, provided the opportunity for group members to build trust with one another and allowed the group to become cohesive (Linder, 1970; Mohr, 2004; Schilling et al., 1984; Seligman, 1993; Singer, Irvin, & Hawkins, 1988; Stallard & Dickinson, 1994). However, having limited sessions also left members believing that they could benefit from additional meetings because there was more to be discussed (Fine & Johnson, 1983). Groups that did not have a fixed number of sessions provided more of an opportunity for group members to gain a sense of belonging in the group and to progress individually over time (King, Stewart, King, & Law, 2000). In terms of meeting frequency, there is a wide range of models within the literature including parent support groups that met weekly, biweekly, monthly, and bimonthly for both closed and open groups (Gaad, 2006; Hammarberg et al., 2014; McCabe & McCabe, 2013).

**Group composition.** Another significant factor that may contribute to the consideration of group format is member composition and the degree to which parents feel they can identify with one another (Hammarberg et al., 2014). Some studies use a broad definition of *disability* that may not distinguish type or severity of disability in sampling but often include data from parents of children with developmental disabilities, though not exclusively so (Lindo, Kliemann, Combes, & Frank, 2016). In contrast, some studies narrowly collect data from parents of children with one specific type of developmental disability (e.g., autism, Down syndrome, and ADHD) and may or may not make a distinction in the level of severity (Papageorgiou & Kalyva, 2010; White & Hastings, 2004).

The degree of *sameness* that parents of children with severe disabilities perceive with their fellow groups members is a significant factor in groups success and is an area that needs to be explored further within the research (Ainbinder et al., 1998; Solomon et al., 2001). Research that compared supports groups for parents (including couples) whose children had similar disabilities and parents whose children had varied disabilities suggest that groups (particularly brief groups) would be composed of parents of children with similar or the same disability so that parents are better able to relate to one another (Fine & Johnson, 1983; McCabe & McCabe, 2013). Other research suggests that though sameness in type of disability was less significant, demographic homogeneity and similarity in severity level of disability was significant for some parents as well as for group functioning (Hammarberg et al., 2014; Linder, 1970; Singer et al., 1988).

**Session content.** Session content simply refers to the format and organizing themes of each meeting. Within the literature, some support groups are primarily discussion based whereas others use discussion as one of multiple session formats; some have structured topics for each

session whereas others allow for a more organic dialog. In terms of format, many groups are multidimensional and offer a combination of advocacy work, skills training from professionals, and open discussion among members. In addition, a mixture of methods (use of discussion, audiovisuals, modeling, written materials, and homework) is also recommended and frequently used (Gaad, 2006; Hammarberg et al., 2014; Schilling et al., 1984; Seligman, 1993; Singer et al., 1988).

It terms of content, it is important that group meetings are both well planned and flexible to balance the needs of various members (Cunningham & Davis, 1985; King et al., 2000). For example, the facilitators in the groups assessed by Fine and Johnson (1983) developed a specific discussion topic for each of their six sessions but allowed members to guide the conversation themselves. Discussion topics focused on improving communication, sharing information, exploring families of origin, and planning for the future (Fine & Johnson, 1983). Similarly, the Singer et al. (1988) research explored the incorporation of skills training to monitor and manage stress reactions (e.g. self-monitoring for psychological reactions to stress, using muscle relaxation, modifying thoughts that cause distress). Alternatively, in order to ensure balance and meet member needs, some studies suggest that session content should be created by the members themselves and that the agenda for each meeting be discussed and agreed upon as a group whether or not the group has a parent or professional leader (King et al., 2000; Stallard & Dickinson, 1994).

**Facilitation.** The role of the facilitator in a support group for parents of children with disabilities is multifaceted and can vary based on the goals or purpose of the group (Seligman, 1993). Much of the research suggests that facilitators be trained in working with groups and

families, articulate, and organized (Cunningham & Davis, 1985; Hornby, 2014; Schilling et al., 1984; Seligman, 1993).

*Peer-to-peer support groups.* Peer-to-peer support groups (also called mutual support groups or self-help groups) are parent-led groups for parents of children with disabilities that are organized and facilitated by the group members themselves. Parent-led support groups for parents of children with disabilities provide members with emotional support, community, a sense of belonging, friendship, and a platform for advocacy and empowerment (Law et al., 2002; Shilling et al., 2013; Solomon et al., 2001). Parents of children with disabilities that participated in parent-led support groups reported that groups were a place for them to share emotions, learn from related experiences of other parents, and gain practical information to navigate institutional barriers and find external resources (Law et al., 2002). Parents who participated in mutual support groups had increased self-esteem and appraised themselves and their family situations more positively (Solomon et al., 2001).

Another type of peer support that is commonly included in the peer support group literature is one-to-one (or parent-to-parent) support (Shilling et al., 2013). One-to-one support pairs are comprised of parents of children with similar disabilities, matching together one referral parent who is new to the program with a veteran support parent who is often trained (Ainbinder et al., 1998; Iscoe & Bordelon, 1985; Santelli, Turnbull, Marquis, & Lerner, 1995). One-to-one groups offer a type of social support that is both formal (pairs are organized and support parents are often trained), and informal (meeting times are flexible, participating parents are generally volunteers, and the relationship is personal). One-to-one parent pairs also create a mechanism for information sharing and emotional support that is important for parents of children with

disabilities and simultaneously allow for flexibility, personalized support, and reciprocal support (Ainbinder et al., 1998; Hartman et al., 1992; Santelli et al., 1995).

***Professionally facilitated support groups.*** Professionally facilitated support groups are led by professionals such as psychotherapists. Initially, support groups for parents of children with disabilities developed as grassroots groups that were self-organized and parent-led (Cain, 1976). Parents began to seek support from one another because they perceived formal institutions, service providers, and professionals as being unable to adequately meet their needs or the needs of their children (Katz & Bender, 1976; McKeever & Miller, 2004). Though the parent-professional relationship has more recently become collaborative, research on the effects of parent-professional relationships on parent well-being and the degree to which parents want professionals involved in support groups is mixed (Canary, 2008; Keen & Knox, 2004; Smith, Gabard, Dale, & Drucker, 1994). Although it is not uncommon for people to access therapeutic services and participate in support groups concurrently, they typically view the two as distinct (though complimentary) resources (Gottlieb, 1982).

Despite the historical divide between support groups for parents of children with disabilities and professionals, professionally-led groups have similar benefits to those found in parent-led support groups (Canary, 2008). For example, parents still rated emotional support, relationship building, and the ability to share experiences, knowledge, and skills all as beneficial aspects of support groups (Cunningham & Davis, 1985, pp. 128-130). Parents also tended to find professionally facilitated groups an effective means to increase social support and learn skills to help manage the stresses associated with have a child with a developmental disability (Lindo et al., 2016).



Often, the use of co-leaders is valuable in working with parents of children with disabilities, particularly when co-leaders included a mental health professional (such as a social worker, therapist, or clinical psychologist) and a subject matter expert (such as a medical professional, occupational therapist, or special education teacher; Fine & Johnson, 1983; Singer et al., 1988). For example, the groups assessed by Fine and Johnson (1983) were co-led by a social worker and an occupational therapist whose primary goals were to educate the parents, facilitate participation, and set rules, goals, and limits. The use of co-leaders was helpful in this case because of the leaders' different and complimentary areas of expertise.

### **Summary**

Social support is one of the most important and powerful resources in helping parents cope with the stresses of having a child with a disability. Although the research demonstrates that support groups for parents of children with developmental disabilities can be designed in several different ways, few have been reverse engineered to ensure that the design is most beneficial to the members (Solomon et al., 2001). A study of families of children with autism suggested that two-thirds of families had participated in support groups, but there has been little research to systematically understand how to best design and facilitate them (Mandell & Salzer, 2007). Furthermore, parents of children with autism who had never attended a group reported that the reason they had not done so was because logistical difficulties in attending (e.g. lack of child care, inconvenient location, inconvenient time) rather than a perceived lack of benefit (Clifford & Minnes, 2013b).

Support groups can be particularly powerful in bridging the gap between formal and informal support mechanisms by offering elements of both. However, the foundation for the evidence-based practice interventions in groups for parents of children with developmental

disabilities, particularly in reference to professional facilitation, is predominantly skills training and psychoeducation groups (Lam et al., 2016; Wang et al., 2016) rather than support groups. Furthermore, the research on support groups for parents of children with developmental disabilities is dated (Cunningham & Davis, 1985; Fine & Johnson, 1983; Linder, 1970; Schilling et al., 1984; Singer et al., 1988), is often based on populations outside of the United States (Clifford & Minnes, 2013b; Gaad, 2006; Hammarberg et al., 2014; Jones & Passey, 2004; McCabe & McCabe, 2013; Papageorgiou & Kalyva, 2010; Venkatesan, 2004), uses samples of parents of children with non-specific disability that includes developmental disability (Law et al., 2002; Lindo et al., 2016; McCabe & McCabe, 2013) or only one specific developmental disability (Mandell & Salzer, 2007; Papageorgiou & Kalyva, 2010), and only rarely identifies the severity of the disability (Lindo et al., 2016; Singer et al., 1988). Not only is little known about what parents want from support groups, but even less is known about what parents would like from their group facilitators. The goal of the present study is to privilege the voice of the clients and consumers (parents of children with severe or profound developmental disabilities) and develop recommendations for effectively designing and facilitating support groups based on the needs and preferences of parents of children with severe or profound developmental disabilities.

## **Chapter 3: Methods**

### **Design of the Study**

The present study is a supplementary analysis (a form of secondary analysis) using qualitative data collected from parents of children with severe or profound developmental disabilities. Secondary data analysis is used when a new question (that was not addressed in the original research study) can be answered using the original data (Irwin, 2013). Supplementary data analysis is used to conduct a more in-depth analysis specifically of the unaddressed aspect of the data (Heaton, 2008). The existing dataset that was used in the present study consists of interview transcripts collected from parents of children with severe or profound developmental disabilities who made the decision to place their children in out-of-home care. Access to the original dataset was obtained through informal data sharing as the data was directly shared by the primary researcher (Heaton, 2004). The primary researcher, Dr. Jeffrey Jackson, shared the dataset (which does not contain identifying information) with me, the secondary researcher, to conduct a supplementary analysis.

The purpose of the present study was to generate recommendations for the design and facilitation of support groups for parents of children with severe or profound developmental disabilities. However, the complete dataset includes questions pertaining to stressors in the home, the process of placement, forms of support, use of therapeutic services, and changes after placement (Roper & Jackson, 2007). As such, only the portion of the interviews pertaining to support services was analyzed for this study.

### **Study Participants and Procedures**

Study participants were selected through a process of theoretical sampling to ensure sample consistency and data saturation (Creswell, 2013; Roper & Jackson, 2007). The initial

research study was approved by both the Utah Department of Human Services as well as the institutional review boards of two universities. The data were collected between March of 2000 and February of 2003 and each individual participant provided written informed consent before data collection began (Jackson & Roper, 2014). The participants were made aware (as a part of their informed consent) that their responses may be reviewed by multiple researchers whom they would not meet. Though identifying information has already been removed from the transcripts, I signed the confidentiality agreement required by the institution review boards that approved protocol of the original study (see Appendix A) to further protect the rights of the initial study participants.

Participants were included in the initial study if they: (a) were the parent of one or more children with a severe or profound developmental disability, (b) had voluntarily placed at least one child with disabilities in out-of-home care when the child was between the ages of 2 and 30 years old, (c) were married when their child was placed, (d) had a child who had been in placement for a year or more (Roper & Jackson, 2007). Participants were living in urban areas in Utah and were recruited through a list of potential participants provided by state and private agencies in Utah.

A total of 19 interviews were conducted with 34 participants whose demographics are shown in Table 1 and Table 2. Interviews were conducted with both couples (15 sets of mothers and fathers who were interview conjointly) and individuals (3 individual mothers and 1 individual father). All the children of the study participants (Table 3) had multiple disabilities with 68% having profound disabilities and 32% having severe disabilities (Roper & Jackson, 2007, p. 150). Demographically (see Tables 1-2), 97% of participants were White, 85% identified as Latter-Day Saints (Mormon), and most families (68%) had four or more children.

Parents had varied levels of education, with most having some education beyond high school (Table 2). The annual household income after adjusted for the value in the year 2016 based on the Bureau of Labor Statics (2017) inflation estimation was \$30,000-\$50,000 for 26% of the sample, \$50,000-\$70,000 for 32% of the sample, \$70,000-\$90,000 for 32% of the sample, and over \$90,000 for 11% of the sample (Jackson & Roper, 2014, p. 204).

Table 1: *Participant Household Demographics (N = 19)*

Category	<i>n</i>	%
Adjusted household income* at time of placement		
\$30,000 – 50,000	5	26
\$50,000 -70,000	6	32
\$70,000 – 90,000	6	32
> \$90,000	2	11
Total number of children		
1	1	5
2	3	16
3	2	11
4	8	42
>5	5	26

\*Income adjusted to 2016 values based on estimations from the Bureau of Labor Statistics.

Table 2: *Participant Demographics*

Category	Mothers (N = 18)		Fathers (N = 16)		Total (N = 34)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Ethnicity						
Caucasian	18	100	15	94	33	97
Asian	0	0	1	6	1	3
Education						
Less than high school	0	0	2	13	2	6
Completed high school	5	28	2	13	7	21
Some undergraduate	7	39	3	19	10	29
Undergraduate degree	4	22	5	31	9	26
Graduate degree	1	5	3	19	4	12
Doctorate degree	1	5	1	6	2	6
Religious affiliation						
Latter-day Saint/ Mormon	15	83	14	88	29	85
Atheist	0	0	1	6	1	3
Unitarian	1	5	0		1	3
Catholic	1	5	0		1	3
No affiliation	1	5	1	6	2	6
Age at time of interview						
30-39	3	17	2	13	5	15
40-49	7	39	5	31	12	35
50-59	6	33	6	38	12	35
60-69	0	0	2	13	2	6
70-79	2	11	1	6	3	9

Table 3: *Child with Developmental Disabilities Demographic Information (N = 19)*

Category	<i>n</i>	%
Gender of child		
Male	11	58
Female	8	42
Severity of disability		
Severe	6	32
Profound	13	68
Type of developmental disability		
Autism	10	53
Behavior disorder	12	63
Cerebral palsy	2	11
Communication impairment	15	80
Developmental delay	17	90
Down's syndrome	1	5
Epilepsy / seizure disorder	10	53
Intellectual impairment	19	100
Orthopedic impairment	5	26
Visual impairment	4	21
Other rare disabilities	3	16

### **Instruments**

Participants were interviewed using semi-structured interview questions. Participants requested to be interviewed in their homes except for one participant who requested to be interviewed at their business office. The interviews were recorded and lasted between 2-4.5 hours. The interview questions were reviewed and revised by subject matter experts before being

used in interviews with participants. After their interview, participants completed written demographic questionnaires. The interviews were transcribed verbatim by multiple transcribers and verified by the primary researcher (Jackson & Roper, 2014).

A subset of interview questions was used to gather participant perspectives about and experiences with support groups (see Appendix B). Participants were asked whether they had attended a support group. Participants who had experience with support groups were asked questions about group structure and to describe the elements they would or would not like to see included in a support groups. Though parents were not asked to specify time of support group participation, parents more frequently discussed experiences that occurred before they placed their child with disabilities in out-of-home care rather than after placement. Participants who had not attended a support group were also asked about what they would like to see included in a support group.

### **Data Analysis**

**Data assessment.** I conducted a supplementary analysis of the data collected through the subset of interview questions about support services and support groups. Supplementary analysis is one of the most commonly used forms of qualitative secondary analysis, particularly when a specific aspect of the data has not been addressed in the primary research (Heaton, 2004). The usability of this dataset was assessed its (a) accessibility, (b) quality, and (c) suitability as defined by Heaton (2004, pp. 94-96) and Hinds, Vogel, and Clarke-Steffen (1997).

Accessibility refers to the format of the data and the degree to which the data can be used by the secondary researcher. In this case, the written transcripts exist as electronic files available via NVivo software. The primary researcher provided me with access to the complete transcripts



of the original interview. As a secondary researcher, I did not have access to the original audio files, but consulted the primary researcher throughout the data analysis process.

The quality of the data refers to the completeness of the dataset as well as the design used to originally gather the data. Though it is difficult to objectively determine the completeness of qualitative data when using semi-structured interviews, all the data that have been collected have been transcribed verbatim and verified for accuracy. As mentioned previously, the original study was designed and carried out in accordance with the standards required by two institutional review boards, and the Utah Department of Human Services. The transcripts have only been altered to remove identifying information, stutters, and filler words. In addition, though I did not have access to the audio tapes, non-verbal communications (such as sighing, crying, and laughing) were indicated in the transcriptions.

Finally, the suitability of the data refers to the degree to which the dataset is an appropriate source of information to answer the research questions. In this study, the research questions were developed as a direct result of the unanalyzed data collected in the initial study. The original intentions of the primary researchers were to analyze the data on support groups as a separate research study. The data I analyzed were originally collected with the express purpose of identifying what parents of children with severe developmental disabilities want and do not want in support groups. Therefore, because this study was designed to specifically utilize the original dataset, the data were highly suitable to generate recommendation for support group design. Although the sample is made up of parents who had placed their child in out-of-home care, the questions pertaining to support services were designed to gather a general information about the use of support groups and participant preferences about them.

**Content analysis.** Given the intersection of the nature of the data as well as the research questions for the present study, methods that are commonly used to analyze data collected from focus group interviews were used. Focus group interview analysis was the most appropriate method of inquiry for the present study due to the similarity in anticipated results. Specifically, focus group interviews are commonly used to gather input for guiding future intervention programs or developing hypotheses that can be tested in future studies (Morgan, 1997, p. 58; Stewart & Shamdasani, 1990). Similarly, the results of the present study provide guidance for the design of future support groups used as an intervention for parents of children with severe developmental disabilities. Therefore, qualitative content analysis, which is often used with both interview transcripts and focus group data (Stewart & Shamdasani, 1990), was used to code the data.

Qualitative content analysis is a set of techniques used to code data to identify themes, meanings and core ideas. Qualitative content analysis provides a structured approach to data coding and shares characteristics with thematic analysis (Drisko & Maschi, 2015). The first step of any qualitative coding process is to become immersed in the data by reading the transcripts in their entirety to get a sense of the whole (Creswell, 2013). In order to immerse myself in the data, I read 10 transcripts in their entirety to develop an understanding of the overall experiences of the participants as well as how the data of interest appear in the interviews. Because the data of interest were localized with the transcripts, I read through the sections referring to support groups in the remaining nine interviews.

The next step after data immersion is to define content units to be coded. I used referential units (parts of the data that refer to the same person, event, or object) and thematic units (parts of the data that share meanings) as the relevant content units (Diehl et al., 1991;

Stewart & Shamdasani, 1990). In addition, the data were pre-coded based on gender in the interviews that were conducted as dyads. Finally, based on the information within the units, open coding (Corbin & Strauss, 2008) was used to create general categories. The categories were organized and reconstructed to create a coherent set of recommendations for support groups (Creswell, 2013; Drisko & Maschi, 2015).

In addition, I coded the data with the intention of conducting several crosstabulation analyses. Crosstabulation is the process of comparing results from two different groups or variables (Tankard, 1994). In this study, I compared the categories that emerged for participants who had participated in support groups versus those who had not by performing the crosstabulation analysis for the relevant thematic unit. Though a specific question was not asked about experiences with facilitation, the type of facilitation (parent-led or professionally-led) was coded when it was discernable based on content of the transcripts.

**Verification.** As is critical in any research study, several verification techniques were used in the data analysis process to ensure accuracy in the results (Creswell, 2013). Specifically, I established trustworthiness based on the criteria of (a) credibility, (b) transferability, (c) dependability, and (d) confirmability, as defined by Lincoln and Guba (1985).

Credibility is the degree to which the results are accurate and reflect reality (Shenton, 2004). One of the methods that has already been undertaken to establish credibility in this study is prolonged engagement (Lincoln & Guba, 1985) with the existing research on support groups and parents of children with severe or profound disabilities. Existing research was also compared to the results of this study to further establish credibility. In addition, frequent debriefing meetings were scheduled with the primary researcher throughout the data analysis process to facilitate idea development and to identify any flaws in the analysis process. The primary

researcher collaborated in the data analysis process as an internal auditor and expert in the field (Shenton, 2004). Finally, thick and rich descriptions from the transcripts were included in the results so the reader can further assess the credibility of the study (Creswell, 2013).

Transferability is the degree to which the study findings can be applied to other contexts or situations (Shenton, 2004). Transferability was addressed by providing the reader with in-depth information about the boundaries of the dataset. Participant demographic information, recruitment strategies, and general context of data collection has been included (see Tables 1-3).

Dependability is the degree to which the results are consistent and can be replicated. Dependability and credibility are strongly linked and, as such, the strategies used to ensure credibility were also employed to ensure dependability (Lincoln & Guba, 1985; Shenton, 2004). Like transferability, dependability was addressed by providing the reader with substantial information about the research design and the process by which it was implemented. The information includes both a description of the original data collection methods as well as a description of the secondary data analysis process.

Confirmability is the degree to which the data objectively support the results. Confirmability was addressed through self-reflection and disclosure of my biases or relevant personal experience. Furthermore, external auditors (two committee members) have assessed research methods and analysis results, in addition to the internal audit conducted by the primary researcher.

## Chapter 4: Results

The data analysis of interviews with parents of children with severe developmental disabilities yielded results focused in two key areas. The first results area focused on the perceived value of support group participation, derived from interviewed parent's insights around what elements they found added value and what elements detracted value. The second results area yielded group design recommendations including recommendations for group structure, composition, content, facilitation, and how to reach out to potential group members. In both result areas, several themes and categories emerged as parallel opposites to one another.

### Assessment of Value

In an overall analysis of each of the 34 individual parents' attendance and general assessments of the value of support groups (Table 4), most parents indicated that support groups were valuable and offered some level of benefit. A total of 47% of parents indicated that they found support groups to be beneficial, 18% of parents indicated that they had a mixed evaluation of support groups citing both helpful and unhelpful aspects, and 29% of parents indicated that they did not find support groups to be valuable. Of the parents who did not assess support groups as valuable, 30% (9% of all parents) had attended at least one support group meeting, whereas 70% (21% of all parents) had never attended. Of the parents that found support groups to be beneficial, 62% (29% of all parents) had attended at least one support group meeting, whereas 25% (12% of all parents) had not. Finally, all parents who indicated mixed feelings about the value of support groups had attended at least one support group meeting. The assessment of value and rate of attendance appeared to be similar across genders (Table 5).

Table 4: *Support Group Participation and Assessment of Value (N = 34)*

	Valuable	Mixed	Not valuable	Cannot discern value	Total attendance
Attended	10	6	3	0	19
1. Regularly attended	6	2	0	0	8
2. Sporadically attended	0	1	1	0	2
3. Few (less than 5) initial meetings attended	4	3	2	0	9
Did not attend	4	0	7	0	11
Cannot discern if attended	2	0	0	2	4
Total assessment of value	16	6	10	2	34

*Note:* The labels “cannot discern” denote that the researcher could not assign a value based on the information in the transcripts not that the participant was unable to discern either their attendance or their assessment of value.

Table 5: *Support Group Participation and Assessment of Value by Gender (N = 34)*

	Mothers (N = 18)				Fathers (N = 16)			
	Valuable	Mixed	Not valuable	Cannot discern	Valuable	Mixed	Not valuable	Cannot discern
Attended	6	4	1	0	4	2	2	0
1. Regular	3	1	0	0	3	1	0	1
2. Sporadic	0	1	0	0	0	0	1	0
3. A few (< 5) initial times	3	2	1	0	1	1	1	
Did not attend	3	0	3	0	1	0	4	0
Cannot discern attendance	1	0	0	0	1	0	0	2

*Note:* The labels “cannot discern” denote that the researcher could not assign a value based on the information in the transcripts not that the participant was unable to discern either their attendance or their assessment of value.

The results presented in the following sections (including Tables 6-11) are based on analysis conducted at the case (interview) level rather than the participant level to not over represent the experiences of the participants who were interviewed as couples over those of participants who were interviewed individually. Furthermore, themes needed to be present in two or more cases unless a single occurrence was in direct opposition to a dominant theme, in which case it was reported. In some coding areas, the sub-category occurrences appear to exceed that of the category occurrences because participants often shared multiple responses across sub-categories.

**Reasons support groups were perceived as valuable.** A total of 15 interviews contained references to elements of support groups that they found to be valuable (Table 6). Value was assessed based on references to things that parents generally perceived to be beneficial about group participation. For example, as one participant said, “It saved our lives.” However, the reasons why parents found support groups to be valuable varied. The valuable elements of support groups as expressed by parents were coded into five themes. The themes suggested that participation in support groups helped parents to feel understood, allowed parents an opportunity to help others, left parents feeling better, fostered connections, and helped parents feel like they were taking action to help their children or themselves.



Table 6: *Perceived Value of Support Groups (N = 19)*

Coding categories and sub-categories	Thematic content	<i>n</i>	%
Reasons that support groups are perceived as valuable			
1. Feeling understood	Being with people who have a shared experience	12	63
2. Helping others	Providing support to other group members	6	32
3. Positive experience	Participating is a satisfactory experience leaving the parent with positive feelings (e.g. relief or joy)	5	26
4. Creating connection	Building relationships and friendships	4	21
5. Taking action	Participating in group ameliorates the situation	1	5
Reasons that support groups are not perceived as valuable			
1. Poor fit	Difficult to find others with a shared experience	6	32
2. Does not help	Participating does not ameliorate the situation or their feelings about it	6	32
3. Comparison to others	Judging self or others based on their actions or emotions	5	26
4. Negative experience	Participating is an unsatisfactory experience leaving the parent with uncomfortable emotions such as depression or resignation	5	26
5. Support from other sources	Other sources of support were perceived as more valuable and more utilized	3	16

*Note:* Coding category and theme frequencies are at the case (interview) level.

***Feeling understood.*** Most interviews (12) contained references to the ways in which support groups provide an opportunity to be with other parents who have a shared experience and understand what it means to have a child with disabilities. As one mother said about her experience having attended a support group, “Sometimes all people want for [*sic*] is somebody to

listen to them, and not try and fix it, not give them advice, not give them answers, but just somebody who listens and says, ‘You know what? I understand.’” In another interview, a father shared the following: “People could share the traumatic experiences that you go through. Until you have an autistic or handicapped child, people that have ‘normal children’ just don’t understand.” The theme of feeling understood was prevalent in several results areas, particularly in those of group composition and meeting content where it is discussed further.

***Helping others.*** Six interviews contained references to the idea that participating in support groups was an opportunity to help and support others. As one mother who had not attended a support group stated: “It’s somewhat rewarding to me to be able to reassure them that they’ll survive it and that there are blessings to look forward to, and that kind of thing. And those kinds of things come out in a group setting.”

***Positive experience.*** Five interviews contained references to the idea that parents felt better (or imagined they would feel better) as result of attending a support group. One father shared that just being distanced from the stresses of home (which the support group provided) was a mechanism to feel better: “You’re always in the trenches—it’s just nice to get away from it.” A significant number of parents discussed that one of the primary mechanisms that made participating in a support group a positive experience (which included feeling reassured, relieved, and encouraged) was through sharing their emotions with other parents in the support group. As one mother said “We could laugh together instead of cry. I mean we did both, but it was wonderful.” The concept of including a space in the support group to share emotion is addressed as a part of session content below.

***Creating connections.*** Four interviews referenced the value that support groups add by facilitating an opportunity to connect to other parents of children with disabilities and build

relationships and friendships together. As one father commented “I think getting groups together would be helpful to share and how you’re dealing with this issue and that issue, and you could develop some relationships. Like this one couple, they became very fond friends of ours for several years.” One mother commented that she also felt that connecting with other parents might help her son with developmental disabilities create connections: “I could find a friend for him who was very much like he is.”

***Taking Action.*** One mother discussed that the value of going to a support group for parents was to feel like she was taking action and doing something to better her and her family’s situation. As she described about going to a support group to gather more information:

It makes you feel like you’re doing something about it, instead of just sitting around and having it rain on you. At least you’re putting on galoshes, or putting up an umbrella, or something, but you’re not just sitting there in the rain, you’re doing something about it.

***Reasons support groups were not perceived as valuable.*** A total of 17 interviews contained references to either elements that detracted value from support groups or the general evaluation that support groups were not helpful (see Table 6). Again, five general themes emerged to explain why support groups were either not helpful, or even detrimental. Those themes included the discussion that often participation in support groups: (a) did not feel like a fit, (b) was not helpful, (c) caused parents to compare themselves to other parent, (d) felt like a negative experience, and (e) felt unnecessary.

***Poor fit.*** Six interviews contained references to the ways in which support groups did not fit the needs of the parents either because of the rarity of their child’s disabilities or because their child had more severe disabilities than other parents in the group. As one mother said,

I've realized I'm not going to find anybody like our child with special needs—he's one of a kind.... So, I don't know how beneficial a support group would have been to me because I had my own unique set of problems that I dealt with.

Several parents also discussed the inability to find other parents with a shared experience and as one father said:

In fact, you go to these groups to feel like you're not alone, and we go to these groups and feel like we were alone again because we had not only two kids with disabilities, but neither one really fit either group.

Another mother shared a similar assessment that going to a group and not fitting in caused more distress than not going to a group at all. As she said: "Instead of it being a situation that I felt like I could walk into and obtain support, I felt really uncomfortable."

***Does not help.*** In six interviews parents referred to the ideas that participating in a support group neither helped their situation nor addressed their feelings about raising a child with developmental disabilities. As one mother stated, "It just hasn't gotten us anywhere." Several parents shared that participating in support groups did not change things for them and that they did not find talking to other parents to be an effective coping mechanism. As one father stated, "Let's go do something—let's not talk about it." In another interview a mother shared that she sees support groups as "nothing but a bunch of whining and complaining." Similar sentiments that support groups are more about feeling bad, or searching for pity, were echoed in several interviews.

***Comparison to others.*** Five interviews contained parents' references to the experience of comparing themselves to other parents. One mother described her experience in a support group as a "crying match" with each group member trying to out-doing the other. One father said, "I'm

not really comfortable honestly... in a setting where you can compare notes. I'm not terribly interested in your notes, and suspect you wouldn't be in mine." In three of the five interviews parents referenced comparing themselves to other parents specifically in regarding the decision to place their child in some type of out-of-home care. One mother described that she felt "ostracized" and implied that she felt judged by the group because she had placed her child with disabilities in out-of-home care. Most parents described that those comparisons often resulted in feelings of guilt, self-judgement, or frustration.

*Negative experience.* In six interviews parents referenced feeling, or expecting to feel, undesirable emotions (e.g., depression or frustration) during support group meetings due to the inherent nature of topics. As one father said "We've lived through it—we don't want to relive it!" A mother described her husband's first support group meeting as follows: "He just got out of there and said... 'That was the most degrading, demoralizing, depressing hour and a half I have ever spent in my life, and I am never going back.' And he didn't." Several parents shared that support groups were difficult emotionally because it was uncomfortable to be around others who may be struggling. As one set of parents shared:

*Mother:* Being with other parents should be a support; but in a way, it just makes it all the more hurtful because you just feel so sorry for them and what's going on in their life.

*Father:* And you know you're helpless to help them.

*Mother:* Yeah, it's just tough. You just don't want to go through it—emotionally you just can't stand that pain and what they're going through—I feel so sorry for them.

*Support from other sources.* Five interviews referenced the theme that support groups were unnecessary because the parent either did not need support or found support from other sources. As one father simply said, "I've never felt the need to go to a support group; I've been

able to deal with this okay.” Several parents also discussed that they felt sufficient support from family and friends and thus did not need additional social support. For example, one father questioned, “What support do we need if all the people to whom we are emotionally close support us? We don’t need a support group.”

### **Support Group Design**

In addition to identifying how parents perceived the value of support group participation, parents also provided suggestions as to what would constitute the ideal support group. All 19 interviews contained recommendations for support group design. The elements of support group design were coded into the categories of group structure, group composition, meeting content, group leadership, and member recruitment.

**Group structure.** Group structure was coded into several categories and sub categories (Table 7). The categories included recommendations regarding meeting length and frequency, group type, meeting accessibility, and ideas for concurrent services.

Table 7: *Support Group Structure Preferences (N = 19)*

Coding category	Description	<i>n</i>	%
Meeting length	Amount of time meetings are held	4	21
1. 1-1½ hours		4	21
Meeting frequency	The degree of regularity for meetings	17	89
1. Once a month		12	63
2. Twice a month		6	32
3. Once a quarter		4	21
4. Once a week		2	11
5. Two-three times a year		2	11
Group type	Duration of group; degree of circulation in group membership	7	37
1. Duration based on need	Length of time parents remain in group is based on their own preferences and needs	6	32
2. Open	Ongoing group; potential for varied member composition	2	11
3. Closed	Same set of members at every meeting for a specific time period	1	5
Accessibility	Ability to attend meetings based on schedule or location	6	32
Concurrent services	Contemporaneous services offered with support groups	8	42
1. One-to-one support	Outreach opportunities for individual, private support	6	32
2. Care for child	Respite care or concurrent group opportunities to occupy child with disability so that parent can attend meetings	3	16
3. Services for siblings	Additional groups for siblings of children with disabilities	2	11

*Note:* Coding category frequencies are at the case (interview) level.

***Meeting length and frequency.*** A total of 17 interviews contained references to the frequency of support groups meetings (how often groups should meet). Most parents (14 interviews) expressed a preference for meeting one to two times per month. As one mother who suggested a once-a-month meeting said, “You can overdose on anything.” Another mother

indicated that anything more often than once a month would require extra respite care for her child with disabilities so that she could attend. One set of parents suggested the meeting frequency be set with consideration for logistical constraints for those who would like to attend: “Maybe have [meetings] two times a month, so that those that couldn’t come to the first one could make it to the second one.” The primary driver for meeting frequency as expressed by several parents was the concern that meeting too frequently would either become burdensome or would become repetitive, but that meeting too infrequently would not meet parent needs.

In terms of support group meeting length, only four interviews indicated a preference for the amount of time that meetings should be held (regardless of frequency). All parents that referenced meeting time suggested a one hour to one-and-a-half-hour meeting. As one mother stated:

We always hated those meetings that went on for hours because you knew your kid was home raising hell, and you were sitting there. If it lasted an hour, fine; but if they go over and over, it would just give me a lot of anxiety wondering what our child with special needs was doing.

***Group duration and type.*** In terms duration, all six interviews that referred to the amount of time a group should run (or the number of session parents may participate in) indicated that the duration would vary based on needs of the parent. As one father stated:

Some of that time would be for you personally, but you may also feel that you should stay with the group for someone else too, so I don’t think you can really predict a time. Once you felt like the group no longer served your purposes, or you were able serve theirs, I’d step away from that.



In terms of group type, only three interviews contained preferences as to whether meetings be open or closed. Two interviews contained preferences that support groups would be open, allowing new members to join groups that are “already formed and going” and other members to leave at any time. In one interview, the father indicated a strong preference for a closed group saying:

I don't think it would be fair to establish a group and then have one of you leave and have a new one come in. You'd have to kind of start over. It would have to be the four or five couples, or three or two couples or whatever, [who] would have to go through it together. And then when they felt like it was no longer beneficial, then they have to disband it.

***Meeting accessibility.*** Six interviews contained recommendations around the accessibility of support group meetings in terms of time and location. In three interviews parents described that attending meetings was difficult because of their schedules. As one father noted, “A lot of times meetings would be scheduled when I was out working,” and suggested that support groups “try to work around so that everybody had a time that would be most beneficial.” In one interview parents described that the location was difficult to access and it would have been helpful to have multiple groups set up in various geographic locations to minimize the “long ways drive back and forth.” Conversely, two interviews indicated that neither time nor location was a relevant factor in meeting attendance. As one father said about meeting time: “It doesn't matter. You make time for the things that are important to you.”

***Concurrent services.*** Eight interviews contained suggestions that concurrent services be offered either in addition to, or as a part of, support groups. In six interviews, parents suggested that groups be used as a conduit to connect to other parents of children with disability for one-to-one mentoring. In three interviews, parents addressed the concern that group attendance was

difficult because of a lack of childcare for their child with disabilities, indicating a need for concurrent childcare services. In two interviews, parents described that only one parent could attend group at a time because the other parent needed to remain home to watch their child with disabilities. As one mother described “We would never be able to go together...my husband would be home, and he would be like, ‘My heck, why are you so late?’ and it just caused more anxiety.” Similarly, one mother described the possibility for concurrent childcare: “And it was just hard to go to them [support group meeting] because it’s hard to find a babysitter to be able to go.

In two interviews, parents suggested having additional workshops, or as one mother called them, “sibshops,” to provide services to their other children. One mother described that additional sibling workshops could address enriching the lives of sibling of people with disabilities.

**Group composition.** A total of 13 interviews contained references to suggestions or preferences regarding group membership (Table 8). In two interviews parents described a desire to include neighbors and community members in support groups, but beyond that, parents discussed group composition in terms of group size and degree of sameness (number of shared characteristics) with the supposition that group members were other parents of children with disabilities.

Table 8: *Support Group Composition and Membership Preferences (N = 19)*

Coding category and sub-category	Description	<i>n</i>	%
Group size	Number of parents participating in meetings	10	53
1. 10 or fewer		6	32
2. 11 to 15		2	11
3. More than 20		2	11
4. 16 to 20		1	5
Degree of sameness	Relevance of and extent to which parents felt they (or their children) were like other parents (or other parent's children)	14	74
1. Type of disability	Children with disabilities sharing a diagnosis or symptoms	10	53
a. Same disability	Parents of children with highly similar disabilities	7	37
b. Different disability	Parents of children with various disabilities	3	16
2. Age of child	Children with disabilities being close to the same age or being at similar developmental stages	7	37
a. Different age	Parents with children of various ages	4	21
b. Same age	Parents of children at similar age	4	21
3. Placement status	Children with disabilities' placement status; parent attitudes	6	32
a. Varied status	Parents with mixed attitudes a experiences with placement	3	16
b. Same status	Parents with similar attitudes or experiences with placement	3	16
4. Severity of disability	Level of severity of child's disability	5	26
a. Similar severity	Parents of children with similar levels of disability	5	26

*Note:* Coding category frequencies are at the case (interview) level.

**Group size.** In 10 interviews parents discussed experiences with, or preferences around, the number of parents who participate in support group meetings. Most of the references to group size were descriptive of what parents who attended support groups had experienced rather than a preference or recommendation. Parents' experiences included attending meetings with fewer

than 10 members (4 interviews), 11 to 15 members (2 interviews), 16 to 20 members (1 interview), and more than 20 members (2 interviews). For the two interviews in which parents did express a preference, the preference was for groups to be composed of 10 or fewer members.

As one father said:

I think it has to be a relatively intimate group to really have some benefit. You have to establish a relationship, you have to feel comfortable sharing with someone else your story.... There will come a kind of time when I think you have to share your heart, and that's tough to do unless you have some respect or feelings for others in that group.

*Degree of Sameness.* In 14 interviews, parents discussed the importance of sharing characteristics with other parents in the group. Feeling understood was an often related theme as parents discussed the extent to which they could relate to other parents. The characteristics they discussed fell into four sub-categories (see Table 8). The sub-categories included their child's type of disability, age and stage of development, placements status, and disability severity.

*Type of disability.* In terms of type of disability, in three interviews, parents suggested that support group members' children did not necessarily have to have the exact same disability. The rationale was that the emotional experience of raising a child with disabilities, regardless of what those disabilities are, would be similar. As one mother said:

It was helpful to have those sessions... and find out how other moms felt even though they did not have autistic kids, they all had special needs kids; and to find out that we all had a lot of the same feelings, and a lot of the same frustrations.

Another mother said:

And really, it was a discussion of how to cope with how I'm feeling and how to cope with the impact this is having on my marriage or on my children.... It wasn't "What do I

do about this mental problem or this physical problem?” It was more of a feeling kind of a thing.

However, in seven interviews, parents described the frustration of not being able to relate to other parents because of the distinctiveness of their child’s disability or their child’s symptoms. Parent’s expressed concern that the topics discussed in the group did not (or would not) pertain to them or that it “dilutes the problem” to have parents with children of varied disabilities in one group. For example, one mother said the following:

I would ask questions, “Well, does your kid burn things in the oven and do they tear their clothes all in holes and everything?” And they’d just kind of looked at me like “No.” And I thought “Well...” I guess I was wanting somebody who was going through the same crap I was.

Several parents also described being frustrated because the information (e.g. medical information or behavioral advice) shared in the group did not apply to their child’s type of disability. As one mother said:

Every child has such a different disability. What we’re faced with is that we want to know something about her legs now —we want to know about her tendons, but that wouldn’t work for someone who has autism—they don’t care. So that’s what the difficult thing is about it because everybody’s family situation is so different.

*Stage of development.* Another significant metric that parents shared about sameness involved the age of their children with disabilities. Seven interviews referred to age or developmental stage as an important group membership characteristic to consider. In four interviews parents discussed that they would have liked to have been a group with children in different developmental stages so that they could learn from others who had older children (two

interviews) and offer support to parents who had younger children (two interviews). One mother said, “We were getting advice from people that had been through it, so that was nice. And then... [later], we were giving the advice because we had been through it.”

In three interviews parents discussed that they would have liked to have had experienced parents with older children in the group, but they often found that they were the furthest along in the developmental process. Being the most experience parent ended up not being helpful and even felt frustrating as parents discussed relevant topics “after it was too late” for them.

In four interviews, parents suggested that having other parents with children at the same stage of development was preferable. One set of parents found it was actually too overwhelming to be with more experienced parents who had older children: “We had a brand new baby and my husband just looked like he was a deer in the headlights—he was just like sick to his stomach. Oh my gosh—it was so depressing.”

*Placement status.* Given that the sample of interviewed participants were parents who had placed their child with developmental disabilities in out-of-home care, several parents (six interviews) discussed placement status and attitudes about placement as important metrics in support group composition. As one father said:

I wish that they could identify those parents [who want to place their children] ... and then have a support group for that because it’s a whole lot different from the other parents that want their kid [to remain at home], and they need help.

In three interviews, parents discussed that they did not want to be in support group meetings with parents who either had not placed a child or who would not consider placement because it evoked feelings of guilt rather than feelings of being supported and understood. One father shared:

That was the reason why I don't give it [the support group I attended] a 10 because people like that, they absolutely refused to place their child until 18, and so they made us feel guilty for placing our daughter or thinking about placing her.

In the other three interviews, parents discussed that they would have liked to have found a group composed of parents who had placed their children in out-of-home care because it was during and after placement that they needed the most additional support. As one mother said, "There was nothing for parents who had placed their children. There was nothing out there." Similarly, another mother shared "I have yet to see a support group for people who have placed their children. I think people who've placed their children need a support group."

*Disability severity.* In five interviews, parents discussed the severity of their child's disability compared to other parents in the group. As one mother said, "None of them seemed as severe as my child.... I just felt like my child was just worse than everybody else's." In all five of the interviews parents described that they wanted to be in a support group with only parents whose children had as severe of a disability as their own. Parents either described how meaningful it was to create connections with parents who shared similar struggles, or they described a frustration of not being understood when they were in a support group with parents of children with comparatively less severe disabilities. As one set of parents described:

*Mother:* If you have some little kid that's just got a little whiff of autism, how can they really relate to what it's really like?

*Father:* Yeah, it'd be nice if you could—

*Mother:* Separate it by level or problem.

*Father:* Yeah, because they might be griping about something, and you're going, "Oh, that's nothing!"

*Mother:* “Oh, you mean your son with disabilities told you that he didn’t like his brother?” And it’s like, “Boy, I’d like to hear our son with disabilities say a word,” you know.

One mother also described that although it was frustrating to be with parents of children with less severe disabilities, “to know that there are worse kids out there.... That would have helped me.”

**Meeting content.** A total of 18 interviews contained references to the topics that are discussed in support group meetings, the format of discussions, and how support group meeting agendas and formats are determined (Table 9). Parents were evenly split with some parents (three interviews) preferring to have a place to share their emotions freely without a set agenda, and with others parents (three interviews) preferring that meetings have a jointly developed agenda based on group needs. In five interviews parents indicated that it was important that the topics discussed in meetings be both applicable and interesting relative to their situations. As one mother said, “You need to try to find out what that [particular] group of people need.” The topics and formats that parents discussed including in support group meetings were coded into the following four categories: sharing emotions, sharing information, formal psychoeducation, and direction for advocacy.



Table 9: *Support Group Meeting Content Preferences (N = 19)*

Coding category and sub-category	Description	<i>n</i>	%
Determination of Agenda	How meetings should run and how session content should be determined or structured	9	47
1. Transparency of agenda	Direction for meeting should be known ahead of time so members can determine their interest in attendance	5	26
2. No meeting agenda	Preference that meeting do not have prespecified direction	3	16
3. Agenda determined by Members	Direction for meetings should be determined by group participants	3	16
4. Structured agenda	Preference that meetings have a prespecified direction	1	5
Sharing emotions	Meetings create a space for parents to talk about their feeling and process their experiences with their child with disabilities	15	80
1. Normalize	emotions are common and that others understand or can relate; reassurance	7	37
2. Hope	Exchange encouragement and increase feelings of hopefulness	4	21
Sharing information	Meetings are an opportunity for parents to exchange and disseminate pertinent information	17	89
1. Peer strategies	Exchange recommendations and share guidance from learned experiences	10	53
2. Obtaining services and navigating the system	Exchange recommendations for working with agencies and public service providers to get/manage support services for child with disabilities	9	47
a. Links to professionals	Exchange referrals for legal, medical, or respite service providers	3	16

Table 9: *Continued*

Coding category and sub-category	Description	<i>n</i>	%
3. Medical information	Dissemination of specific medical information related to child's disability or treatments	6	32
Formal Psychoeducation	Inclusion of professional guest speakers disseminating specific information in the form of a lecture or training	13	68
Advocacy	Meetings are an opportunity to discuss systemic issues and understand ways to advocate for change	4	21

*Note:* Coding category frequencies are at the case (interview) level.

***Sharing emotions.*** The idea that support group meetings create a space for parents to talk about their feelings with one another was referenced in 17 interviews. As one mother said, “I think probably the most beneficial would be to be in a setting in which you have the opportunity to discuss your issues, and your thoughts, and your feelings, and have somebody listen to you.” For most parents, the value of sharing emotions stemmed from the desire to be reassured, understood, and have their emotional experiences normalized. As one mother shared:

It would have helped—it wouldn't have eliminated everything—but it might have helped make it a little bit smoother and it certainly could have diminished the fears.... But I would want to know how other people dealt with it. I would want to know about their successes. And for me, I'd want to know about the things they fought and struggled with, just to know that maybe somebody else had the same guilt and struggles, and once again it was normal because you always—when you deal with things like that—you think you're the only one that's ever felt that way—especially if it's negative—and to know that others have been there—it's a good thing.

Parents in four interviews also discussed that sharing hope and encouragement or being in a support group with “more people that are more uplifting” was another significant aspect of what made participating a positive experience. As one mother said, “We all want someone to spray sunshine on us.”

*Sharing information.* Almost all interviews (17) had references to support groups being “a place where you can go to gather information.” Parents discussed wanting information on strategies from other parents, recommendations for working with social services and other agencies to obtain services, and updates about medical care.

*Peer strategies.* Of the parents who discussed wanting support group meetings to be a place to share information about half (10 interviews) wanted to have an opportunity for themselves and other parents to share strategies that they had learned based on what they had experienced. One mother shared:

Just being there with each other and talking about the problems... each of us were having and to be able to help one another to see what ways we could help them from our experiences, then they could learn...how they can deal with them because the more people you have together the more ideas that you can get.

Parents also discussed sharing strategies on topics such as “specific interventions,” ideas for “structured activities,” “how to help their [child’s] behavior,” and “places that you can go” (places that the family can go together with their child who has disabilities).

*Obtaining services.* In nine interviews, parents discussed a desire to learn how to work with the public system and agencies to obtain support and care services for their child with disabilities. One mother shared that she would like to have received information on the following:

Support services and resources that are available to families—resources as in what is available in the community, areas of expertise, those kinds of things. Get working parents—they have never done that—how they solve the problems. Show how systems work and how to work systems—how you can be an advocate for your child.

Several parents also discussed the desire to gain information about obtaining support from the school system. One father shared that he would like a good support group to provide the following:

Have information about the responsibilities of the school system and how parents have to work with the school system to make sure the services are provided. There are parents who just have to stand up and go into battle to get a school to perform—and some of them are successful after they become very assertive, but parents who have young children with disabilities need to understand what schools are responsible for and how to take on a school.

Finally, three sets of parents suggested that referrals to professionals who work with children with disabilities be shared among parents in support group meetings. One set of parents suggested sharing information for respite care providers, two sets of parents suggested sharing referrals for medical care providers (doctors or dentists), and one parent suggested sharing referrals to legal professionals.

*Medical Information.* In addition to wanting support groups to disseminate information about additional support services, six interviews contained references to sharing medical information in the group. Because many parents had children with uncommon types of disabilities, gathering pertinent medical information was a struggle for many of them. As one father shared, getting information on “developmental milestones...because our children didn’t fit

the mold” and what to expect in his case would have been helpful. A mother also suggested that “It would be great if it was also a place where they could go to obtain information on new products that are available, as far as assistive devices, or maybe new treatments that are available now.” However, one of the references to sharing medical information was from a set of parents who indicated receiving too much medical information was unhelpful and overwhelming. After attending a conference, one mother shared “I’m not there for a medical degree or to get class credits or anything like that... You come away with a bunch of pamphlets and booklets, but nothing you really understand.”

**Formal psychoeducation.** A total of 13 interviews referenced formal psychoeducation or training in support group meetings. In 12 interviews parents expressed some desire to have a specialist or “knowledgeable people who know what they’re doing... experts who studied and know and who’ve dealt with the worst of the worst” come and lecture about specific topics. For example, one parent suggested having a specialist on a specific disability come and share new research, and another parent suggested having a training on Medicaid and advocacy. However, in one interview, parents explicitly preferred “not [to] have somebody up there lecturing,” instead favoring meetings where parents had a space dedicated to talking to each other. Two sets of parents suggested that guest lectures be included either once every few meetings, or that meetings be divided with half being for discussion and half being for a guest speaker.

**Direction for advocacy.** In four interviews, parents discussed the ways in which support group meetings could address issues of advocacy and help make changes to the state system. One mother said of the support group she attended,

I think they did some good lobbying, and I really felt like that made a difference in the services that became available in this state; I think that was the thing that I found—it was like a place where you could go that there was a chance you could do something.

Another mother shared her experience of working for a larger cause, “I don’t think any of us did it just for our own children. It was for others, also. So it was a benevolent thing, too.”

**Group leadership.** Five interviews referred to group leadership (Table 10). In only two of the five interviews was the type of facilitation discernable, with one set of parents (one interview) having attended a parent-led group and another set of parents (one interview) having attended a professionally facilitated group. All five interviews that contained references to group leadership indicated a preference for a strong leader or “just one person that would kind of pull it all together.” However, in one interview, a mother expressed concern regarding group leadership:

The people running the meeting did not want to hear any opposing points of views. So somehow, I think these support groups need to be run by an unbiased person because otherwise, to me, it gets to be more concentrated on the person that happens to be running it and their point of view of what they think needs to happen.

The same mother though, agreed with her husband when he shared that having a strong committed leader was critical to a successful support group. One set of parents shared that having a professional “to kind of monitor it [the support group meeting] and give you some suggestions” was helpful. Similarly, another mother shared that in the support group she attended, “There was a lack of leadership —a lack of a sense of direction.”

Table 10: *Support Group Meeting Facilitation Preferences (N = 19)*

Coding category and sub-category	Description	<i>n</i>	%
Facilitation	Meetings with a defined leader or professional moderator	5	26
1. Leader or moderator	Preference to attend meetings that have a defined facilitator	3	16
2. Leader qualities	Preferred qualities of a group leader (e.g. unbiased, committed, enthusiastic)	2	11

*Note:* Coding category frequencies are at the case (interview) level.

**Member Recruitment.** In 15 interviews, parents discussed how they had either heard about support groups in their area, or means they recommended for outreach (Table 11). The majority of parents, (8 out of the 15 interviews) suggested that a “central point” such as social services, state agencies, or local and national organizations, help connect parents to support groups. One father explained, “If you got a hold of one agency they ought to suggest, ‘You ought to consider this.’ To get down and get the ball rolling, I’m not sure many people on their own would, unless you’ve talked to someone.” Similarly, in seven interviews, parents suggested that caseworkers or other service providers refer parents to support groups.

In five interviews, parents suggested that schools or teachers who work with children with disabilities let parents know about support groups. As one father suggested, “The schools can also contact the parents and say, ‘There’s a support group that’s available for children with the problems your child’s going through.’” One mother suggested that schools reach out to parents once it is clear that the child has a disability, whereas another mother suggested that waiting until the child is school aged is already too late. She suggested, in addition to the parents in two other interviews, that hospitals and medical professionals share information about support groups. Other experiences and recommendations for outreach included advertising through print

(such as newsletters), electronically (such as a website), word-of-mouth between parents, direct outreach through mail or email, or from placement locations.

Table 11: *Support Group Member Recruitment Preferences (N = 19)*

Coding category and sub-category	Description	<i>n</i>	%
Member recruitment	Recommendations for how parents either found out or would like to have found out about relevant support groups	15	80
1. State program, agencies, or organizations		8	47
2. Caseworker or other non-medical service provider		7	37
3. School system		5	26
4. Outreach from the support group		4	21
5. Publications on the internet, newsletters, or newspapers		4	21
6. Placement facilities		3	16
7. Hospitals or doctors		3	16
8. Direct outreach through mail or email		3	16
9. Word of mouth		2	11

*Note:* Coding categories are at the case (interview) level. *n* of each category includes strategies for recruitment that were used as well as strategies that were recommended but not necessarily used.



## Chapter 5: Discussion

### Summary

Parents of children with severe or profound developmental disabilities wanted support groups to be a place where they could feel understood and a place where they could learn how to better support their child with developmental disabilities. Prevalent themes throughout the interviews that guided many of the recommendations for support group design included both the desire to feel understood and the desire to get information. As is consistent with previous research, parents valued learning from peers, exchanging ideas, and sharing strategies in support groups (Law et al., 2002). Based on a review of the literature, research typically samples parents who have actually attended support groups; parents who have participated in support groups universally find groups to be valuable because it provided a space to get information from other parents, which was associated with easing uncertainties and fostering a sense of empowerment (Solomon et al., 2001). Not all parents in this study, however, found support groups to be valuable; often, parents who did not find support groups to be valuable had never attended a meeting. Though negative experiences of support groups are less frequently cited in the literature, they are clinically significant to understand (Galinsky & Schopler, 1994). One of the contributions of the present study is that participants included both parents who had attended support groups as well as parents who had not, which may account for the varied assessments of value of support groups among parents. Many (64%) of the parents who did not attend support groups did not believe they were valuable, whereas a majority (84%) of parents who had attended support groups, believed there was at least some level of value inherent in support groups.

Whether support groups were perceived as a valuable resource was ultimately based on the degree to which support groups addressed the parent's needs. Using the Double ABCX model (see Figure 1), support groups can be conceptualized as a coping resource and they are perceived as valuable when they effectively moderate the effects of a stressor or ease adaptation (Pickard & Ingersoll, 2017). As is consistent with previous research on coping resources, parents who reported that support groups were valuable indicated that group participation helped to address the stressors of having a child with severe developmental disabilities (bonadaptation), whereas parents who reported support groups were not valuable indicated that support groups made them feel indifferent, or even worse, about their situation (maladaptation; Jones & Passey, 2004). Although the specific stressors may have been different for each parent, value assessment was linked to the degree to which support groups addressed those stressors at a given time.

Overall, several parallel opposites emerged as parents discussed why they valued (or did not value) support groups and what they recommended in terms of support group design. Within those opposites, two different patterns emerged. In the first pattern (which appeared more commonly in parents' assessments of support group value), parents wanted similar things but expressed their preferences in opposite ways. In the second pattern (which appeared more commonly in the recommendations for support group design) parents had opposite preferences.

The first pattern of parents wanting the same things out of support groups but discussing those things in opposite ways, frequently occurred in the context of what makes a support group valuable. For example, feeling understood and feeling a sense of belonging was the most commonly cited reason that parents found support groups be helpful. Conversely, poor fit due to not feeling understood was the most commonly cited reason why support groups were not seen as helpful or valuable. Furthermore, not feeling understood often left parents with the sentiment

that the information they received in support groups was not applicable or that they could not learn from other parents in the way that they would have liked. Support group efficacy tends to decrease when parents cannot find a shared identity with other group members, or when support group member needs are not the same (Shilling et al., 2013). Consequently, although parents used opposite language to express their preferences (things they *did not* want versus the things they *did* want), often they were discussing the same overall concept of valuing feeling understood.

Several other examples of the pattern of similar assessments expressed in opposite ways emerged from the data. For instance, regardless of whether parents left support groups feeling better (positive experiences) or worse (negative experiences), the way they felt as a result of support group participation seemed to partially determine how valuable they perceived support groups to be. Additional examples included that support groups were helpful in creating change in the parents' life, or the opposite—that groups were neither helpful nor facilitated positive changes; and that support groups provide extra social support that was needed, or the opposite—that parents did not believe there was a need for additional social support.

The second pattern that emerged from the data was that different parents had opposite preferences all together. One example is that some parents believed that being in a support group with parents facing similar challenges was an opportunity to learn from others and help each other. However, other parents believed that being in a support group with parents dealing with similar challenges would create a situation where they may compare themselves in a way that would make them feel worse rather than better. Moreover, because parents frequently expressed opposite preferences around support group design, the clinical recommendations for support

groups design presented in the next sections were developed to accommodate parent preferences even when there was variation in preferences.

### **Clinical Implications**

Parents indicated that support groups could be made more valuable if they are designed in specific ways. The following recommendations for support group design address the elements of structure, member composition, meeting content, and meeting facilitation. Because parents often wanted different things out of support groups and the very things that some parents wanted were exactly what other parents did not want, the recommendations presented here provide concrete suggestions that meet the wide variety of needs and preferences of parents with children with severe developmental disabilities (Table 12). For ease of identification, specific recommendations are italicized in the following sections.

Table 12: *Support Group Design Recommendations*

Design element	Recommendation
Meeting length	Total meeting length of 60-90 minutes with possibility of splitting meeting in to two, shorter meetings (either for different formats or for subgroup meetings) of 30-45 minutes each.
Frequency	Meetings scheduled twice a month; adjust as needed to maintain group size.
Format and duration	Open ongoing group; one-to-one parent pairs.
Accessibility	Offer alternative meeting times and locations with first meeting of the month scheduled on a different day and time than second meeting to increase flexibility in attendance (e.g., meeting one on the first Monday of the month in the evening; meeting two on the last Saturday of the month in the morning); Option to participate remotely.
Concurrent services	Offer groups for siblings of children with disabilities occurring at the same time as support group meeting; offer additional child care for siblings not participating in group and respite care services for children with disabilities.
Additional resources	Groups should serve as a hub to direct parents to other parents (one-to-one), other services, or other support resources that may be beneficial to them.
Group size	Approximately 10 parents in group meetings; adjust meeting frequency to maintain size.
Children's disability	Children of parents in the support group have similar severity of disability; children have the same disability, or have similar types of impairments (e.g., all have cerebral palsy, or all have severe physical limitations).
Age of child	Include either parents of children of various ages or of similar ages; include session topics or guest speaks as is appropriate to include parents with additional experience.

Table 12: *Continued*

Design element	Recommendation
Placement status	Parents of children who have placed their child should have a separate group or separate subgroup to address their specific needs.
Agenda	Parents have input in meeting agenda and are provided with possible meeting topic options; schedule is created so parents can determine which meetings they want to attend; if meetings are split by subgroup, topic, or format (discussion or psychoeducation) parents may choose to attend one or both shorter meetings.
Discussion	At least half (30-45 minutes) of the total meeting is devoted to parent discussion; parents may decide on discussion topics that address their emotional experiences as well as allows a space to share information and hear about strategies other parents have used to address specific issues.
Psychoeducation	Guest speakers are scheduled based on parent interests; option for half (30-45 minutes) of full session; possible examples include legal professional, medical professionals, financial experts, activists, etc.
Facilitation and leadership	Support group should have a leader that organizes and maintains the structure, composition, and content of group meetings; facilitator should be collaborative and trained though does not need to be a helping professional.
Advertising	Support group should advertise by as many means as possible, including schools, hospitals, state agencies, or direct outreach; advertising should include group schedule, topics of discussion, and other significant information (e.g., information about leadership, target audience, parent characteristics).

**Group structure recommendations.** Parent sensitivities to time away from their child with disabilities and other children is often what guided their recommendations around the ways support group meetings should be structured. The length of meetings was a significant factor for some parents because it was a set amount of time that they knew they would not be able to be

with their children. For many parents, being away from their children was an obstacle and often required that they find additional care resources so that they could attend support groups. In other words, parents found themselves in a position of having to prioritize their coping resources and decide between utilizing support groups but depleting other resources, or saving other resources and not utilizing groups. Similarly, previous research has found that having limited time and resources is a common struggle for parents of children with disabilities, and that parents often prioritize the needs of their child over their own (Kingsnorth, Gall, Beayni, & Rigby, 2011; Nicholas & Keilty, 2007; Shilling et al., 2013). In an effort to minimize the time away and child-care dilemma, some parents suggested that *support groups offer concurrent child-care services both for children with disabilities and siblings of children with disabilities*. Primarily, the concurrent services might include respite care for the child with disabilities and workshops (or even group therapy) for their siblings. In addition, parents expressed that support group meetings should not last too long in consideration of the fact that they would be away from their children. As a result, parents generally recommended that *support group meetings run no more than 60-90 minutes* to decrease the depletion of other care resources they may need to utilize so that they can attend.

Almost all parents spoke about how often support groups should meet, suggesting that meeting frequency was one of the most important aspects of group structure. Parents recommended a variety of different meeting schedules that were widely variable (ranging from weekly to once every six months) and similar to that which is often found in the literature (Gaad, 2006; Hammarberg et al., 2014; McCabe & McCabe, 2013). However, most parents suggested a meeting frequency of once to twice a month. Meeting time and location was cited as a common reason parents had difficulty attending meetings, which is also consistent with previous findings

(Wynter, Hammarberg, Sartore, Cann, & Fisher, 2015). Furthermore, irregular attendance is a common problem in support groups and is one of the most common reasons that they disband (Galinsky & Schopler, 1994; Wituk, Shepherd, Warren, & Meissen, 2002). Therefore, it is recommended that *support groups have scheduled meetings twice a month, at different days, times, and locations*. Ideally, of the two bi-monthly meetings, each would be scheduled on different days of the week, at different times, and at different locations so that if for example a parent cannot attend the first meeting of the month due to logistical barriers, they may still be able to attend the other. It is also recommended that *support groups be open, allowing members the flexibility to attend as needed and when convenient*. Structuring groups as open allows parents who only want to attend once a month, once a quarter, or even less frequently the flexibility to do so.

Additional structure options may also be utilized to provide parents the most flexibility in attendance and participation. For example, parents who would like to participate in support groups, but are unable to physically attend may participate remotely via phone or video conference. Furthermore, an alternative support group structure option that could be used to accommodate parent schedules is one-to-one peer support. In the one-to-one structure, parents can meet either over the phone or in person whenever is most convenient based on their personal schedules. As has been cited in previous literature, meeting one-on-one allows for individual support and more time flexibility, which is a significantly limited resource for parents of children with developmental disabilities (Bull, 2003; Hartman et al., 1992).

**Group membership composition recommendations.** With an open support group meeting up to two times a month, group size will inevitably vary. About half of parents spoke about group size, suggesting that it is a moderately important factor in support group design. The



majority of parents who spoke about group size were either comfortable with or preferred that meetings be attended by fewer than 10 parents to facilitate intimacy and connection. Similarly, previous research has found that to increase group cohesion and the and encourage beneficial interaction, the ideal group size is 5-10 members (Yalom & Leszcz, 2005). With that in mind, the target group size is *approximately 10 parents per meeting*. By nature of groups being open, attendance will inevitably vary meeting to meeting as not all not all parents will attend all meetings (Wituk et al., 2002). If groups routinely have more than approximately 10 attendees, it is recommended that group leaders consider increasing the meeting frequency to maintain the recommended group size at each meeting.

About two-thirds of parents discussed the importance of “sameness” among group members, indicating that it was one of the more important aspects of support group composition. Because the degree of sameness was often linked to the desire to feel understood (which was expressed by almost all parents), it is recommended *that support group membership be relatively homogenous in relation to the type and severity of the children’s disabilities*. For example, parents of children with severe behavioral issues should be in a different group than parents of children with severe motor impairments because the types of challenges that they may be dealing with will likely be quite different. As is consistent with previous literature, most parents preferred that meetings be composed of parents who are the most similar (with children having similar disabilities and similar severity of disabilities) to foster a sense of belonging and encourage social support from others in comparable situations (Fine & Johnson, 1983; McCabe & McCabe, 2013; Wynter et al., 2015). In addition, the more similarities parents share, the more applicable their advice and the information they share will be (Robert et al., 2015). Although some parents recognized that experiences could be similar even in groups of parents whose

children had varied severity and types of disabilities, none of the parents expressed that they preferred to be with parents they could not directly relate to. Therefore, by designing groups with parent similarity in mind, parents are likely to find support groups to be beneficial.

Although parents valued being in a group with parents who were facing similar issues, some also expressed a desire to be with parents who had more experience so that the more experienced parents could serve as a resource. However, though parents wanted to be in groups with more experienced parents, no one wanted to be the parent with that distinction. In many cases, the idea of experience was attached to the developmental stage, or age of the child with disabilities and how much parents had been through already. As has been previously reported, it is a common problem in open groups that members may be dealing with different struggles because they are at different stages and have varied experiences (Galinsky & Schopler, 1994). Because, for example, parents were evenly split on whether they wanted to be with parents of children at the same or different ages, the recommendation is that support group leaders note the variations in parent experience and compensate for parent needs accordingly rather than restricting group membership. For example, in a group with parents whose children are at different stages of development, group leaders may consider having more experienced parents serve as mentors and volunteer to co-facilitate support group meetings. Similarly, in groups where parents are of similar ages, guest speakers may come and specifically address what parents can expect in the future.

It is also recommended that *parents who have placed a child, or who are considering placing a child in out-of-home care, have a distinct support group or subgroup*. As several parents reported, the needs of parents who are still caring for their child at home will be vastly different than those who are utilizing out-of-home care (Jackson & Roper, 2014; Roper &

Jackson, 2007). Therefore, as several parents shared, they may be better served in a group that specifically addresses the changes that are associated with placing a child. However, the topic of placement was still something that parents wanted incorporated in support group meetings for parents who had their children in the home. For example, some parents shared that it may be helpful to discuss the topic of placement in support group meetings, or have parents who have placed their child in out-of-home care come as a guest speakers.

Depending on the community or location of a support group (e.g., rural versus metropolitan) it may not always be feasible to have groups of the recommended size of 10 members with very specific shared characteristics (e.g., placement status, level of experience, severity and type of disability). In cases where support groups may need to be composed of parents with more varied circumstances, it is recommended that subgroups be created. The subgroups may be smaller and either meet for a portion of one or both of the twice-monthly 90-minute meetings, or schedule additional times to meet. If there is not enough membership to support subgroups, parents may be provided the option to use one-to-one peer support and reach out directly to one or two sets of parents with whom they share characteristics.

**Meeting content recommendations.** The content of support group meetings was one of the most significant aspects of support group design, and was commonly addressed in tandem with what made support groups valuable. Most parents wanted support groups to provide a space where they could share both information as well as emotions with one another. In addition, some parents preferred a more structured dissemination of information (e.g., guest speakers or lecturers), whereas other parents were opposed to more structured dissemination of information. Therefore, with a bi-weekly, 90-minute session structure in mind, it is recommended that each *support group meeting be divided into two parts, with one part for formal psychoeducation and*

*the other part for discussion.* By dividing the meeting, parents then have the option to attend only half or the full meeting based on their needs. As has previously been reported, sometimes open or unregulated discussion can be threatening in groups (Shilling et al., 2013); therefore allowing parents the option to choose to participate in the discussion portion can mitigate that threat. Similarly, some parents explicitly did not want to share emotions and some parents explicitly did not want to be given advice. One possibility would be that the discussion portion of the first meeting of the month be focused on emotional experiences and the discussion portion of the second meeting of the month be focused on sharing peer advice. It is also an option that the formal psychoeducation portion be the same at both meetings so parents who are unable to attend one scheduled meeting can still receive the same information that month.

Current findings suggest that providing parents with a sense of what meeting content will entail prior to attending increases the likelihood that they will be able to utilize support groups as a resource. As is consistent with previous research, the content of support meetings was a significant factor for parents because they often had varied needs and wanted the content of meetings to be suited to those needs (Bull, 2003; Nicholas & Keilty, 2007; Robert et al., 2015). One way to address the concern of meeting applicability is to *have parents select the topics that would be most helpful to them, in advance of the meeting.* Support groups could potentially offer a series of possible discussion and psychoeducation topics that support group members (or potential support group members) could select (Table 13). In concert with previous research, parents expressed a desire to talk about emotions, share practical advice and information (medical and otherwise), understand the education system, and discuss advocacy opportunities (Diehl et al., 1991; Wynter et al., 2015). However, as is also consistent with the literature, some parents were particularly hesitant about certain topics that may be addressed in group meetings

(Nicholas & Keilty, 2007). After parents have provided input on preferred meeting topics, group leaders should *create and distribute a schedule of what topics are offered on what days so that parents can choose* to attend meetings with topics that are the most germane to them (King et al., 2000; Stallard & Dickinson, 1994).

Table 13: *Support Group Meeting Agenda Options: Sample*

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Discussion topic (30-45 minutes)
<ul style="list-style-type: none"> <li>• Open discussion: no predetermined topic for the meeting; parents can discuss different topics at will.</li> <li>• Addressing anxiety: share experiences with anxiety and coping strategies.</li> <li>• Managing guilt: share experiences with guilt and coping strategies.</li> <li>• Success stories: share stories of hope and encouragement; positive experiences.</li> <li>• Frustration at home: discuss struggles or challenges that appear in the home environment.</li> <li>• Addressing partner relationships: discuss challenges and successes in your relationship with your partner.</li> <li>• Networking with other parents: discuss relevant opportunities or activities with other parents.</li> <li>• Time management: share experiences and strategies for balancing multiple responsibilities.</li> <li>• Navigating the state social service system: share experiences and strategies for obtaining public services.</li> <li>• Navigating the school system: share experiences and strategies for obtaining education services.</li> <li>• Finding professionals: discuss experiences working with various service providers (e.g., therapists, doctors, lawyers) and share referrals.</li> <li>• Addressing the community: share experiences and strategies for dealing with neighbors or other community members (e.g., friends, clergy, teachers)</li> <li>• Thinking about out-of-home placement: Discuss the emotional and logistical aspects of placement.</li> </ul>
Guest Speaker / Training (30-45 minutes)
<ul style="list-style-type: none"> <li>• Advocacy and lobbying: hear from local government representatives or rights activists for persons with disabilities.</li> </ul>

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Table 13: *Continued*

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- Guardianship and other legal issues: hear from lawyers and legal experts on pertinent legal issues.
  - Medical treatment: hear from doctors and medical professionals on new or existing treatments for specific symptoms or specific disabilities.
  - Developmental expectations: hear from medical professionals (e.g., doctors, occupational therapists) on what to expect regarding your child’s growth and development.
  - Financial management: hear from financial experts (e.g., accountants, financial planners) on ways to manage finances currently and in the future.
  - Navigating the state social service system: hear from experienced parents and local representatives for ways to access public services.
  - Navigating the school system: hear from experienced parents, teacher and school administrators about what to expect from the school system.
  - Out-of-home placement information: hear from parents who have placed, professional parents, and from representatives from local placement locations (e.g., group homes, residential care centers).
  - Stories from experienced parents: hear personal stories from experienced parents of older or adult children with severe developmental disabilities.
- 

*Note:* Example agenda topics are grounded in the data that were analyzed and were generated based on parent experiences and suggestions.

One of the additional functions of *support groups should be to serve as a “hub” of resources* for parents of children with disabilities. Parents often described that services were decentralized and that it was difficult to connect to other parents in similar circumstances, to find the right kind of support, or to adequately navigate the system. The ideal support group would be designed to address as many of the needs of the parent members as possible, and either serve as a resource itself, or direct parents to other resources that may be more beneficial for them. As has

been previously reported, parents need an array of different and flexible resources, and it is important that a support group be designed to provide that (Nicholas & Keilty, 2007).

**Meeting leadership and facilitation.** Only a few parents discussed the aspect of meeting leadership, suggesting it was a less significant factor in group design. Although most of the parents that spoke about group leadership did not specify if they would have preferred a parent or a professional to lead the group, they generally felt it was important to have someone with specific qualities (e.g., unbiased, committed, enthusiastic) in that role. Additionally, previous research has found that parents value facilitation more so than they value if the facilitator is a professional or a peer (Kingsnorth et al., 2011). Therefore, *support groups should have a specified leader (or co-leaders) who have had some type of training in group facilitation.* A charismatic leader increases the likelihood that groups will be successful (Bailey & Grochau, 1993; Mohr, 2004). The leader does not necessarily need to be a therapist or professional, but ideally would have some type of training to empathize and facilitate meaningful conversations (Cunningham & Davis, 1985; Hornby, 2014). As mentioned previously, parents discussed wanting to have more experienced parents in the group, but often, the more experienced parents no longer attended the group. One suggestion is that the group leader (or at least one group leader if there are co-leaders) be a more experienced parent who is already navigated the difficulties of their child's various developmental stages.

In addition, a group leader needs to also serve as an organizer to manage meeting content (compile and execute parent agenda topics), membership (groups and subgroups), and maintain group structure as specified in the present study. Previous research has suggested that it is important for multiple group members to have ownership in group leadership to both maintain their involvement and to prevent leader burnout (Wituk et al., 2002). However, though parents in

the present study expressed some desire to have a say in the meeting content, they did not express that their involvement or lack of involvement was related to their perceived ownership of the group.

**Member outreach.** Like what has been previously reported, parents suggested a variety of ways to reach out to potential group members, such as through social services, the state, the school, or through direct advertising (Mohr, 2004; Wituk et al., 2002). It is recommended that *outreach to parents, whatever the means, directly address some of the concerns expressed by parents who did not feel support groups would be valuable.* Most parents who believed support groups would be valuable had attended a support group whereas most parents who did not see value in support groups did not attend a support group. One suggestion for addressing parent concerns in the outreach process is to include a description of support group design and details about session content as a part of advertising.

### **Limitations**

One of the primary limitations of the present study is that the demographics of the sample participants were relatively homogeneous: most participants were Caucasian, married, and identified as Mormon. In addition, the participants were localized geographically in Utah. Being that many of the services provided for parents of children with severe disabilities are administered by the state, results may have varied if participants from other states had been included. It is possible that parents in other states may receive different types of resources; therefore, their needs and what they would like from support groups could be vary from the results of the present study.

A further limitation regarding the data collection is that some of the interviews were conducted with couples and some were conducted with individuals. Although the data were



analyzed at the case level, I did not analyze the interdependence of experience between parents in the dyadic interview because that would not have been possible for the non-dyadic interviews. Had the interviews been conducted with the intention of being analyzed as dyads, the category occurrences in different results areas may have been different.

The data were retrospective interviews requiring parents to reflect on experiences that occurred years in the past. Participants were asked when they had placed their child in out-of-home care (which ranged from 2-42 years prior to the interview) and not asked when they had participated in support groups. Although the amount of time that had elapsed between support group participation and data collection could generally be inferred based on the context of the interview, the lack of specific data for when parents attended support groups prohibited analysis to determine possible impacts on the results. Furthermore, participants consisted of parents who had placed their child with disabilities in out-of-home care; conducting a similar study with parents who had not placed their children may yield different results, particularly in relation to the resources parents reported that they needed the most (Werner, Edwards, & Baum, 2009).

Although one of the strengths of the present study is that the sample included parents who had both attended and not attended support groups, it is possible that the recommendations provided by parents who had not attended were more subjective because they were not grounded in a specific experience. In retrospect, it would have also been important to include specific interview questions about meeting facilitation in the support groups that parents had attended because in most cases this was not discernable. Knowing what type of facilitation was utilized by participants may have affected how the preferences around group leadership were interpreted but those data were not collected in the original interviews and was a limitation of utilizing secondary data.

**Directions for Future Research**

Similar studies with more heterogenous participants in different geographical locations should be conducted to confirm or disconfirm the results of this study (Creswell, 2013; Jackson & Roper, 2014). Subsequent studies should replicate this study with parents who have not placed their child in out of home care, and are caring for their child at home to gather data on their current experiences with support groups. Data collection instruments should also include more targeted assessments regarding preferences and experiences with group leadership, as well as when support group participation occurred. In addition, future research may incorporate the concept of online support groups or the use of online forums, which have become more prevalent since the time the data in the present study were collected (Clifford & Minnes, 2013a; White & Dorman, 2001). Finally, subsequent research should assess and evaluate support groups designed using the recommendations in the present study.

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## Appendices

## Appendix A: Confidentiality Agreement

**Confidentially Agreement**

The following paragraph contains the policies to which the participants in this study agreed. Please read it carefully as you will be required to help us protect the confidentiality and rights of the study participants.

All information disclosed by you either during the interview or in the surveys will be kept strictly confidential, as will be your name. The manner in which the results of this study will be reported will assure confidentiality by preventing individual identification and assuring anonymity. Any disclosed or suspected child abuse, disabled adult abuse, or elder abuse will be reported to the appropriate authorities in accordance with federal and state laws. Any disclosure of illegal acts or any suspected illegal acts will also be reported to authorities in accordance with federal and state laws.

I, (print name) Sarah Steward, understand that through the experience I will have in working on this research study, that I must maintain strict confidentiality as to any identifying information of the study participants; any information as to the participants and/or their families must remain within strictest confidence in order to protect the privacy, rights, sensitivities, and feelings of the participants involved in this study.

My signature below signifies that I will abide by this confidentiality agreement.

MUA  
Signature

11/16/16  
Date

(Your copy)

## Appendix B: Interview Questions

Available SupportsSupport Groups

1. How helpful or valuable do you think a support group would be for you?
2. Have you ever thought about attending a support group for parents in your situation?
3. Were you able to attend some form of support group before, during, or after you made your decision about placing your child?
  - 3a. What was it like?
  - 3b. What things did you like about it?
  - 3c. What things would you like to see improved?
4. What would the ideal support group be like?
  - 4a. How would they function/work?
  - 4b. What issues would you want to see discussed?
  - 4c. How often would you want the group to meet?
  - 4d. How long do you think you would continue attending?
  - 4e. What would be the best way of letting other parents know about the group?