

Parental Differential Treatment and Sibling Relationship Quality in Families with a Child with a  
Developmental Disability

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## ABSTRACT

### Parental Differential Treatment and Sibling Relationship Quality in Families with a Child with a Developmental Disability

Marie-Michèle Truchon

While raising a typically developing child can involve several challenges for parents, this process may be even more complex for families in which there is a child with a developmental disability (DD). This qualitative study utilized a family systems framework to explore the experiences of nine families with regards to examining the effect of parental differential treatment on the quality of sibling relationships when one sibling has a DD, and the other sibling does not. Questionnaires and in-depth, semi-structured interviews (45-60 minutes) that consisted of open-ended questions were used. These methods were designed using a variety of question types to gain insight about parental differential treatment and sibling relationship regarding their interactions and the type of social play in which they engaged. The data were analyzed using In Vivo and Axial coding to ensure that concepts emerging from the interview data set captured the key elements of what the interviewee described. Overall, both parents and the typically developing child report that having a sibling with a DD is related to both positive and negative features of the sibling relationship. Furthermore, this study demonstrated that when present, PDT may be linked with less loving and fulfilling sibling relationships from the perspective of all participants. The findings support the importance of implementing, introducing, and teaching methods to parents so that they can take an active role in fostering a positive relationship between their children.

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## Differential Treatment and Sibling Relationship Quality in Families with a Child with a Developmental Disability

### **Statement of the Problem**

Past research demonstrates that children brought up in the same nuclear family are distinct from one another in terms of personality traits and diagnoses of psychopathology (Dunn & Plomin, 1990; Plomin & Daniels, 1987; Scholte, Engels, Kemp, Harakeh, & Overbeek, 2007). In fact, theorists argue that relatives who are raised in the same household may be as different from one another as those children who are brought up in dissimilar families (Plomin & Daniels, 1987; Scholte et al., 2007; Turkheimer & Waldron, 2000; Volling, 1997). One significant family element that may contribute to this variation is parental differential treatment (PDT) (Scholte et al., 2007). PDT is defined as the within-family differences in parenting experienced by siblings, which, in turn, is associated with the quality of sibling relationships (Richmond, Stocker, & Rienks, 2005; Rivers & Stoneman, 2008; Scholte et al., 2007).

Children are often concerned about whether parents treat their sibling(s) more favourably than they are treated (Volling, 2003). Starting at a young age, children start to monitor their parents' behaviours towards themselves and their sibling(s) to potentially detect any differential treatment (e.g., attributing more attention to one child than the other) (Volling, 2003). Indeed, recent evidence suggests that PDT is associated with greater sibling conflict, poor sibling relationships, and less warmth between relatives when one child perceives his/her own treatment as less favourable compared to the sibling (Meunier, Roskam, Stievenart, Van De Moortele, Browne, & Wade, 2012; Plomin & Daniels, 1987; Richmond et al., 2005). For instance, Hetherington (1988) found that when mothers and fathers provided one sibling with less warmth and affection and more coercion, discipline, irritability, and a hostile environment than the other

child, brothers and sisters were more likely to act in a more forceful and perturb manner toward their sibling (Kothari, 2010; Volling, 2003). On the other hand, when children justified the unequal treatment due to age differences and a difference in personal attributes, PDT was not associated with poor sibling relationships (Volling, 2003). In fact, PDT was only related to poor sibling relationships when the children interpreted the differential treatment as unfair (Volling, 2003).

Previous research on PDT has focused primarily on typically developing children and has neglected how PDT applies to families in which there is a child with a DD (Boll, Ferring, & Filipp, 2005). The term developmental disability (DD) includes diagnoses such as Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, which are now replaced by one umbrella term: Autism Spectrum Disorder (ASD) (American Psychiatric Association, 2013). In order to be inclusive of both the previous and the current diagnostic labels, this study will include the previously separate labels of Autistic Disorder, Asperger Disorder, Pervasive Developmental Disorder, along with the newer umbrella label of ASD. This was decided in order to eliminate any possible confusion for families of children diagnosed under the different DSM classifications, and to be respectful of children and their families who identify strongly with a diagnosis made under the DSM-IV or the DSM-V.

Children with a DD require more attention from parents, which adds another layer of complexity that is not found in other families. Studies in which siblings of children with a DD participated failed to include how typically developing siblings perceive fairness, which may account for the associations between differential treatment and poor sibling relationships (Shanahan, McHale, Crouter, & Osgood, 2008; Thompson, Curtner, & O'Rear, 1994; Wolf, Fisman, Ellison, & Freeman, 1998). It is essential to incorporate siblings' self-reports in order to

fully capture all the effects of differential treatment on children and integrate such results into broader applications.

While a large body of literature has investigated PDT, focusing primarily on maternal and combined (i.e., maternal and paternal) parenting, a less substantial amount of research has been conducted regarding siblings' differential experiences with their fathers (Kowal & Kramer, 1997; McHale & Pawletko, 1992; McHale, Sloan, & Simeonsson, 1986; McHale, Updegraff, Jackson-Newsom, Tucker, & Crouter, 2000; Scholte et al., 2007; Thompson et al., 1994). Investigating the father's role could provide a more complete picture of the functioning of family systems (McHale et al., 2000). Furthermore, there has been a lack of interviews with both parents and children in their home setting as a method to identify parental differential treatment, particularly with families with a children with a DD (Thompson et al., 1994). Interviews of the parents and siblings living at home would contribute to a better understanding of PDT in these families. Finally, methodological issues have not gone unnoticed in previous research, and will be explored later in this thesis.

Thus, the aim of the present study is to assess the effect of PDT on the quality of sibling relationships when one sibling has a DD, and the other child does not. Specifically, this study will examine whether, in the presence of perceived PDT, typically developing siblings tend to regard their sibling with a DD as a rival or in more positive terms. Perceived rivalry and positive feelings will be assessed by analyzing the extent of negative sentiments such as anger, jealousy, and resentment and the extent of positive feelings such as warmth and affection that are expressed by the typically developing sibling towards their sibling with a DD. This will then serve to examine how the sibling relationship is impacted.

## **Theoretical Frameworks**

A number of explanations have been proposed and contribute to the understanding of the association between PDT and the outcomes of children's behaviour regarding their sibling relationships (Kowal & Kramer, 1997; Kowal, Kramer, Krull, & Cricks, 2002). These orientations include the family systems framework, ecological systems theory, attribution theory, distributive justice framework, social information processing models, as well as social comparison theory (Kowal et al., 2002; Kowal & Kramer, 1997). Yet, most explanations focus on three distinct notions: ecological systems theory, family systems framework, and distributive justice theory, therefore, these three theories will be discussed systematically before examining the empirical research on the complexity of sibling relationships and PDT in families of children with a DD (Meunier et al., 2012; Volling, 1997).

**The ecological systems theory.** It would be challenging to understand the intimate relationships between a child and his or her siblings without primarily understanding how the different aspects surrounding a family affect the interaction between immediate relatives and the rest of a family (Bronfenbrenner, 1979, 1986). Designed by the psychologist Urie Bronfenbrenner, the ecological systems theory looks at how a child develop within the different components that comprise his or her environment (Bronfenbrenner, 1979, 1986). His theory posits that each child is part of a complex set of layers of environmental and contextual influences, each of which has an impact on an individual's development (Bronfenbrenner, 1979, 1986). The ecological systems theory holds that each layer may influence our behaviour in varying degrees (Bronfenbrenner, 1979, 1986). These systems include the microsystem (e.g., immediate family, school, peers, religious institutions, and neighbourhood), the mesosystem (e.g., relationships between the microsystems), the exosystem (e.g., community norms), the

macrosystem (e.g., government), and the chronosystem (e.g., attitudes and ideologies of the culture during a certain period of time) (Bronfenbrenner, 1979, 1986). In this theory, the subsystems all function together as part of an embedded system that provides a broader picture of the child's development (Bronfenbrenner, 1979, 1986). For the purpose of this study, the microsystem will be explored. Specifically, components of the microsystem, such as the immediate family, will be considered. This layer is essential when analyzing sibling relationships because research studies reveal that the child's immediate family can enhance or diminish the quality of sibling relationships between the child with a DD and the typically developing sibling (Bronfenbrenner, 1979, 1986; Ihinger-Tallman, 1987). For instance, positively experienced components (e.g., comfort and benign understanding of differential parenting) may serve as a buffer for potentially negative sentiments on the part of the typically developing sibling when they perceive preferential treatment towards their sibling with a DD (Bronfenbrenner, 1979, 1986; Feinberg, Neiderhiser, Simmens, Reiss, & Hetherington, 2000). Alternatively, if the typically developing sibling negatively experiences parent-child interactions (e.g., always being the recipient of negative feedback and unrealistic expectations), this may serve to exacerbate negative sentiments towards their sibling with a DD. Although the main focus of this study will be on the microsystem, conditions in the mesosystem, exosystem, and macrosystem will also be taken into consideration due to the fact that they all have an impact on sibling relationships.

**The family systems framework.** Derived from the general systems theory, the family systems framework focuses its attention on the dynamics of family interactions, as well as to the environment in which sibling relationships mature and progress (Whiteman, McHale, & Soli, 2011; Bertalanffy, 1950). Bauminger et al. (2008) explain that in this theory people are viewed as open systems in active exchange with their surrounding environments. Moreover, they claim

that “a system is an entity that maintains its existence and functions as a whole through the interaction of its parts” (Flower, 2005, p. 118). That is, through interacting with one another, relationships serve to develop social-emotional functions and resources that in turn fulfill an individual’s basic social needs.

This theory also highlights the fact that families are hierarchically structured into subsystems (e.g., parent-child relations), which are interactive, interdependent, and reciprocally influence one another (Whiteman et al., 2011). Therefore, it is essential to acknowledge that parental differential treatment not only affects each individuals of a family, but the family as a whole including all of the relationships within the family (Whiteman et al., 2011). Because families are “best understood when studied holistically”, it is important to consider all family members when conducting a study (McHale, Updegraff, & Whiteman, 2012, p. 340). Each individual possess unique characteristics, and studying families as a whole enables one to capture a larger range of perceptions and experiences (Whiteman et al., 2011). Lastly, the notion of interactive and reciprocally influential parent-child relations is important for the purpose of this research. This concept of fluctuation and change indicates that there is potential for amelioration of and enhanced parent-child relations, which, in turn, may help to ameliorate sibling relations through the mitigation of possible negative PDT effects (Whiteman et al., 2011).

**The distributive justice theory.** The distributive justice theory proposes a viewpoint on social justice highlighting the fair allocations of resources (Deutsch, 1985). This framework suggests that individuals frequently develop judgments about whether resources are equally allocated between themselves, their colleagues, and/or other individuals (Deutsch, 1985). Accordingly, individuals may demonstrate negative and undesirable behavioral actions when sensing that there is a lack of coherence between the treatments they receive and what they think

they deserve (Meunier et al., 2012). This theory highlights how important it is to consider children's perceptions of PDT, as well as whether they perceive differential treatment as fair or justified by the sibling's specific needs and interests (Deutsch, 1985; Meunier et al., 2012). In fact, the extent to which toddlers and young adults sense that parental differential treatment is necessitated is associated with positive consequences, even when the extent of differential treatment is perceived as high (Deutsch, 1985; Meunier et al., 2012).

### **Review of the Literature**

**The sibling subsystem.** Children grow up within the context of family and family subsystems, which includes parents, grandparents, friends, and siblings (Criss & Shaw, 2005; Dunn, 1983; Parke & Buriel, 1998). The family systems framework emphasizes how important siblings are "in the regulation of behaviour and affect, not only as children develop but in fact, throughout the life span" (Cox, 2010, p. 95). Approximately 80% of Western families have more than one child (Howe, Ross, & Recchia, 2011). Yet, the literature on family relationships demonstrates how relatives are recurrently overlooked when family dynamics are explored (McHale et al., 2012). As a result, investigators have been encouraged to include siblings and examine sibling relations in their research to understand family dynamics better (Kothari, 2010).

It is crucial for this gap in the research literature to be bridged, due to the importance of sibling relationships (Howe et al., 2011). In fact, some of the longest lasting relationships are those formed with siblings (Howe et al., 2011). Siblings play a powerful role and exert an enormous amount of influence on one another, which may have a substantial impact on each other's development and adjustment (Dunn, 2002; Sage & Jegatheesan, 2010; Volling, 2003). For instance, siblings can serve as friends, advocates, allies, playmates, as well as encourage social understanding, moral reasoning, and conflict-resolution skills (Brody, Stoneman, &



McCoy, 1994; Volling, 2003). Although sibling relationships may grow, develop and change over time, McHale and Crouter (1996) report that children devote a greater quantity of time to their siblings than they ever will with friends, parents, or by themselves (Larson & Richards, 1994). A considerable amount of research supports the importance of sibling relationships; however, less work has incorporated the impact on sibling relationships when one of the siblings has a DD.

**The sibling subsystem of children with a developmental disability.** Although providing for any child in general is no easy task, providing for a child with a DD is highly demanding, not only for parents, but for siblings as well. It is often described as a unique shared experience for families that can possibly impact different aspects of family functioning (Bronfenbrenner, 1979, 1986). A large volume of published studies divulges both positive and negative consequences of cohabiting with an individual with a DD (Green, 2013). Research demonstrates that living with a child with a DD can have a powerful influence on parents, siblings and the extended family (Rivers & Stoneman, 2008; Schopler & Mesibov, 1984). In fact, children with a DD can drain enormous amounts of energy and place great demands on parents' time and resources. For instance, DeMyer (1979) found that families are intensely affected by the challenges presented to them when trying to satisfy the needs of a child with a DD. Moreover, she demonstrated that those challenges may affect the parents, their marriage, the parent-child relationship, and the other individuals (e.g., children) in the family (DeMyer, 1979). As a result, each family coping with a child who is affected by a DD has a set of different challenges.

As previously mentioned, sibling relationships are extremely important and unique. The benefits or development of that relationship may be altered when a sibling has a DD, (Crnic & Leconte, 1986). Most individuals with a DD have cognitive limitations and social and

behavioural characteristics (e.g., impairments in social reciprocity and rigid behaviours) that might challenge the sibling relationship (Orsmond & Seltzer, 2007). In fact, having a sibling with a DD can have repercussions for the feelings and actions of the typically developing sibling. For instance, DeMyer (1979) found that approximately one-third of the siblings expressed feelings of neglect because so much time was dedicated to the child with a DD. Beginning with potential resentment over their seemingly neglected needs as the parents focus most of their energy and attention on the child with a DD, typically developing siblings may be fearful, worried, anxious, and angry at the situation, which may in turn, affect the quality of the sibling relationship (e.g., increased sibling conflict and antagonism) (Kowal & Kramer 1997; Schopler & Mesibov, 1984).

Although previous research demonstrated that siblings of children with a DD may be more at risk of developing emotional and developmental problems, recent studies report that the effects may not be as detrimental as originally indicated (McHale et al., 1986). There are some studies describing how children with siblings with a DD do not necessarily differ from children with typically developing siblings (McHale et al., 1986). There has also been an increasing amount of literature on how a child's disability can positively affect sibling relationships. For instance, in a study by McHale, Sloan, and Simeonsson (1986), results show that having a sibling with a DD does not essentially result in difficult and challenging sibling relationships. Furthermore, Pit-Ten Cate and Loots (2000) demonstrated how siblings of individuals with a physical disability generally do not experience significant problems. Finally, Grossman (1972) reported that 45% of the participants in his study believed that there are benefits to having a brother or sister with a DD. He also showed that siblings of children with a DD demonstrated a greater understanding of people within their community (Grossman, 1972). Although both

positive and negative feelings arise between siblings, assessing the different aspects that may impact the sibling relationships of children with a DD will contribute essential information about how children function within the sibling subsystem, the parent-child subsystem, in addition to the family system (Grossman, 1972; McHale et al., 2012).

While all siblings experience parenting, Plomin and Daniels (1985) found that siblings may experience and/or understand their experiences differently. Research demonstrates that children raised in the same family differ considerably from one another (Dunn & Plomin, 1991; Plomin & Daniels, 1985). In fact, comparisons of adoptive and biological siblings propose that sibling's experience of differential treatment is primarily environmental (Plomin & Daniels, 1987). Studies examined the different components of the nonshared family environmental influences and the ways in which those factors impact siblings differently (Plomin & Daniels, 1985). PDT is a factor that received attention, which may account for some of the differences in sibling relationship.

**Parental differential treatment.** The belief that parents should attempt to remain equal when educating their children is widely held in Western cultures (Jensen, Whiteman, Fingerman, & Birditt, 2013; Kowal & Kramer, 1997; Kowal et al., 2002). Yet, it has been shown that “providing equal treatment is nearly impossible” given that children's needs and developmental stages may be so different (Jensen et al., 2013, p. 438). Although parents are encouraged to provide equal treatment, siblings are often treated differently. PDT may be appropriate or even desired in some instances. Children living within the same nuclear family are often of different ages, of opposite gender, and possess different needs and interests, all of which require different types of parental attention (Kowal & Kramer, 1997). For instance, studies demonstrate that most parents treat their children differently to accommodate each of their needs given their different

ages and developmental levels (Dunn & Plomin 1990; McGuire 2002; Plomin & Daniels, 1985). As a result, educating children differently also suggests sensitive child-rearing practices, which aims to accommodate each child's individual needs and/or characteristics.

Nevertheless, pronounced levels of PDT may also become problematic over time (Conger & Conger, 1994; McHale et al., 2000; McHale, Crouter, McGuire & Updegraff, 1995). Research demonstrates that parental partiality for one child in the family may have detrimental effects on children (Dunn, Stocker & Plomin, 1990; Kowal & Kramer, 1997; McHale et al., 1995; McHale et al., 2000). In fact, PDT may have consequences on children's self-esteem, behavioral and emotional adjustment, as well as the quality of the sibling relationships (Shebloski, Conger, & Widaman, 2005; Wolf et al., 1998).

A quantity of studies has shown clear links between the presence of PDT and children's sibling relationships (Boll et al., 2005; Brody, Stoneman, & McCoy, 1992; Bryant & Crokenberg, 1980; Kowal & Kramer, 1997). Jensen et al. (2013) obtained results supporting this idea when they examined 151 families with at least two participating typically developing college-aged siblings ( $M = 23.90$  years). Their results indicated that larger differences in parental treatment were linked with less sibling intimacy (Jensen et al., 2013). Furthermore, when conducting a longitudinal study, McHale, Updegraff, Jackson-Newson, Tucker, and Crouter (2000) discovered that school-age siblings ( $M = 8$  years) who received relatively less warmth from their parents reported less positive sibling relations. Lastly, Meunier et al. (2012) examined how PDT and children's perceptions of parental favouritism impact their externalizing behaviour and quality of their sibling relationship. They collected data from 167 children between the ages of four and six who had been referred to a clinic because of their externalizing behaviour (Meunier et al., 2012). Their study revealed that the quality of the sibling relationships suffered

when children were observed externalizing behaviours (Meunier et al., 2012). Furthermore, similar results were obtained when parental differential treatment was reported (Meunier et al., 2012). These findings highlight the interdependence between differential treatment and the quality of sibling relationships (Kowal & Kramer, 1997; Shanahan et al., 2008).

***Perceived fairness of parental differential treatment.*** As previously mentioned, the degree to which PDT occurs in families, and whether PDT is justified or not, may have an impact on the quality of the sibling relationship (Kowal & Kramer, 1997). Another important factor that may have a consequence on the quality of the sibling relationship is the extent to which children perceive parental differential treatment to be fair or unfair (Feinberg, Solmeyer, & McHale, 2012; Kowal & Kramer, 1997; Kowal et al., 2002; Kowal, Krull, & Kramer, 2004; McHale et al., 2000; Quittner & Oipari, 1994). Opinions regarding fairness may temperate the associations between the extent of PDT occurrence and the quality relationships in general (Kowal & Kramer, 1997; Kowal et al., 2004).

Siblings' perceptions of whether PDT is perceived as fair or unfair may influence the quality of the sibling relationship (Kowal & Kramer, 1997; Kowal et al., 2002; Kowal et al., 2004; McHale et al., 2000). In fact, research demonstrates that children who perceive PDT, and assess it as fair, usually report having a warm and close relationship with their sibling (Kowal & Kramer, 1997; Kowal et al., 2004). For instance, in a study conducted with pairs of sibling in middle childhood and adolescence, PDT was associated with a positive sibling relationship when PDT was perceived as fair (McHale et al., 2000). Alternatively, children who perceive PDT as unfair may feel resentful, hostile and convey anger towards their sibling (Kowal & Kramer, 1997; Kowal et al., 2004). For instance, McHale, Crouter, McGuire, and Updegraff (1995) studied perceptions of fairness of PDT among sibling pairs in middle childhood. They found that

children who received less warmth and/or more control from their parents compared to their brothers and/or sisters reported poorer sibling relationships (Jensen et al., 2013; McHale et al., 1995; McHale et al., 2000).

***Parental differential treatment in families of children with a developmental disability.***

In the past, only a few studies have focused on the occurrence and impact of PDT within families with a child with a DD (Quittner & Oipari, 1994). In fact, most research on PDT was performed utilizing families with typically developing children (Feinberg et al., 2012). However, providing for a child with a DD is often highly demanding, and may surpass the demands of caring for a typically developing child. This can cause notable strain on both parents and siblings. Parents often spend a great deal of time caring for a child with a DD. As a result, “balancing the different and sometimes competing needs and interests of siblings is a significant childrearing challenge for parents” (McHale, Updegraff, Shanahan, Crouter, & Killoren, 2005, p. 1259). Wolf, Fisman, Ellison, and Freeman (1998) demonstrated that siblings of children with a DD typically receive less parental attention, participate less frequently in outside activities, have less parental companionship, and more chores and responsibilities in the home setting. Indeed, researchers report that PDT is more prevalent in families of children with a DD (McHale & Pawletko, 1992).

For example, a study by Quittner and Oipari (1994) examined PDT between two siblings in early childhood, where one sibling was typically developing and the other had cystic fibrosis. These children were compared to families with typically developing children. The results showed that mothers with a child with cystic fibrosis spent a greater amount of time caring for the child with special needs than they did with their typically developing child (Quittner & Oipari, 1994). In addition, these mothers rated their relationship with their typically developing child more negatively than did mothers with typically developing children (Quittner

& Oipari, 1994). However, Quittner and Oipari (1994) did not examine whether PDT affected the sibling relationship quality. Nonetheless, they speculated that higher levels of PDT found in families with a child with special needs may in some cases have detrimental consequences on the typically developing sibling.

Similarly, McHale and Pawletko (1992) performed a study in which 62 siblings and their mother were interviewed. Half of the participants had a younger sibling with a disability and the other half had a younger typically developing sibling (McHale & Pawletko, 1992). The siblings were, on average, four years apart. The authors examined reports of differential maternal involvement, discipline and chores in both types of family composition (McHale & Pawletko, 1992). Their results demonstrated that, on average, mothers reported greater levels of PDT when educating a child with a DD (McHale & Pawletko, 1992). Although PDT was more likely to occur in families with a child with a DD, PDT was associated with very few negative effects on sibling relationship quality (McHale & Pawletko, 1992). In fact, an increase in differential maternal discipline and affection was related to more positive sibling behaviors in families with a child with a DD (Kowal & Kramer, 1997; McHale & Pawletko, 1992). Following the findings, McHale and Pawletko (1992) stated, “children with siblings with a DD may view their sibling’s additional needs and limitations as legitimizing PDT” (Kowal & Kramer, 1997, p. 114). It appears that children’s interpretations and understanding of PDT depends on their siblings’ needs and characteristics. In fact, these findings indicate that although PDT may be associated with positive and/or negative emotions for the typically developing child, the perceived fairness of PDT is a stronger predictor of sibling relationship quality than the magnitude of PDT.

Schuntermann (2007) investigated the importance of perceptions of PDT as a predictor of the sibling relationship quality for siblings of children with pervasive developmental disorder

and/or with a disability. Furthermore, he discussed the occurrence of PDT in families with a child with a disability, where typically developing siblings may be expected to perform household chores and/or take on an adult role for their sibling (Prizan, Meyer, & Lobato, 1997; Schuntermann, 2007). His findings suggested that the unrealistic expectations parents may have for their typically developing child may be associated with sibling conflict and negative sibling relationships (Schuntermann, 2007). However, he also emphasized the importance of children's understanding of PDT (Schuntermann, 2007). He explained that in instances where PDT is justified by the typically developing sibling, the sibling relationship may be positive (Schuntermann, 2007).

Lastly, studies have only recently considered the role of fathers. These studies reveal that mothers and fathers have a tendency to favor children of the same gender (Kowal & Kramer, 1997; Meunier et al., 2012; Scholte et al., 2007). For instance, a study performed by Kowal and Kramer (1997), which interviewed sixty-one children aged 11-13 years and their siblings about PDT, examined whether established associations between PDT and "sibling relationship quality are moderated by children's perceptions and attributions about parental behavior" (p. 113). Their results indicated that paternal differential controlling behaviors were linked with greater rates of undesirable behavior in children compared to maternal behavior (Kowal & Kramer, 1997). Thus, the relevant research to date divulges the importance of exploring both maternal and paternal practices of PDT (Kowal & Kramer, 1997).

### **The Present Study**

Although the concepts of PDT and sibling relationships have been studied in several family contexts, there is limited research in the context of families in which there is a child with a DD. Also, there is limited research on PDT that includes analyses of siblings' differential



experiences with their fathers. Lastly, previous research and theory provides evidence for associations between PDT and its impact on the family dynamics, yet has not fully explored direct repercussions of PDT on the sibling relationship.

As a result, this qualitative study examined the associations between PDT and sibling relationship quality during the period of middle childhood in families in which there is a child with a DD. The typically developing sibling was interviewed and asked to complete two questionnaires to gather data on PDT, sibling relationship quality, and other pertinent information. Parents were asked to complete a demographic questionnaire and an interview to collect data on how they perceived the sibling relationship quality and PDT. The first objective was to identify whether PDT was perceived or not by the typically developing sibling. The second objective was to, in presence of perceived PDT, investigate whether the typically developing sibling perceived PDT as fair or unfair. The third objective was to examine whether typically developing siblings tended to see their sibling with a DD as a rival/competitor or in more positive terms. Finally, the last purpose was to assess whether the sibling relationship was impacted when the typically developing child expressed feelings such as anger, jealousy, and resentment or alternatively more positive feelings towards his/her brother or sister with a DD.

## **Method**

### **Participants**

Snowball, convenience, and criterion sampling (e.g., word-of-mouth, community centers, and relevant organizations) were used to select participants. Participant selection was criterion based and thus came from a pool of families who had the following characteristics: multiple children within the age range of 4 to 14 years, at least one child with a DD, and geographically situated on the island of Montreal or the surrounding areas within a 278 km radius. A total of nine French-speaking families were selected to participate in the study including 10 typically

developing siblings. Recruitment took place over a period of four months, after which recruitment was halted in order to begin analyses. All families provided written consent to participate and the participating child gave verbal consent (see Appendix A and B for the consent/assent forms and the ethics form)

Siblings of children with a DD could be younger or older, and if there was more than one typically developing sibling, the one closest-in-age was asked to participate. Six siblings (60%) were younger than their brother or sister with a developmental disability, three were the same age (i.e., one set of twins and one set of triplets) as their brother or sister with a developmental disability (30%), and only one was older than their brother or sister with a developmental disability (10%). All siblings were between the ages of 6-11 years old at the time of participation. There was one 6-year-old, one 7-year-old, one 8-year-old, three 9-year-olds, two 10-year-olds and two 11-year-olds. The mean age of the children was 9 years, with a standard deviation of 1.63.

Six of the nine children with developmental disabilities were male (67%) and three were female (33%). Parents described their children's developmental disabilities as Autistic Disorder, and/or Pervasive Developmental Disorder; the two diagnoses are now included under the diagnosis of ASD (American Psychiatric Association, 2013). Parents assessed the severity of their child's diagnosis according to their estimations of the level of support their child required. Five families noted their child required very substantial support, two families marked that their child required substantial support, while two families wrote that their child required support. Some parents also indicated that their child had certain specifiers, which is the term employed in the DSM-V. For instance, some children were identified as having an intellectual impairment, and/or a language impairment. In addition, some diagnoses were associated with a known

medical, genetic condition, or environmental factor (e.g., Rett syndrome, epilepsy). Lastly, some additional neurodevelopmental, mental or behavioral conditions were noted (e.g., attention-deficit disorder; Tourette's disorder).

Almost all families surveyed, with the exception of one, included a mother and father living together with their children. One family was a single-mother family. There were seven families with two children (78%), one family with three children (11%), and one family with five children (11%). In terms of employment, 56% of mothers and 78% of fathers were employed. Of the 17 parents (mothers and fathers), 35% have attended some level of university. A sample of job descriptions included elementary teacher, agronomist, machinist operator, computer scientist, school supervisor, animal health technician, chief strategist, hairdresser, sales manager, heavy vehicle driver and youth worker. Regarding family income, two families reported making less than 20,000\$ per year, one family between 40,000\$ and 49,000\$, another family between 50,000\$ and 74,999\$, three families between 75,000\$ and 99,999\$ while one family stated making 150,000\$ or more. In terms of religious beliefs, 67% of the families were Christian and 33% were Atheist. With regards to assistance, 33% of the families received some kind of help with their child with special needs within the home, while 67% received help outside their home environment. Lastly, 44% percent of siblings attended, or have attended in the past, a monthly sibling support group to discuss what it is like to have a sibling with a DD.

## **Measures**

**Demographic questionnaire.** In a self-report questionnaire, parents were asked to provide their personal and family demographics (see Appendix C), such as their age, gender, marital status, type of employment, level of education, annual income, and cultural and religious affiliation. Parents were also asked to provide information about their children regarding their

gender, date of birth, and birth order. In addition, several questions about the child's DD and family resources concerning their child with a DD were included in the questionnaire. This demographic information was gathered primarily for descriptive purposes.

**Sibling Inventory of Differential Experiences - revised format (SIDE-R).** The SIDE-R, a self-report questionnaire, contains nine items, which assess two main factors of PDT (see Appendix D): differential affection (five items; numbers 2, 3, 4, 6, and 8) and control (four items; numbers 1, 5, 7, and 9) (Plomin & Daniels, 1984). There is a similar form for both children and parents. On each form, the Control scale assesses parental strictness, punishment, discipline, and blame. A sample item from the Control scale is as follows: "When your mother/father punishes you and (your sibling), do they punish you both the same amount, or do they punish you more or (your sibling) more?" The Affection scale measures relative parental pride, enjoyment, sensitivity, favoritism, and interest. A sample item from the Affection scale is as follows: "When your parents are sensitive to you and (your sibling), are they more sensitive to (your sibling), or you, or are they equally sensitive to both of you?" Both the sibling of a child with a DD and both parents were administered the SIDE-R. Plomin and Daniels (1985) report that psychometric data on the SIDE suggests that it is a trustworthy measure of sibling differential experience. In addition, there is noticeable variability in each respective area with respect to how siblings understand and perceive their own experience (Plomin & Daniels, 1985).

**Sibling Relationship Questionnaire (SRQ).** The typically developing child completed a modified version (16 items) of the 49-item SRQ to evaluate the relationship quality with their sibling who has a DD (See Appendix E) (Furman & Buhrmester, 1985). Four dimensions were assessed: (a) warmth/closeness (e.g., "How much do you and your brother go places and do things together?"); (b) relative power/status (e.g., "How much do you admire and respect your

brother?"); (c) conflict (e.g., "How much do you and your brother disagree and quarrel with each other?"); and (d) rivalry (e.g., "Who gets more positive attention from your mother, you or your brother?"). Participants were able to select one of the following options on a 5-point Likert scale: 1 (hardly at all), 2 (not too much), 3 (somewhat), 4 (very much), and 5 (extremely much). The SRQ has shown to be an effective and consistent tool for assessing diverse aspects with regards to sibling relationship quality (Furman & Buhrmester 1985). In fact, Furman and Buhrmester report a mean test-retest reliability over a 10 day period of 0.71.

**Perceived Fairness of Parental Differential Treatment.** Developed by Kowal et al., (2004), the perceived fairness of parental differential treatment is a measure used to analyze the respondent's perceptions of whether differential treatment was perceived as fair or unfair by the children when it occurred. Participants were asked to circle fair or unfair for each item on the SIDE-R. For instance, a child would have to answer the following question: "If your mother/father has been disciplining you differently from how she/he disciplined your sibling, was this fair or unfair?" Since the perceived fairness of parental differential treatment measure fulfills a supplementary role to the SIDE-R, the reliability and validity of this measure is rarely evaluated and discussed on its own.

**Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire (PEPC-SRQ).** This questionnaire, developed by Kramer and Baron (1995), looks at parental perceptions of sibling relationships (see Appendix F). For the purpose of this study, only the second section of the questionnaire was used. The second part of the questionnaire, titled "How I see my children's sibling relationship" contains 27 items. The first portion asks mothers and fathers to rate the frequency of each event in their children's relationship, to which they can answer on a 5-point Likert scale: 0 (never), 1 (rarely), 2

(sometimes), 3 (usually), or 4 (always). After indicating the frequency, parents have to report on how much the issue causes a problem for their children. They can select one of the following options on a 4-point Likert scale: 0 (it's not a problem), 1 (it's a small problem), 2 (it's a big problem), or 3 (it's a very big problem). Part 3 of this section only needs to be completed if parents perceive the issue to be a problem. It also asks the parent to state how easy it would be for them to improve that issue, to which they can respond on a 5-point Likert scale: (1) very difficult, (2) difficult, (3) neutral, (4) easy, or (5) very easy. Finally, the last portion asks the respondent to convey how much help they would like to receive with the particular issue using a 3-point Likert scale: (1) no help, (2) a little help, or (3) a lot of help. Construct validity is supported by comparisons with other standardized measures of sibling relationships (e.g., the Sibling Relationship Questionnaire; Furman & Buhrmester, 1985), which use comparable domains in their evaluation (Kramer & Baron, 1995).

**Interviews.** The parents' interviews consisted of answering fourteen open, semi-structured, predetermined questions (see Appendix G). Each interview lasted between fifteen and twenty minutes. Both parents answered the same sequence of questions. These were designed using a variety of question types to gain insight about their family dynamics, in terms of the relationship between themselves and their children, and the relationship between their children.

The siblings' interviews consisted of answering sixteen open, semistructured, predetermined questions (see Appendix H). The interview lasted between five and ten minutes and focused on PDT and the sibling relationship. The researcher asked follow-up and/or probing questions to the child and parents to further engage the participants and to get a more thorough understanding of their experiences.

## **Procedure**

Data for this project were collected during the winter semester of 2015. Participants were first presented with a short description of the study and questioned if they would be interested in getting implicated and involved. If they agreed to participate, the researcher communicated with them, and arranged a convenient time to meet (e.g., week nights and/or weekends). An information letter with the description of the study, the consent forms, and the demographic questionnaires were sent to the participants prior to the study. The participants were given a choice to complete the demographic questionnaire prior to, during or after the study. A self-addressed return envelope was provided if necessary.

Participants were given a choice about where they would like to be interviewed. They were informed that if they did not wish to be interviewed in their home environment, public places were available (e.g., public library, coffee shop). This strategy was used to make sure that the place of the interview was convenient to the participant, private, as well as familiar to him or her (Hays & Singh, 2012). In addition, these options were considered to ensure that participants felt comfortable and secure throughout the interview process (Hays & Singh, 2012). Although they were given different options, all families that participated in this study chose to be interviewed in their home environment. The home visit lasted between sixty and ninety minutes. On the day of the meeting, the children's parents were required to provide consent by signing the parental consent document for their own and for their children's participation. The typically developing sibling was also asked to provide verbal assent to participate. Furthermore, the participants were reminded of their right to withdraw from this study at any time. After receiving the proper consent, the researcher was responsible for conducting an individual interview with each parent and the typically developing sibling.

Parents completed two questionnaires: (a) SIDE-R (Plomin & Daniels, 1984), which assesses PDT; and (b) Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire (Kramer & Baron, 1995), which investigates parental perceptions of sibling relationships. Separate forms of each questionnaire were provided for mothers and fathers to answer privately and separately. Once the questionnaires were completed, parents were individually interviewed in a counter balanced order across families.

Prior to beginning any meetings with the typically developing child, the researcher established rapport by engaging in a casual discussion to put him/her at ease. Children started the process by completing two questionnaires: (a) SIDE-R (Plomin & Daniels, 1984), which assesses PDT; and (b) Sibling Relationship Questionnaire (Furman & Buhrmester, 1985), which measures perceptions of the quality of interactions with one's sibling. These questionnaires aimed at gathering data on PDT, sibling relationship quality, and other pertinent information. Separate forms of the SIDE-R were provided to the focal child for their ratings of maternal and paternal treatment. After rating the magnitude of the affection and control items on the SIDE-R, participants were requested to specify whether they perceived the parental behavior as fair or unfair. Both questionnaires were read aloud to the child if requested/needed, and then all the children were interviewed privately. After the interviews, participants were sent a final summary of the data obtained during their interviews. The child and his/her parents were given the opportunity to read the summary and determine if it was a truthful and accurate representation of what they shared during the interview. Any inaccuracies were corrected as per the parents' requests. The child that participated in the study was offered a choice of a book to thank them. Additional children in the family were also invited to choose a book.



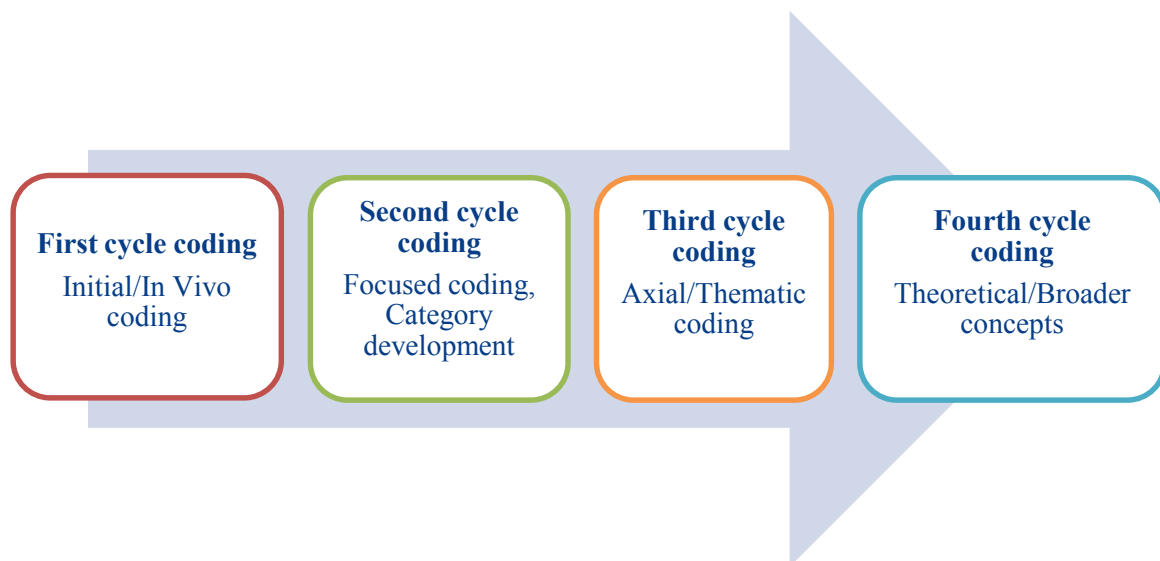
## **Data Analysis**

The list of interview questions originally prepared served as an initial set of codes. To organize the analysis, the participants' words also known as In Vivo Coding were utilized to ensure that concepts emerging from the data set captured the key elements of what the interviewee described. During the second cycle of coding, level 1 codes were re-examined and the data were further focused. To do so, a new set of codes was created by combining two or more of the codes created in the previous step. In the third level of coding, the themes were further analyzed using Axial Coding. The data were reassembled and relationships were identified among the previous set of codes. Broader categories and highly refined themes were then developed. Lastly, in the fourth level of coding, a final set of data emerged from saturated categories and themes. Each unit of data was assigned its own unique code. Multiple codes were used when the response covered multiple topics of interest. The collected data were reviewed several times prior to establishing a final coding system. All coding was done manually in the word document originally organized on the computer. The data coding process was repeated three times, that is once for the sibling, once for the mother and then father (see Figure 1 for a diagram outlining the coding process). The MA student was assisted by an undergraduate research assistant to complete the coding process.

## **Data Authenticity**

Several strategies were used to minimize biases and help warrant the trustworthiness and reliability of the data collected and findings (Merriam, 2009). Initially, member checking was used to help better the exactitude, reliability, validity, and transferability of the data (Hays & Singh, 2012; Merriam, 2009). Final summaries of the data obtained during the interviews were sent to the participants. They were then given the opportunity to read the summary to confirm

that their views were authentically expressed during the interviews. Any inaccuracies were corrected as per the parents' requests. Lastly, collaborative inquiry with the research team (i.e., supervisor and undergraduate student) was conducted. Meetings between the two coders were held several times a week to ensure that the coding was reached by consensus.



*Figure 1.* Data coding procedure.

## **Findings**

The first part of this section includes a report of the quantitative findings regarding the questionnaires given to the siblings and parents. Due to the small sample size, only selected descriptive statistics were conducted to analyze the instruments. The second part of this section is a qualitative analysis of the sibling and parent interviews.

### **Descriptive Statistics for Sibling and Parent Questionnaires**

Table 1 (see end of this subsection) shows the range, mean, and standard deviations for each of the four scales on the Sibling Relationship Questionnaire. The results indicate the participants' ratings in terms of how warm or close they feel to their siblings and this score has a higher mean than how children rated their sibling in terms of any other type of experience. Specifically, the means are lower for how much rivalry they report having with their sibling, how they rate the relationship in terms of power/status, or how much they fight or disagree with their sibling.

The range, mean, and standard deviation for the three subscales on the Parental Perceptions of Children's Sibling Relationships Questionnaire (PEPC-SRQ) can be viewed in Table 2 (see end of this subsection). It can be seen from the data that both mothers and fathers appeared to agree in terms of how frequently warmth occurs in their children's relationship. Similarly, both parents rated a similar amount of agonism in their children's relationship. Lastly, mothers' and fathers' ratings for perceived sibling rivalry were somewhat different; specifically, the mean for mothers' perceived rivalry in the sibling relationship appears to be higher than the mean for fathers' rivalry.

The range, mean, and standard deviation for the three subscales of the Sibling Inventory for Differential Experiences questionnaire as reported by mothers, fathers and children are shown in Table 3 (see end of this subsection). Both mothers and fathers appeared to agree when

reporting on differential control and affection because the means were very similar. On the other hand, children rated their mother's differential control as higher than their father's differential control. Lastly, children appeared to agree when reporting about their mother's and father's differential affection. Overall, the child ratings appeared to always be lower than the parents' rating of the two variables (control and affection).

Finally, results from the Perceived Fairness of Parental Differential Treatment questionnaire can be seen in Table 4 (see end of this subsection). These ratings suggest that, overall, children perceived differential control and affection by both parents as fair and rated both parents in a similar manner.

Table 1

*Ranges, Means, Standard Deviations, and Variance for the Sibling Relationship Questionnaire*

Scales	<i>n</i>	Range	Mean	Standard Deviation
Warmth	9	2.25 – 4.50	3.39	0.67
Rivalry	9	1.00 – 3.00	2.49	0.64
Power	9	1.25 – 4.25	2.50	1.00
Conflict	9	1.00 – 4.75	2.99	1.56

*Note.* The rating scale for each item ranged from 1 to 5.

Table 2

*Ranges, Means and Standard Deviations for the Parental Perceptions of Children's Sibling Relationships Questionnaire*

Perceived Sibling Behaviours	<i>n</i>	Range	Mean	Standard Deviation
Perceived warmth by mothers	9	28.00 – 56.00	41.33	9.97
Perceived warmth by fathers	8	34.00 – 48.00	41.63	5.68
Perceived agonism by mothers	9	9.00 – 34.00	24.67	8.56
Perceived agonism by fathers	8	11.00 – 35.00	22.13	7.28
Perceived rivalry by mothers	9	4.00 – 13.00	9.00	3.32
Perceived rivalry by fathers	8	3.00 – 10.00	6.38	2.67

*Note.* Ranges were calculated from the summed items to create the subscales; Parent's report on the frequency of each event in their children's relationship could be rated on a scale of 1 to 5; Parent's report on how much the issue causes a problem for their children could be rated on a scale of 1 to 4; Parent's report on how easy it would be for them to improve that issue could be rated on a scale of 1 to 5; Parent's report on how much help they would like to receive with the particular issue could be rated using a scale of 1 to 3.

Table 3

*Ranges, Means, Standard Deviations, and Variance for the Sibling Inventory for Differential Experiences Questionnaire*

Items	<i>n</i>	Range	Mean	Standard Deviation
Differential control reported by mothers	9	3.00 – 4.75	3.72	0.64
Differential control reported by fathers	8	2.50 – 5.00	3.75	0.86
Differential affection reported by mothers	9	2.80 – 4.60	3.27	0.54
Differential affection reported by fathers	8	2.60 – 3.40	3.00	0.30
Differential control (mothers) reported by the child	9	2.50 – 5.00	3.49	0.75
Differential control (fathers) reported by the child	9	2.75 – 5.00	2.64	0.72
Differential affection (mothers) reported by the child	9	2.80 – 3.80	3.09	0.30
Differential affection (fathers) reported by the child	9	2.40 – 3.20	2.84	0.24

*Note.* Each item could be rated on a scale of 1 to 5.



Table 4

*Ranges, Means, Standard Deviations, and Variance for the Sibling Inventory for Differential Experiences Questionnaire – Fairness Evaluation by Children*

Subscales	Questions ( <i>n</i> )	Fair ( <i>n</i> )	Unfair ( <i>n</i> )	Mean ( <i>SD</i> )
Differential control:				
Mothers	36	28	8	1.22 (0.26)
Fathers	36	27	9	1.26 (0.44)
Differential affection:				
Mothers	45	43	2	1.03 (0.10)
Fathers	45	44	1	1.01 (0.03)

*Note.* The rating scale for each item ranged from 1 to 2.

## **Analysis of Siblings' Interviews**

In the first section of this qualitative analysis, the siblings' interviews are reviewed while taking into considerations the emergent patterns, themes and concepts. Figure 1 (see end of this subsection) provides a graphic representation of the emerging themes that were identified and collapsed into overriding categories. Note that all of the direct quotes have been translated from French to English in the following sections. The translation was verified by a research assistant.

**The sibling subsystem.** Children described numerous types and qualities of interactions between themselves and their brother or sister with a DD. Some of the emerging themes include their interpretation of their relationship, the consequences of having a sibling with a developmental disability, the different activities they engage in with their brother or sister with a DD, and the different responses they may have regarding their brother or sister with a DD.

**Perspective of the relationship.** Overall, most interactions were described by the children as negative. Several children reported their interactions with their brother or sister with a DD as aggressive, unpredictable, fluctuating, difficult, complex, and busy. For instance, child 9 stated: "In general, we don't really play together often. We usually fight when we're together or we don't speak at all." Child 5 mentioned that: "It's a little difficult, like busy." After the interview, the child clarified that she meant that she is often busy taking care of her sister, which she finds very difficult. Child 2 claimed that the relationship she has with her brother who has a DD constantly varies. In fact, she said that, "sometimes he is upset, sometimes he is happy, so we always have to expect the unexpected." Another negative issue that arose was the lack of communication when a child attempted to communicate or play with his or her sibling with a DD. Child 8 described her relationship with her brother who has a DD: "When we talk, we either don't get along or he doesn't want to talk to me because he is doing his own thing. But yeah,

that's it, we don't always get along because he doesn't want to share, he doesn't want me to do this, he doesn't want me to do that, and it's not really fun." Lastly, child 4, who has a sister with a DD (according to the parents, a severe diagnosis), mentioned that, "I don't really spend time with her, with my sister, because I don't know what to do with her."

Participants also spoke about aggression and verbal disagreements. When sharing a story about a verbal argument, child 9 stated: "I start to insult him when he bothers me." Child 2 explained without any flaws the physical aggression he was the recipient of: "Sometimes, he gets too excited and he scratches me." Child 3 mentioned that it is extremely difficult to manage her brother with a DD when he is frustrated. She stated: "Sometimes I talk to him and I tell him to come eat and he hits me and tells me go away. I am upset".

Although it was less frequent, participants also claimed to have positive relationships with their siblings. Some of the constructive and encouraging comments from the participants focused on a minimum amount of disputes, as well as friendships between the siblings. For instance, although child 3, mainly focused on the negative aspects of the relationship, she also stated, "we really get along, well when he wants we can really get along." Child 7, also said that, "overall, it goes quite well." Child 8, had a similar response: "Uh, it's not that bad." Although children shared some positive aspects of the relationship, these were repeatedly followed by a negative statement.

On a few occasions, siblings gave strikingly different responses or appeared confused with the questions that were posed. For instance, when asked about his relationship with his sister, child 1 responded, "Well, we went to the same school but now my sister changed schools. She is at School 1 and I am at the same school at School 2." Child 8 required clarification about what was demanded: "Uh, what are you saying exactly?" Rather than repeating the question, the

researcher rephrased the question as, “Do you get along with your brother?”, given the child’s confusion.

*Activities.* The participants described the types of activities they engage in with their brother or sister with a DD. Additionally, some of them mentioned the activities in which they participate together as a family. These included skiing, playing video games, playing outdoors, watching movies, and bowling. For instance, child 6 made a suggestion to her father that the family interact more together given that they were so focused on solitary activities in the past: “My brother and I didn’t do much together, we played on our Ipad, Ipod, so I asked if we could, every night if we have enough time, to play a board game.” Similarly, child 7 described going bowling with her family: “He really enjoys going bowling. So, once, we went with the family and it was fun.” Child 9 shared that he often interacts with his brother. In fact, he stated: “Sometimes we play ‘Minecraft’ and sometimes we go play outside and we throw snow balls at each other.” In addition, child 10 claimed that although the relationship can be difficult at times, she and her brother also play together, evidenced by her statement “Sometimes we play laser tag.”

Children also shared elements that prevent shared activities from happening on a daily basis. For instance, child 3 stated that, “If we propose to do something, he can say no and we have to listen to him otherwise he is going to get upset.” Other children shared that a lack of common interests, a lack of communication, and a short attention span are some of the reasons that prevent shared activities from taking place. For example, child 7 said, “it’s more for vacation, we can’t really travel far away or for long periods of time because he gets annoyed or it isn’t part of his interests.” Similarly, child 8 stated:

He doesn't prevent me from doing them completely but he prevents me from doing them the amount of time I would like to. Let's say we go to the museum, he would probably only do half of the exposition and I would like to do it all but since it is too much to ask from him, we have to go and do something else.

While it was mentioned in different contexts, elements that prevent shared activities from happening appeared to be a common thread across all participants.

*Coping strategies.* Several coping strategies emerged from the interviews with the participants in response to difficult situations they had faced with their sibling who has a DD. Examples of the strategies used by children included the participants isolating themselves, seeking support from friends and/or family, as well as combining several strategies.

A common coping strategy identified by the participants consisted of withdrawing when difficult situations arose. After facing a challenging situation with her brother who has a DD, Child 8 said: "Well, sometimes I go in my bedroom to calm myself." Similarly, child 6 said "I go in my bedroom to get away and go on my computer or Ipad." None of the children reported retreating excessively.

A reoccurring strategy also used by the participants involved obtaining help and/or support from friends and/or family. For instance, child 4 sought support from a friend, and noted: "I talk with a friend whose mother is the president (of an organization) that defends people with handicaps." Child 8 mentioned: "Sometimes we fight and we battle and sometimes I go tell my parents." Another example emerged from the interview with child 7: "Well I for sure ask, I try to ask my mother or father for help because I don't really know how to act and they can help me."

Lastly, some children seemed to combine the aforementioned strategies when faced with difficult situations. For example, Child 10 said:

If he pushes my limits then I yell really loud. In general, it shuts him up. After that, I start insulting him or I attempt to remain calm while saying words that are not too insulting or I just withdraw and go to my bedroom and I leave him alone. Sometimes also, sometimes I'll go see my mother.

Also, child 3 mentioned: "I go see my parents and I walk away, and I say my brother hit me and they tell me, ok leave him alone and he can come after." Overall, children appeared to withdraw only when they deemed it essential and only for a limited period of time.

***Cohesion between siblings.*** These responses included responses related to the themes of pride and also concerns for the welfare of the sibling with a DD.

***Pride.*** Many children were proud of the achievements of their siblings with a DD. These achievements were assorted and comprised sports accomplishments, school successes, and artistic ability. For example, child 3 spoke highly of her brother when he won an athletic competition for children with a DD. She stated:

Yes at a track and field and at a hammer throw event and I was the one who trained him so I was like ah yes and in bronze and I told myself there are so many handicap children so I was like ah yes, I was very proud of him.

Throughout another interview, child 8 shared that her brother builds different structures using "Minecraft". She stated that, "he built the Quebec Bridge and he showed it to me and it was very cool." She went onto describe how he copied every detail of the bridge, which made her proud: "I was like woowoah, you're good." A sense of pride was also apparent in child 10's interview. In fact, she was rather impressed with the school grades of her brother who has a DD: "He often had better grades than me and I am quite happy for him."

*Concerns.* A reoccurring theme throughout the interviews was the siblings' concerns and anxieties about their brother or sister with a DD. Concerns included worrying about the future career of their sibling, safety, reactions from others, and the health of their brother or sister with a DD. For instance, child 10 shared that she worries about her brother's future career.

One example emerged from the interview with child 8 when she appeared to be worried about the upcoming school changes involving herself and her brother who has a DD. She explained: "I worry a little bit because next year, he will be coming to my high school." She pursued her thought and said, "He will be in specialized classes but he will be taking the same school bus as me and if he starts throwing tantrums, I will attempt to calm him down but it will be strange to do so, but ya, I will have to do it, I do not have a choice." On the other hand, child 7 appeared to worry about her brother's safety. In fact, she stated, "That's it, people do not know how to react, and sometimes they are not very nice." Other examples included worries about the future of the sibling with a DD.

He wants to become an architect but he says that he does not want to draw plans so we are not really sure. He draws pretty well but he wants to become an architect but we're not really sure because he claims not wanting to draw in the future.

Another example stemmed from child 3's interview when she described her worries about the future lifespan and quality of life of her brother who has a DD:

I am worried. We know that his life expectancy is not as long as ours because he won't live as long as us and what worries me is that he will be in a specialized home that's for sure and that I won't be able to visit him, and that he will become unhappy and I don't like imagining him like this alone.

Furthermore, some children worried about what would happen to their brother or sister with a DD when their parents die, while others were apprehensive about their sibling with a DD's future in general. For instance, child 5 stated: "I wonder when both of my parents die and my sister won't be able to lift herself up, who will take care of her?" In addition, child 6 mentioned: "I am a little worried about when he grows up, what will he do? I will probably live with him or something because he has autism. We won't leave him alone, we don't know what will happen, probably get lost."

In sum, the children talked about both their sense of pride but also voiced concerns about the future lives of their sibling with a DD.

**Parental Differential Treatment.** Children reported on whether they perceived parental differential treatment or not and if so, if it is perceived as fair or unfair. Some of the emergent concepts include the joint activities between themselves and their parents, the rules in the household and whether these are perceived as fair or not, and whether they take on supplementary responsibilities for their sibling with a DD (Dew, Balandin, & Llewellyn, 2008).

***Joint activities between children and parents.*** A recurrent theme in the interviews was a sense amongst participants that they engaged in a variety of activities with their parents while their sibling diagnosed with a DD is away or occupied elsewhere. These activities included being taken out for a special meal, watching television series or movies, going on road trips, playing hockey, as well as going on shopping trips. Responding to the question, "What kind of 'special time' or 'special activities' do you have with your parents?" child 1 mentioned: "We play hockey because later we will go skating, so we played hockey a little bit." Child 8 also described her thoughts about engaging in 'special' activities:



Um when it is with my mother, it's like when my sister is at her friend's house, my father is in the basement working and my brother is doing his own thing in the basement sometimes I go shopping with my mother, and yes that's fun. With my father it's like um, he cooks duck ok and we go get the ducks at Île d'Orléans so we do kind of a road trip. It's like one hour and a half and it's fun.

Although children reported having joint activities with their parents, in most cases, these were reported as happening rarely. When asked about 'special' time or activities with her parents, child 3 stated:

When my brother goes to respite camps, we have time just the three of us together but it's quite rare, but we spend time together when he is in his bedroom and we watch movies together. He used to go more often, once a month, but now it's not as frequent.

Another example came from child 6's interview when she shared her opinion regarding special activities with her parents: "It's really rare. Euh sometimes me, well very, very rarely my mother and I go shopping while my grandmother babysits my brother." Similarly, child 7 mentioned: "Sometimes we play with board games and my brother doesn't understand so he doesn't do it or we will watch tv shows together with my other sister." Talking about this issue, child 4 said: "Euhhh I don't really do activities with my parents." However, later in the interview, he mentioned: "Sometimes I go to the movie theatre with my father but it's more with my mother." Lastly, child 2 stated: "It happened, well my mother sometimes comes and picks me up from school to go eat lunch at Tim Horton's." Only one child interviewed suggested that he does not spend time one-on-one with his parents: "No, we have had special activities in the past but the entire family was there."

**Rules.** A variety of perspectives were expressed with regards to the rules established in the household of each participant. The participants on the whole shared that having to respect rules was part of their household. However, in most households, these were either different rules (i.e., less demanding) for the child with a DD or they had, for that matter, no rules to follow. For instance, child 3 expressed her thoughts about the household rules in the house as well as the fairness associated with this:

We can't yell at each other. It depends for whom because sometimes we are overwhelmed and we yell, we yell at each other. But when my brother is mad, and a second later he is happy and he always wants to do everything so it's not the same rules between him and me. I don't find it necessarily fair because I go in my bedroom for one hour and he only goes for five minutes and after he gets out, he apologizes and I have to wait one hour before I can apologize and it's a similar situation.

This view was echoed by child 6 who mentioned: "I'm not allowed upsetting my brother, and I am not allowed yelling. I have to be polite, respectful and everything." When asked whether she thinks these rules are fair she stated: "Sometimes yes, sometimes no. My brother has no rules at all. It's a little unfair but he has autism." Another interviewee alluded to the notion of fairness regarding the rules. In fact, when asked about whether there are rules in the house or not, child 5 said: "yes." She continued and stated: "It's not always fair because my sister never gets in trouble but I think that overall it's fair because she has a problem, it's normal." Although the children indicated that they did not always find the rules to be fair for themselves and their sibling with a DD, most of them mentioned understanding why this may be necessary. It also seemed that sometimes the siblings were using the DD as an excuse to accommodate their parents for why there were no or less stringent rules, as is apparent in the last quote.

***Responsibilities allocated to the typically developing children.*** Throughout the interviews, siblings often reported taking on additional responsibilities for their sibling with a DD. Some of these included household chores such as cleaning their bedrooms, cleaning the dishes, and so on. For example, child 7 stated: “Well we do more chores because I don’t think he understands how to do everything and for him it is long so sometimes it’s less fun because we have more chores to do and he has fewer.” She went on and said:

I also have to clean my bedroom and I have to help set up the table and clean it.

Sometimes I find, that’s it, I find it a little unfair because he does less but it always depends. Sometimes I don’t say anything, and sometimes it really bothers me.

Similarly, child 8 mentioned: “Yes I gotta clean my bedroom. But my brother, like my mother helps him a lot and she helps me too but I really have to do it on my own. I think it is normal but it’s still something that I don’t find fair.” She continued and stated:

If my mother asks me to do something, I do it, I linger around for a little bit but I do it after but my brother, when he doesn’t to do something, he walks away and my parents never force him and that I find a little unfair because I feel obligated and he can just walk away and not do what was asked.

On the other hand, child 10 described feeling rejected when attempting to help her parents with tasks related to her brother who has a DD: “If my parents don’t understand his homework, sometimes they come ask me but often my brother doesn’t allow me to come help.”

Some children also reported being faced with roles and responsibilities that were not necessarily appropriate for their ages and abilities. In fact, it was commonly reported by children that they felt responsible for the well-being of their siblings as well as taking on emotional responsibilities from their parents. For instance, Child 3 (age 10) was informed by her parents of

the dangers her brother can potentially face. As a result, she is responsible for administering a medication when her brother has epileptic seizures and her parents are not available:

When he has epileptic seizures, I absolutely need to go get the DIASTAT, and everything and yes sometimes I have to put him to bed because there are people over and my parents can't do it but other than that I don't have other responsibilities, usually it's like I do volunteer work.

Child 6 reported having to prepare meals for her brother who has a DD:

During the summer, I am not happy, at some point I went to wake up my father, I think it was last summer or the one before, it was approximately 9:15 – 9:30 and I said 'wake up' and he said 'go make breakfast for your brother'. During the summer I have to make him breakfast and it's really not cool but I have no choice.

Similarly, child 5 mentioned having extra responsibilities in regards to her sister who was diagnosed with a DD:

Like giving her milk, looking after and for instance if her Ipad is done and she cries, I have to go see her and restart her show, or for example, if her leg is not placed properly, I will move it around to make her comfortable.

Although most children reported having extra responsibilities for their brother or sister with a DD, child 9 stated that he did not have any extra responsibilities. When asked why, she stated: "They never ask me."

**Knowledge about the Developmental Disability.** Throughout the interview, reoccurring patterns were seen in the participants' overall knowledge about their sibling's DD. In fact, children appeared to have been given small bits of factual information about the disability. For instance, although child 8 was told what the DD was, she did not appear to understand her

brother's DD itself but rather the observable behaviours and symptoms. She stated: "I think when I started realizing I told myself in my head that my brother was different than us. But still it is difficult to accept because he doesn't have the same permissions as us." This view was echoed by child 3:

I was maybe, because he was born before I was, so I was maybe 5 years old since at the beginning I thought having a big brother was that. I started finding it weird and at 5 years old this is when I finally learned that he was handicapped, I first thought he was a normal brother.

Although most children were able to name their sibling's DD, only a limited number of children indicated remembering vaguely when they learned about their sibling's DD. For instance, child 7 stated, "I think I was quite young but I didn't really have the knowledge to understand." And child 6 commented "Well I started understanding what it is when I was younger." Similarly, child 5 mentioned: "I know I was very young but I can't really remember when my parents told me exactly about the Rhetts syndrome."

On the other hand, in most cases, the informants reported remembering whether someone explained their sibling's DD to them or not. For instance, some children felt that their knowledge about the DD came from their own self-realization, while others considered that their understanding was due to their parents' persistent and ongoing explanations. Child 7 reported that "Well they always tried and made sure we understood what autism is." Child 3 commented: "Well at first when I was 5 years old I started understanding on my own, it's around 7 years old that my parents explained to me what it is." When asked if her parents told her about her sibling's DD, child 8 said: "Yes, probably, I imagine that they did." Lastly, after being asked the

following question: Did someone explain your sibling's DD to you?, child 9 answered: "Yes, my mother."

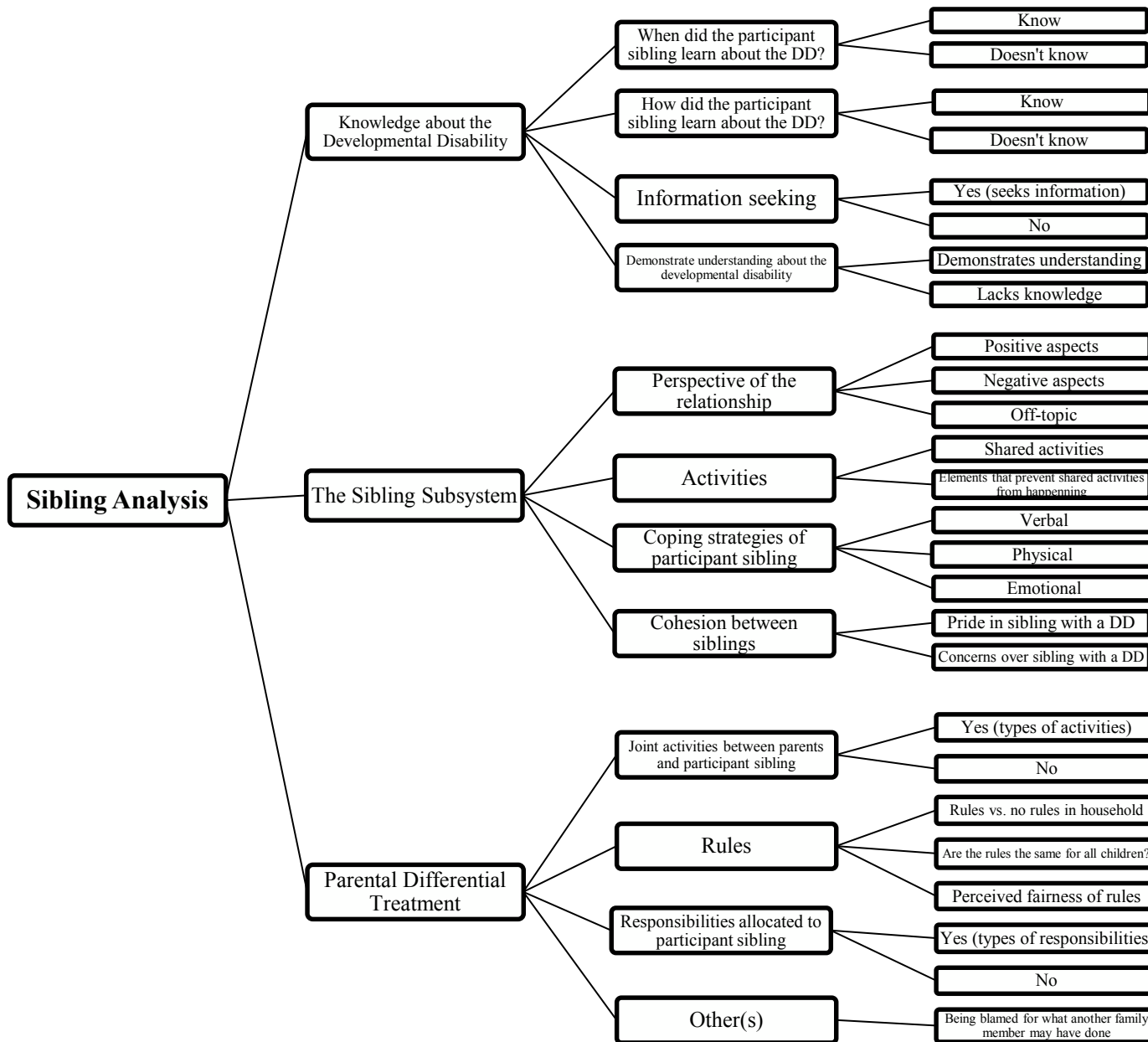


Figure 2. Sibling analysis.

## **Analysis of Mothers' Interviews**

In the following section, the mothers' interviews are analyzed and reviewed. The emergent patterns, themes and concepts are also discussed. Figure 2 (see end of the parents' subsections) demonstrates the emergent themes that were identified and collapsed into overriding categories.

**The sibling subsystem.** Mothers described numerous types and qualities of interactions between their child who has been diagnosed with a DD and their typically developing child, and if there was more than one typically developing sibling, the one closest-in-age was considered. These emerging themes included their interpretation of the relationship and the activities their children engage in when together.

***Perspective of the sibling relationship.*** Mothers were initially invited to report on their children's relationship. Although most mothers focused on the negative aspects of the relationship, some positive aspects were also revealed. Their opinions are reviewed below.

For instance, mother 5 noted during her interview, "(...) the relationship is a little forced I would say. It's more euhhh, we, we push our typically developing child towards our child with a DD." Similarly, mother 9 said of her children, "It's a conflictual relationship. It's often my son that does not take well words or phrases, and my daughter gets upset right away and there is a lot of arguments back and forth which escalate right away." She continued and described how difficult it was for her children to interact with one another as her child with a DD is extremely sensitive to noises and odors:

Yes, that's it and my daughter has good intentions. But at some point she becomes sad often because she gets snubbed by her brother, she loves her brother and he loves his sister too, but it's very conflictual, that's one thing. He only understands things at a



certain level, but the second thing that often causes the fights, it's that my son is hyper sensitive, like autistic children to noise and odors. So, in the morning when she wakes up and she walks past him, and he says that she doesn't smell good, my daughter doesn't react well in these circumstances, and I wouldn't react well either (...). He is hyper sensitive. If she is first to go change in the bathroom, he blocks his nose, he goes and brushes his teeth while blocking his nose, it is very insulting for her.

Similarly, mother 6 highlighted how she thinks her typically developing daughter is affected by her brother's DD: "The roles are reversed. She has the role of the older sibling, although she is younger."

On the other hand, some mothers talked about how much their children admire and love each other, and that they get on well, with some fighting and falling out, as is generally typical of siblings. For instance, mother 8 shared how close her children are: "Well, they are extremely close together. They are extremely close to one another and, honestly, they play together on a daily basis." Although her main focus was the positive aspects of the relationship, she continued and mentioned:

Sometimes the child with a developmental disorder, well since they don't go to the same school anymore, it's not as bad but there was a time when the typically developing child was always seeking the child with a developmental disorder's attention and at some point the child with a developmental disorder could no longer support his brother, but since they don't go to same school anymore, it's going better. There was a time when they were always fighting because the child with a developmental disorder thought that his brother would be too much in his bubble and everything. So, since they are always together hugging but they still fight quite a lot, but they are still very close to one another that way.

**Activities.** Mothers also touched upon activities their children engage in when together.

These included watching television and movies, outdoors activities (e.g., skiing), playing with Legos, and playdough. According to most interviews, it appeared that although children participated in activities together, it was for a very limited amount of time or with limited interest. One example stemmed from the interview with mother 9 who commented: "...play tag, things like that, they like that stuff. Watching a movie together, but sometimes my son with a developmental disorder talks and comments so it annoys my daughter." Mother 1 explained how her children play together in short-lived phases:

Yes but it comes in short-lived phases and it doesn't last long. It's like a firecracker, it's transient. Once it cracks though. Effectively Legos. At some point my daughter with a DD, became obsessed with something but it didn't last long, but they have both things. (...) her birthday is in January and his birthday is in March. So the Lego phase started being popular then. So for her birthday, she asked for some. When he noticed that she had an interest in Legos, he also asked for some. So yes that had a little phase, but once we got to summer time, forget it, the Legos, everything was over, and even her Legos are still in the box to this day."

Mother 3 echoed Mother 1's statement by describing how her children's interactions usually start off positive but end in arguments:

Usually it starts well, because my typically development child, euh, is open to negotiation and is generous with her brother, but becomes fed up over time, and the fighting starts. The interactions always end in fighting. Ah, usually it's, in general, the first half of the activity goes well. And after when one child starts to get tired, fighting starts.

On the other hand, mother 6 mentioned how structured activities work well with her children:

If there is a structured activity, like the other day it was with playdough and she made a lion for her brother. It went really well. If there is something structured like that, it goes really

well. If not, like I was saying earlier that he has obsessive-compulsive behaviors on top of his autism, it's not pervasive developmental disorder, it's really autism. (...) When he begins with his obsessive-compulsive behaviors (e.g., touching everything that typically developing child touches) it becomes very difficult.

Similarly, mother 8 revealed how close her children are:

They both have tablets and they play together in the same game. I don't really know how it works, but anyways. Other than that, they play a lot outside, in fact, it's all the time. For example, they are very interested in knights and fighting. It's pretty much the games that they'll always play.

**Child rearing.** Raising a child with a DD is full of challenges, rewards, and entirely unique experiences. While sharing their unique stories, mothers discussed about child rearing. Some of the emerging concepts include the acceptance of their child's diagnosis, the support they may have received from friends, family, and/or professionals, the rewards and the challenges of raising a child with a DD, and finally the fears they may have with regards to their child's future.

**Acceptance.** Overall, two mothers touched upon the topic of accepting their child's diagnosis or experiencing a sense of mourning given that they were grieving the "normal" child they hoped to have. The first example stemmed from the interview with mother 4 who went to therapy for several years to accept the condition of her child: "Because listen, I've been to a lot of therapies, therapies for before we received a diagnosis, to accept the diagnosis, after the diagnosis." On the other hand, mother 2 demonstrated acceptance of her child's diagnosis:

Well, we, I think the difference is that I think sometimes that it's because we are very accepting of the diagnosis and the family situation we are in. Very, very well, and socially too. When we go to the restaurant, I tell people right away, and if people look at

us strangely, at our son or something, well, he has autism, that's all. And I think that it is liberating as parents to be capable to tell other people this instead of pretending or hiding our child or telling him not to do this or tell him to stop.

**Support.** Given that family members of individuals with a DD are often presented with many challenges throughout their lives, several mothers reported needing help from professionals while raising their child with a DD. Although all mothers appeared to have requested help at some point, most of them mentioned having to go to the private sector given the lack of resources in the public sector. For instance, in an effort to ease the fears and provide her typically developing child with insightful information about the DD of her brother, mother 7 had her daughter seen by a psychologist: "We went and got help for our typically developing daughter in the private sector. But finding help in the public sector with the school, it was impossible." Another family sought help from a private specialized educator for a few sessions to help their typically developing son:

I asked maybe two years ago, at a CLSC (local community service centre), and what I was told was, 'Madam if you are overwhelmed, bring your son to daycare, he will play with other children there.' So, what we did is hire a private specialized educator, but only for a few sessions because it was too expensive.

Mother 6 reached out to a non-profit organization to provide her typically developing child with a role model: "I requested having a big sister for my daughter with an organization but it's not really helped, it's more of a role model for her to follow." Lastly, mother 9 mentioned how she and her husband requested help/support for her typically developing child, but are, is still waiting: "I requested help from the CRDI, I asked in November and I am still waiting (5 months)."

**Rewards.** Several mothers reported that raising a child with a DD is very rewarding. Sparked by her personal experiences, this became an extension for mother 1's professional life by researching goals and motives for the families she works with in her job. Although it is difficult for her at times to differentiate work from her personal life, she labels herself as compassionate, and appears to be very focused on understanding and meeting her own child's needs and those of other children. She noted during her interview:

Valued? It might sound silly but I am a specialized educator at the SRSOR (Readaptation services center) and I find that it really helps me in my work because I see both sides of the coin. I understand, I understand even more the parents when they are waiting for services because I went through it myself. So I find that I have a lot more compassion. I feel valued as a parent raising a child with autism with regards to my career, but I also find it harmful. Because I understand it too much. Some days, to do your work, and to come home and continue your routine and that's it. For me, it's like my day at work continues until the kids go to sleep. Yes, yes, yes so that's it exactly. But I do feel valued because it brings me that.

Another example stemmed from mother 3 in which she feels very proud of herself:

I am very proud to have succeeded. I am proud to have lived and survived through the experience. My son is now 14 years old so the most difficult years are behind me, but I would definitely not go back in time. So do I feel valued compared to other people, me, me personally I am very proud, but I am not sure that others see it as anything special.

Lastly, mother 9 mentioned how she does not necessarily feel valued but is proud of how far they have come as a family:

Yes, I am often told, you're good to do that. I say yes but every family has their own set of challenges so I want to say, there was one moment, well before when we were speaking and the microphone was off, some families that are in crisis that you spoke to for 3 hours, we passed through the years of when we were in a crisis like these families. We are autonomous, it's going well, we know where we're going, we know how he functions, we know where, we have tricks but when you're faced with turmoil, when your child is 5-6 years old, we went through various emotions, grieving the perfect child, and at some point you need that approbation, 'ah you're good, you guys are doing well', 'well thank you very much.' And it made us feel good. We are now at a stage where we do our job.

**Challenges.** Families are faced with multiple challenges while raising a child with a DD, setting them apart from other family groups. Having a child with a DD can be emotionally devastating for parents. There is not only the anxiety associated with the complications of the therapy schedules, but parents also have to decipher with which intervention plan is best suited for their child. Other anxiety evoking issues include juggling family commitments with employment responsibilities. Mothers shared the challenges they are faced with during their interviews. These are reviewed below.

For instance, mother 1 noted some of these challenges during her interview:

Just other people accepting the fact that we have a child who is different, particularly family members. Over the years, the number of friends we used to have has diminished over the years. There's also the fact that when I want my children babysat, I must have two separate babysitters. I cannot have both babysat at the same place because there will

be fighting. Slowly, I will be honest with you, I see that there has been a slight improvement.

Mother 7 shared how repetition was her biggest challenge while raising a child with a DD:

Well, it's a lot, it's a lot of repetition with these children. You have the impression that you're giving, just to give you an example, for him to learn how to take a shower on his own, we had to work, I had to work with him for 1 year, it hasn't been long since he goes through all the steps on his own and he is almost 13 years old. So these are everyday challenges, and we also have moments where things go well, but right after BANG, we fall back into old problems. And then you're there, oh my god, it won't start again, it lasts for a little bit, and we come out of it, and then BANG, we fall again in something else. Children with autism are like a mountain. Yes, there are challenges every day.

This view was echoed by mother 9 who mentioned:

Do you have 2 hours? We had major challenges it's undeniable. Sometimes it is frustrating, you try to explain something to him and he understands but he is very far from comprehending, but you need to be patient. I learned that with him, because he surprises us. There are pieces that come together in his head but sometimes it takes 2 years. Sometimes he'll come to me and says 'yes that thing.'

***Cohesion between family members.***

*Fears/Worries.* All mothers expressed being worried for the future of their child with a DD. For instance, some of them appeared to worry that their child will never lead a normal social life with meaningful friendships, while others appeared to be concerned about the behaviours and obsessions of their child, since they could potentially interfere with their day-to-day functions.

One other major concern was that no one else would be capable or willing to take care of their child with a DD in the event of their mother's deaths.

For example, mother 6 explained:

Well, what will happen after me, after his father, listen where is he going to end up? Because it's what my daughter has always said since she was young that she would take care of her brother. I've always told her that it isn't her responsibility. If you want to, and it makes sense logistically, fantastic, but you have the right to have your own family and you're allowed to not have that responsibility.

Mother 5 commented: "My only hope is for my daughter to live life. I am scared that she will die too young." On the other hand, mother 8 appeared to be worried about her child's social life:

I think he will be well-functioning in life, but it's more about human relationships that I wonder how it's going to go, he is not, he is not conscious about others. Well, he sees other people's pain, but if you're sick, he doesn't care.

Lastly, mother 3 appeared confused about whether she was worried about her child with a DD's future. In fact, she shared that she and her husband were able to let go of a lot over the years. She stated,

Yes and no. I think that we were able to let go of a lot. I think we are able, and our daughter told you, he has severe epilepsy. So we tell ourselves, either way, he will die one day, so we might as well take advantage of the time we have with him and when he dies, he dies.

**Parental Differential Treatment.** Parenting challenges in families of children with a DD often include PDT. Mothers shared their experience with respects to how they attempt to remain fair while meeting the needs of all their children. Some of the emerging patterns include the time



and attention spent on each child, their reports on how their children may perceive their relationship with each child, and their perspective of the effects of the child with a DD on the typically developing sibling (Chan, & Goh, 2013).

***Time and attention spent with each child.*** Raising a child with a DD often places additional demands on siblings and on other family members (e.g., extended family). Prime among these demands is the lack of sufficient hours in a day to do all the family activities that one perceives as necessary. More precisely, meeting the needs and desires of a child with a DD may impact the amount of time parents can allocate to the other children in the family. For example, mother 9 mentioned how her child with a DD takes up most of her time, leaving very little for her typically developing daughter: “Homework take three times longer, although we developed his autonomy for homework, he still requires support.” She continued and said,

He has to open his homework; he has to reread a lot of stuff, so we have to develop these skills. But, yes, he requires more time, but maybe not twice as much, he maybe requires one third more for me.

Mother 2 highlighted how she and her husband attempt to provide equal time for both children:

I would say yes, with time I would say no, it's very hard to share though all that time because it's not the same type of time. (...) playing fifteen minutes with our typically developing son, and the time with our child with autism will be spent with letters, you know, sharing time, we attempt to share time equally. Do we spend more time with one than the other? I don't think so.

In a similar way, mother 3 also found it a challenge to spend an equal amount of time with each of her children (Chan & Goh, 2013), leaving her typically developing child thinking that she needs to perform to receive the same amount of attention as her brother:

Absolutely. He is like a 2-3 year old child. It's very intensive, constant, and annoying. He is very grateful though. He knows that mom loves him, and knows that his dad loves him. And for him, it is very simple. It is very zen, and he lives in the present moment. He does not worry about the relationships he has, I think he feels like his relationship with us is solid. Our daughter, it's like, oh my god, if I don't perform well my mom won't love me. Oh my god, if I didn't do all my homework, or if my teacher warns me, nobody will love me anymore. She is very into performing and into proving that she is a big girl and that she does what she has to do, and that I tell her all the time, we are not robots, everyone is human, everybody makes mistakes. When she makes a mistake, she becomes devastated, ahhhh I made a mistake! She is very insecure in her relationship with us and she is always thinking that it will crumble into pieces.

***Mothers' reports of children's perception of parent's relationship with each child.***

Mothers also reported on how they think their children perceive the relationships they have with each of the children in their families. For instance, mother 7 noted during her interview:

“Sometimes they will tell me that I am unfair but I ask more from them than I ask of my son. I would say that it revolves mostly around tasks and responsibilities.” During her interview, mother 6 echoed mother 7's statement:

I think that my daughter finds it sometimes a little unfair.... Because it's different, with her, I can explain things, I know she understands. So, I am a little stricter. My son doesn't have that comprehension, so there are little things, the rules are not the same for both children.

Another example stemmed from the interview with mother 4 who stated:

I think that he perceives that we give a lot to his sister.... At some point last year, he was saying you prefer my sister. It's my sister that you like the most, it's her, you want to, you want to get rid of me, you don't want me anymore.

On the other hand, mother 8 mentioned how her son does not necessarily verbalize how he feels, but she notices it in his actions and behaviors: "I think he finds it unfair but he does not say it. I see it in his behaviors. He acts out in order to get attention." Lastly, mother 9 shared that although she attempts to behave in equal ways with her children, she is more permissive with her child with a DD, and hopes that her typically developing child does not notice anything:

No, but we have to be careful because we are fair. I am fair between both but sometimes I am a little bit more permissive with my son, but I do it in a way that my daughter does not notice anything. It is a necessity to let some things go with my son.

***Mothers' perspective of the effects of child with a DD on typically developing sibling.***

Mothers also spoke about the effects that their child with a DD may have on their typically developing siblings. Key problems they discussed included intimidation, grieving the normal sibling and their typically developing child feeling rejected by their sibling who has a DD. For instance, mother 7 stated, "Grieving the normal brother was the most difficult part for them." Another example stemmed from the interview with mother 9, who stated, "Of course, oh yes, it makes her bitter. She feels rejected. She feels rejected by her brother." She continued and shared a few examples:

When she walks by and he says that she smells bad, or when it elevates quickly, she feels like it's unfair, she feels rejected by her brother, she's already told me, she cries a lot and mentions that her brother does not love her.

Other parents shared how the highly demanding schedule associated with having a child with a DD left very little time for their other children. For instance, mother 8 mentioned:

I find that our typically developing child is often left on his own compared to him, the attention is always on our child who has autism because he is the one with a lot of appointments, that is followed by specialists so for our typically developing child, he is not an angel....I find that our typically developing child is often left out.

Lastly, when asked about whether having a child with a DD affected her other children, mother 6 answered:

On every level I would say, yes. First of all, she is more mature than she should be for her age. It affects her regarding friendships and activities. Euh she can't do, I cannot free myself to bring her to meet with her friends, or if she has a friend over, like the other day, her brother came out of the bathroom naked, so that was embarrassing for her. If we want to do outings, it's always, I always have to think in advance about what we will do, what is the logistic behind it, etc. Or simply going to the park, often he won't want to go and if I force him to go, we will be at the park for 5 minutes because it deteriorates pretty quickly.

### **Analysis of Fathers' Interviews**

In this last section, the fathers' interviews are reviewed and analyzed. The emergent patterns, themes and concepts are also discussed. Figure 2 (see end of the parents' subsections) demonstrates the emergent themes that were identified and collapsed into overriding categories.

**The sibling subsystem.** Similar to the mother's analysis, fathers also described numerous types and qualities of interactions between their child who has been diagnosed with a DD and their typically developing child, and if there was more than one typically developing sibling, the

one closest-in-age was considered. These emerging themes included their interpretation of the relationship and the activities their children engage in when together.

***Perspective of the sibling relationship.*** According to the fathers' interviews, having a child with a DD affected the sibling relationship both positively and negatively. Although many of the children had a typical relationship with their siblings, their relationship also differed from many siblings due to the nature of the DD.

In fact, most fathers felt that the sibling relationship had been negatively affected by having a brother or sister with a DD. Fathers stated that it was extremely hard for their children to interact with one another. For instance, father 1 noted during his interview, "The relationship is tense. It depends on the moment, it can go really well in some instances and other times it can be bad." He also described how difficult it was for his children to play together, as his child with a DD is extremely introverted: "It's more her since she is so introverted and withdrawn. She thinks her brother takes too much space, while he would like to play with her, do something with her, but it is difficult." Similarly, father 4 said, "I would say that the relationship is difficult because my child who has a DD doesn't like to interact, she doesn't speak, doesn't move, and she is starting to learn how to walk." Speaking about his children's relationship, father 3 reported,

In a way, it's normal in some respects and in other respects it's not. It's normal, you know, because like every brother and sister they have their little things that get on each other's nerves and they, you know, they'll smack each other or get angry at each other or whatever it is. So they do things that are normal, but on the other hand, the complexity is hard on my daughter. I mean, it's just something she never asked for and she has to deal with what he's putting into the mix day in, day out, so that probably is a complex thing

for her to deal with because, you know, you're a kid, you don't understand why, you don't understand how.

Conversely, some fathers talked about how much their children respect and love each other and how they got on well, with some disagreements as is generally typical of siblings. For example, father 9 said:

My son with a DD and daughter respect each other. My son is often intolerant. My daughter will enter my son's bubble, for example if they watch television together, my son will have a hard time tolerating some of his sister's behaviours since they are bothersome to him.

This view was echoed by father 8 who mentioned, "In general, it goes well. They often play together and there's a little bit of competition." Lastly, father 7 described his children's relationship as different than any other triplet's relationship. He stated,

It is important for him to have his sisters by his side as he likes it less and less to be on his own. He often requests their presence, that they play with him, which wasn't the case before. There's a lot of progress but it's a relationship that is different.

**Activities.** Fathers talked about their children enjoying a range of activities together that included watching television and movies, playing computer games, and playing outside.

According to some of the interviews, video and computer games appeared to be popular amongst some siblings. It was the case in the interview with father 9 who reported:

It can be at the computer, sometimes he needs help, he isn't as comfortable with the computer as his sister, so his sister will come help him, give him tips, save what he is doing on 'Minecraft', she is more agile, and she'll unblock things for him.

Several fathers described how much their children enjoyed performing outdoor activities

such as skiing, playing in the snow, swimming, and riding their bikes. For instance, father 3 mentioned, “Today we were at Valcartier tubing, you know, so we do those types of activities and then in the summer we go swimming, you know, we try to do stuff together outside, biking and stuff like that.” Father 8 commented: “They engage in funny games together. They don’t do sports but they play outside.” Additionally, a few fathers mentioned that their children enjoyed pretend play and games with fantasy characters. For instance, one boy enjoyed fantasizing about being a superhero while another enjoyed re-living video games he plays with.

However, most fathers also reported that their child with a DD has very limited interests and could perform an identical activity, like watching a movie, repeatedly, which hinders the sibling relationship. For example, father 3 reported:

Inside the house, you know, what are their activities, limited to stuff he is capable of, so you know, they’ll watch a movie together but it’s less frequent today because she’s moved beyond the age of the shows that he likes to watch, so they do that, eum, you know, they’ll play different little games, you know.

Another example stemmed from the interview with father 4, who claimed:

No, because I could say that she only enjoys her own television series. She is not able to watch anything else. They have too much of an age difference now, well they only have 3 years, but mentally, there’s a bigger difference.

**Child Rearing.** Through the interviews, fathers discussed their experience of raising a child with a DD. Some of the emerging concepts include the acceptance of their child’s diagnosis, the support they may have received from friends, family, and/or professionals, the rewards and the challenges of raising a child with a DD, and finally the fears they may have with regards to their child’s future.

**Acceptance.** Parents experienced a wide range of emotions and reactions when they initially received the verdict for their children's diagnosis. These include feelings such as disbelief and a sense of bereavement for the child they fantasized and hoped they would share their lives with. Although many parents touched upon shock and bereavement, only one father talked about this and the family's acceptance of his son's diagnosis. In fact, father 7 had to face reality sooner than he had expected because he realized that his expectations were not necessarily in line with reality:

When I first learned I was having triplets, I started making up scenarios in my head of what I could do with my children. I will do this and do that with my children, but it wasn't long before my ideas were erased and replaced.

He also normalized his daughters' paths to accepting their brother with a DD by sharing his own experience:

Yes, of course, for a long time they didn't want to say anything but now they discuss it more openly. But you know, I am not ashamed of saying that I went through a similar path. Today it doesn't bother me, but at first I would only talk about it if people asked me, I wouldn't talk about it openly.

It seemed that some fathers did not touch upon acceptance given that some of the families interviewed may still possibly be at the grieving stage.

**Support.** Some fathers described the importance of receiving support for their families from professionals while raising a child with a DD and found various health and/or education professionals helpful. Some fathers, however, indicated their discontent with the public sector and having to seek private practice professionals to get the care needed. Some of their answers are discussed below.



The majority of fathers indicated receiving help for their typically developing child to help him/her cope with the DD of their siblings. For instance, following a bullying episode in regards to the DD of his sister, the typically developing child from family 4 had received support from the private sector given the lack of resources in the public sector:

I'm trying to find the terminology. If we take a look at organizations that assist us, for example, the CLSC (local community service centre) or the SRSOR (Readaptation services centre), and all of those organizations, no. We had to request help from a private educational psychologist for a few meetings. It really helped. It was private, it didn't come from the school, nothing from the exterior, we had to go private.

Likewise, when asked about whether his family received any type of support/help from the private sector to assist his children in accepting/coping with the sibling's DD, father 7 said:

“Well, for child 1 not directly, child 2 like my wife said I can imagine, we had to get help from a psychologist. It helped.” After being asked if his daughter received any type of support, father 3 stated that his daughter took a class a few years ago for siblings of children with a DD: “A course that she did a few years ago to help her cope with the DD, but other than that, no.”

Although most fathers focused on support received for the typically developing child, it was also noted that some families obtained help for their child with a DD. For instance, father 1 mentioned getting help from a social worker: “We receive outside help from a child and youth's worker that comes over to the house.”

Another parent defined extracurricular activities as a form of help and/or support for his typically developing child while coping with the sibling's DD: “Euh, well, no, it's more extracurricular activities. He takes karate classes, that he really likes, he skies, we do a lot of activities, play soccer during the summer.”

Lastly, two parents (fathers 9 and 5) reported not receiving any type of help for either their typically developing child or their child with a DD. Father 5 commented: “No.”

Additionally, father 5 commented: “No, she has homework but other than that, there’s nothing related to the DD of her sister.”

**Rewards.** The experience of having a child with a DD greatly affected the lives of most fathers, according to their reports. They talked openly about both the positive and negative aspects of this impact. For instance, many fathers described their children as being “a source of pride”, “a victory”, “surprising”, and “really good fun to be with”. For instance, when asked about whether he felt that there were any rewards of having a child with a DD, father 3 stated:

Eum ya, ya sometimes there, there, they don’t come often but there are ya, ya you know the skiing thing, you know just little things like that or you know we go on the mountain bikes and he, well ya we go on the mountain bikes and I was surprised one time a couple years ago, I said you know what we’re gonna try this off route thing. He’s got a little stability problem and off we go, and he did it. Little moment like that, that are just like I never thought we could do that!

Similarly, father 7 noted during his interview, “ (...) Well euh, just raising triplets, well it’s not, it’s not a small thing, well raising triplets and having a handicap child, well yes, it is a source of pride.” Another father shared how proud he feels when his son with a DD reaches a milestone (e.g., potty training):

Valued? I can’t say that I feel valued as a parent of a child with a DD. Well, I don’t feel valued but it’s, it’s small victories, there are things that a normal child would do, it’s, it’s banal, but for us it’s, it’s a big victory (...).

On the other hand, father 5 shared how he became more understanding and less

judgmental of differences amongst individuals because of his daughter's DD: "It made me more sensitive, developed other things, but valued? No. I don't know, there are not many positive aspects other than being more open-minded and, euh, more sensitive towards particular situations."

Lastly, father 4 appeared to be extremely frustrated with how Quebecers act towards people who have a child with a DD, comparing his own experience to friends who traveled to the United States:

Well, I would say that some friends... I have friends, I am giving an example, who went to the United States, euh, they were offered a free meal, so they were wondering what had just happened, well for example, and the manager came to see them and he told them that he was so happy to see parents taking care of a handicap child that for him they were extraordinary. And he paid for their meal. I wouldn't say that this happened to us.

He continued and mentioned how grateful he was for the Make a Wish Foundation who offered a trip to Walt Disney to his family:

Well, we got a trip from "Make a Wish". It really helped, yes, it made us realized that it was because of our child with a DD.... I would say that, overall, this is when we felt valued and that our daughter was really the center of attention there. Over there, you can go in front of people, over there it is respected, even sometimes there are comments "ah, they are this group, ok it's good, it's ok". It's nice, but here in Quebec, forget it. They are going to shut the door in your face and they won't even let you in.

**Challenges.** One of the challenges that was most often talked about by fathers was their children's communication challenges. Fathers mentioned how their children struggled while developing language skills, but they also found it difficult when they were unsure of what their

child was saying. For instance, father 4 stated, “Well, the challenges for us is to develop a means to communicate with her, since she does not speak.” Father 5 explained how they have no mean of communication with their daughter:

Lots of challenges. Just understanding is a big challenge. It’s to know, we have no means of communication for her at the moment. Euh, the big challenge is...has mainly to do with communication and transportation.

Likewise, father 2 reported how his son with a DD appeared to understand certain topics that hold his interests, while other subjects do not seem to be understood. He stated:

Well it’s, it’s the nonverbal, this is what is the most difficult, it’s the fact that he does not communicate, we don’t know, we know he hears, but we don’t know if he understands.

There are things, sometimes we tell ourselves that he understands what he wants. It’s like any child. Because sometimes he reacts, when we tell him to come eat, if he is hungry, he comes instantly, brush his teeth, everyone come gets dressed, he comes but for other actions sometimes we tell him to come do something, and he has no reactions, so it’s difficult to evaluate what he reacts to. In the morning we go skiing, I say “we’re going skiing with your brother, do you want to come”? He uses nonverbal cues to say yes.

Moreover, a few families appeared to be struggling with the sleeping and eating habits of their child with a DD. For instance, father 9 commented: “He had an eating disorder but we realized that he was gluten intolerant.” Regarding the eating patterns of his son with a DD, father 3 stated, “It’s hard to get him to the table sometimes. It depends what the food is, spaghetti he’ll run.” He continued and talked about his son’s sleeping habits:

It’s always there, all the time, it’s always on and you know like, euh, just a simple thing like you know she is 10 and a half and he is 14, well by the age of 14, you’d think that he

would be sleeping in till 9h30, 10h00 on the weekend. Uh, uh, he's up at 6h00 o'clock, 6h30 all the time. He wakes me up and, so you know as a, as a, an example of normal versus not normal. And I am not saying that in every household that kids sleep till 9h30, but you know it's not every household where they get up and they start doing that, 6h00 or 5h00 in the morning and the first you're hearing is the key chain rapping cling, cling, cling, cling, you know if you ask him to stop, well, sometimes he'll stop, and if he is in a bad mood that morning then what he does, he screams in the house, he starts to yell or something, you know, and, oh, he comes in and gets me.

Lastly, he stated:

So, so, is it's just not normal and those little things are, I wouldn't, I wouldn't say everywhere, but there's a lot of and, right, that stuff adds up over time and it's just, it's hard, and so you know for the two of us it's hard and that...that wears off on our daughter.

***Cohesion between family members.***

*Fears/Worries.* Most fathers expressed being worried for the future of their child with a DD, specifically, what would happen to their children when he/she becomes an adult. Some questions that fathers asked included: "Who will take care of my child when my spouse and I die?"; "What sort of life will he or she have?". For instance, after being asked about what fears he had and how they were addressed, father 2 answered:

Oh yes, for sure, for sure. Just being socially accepted worries us. We are well aware that it can be difficult for a typically developing child at school, I am expecting, well we know because we know friends who have children with autism that are much older, some are verbal and as a result they went to a regular school. They did not always have good

moments. We are very apprehensive about the school experience and the future also. What will happen? I got my kids when I was older, I am 56 years old. I had my children when I was 50 years old. It's hard to know his level of autonomy when he becomes older. Will we be able to take care of him if we are still around? I will be 80 years old when he is 30 years old, will I be able to sustain him? If not, will we have to place him in a specialized home? It's all these things that we're trying to figure out, but we try not to think about it too much and live day by day.

Similarly, father 4 appeared to be afraid of what will happen after he and his wife can no longer care for their child: "Oh my god, if we die, who will take care of her?" He continued and mentioned "What will happen, because she might be in a good mood one night and we could find her dead the next morning. We don't know, that's what the syndrome is. All we know is the critical age for these individuals with similar diagnosis is 11 years old or 12 years old." Lastly, father 9 stated: "I am scared that he will be taken advantage of, abused or that he will follow in my footsteps."

Also, many parents were concerned about the lack of autonomy and independence of their child with a DD. Though some of the children were reported as being high functioning, parents were apprehensive about their ability to organize their daily lives and leave the household one day. One father in particular worried about his son's level of autonomy: "As long as he progresses, there is still hope. But yes, I am worried that, my biggest worry is that he doesn't become autonomous and independent and will remain at our house his entire life."

**Parental Differential Treatment.** All nine fathers claimed being involved in differential treatment with their children. However, they all justified their behaviours given the multifaceted needs of the child with a DD (Chan & Goh, 2013). Some of the emerging concepts include the

time and attention spent with each child, their reports on how their children may perceive their relationship with each child, and their perspective of the effects of the child with a DD on the typically developing sibling (Chan & Goh, 2013).

***Time and attention spent with each child.*** Overall, most fathers spoke about how they attempted to provide their children with equal treatment. However, for most families, this was often not achievable (Chan & Goh, 2013). Given the high demands associated with caring for a child with a DD, fathers would often report spending a greater amount of time and providing the child with a DD with more attention than the typically developing sibling. Father 2 highlighted how he and his wife attempt to behave in equal ways but given the severity of the child's disability, they had no choice but to spend more time with the child with a DD: "Sometimes yes, but we, like I said earlier, we talk a lot to manage this attention, we don't want to give him more, but because of his status we do not have a choice." Likewise, other fathers found it difficult to spend a similar amount of time with each of their children (Chan & Goh, 2013). In fact, they often found themselves giving most of their attention to the child with a DD. As a result, the typically developing siblings would sometimes misbehave to gain parental attention.

When she was younger, I remember younger she would imitate her brother so it was a way for her to, well, she had probably noticed that we showed more care to her brother so in doing what he did we would automatically show more care to her.

The parents were not only aware of the lack of time and attention devoted to their typically developing child, but they were also mindful that their child with a DD has different demands (Chan & Goh, 2013). For example, father 7 stated:

Well, what I just said, inequality. I can't ask the same thing to our son with a DD that I ask of the two girls because they are typically developing. He is different and even though we tell the girls, they get frustrated and I understand, I would do the same.

He continued:

And he has responsibilities based on his abilities, the girls, we ask them to complete tasks and all the time it's: "Well he doesn't do it, he doesn't do it." Yes, but he is handicapped and not you. "Yes but it's not fair, it's not fair, it's not fair.

*Fathers' reports of children's perception of parent's relationship with each child.* The fathers also reported on how they think their children perceive the relationships they have with each of the children in their families. Most of the time, fathers thought their children would report their parents' behaviors and actions as unfair. For instance, father 1 noted during his interview, "Sometimes my typically developing child comes and hugs me a little bit. She shows me that she needs more attention (...)." When asked how he thinks his children perceive the relationships he has with each of them, father 2 stated:

Well, the typically developing child, we can't know with the child with a DD. Well, the typically developing child, I think, I think it is ok. Sometimes, on occasion, like a normal child, he'll say, he'll say: "you guys like him more than me". It's rare, he doesn't say it often, but it's happened. Every time he says it, we take the time to sit down with him, and we took the time to explain to him, so I think it is ok.

Similarly, father 4 said of his son who is a typically developing son, "Well, I would say that he often blames us for spoiling his sister more than we spoil him. She receives a lot more gifts." Speaking about how his typically developing children perceive the relationship he has with each of the children in the family, father 7 reported, "In one word, unequal. I am certain that for the



two girls, they perceive, especially for one of the twins, it's illegal, euh unequal. Totally unequal." Lastly, father 1 claimed that he is not sure whether his children notice anything about the relationship he has with each of his children: "I don't know if they notice, I don't know if they see the difference."

***Fathers' perspective of the effects of a child with a DD on typically developing sibling.***

Many fathers raised the issue of struggling with regards to how to respond appropriately to the needs of their family. A range of responses were elicited in response to the questions: "Does having a child with a DD affect your other children? If so, how?" and "How do you think (name of the child with a DD) affects (name of the typically developing child) emotionally, physically, and socially?". Most fathers described how their typically developing children were affected by the DD of their sibling.

Given the time involved in meeting the needs of a child with a DD, some fathers reported having very little time for their other children. A few participants described how their typically developing children felt left out because their parents were more attentive to the sibling with a DD. Some fathers reported experiencing a continual tension between the needs of the child with a DD and those of the typically developing child. For instance, father 9 noted, "It was more intense during the first years because she was often put to the side given that we had to dedicate such an important amount of time with the child who has a DD." Father 2 commented: "Well, he often, he thinks, well, we're very careful but, he often thinks that sometimes we give more attention to his brother. Well, he often says "yea that's it, you love my brother more than you love me." Likewise, when asked about whether having a child with a DD affects his typically developing child, father 5 said:

Well yes, I think so. She's already told us. Because we spend less time with her because

we have to take care of the child with a DD. It limits us in the activities we can do as a family because she has special needs. It also takes up a lot of our energy, so we have less time for the others. It maybe affects her emotionally, she is a little ball of emotions.

In some cases, the typically developing children had social difficulties. For instance, father 9 blamed the fact that his typically developing daughter does not have any friends due to her brother's DD: "She has fewer friends than her brother with a DD, well, she doesn't have any. She does not have any friends. She doesn't have anyone to disclose to, which is most likely related to her brother." Father 4 claimed that the bullying and the intimidation happening at school to the typically developing child was related to his son's sibling's DD: "Yes, we once celebrated a child's birthday here and his friends were asking, "what is wrong with your sister?", a lot of denial, and it had even spread out, there were even repercussions at school. He was intimidated."

Lastly, a few fathers claimed that having a child with a DD affected not only their typically developing daughter, but the family as a whole. For example, father 3 stated,

Oh yes, just the way we interact as a family, because we're forced to cooperate, eum, into how we deal with her, so some stuff you know is, euh, it's even little stuff like, euh, just getting ready you know, he has trouble with motor skills, so getting him dressed, getting him out the door in the winter is a big production and at his age, you know, if he, if he was in quote 'normal' you know, you would say "let's go" and he'd put his stuff on and close the door, we'd go. And you say that to her and yet then you have to come along with him and get him all ready, get him going, and I think, you know, at times she feels a little bit, I have to do everything on my own...it just puts added pressure on the family, you know, it puts pressure on her."

Similarly, father 7 mentioned how his son who has a DD affects his entire family:

Yes, of course. I go back to the same example, for example we go apple picking with the twins association and we have been apple picking and at some point he started having a crisis and it affected everybody. When he gets disorganized, for instance when we go clothes shopping, well, it affects everybody.

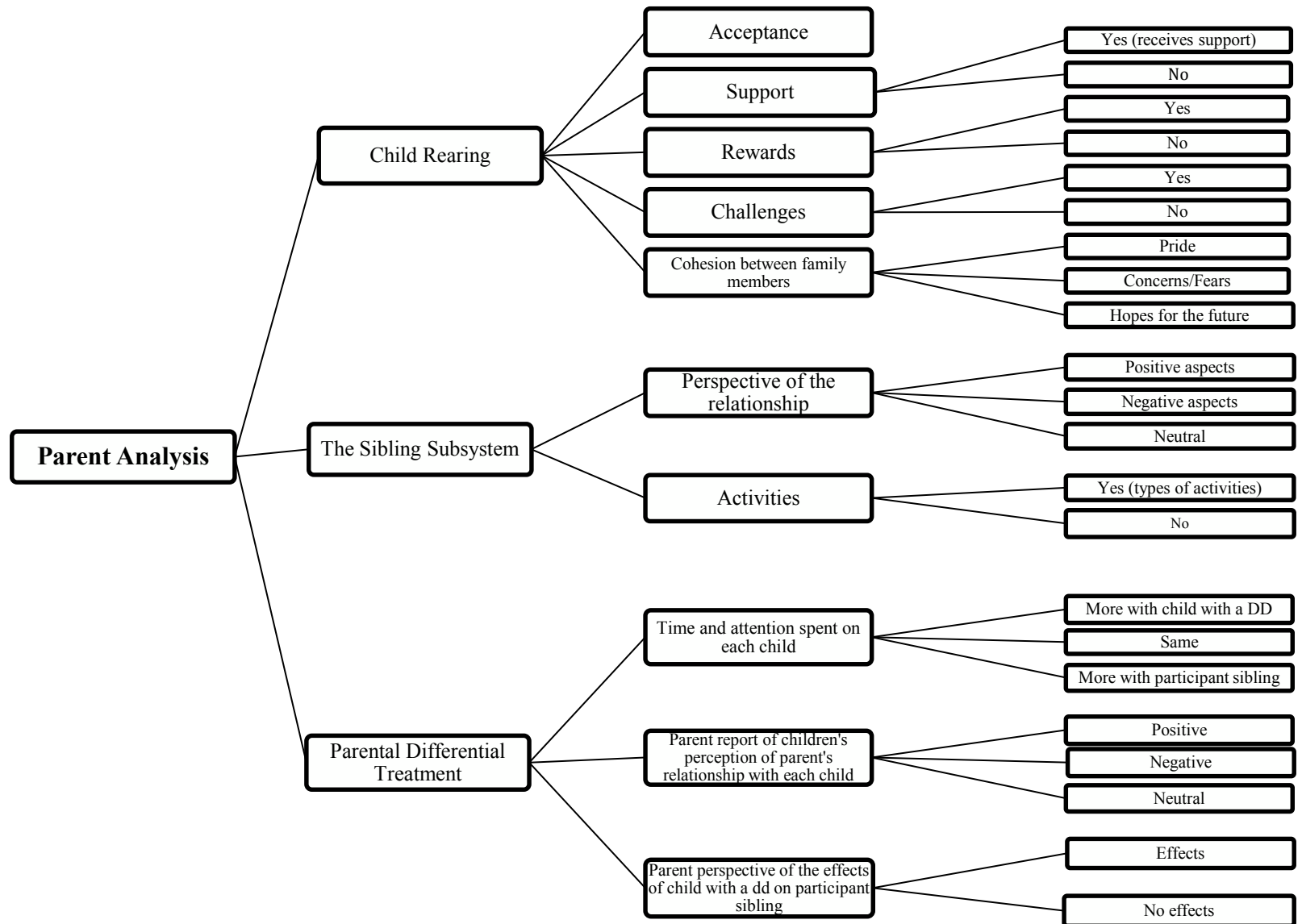


Figure 3. Parent analysis.

## Discussion

The main purpose of this qualitative study was to provide a phenomenological perspective on the associations between PDT and sibling relationship quality during the period of middle childhood in families in which there is a child with a DD. Through open, semi-structured interviews and questionnaires, mothers, fathers, and typically developing siblings were interviewed separately and shared their unique perspectives on the sibling relationship, the treatment services available, whether they perceived evidence of PDT and if so, if they sensed it as fair or unfair, and the rewards, challenges, and fears they may have concerning the child with a DD. Although parents and children were interviewed separately, their perceptions were generally consistent with one another, especially mothers and fathers. In fact, participants reported a variety of positive and negative responses with regards to their experiences. The different themes will be discussed and compared to the relevant empirical literature and theory in this section. The discussion section is organized to address the four aforementioned research questions as well as unforeseen themes that emerged through data analysis. The implications, limitations and future directions of these results will also be discussed.

### **Do Family Members Perceive PDT? If so, do they Sense it as Fair or Unfair?**

The first research questions aimed at investigating if mothers, fathers, and typically developing children agreed on whether they perceived PDT or not. One of main findings demonstrated that most children reported being recipients of PDT. Children commonly reported during the interviews feeling responsible for the well-being of their siblings, as well as taking on emotional responsibilities from their parents, which were not expected of the sibling with a DD. In addition, some children also stated they assumed responsibilities (e.g., household tasks), given the limited capacities of their brother or sister with a DD. As a result, they often perceived their brother or sister with a DD as a burden. The present study confirms

the findings of Angell, Meadan, and Stoner (2012) whose interviews with 12 children aged seven to fifteen with a sibling with autism, showed that participant siblings often reported engaging in roles such as being the entertainers when their siblings needed to be taken care of or the parents' assistants.

Similarly, while most parents attempted to spend equal amounts of time and give equal attention to all their children, it was often not achievable (Chan & Goh, 2013). Interestingly, most mothers and fathers also reported during the interviews treating their children differently given their different needs and developmental stages (Chan & Goh, 2013; Jensen et al., 2013). These results corroborate the findings of Jensen et al. (2013), who suggested that providing equal treatment is nearly impossible given that children's needs and developmental stages may be so different. However, given the pronounced levels of PDT that were often reported in the current study, it is important to question if these behaviours could have had detrimental consequences on the children's well-being and relationships as McHale et al. (2000) suggested. The findings from this study demonstrate the need for mothers and fathers to communicate with their typically developing children about different and unequal treatment. This would allow them to assist their children in understanding the reasons behind their behaviours and actions (McHale et al., 2000).

The current results suggest that mothers, fathers, and children appeared to perceive episodes similarly when differential treatment of siblings was concerned (Kowal & Kramer, 1997). For instance, child 7 mentioned although she finds it unfair, she takes on additional responsibilities given the limited capacities of her brother. Similarly, it was reported by mother 7 that she asks more of the typically developing children than she does of her child with a DD. Although, these results differ from some published studies (Furman, Jones, Buhrmester, & Adler, 1989; Kowal et al., 2004; Larson & Richards, 1994), they are consistent with the family systems framework as well as understanding family processes,

which suggest that communication and interactions between individuals from the same nuclear family is an approach with which families generate a shared reality (Broderick, 1993; Kowal & Kramer, 1997).

Interestingly, children, mothers and fathers reported low levels, if any, of differential experiences when filling out the Sibling Inventory for Differential Experiences Questionnaire. While parents and children commonly reported PDT during the interviews, their answers did not appear to be consistent with their reports on the questionnaires (Harris & Brown, 2010). In fact, most participants seemed more comfortable talking about PDT during the interviews when they were able to qualify their responses as opposed to quantifying their experiences on the questionnaires. Overall, the interviews allowed the participants to justify their actions, which was obviously more difficult to do on the questionnaires.

Following from the concept of distributive justice that “emphasizes the importance of considering not only children’s perceptions of differential treatment, but also the degree to which children feel the differential treatment is warranted”, the second research question consisted of examining whether children perceived that particular parental behaviours were fair or unfair (McHale & Pawletko, 1992, p. 68). Overall, most children reported understanding why differential treatment was necessary. In line with these findings, several researchers argued that the degree to which children believe that differential treatment is necessitated is associated with positive consequences, even when the magnitude of parental differential treatment is rated as elevated (Kowal & Kramer, 1997; Kowal et al., 2002; Larson & Richards, 1994; McHale & Pawletko, 1992; McHale et al., 2000, Meunier et al., 2012). However, in the current study the children explanations were often followed by statements expressing how although they understood why their parents treated the children in the family differently, they still rated their parents’ behaviours as unfair. While reviewing the

transcripts, some children may have possibly felt guilty speaking about their parents' behaviours in such a way. As a result, some children seemed to be making excuses for their parents' resentful behaviours, such as being forced to prepare meals for their siblings with a DD. In contrast to earlier findings, these perceptions and behaviors have not previously been described in the current literature.

Interestingly, children's responses when asked to rate their parents' behaviors as either fair or unfair on the Sibling Inventory for Differential Experiences (SIDE-R) did not coincide with their interview data. Overall, children rated differential control and affection by both parents as fair on the SIDE-R. These results are consistent with those of Kowal et al. (2002) who demonstrated that children are not constantly opposed to being treated differently from their brothers and/or sisters. Once again, children may have been more comfortable talking about issues related to perceived fairness of PDT during the interviews when they were able to justify themselves.

One of the primary purposes of this project was to look at how the magnitude and intensity of differential treatment, as well as its fairness were linked to the quality of siblings relationships. In general, it appeared that the small number of children who reported no PDT or fairness spoke highly of their sibling who has a DD. In fact, some identified their sibling as their 'best friend'. These results corroborate the ideas of Kowal and Kramer (1997) who suggested that in a study conducted with siblings in middle childhood and adolescence, PDT was associated with a positive sibling relationship when children perceived it as fair.

On the other hand, children who reported being the recipient of PDT and rating it as unfair appeared to focus on the negative aspects of their relationship with their sibling as opposed to the positive facets. This may suggest a lack of interaction and communication as well as an absence of a collaborative relationship between the two children. This perceived experience may not be conducive to building a trustworthy and strong relationship between



the siblings. The findings are in line with Jensen et al. (2013) who found that larger differences in parental treatment were associated with less sibling intimacy. In addition, these results are in agreement with research performed by McHale et al. (1995), which reported that siblings who were the recipient of less parental warmth or more parental control compared to their brothers or sisters reported construed sibling relationships.

Overall, the findings of the current study may indicate that there is an association between less favourable parental treatment and a poorer quality sibling relationship, as at least as perceived by the typically developing child. Of course, this pattern would need to be replicated in a larger sample, although the pattern appears to be in line with the literature cited above regarding PDT in families with only typically developing children.

### **Perceptions of the Sibling Subsystem**

The third and fourth research questions examined how mothers, fathers, and children perceive the sibling relationship. Although scattered positive aspects were revealed, most of the issues that emerged from the interviews included a negative perception of the sibling relationship, a lack of interactions and communication, as well as elements and behaviours that prevent shared activities from happening. Overall, these findings are reflective of the various sibling relationship issues discussed in the literature, in particular, for families in which there is a child with a DD (Greenberg, Seltzer, Orsmond, Krauss, 1999; Knott, Lewis, & Williams, 1995; Schopler & Mesibov, 1984; Seltzer, Greenberg, Krauss, Gordon, Judge, 1997; Seltzer, Krauss, Shattuck, Orsmond, & Lord, 2003; Seltzer, Orsmond, & Esbensen, 2009).

The initial interview questions required participants to speak about and describe the sibling relationship. Although children, mothers, and fathers did not use the same terminology when expressing their thoughts and feelings about the relationship, they all appeared to report a similar reality. For instance, some of the words participants used when

describing the relationship included aggressive, unpredictable, fluctuating, difficult, complex, forced, conflictual, and busy. These results appear to be in agreement with those obtained from the parents' reports on the Parental Perceptions of Children's Sibling Relationships Questionnaire (PEPC-SRQ). Although there were some discrepancies between the mothers' and fathers' answers, both reported that warmth did not occur on a regular basis, and they occasionally stated that agonism and rivalry were present in their children's relationships. Given that all participants did not commonly describe the presence of sibling rivalry, it would be interesting to evaluate whether the participants' answers were influenced by the lack of interactions between the typically developing sibling and the child with a DD. In other words, would rivalry be more common if children cooperated and intermingled a little more? These results are in accord with recent studies indicating that typically developing siblings of children with a DD divulged less intimacy with their sibling and less nurturance than brothers and sisters of children with Down syndrome and typically developing children (Kaminsky & Dewey, 2001). In addition, the aforementioned patterns differ from typically developing comparison children, wherein intimacy and closeness tends to be a recurrent theme (Larson & Richards, 1994; McHale & Crouter, 1996).

Another common theme mentioned by most participants included the lack of interactions and communication between the typically developing child and the child with a DD (Sullivan, 2011). In fact, both children and parents reported a lack of interactions between the typically developing sibling and the child with a DD (Sullivan, 2011). Some children reported not engaging in any type of interaction with their sibling. As a result, siblings missed opportunities to care and provide support for one another and engage in activities together. Opperman and Alant (2003) reported similar findings in a study of adolescents between the ages of twelve and fifteen years who had a sibling with severe disabilities. Their results indicated that siblings of children with an autism spectrum disorder

often have limited interactions with family members (Opperman & Alant, 2003).

Furthermore, these results are also consistent with those of Knott et al. (1995) who found that “siblings experienced less closeness, had a decreased number of interactions, and viewed the brother or sister with an autism spectrum disorder as a burden” (Seltzer, Orsmond, Esbeben, 2009, p. 70).

The findings of the current study are in accord with recent studies indicating that the sibling’s behaviours may impact the sibling relationship negatively (Greenberg et al., 1999; Kowal & Kramer, 1997; Seltzer et al., 2003; Seltzer et al., 2009). In fact, it has been reported that siblings may be less enthusiastic with regards to engaging in activities with their sibling with a DD given their fear of physical and verbal aggression (Seltzer et al., 2009). Difficult behaviours, such as the inability to communicate, intolerance to odours and noises, an extremely short attention span may also implicitly impact sibling activities, as was evident in the current study (Seltzer et al., 2009). Moreover, “parents may be less willing to engage in family activities such as going out for a meal and therefore limiting the opportunity for siblings to engage in shared activities” (Seltzer et al., 2009, p. 9).

In sum, these findings suggest that the nature of the family system and family dynamics are influenced by the presence of a child with a DD, which may indicate that these families are distinct in some ways from families with only typically developing children. Clearly, having a sibling with a DD may sometimes hinder the development of a high quality sibling relationship, although warm and caring interactions were reported by some typically developing children.

### **Child Rearing Issues**

When asked about whether their family received any sort of support for their typically developing children, only some participants claimed receiving help for their children. The most common complaints mentioned by parents included the long waiting lists for

intervention services as well as the lack of resources in the public sector. Some parents even reported being refused a service or waiting as much as several months for services, resulting in missed opportunities to help children create healthy relationships with their siblings, as well as other family members and peers. These results are in line with those observed in earlier studies in which it was shown that services are not routinely available for siblings and continue to be seriously lacking (Banks, Cogan, Deeley, Hill, Riddell, & Tisdall, 2001; Lukens, Thorning, & Lohrer, 2002; Naylor & Prescott, 2004). Only a few families from the present study had the opportunity to seek help from the private sector, given its associated financial costs. Some families indicated they had to raise funds for their children to receive the appropriate help. The experience of waiting for services could result in elevated stress and challenges, resulting in siblings' and families' needs left unmet, thereby compounding the challenges they face as well as the quality of the sibling relationship (Eisenberg, Cumberland, & Spinrad, 1998). This finding provides support for Bronfenbrenner's ideas about the importance of the exosystem and its influence on children's development and family dynamics (Bronfenbrenner, 1979, 1986). An important point to consider for further research is whether all parents are able to recognize that their children may need help given the stressors and challenges the families face. Given that only a few families sought help, we questioned whether they did not recognize the stress and challenges their child with a DD may bring into the family, and as a result, they did not seek support.

Lastly, both children and parents commonly expressed concerns for the future of the child with a DD. For instance, participants repeated in several instances that they wondered what would happen to the child with a DD when both parents die. In addition, some participants expressed concerns for the upcoming experiences of this child, such as entering high school, possible difficulties in forming significant friendships, and being independent. Lastly, parents reported many concerns regarding the diminished quality of life for their

child, such as the health risks associated with the DD of some children (e.g., greater risks of early death). Interestingly, children and parents appeared to agree on this matter. The typically developing children were extremely aware of the situation and it appeared to be a great concern to them. These results seem to be consistent with other research, which found that children tend to be concerned about the future of their siblings with a DD (Hastings, 2003; Ross & Cuskelly, 2006). In addition, these results corroborate the arguments of Lee, Harrington, Louie, Newschaffer (2008), who suggested that mothers and fathers of children with autism had serious worries and apprehensions about their children's comfort and happiness.

Although participants enumerated several factors that may hinder the development of a positive sibling relationship, it seems that there is a few elements that can undertake the role of 'buffers' to these risks (Kaminsky & Dewey, 2001; McHale et al., 1986; Ross & Cuskelly, 2006). These include: parents showing low levels of preference, making sure there is time devoted to the typically developing child, enabling the family to engage in activities together, informing the typically developing children about the DD, providing high levels of support to the family, and finally, planning ahead to provide safeguards for the long-term well-being of the child with a DD (Kaminsky & Dewey, 2001). It is evident that introducing, implementing, and teaching methods to parents so that they can take an active role in fostering a positive relationship between their children would enable more viable relationships. Furthermore, providing children with tools would enable them to socialize with their siblings, as discussed below in the implications section.

### **Role of the Researcher**

Prior to commencing this study, the role of the researcher necessitated the identification of personal and professional issues, personal value systems, interests as well as assumptions and biases (Hays & Singh, 2012). For this study, neutral questions were chosen

to allow the interviewees to decide upon answers without directions or pressure (Orsmond & Seltzer, 2007). Given that the researcher served as an educator in centers offering specialized services for adults and children with a DD for several years, she was exposed to children with a DD and their families. The researcher considers that these experiences enhanced her mindfulness, comprehension, and understanding of the issues being tackled in this research project (Orsmond & Seltzer, 2007). Although every effort was made to guarantee neutrality throughout the process, the investigator is conscious that her roles as a daycare worker, student, and researcher could potentially lead personal biases in how she views and understands the data that was collected and their interpretation (Hays & Singh, 2012; Orsmond & Seltzer, 2007). She recognized the need to remain as neutral as possible when analyzing the data to ensure the validity of the answers as well as to understand the experiences of the participants (Hays & Singh, 2012; Merriam 2009; Orsmond & Seltzer, 2007).

### **Limitations and Future Directions**

Given that previous research was lacking in providing a phenomenological perspective of the associations between PDT and its impact on the family dynamics of families with a child with a DD, this study was designed to address some of gaps in the current literature. Although this qualitative study contributes to the research on parental differential treatment and sibling relationship quality in families in which a child was diagnosed with a DD, several limitations should be considered.

First, the small sample size might have been a limitation. This research was based on nine volunteer-based Caucasian family of French decent. As a result, it may not be illustrative and typical of the rest of the population, especially with regards to cultural diversity (Seltzer et al., 2009). In refining this project, it could be useful to replicate this study with families from diverse backgrounds. The way individuals perceive a DD varies

from culture to culture. Beliefs, cultural traditions, and values affect how people cope with, view, and adapt to a DD. In addition, researchers discuss the lack of knowledge regarding families from diverse backgrounds who have children with a DD (Sage & Jegatheesan, 2010). Given these suggestions, it would be important to include a wide range of participants and take into account cultural influences when studying this phenomenon.

Secondly, most of the data in this study were collected through participant self-reports, which may be another limitation (Hays & Singh, 2012; Merriam, 2009). When answering the interview questions, the participants may not have been able to recall or remember events that occurred at some point in the past (Creswell, 2007). As a result, participants may have exaggerated and embellished events as more significant than they actually were when they occurred (Creswell, 2007; Hays & Singh, 2012; Merriam, 2009). To improve the validity and reliability of this study, “open questions could be added to allow respondents to expand upon their replies and confidentiality could be reinforced to allow respondents to give more truthful responses” (e.g., limit the amount of personal information collected) (Attia, Gratia, De Herde, & Hensen, 2013, p. 9). Nevertheless, the data do indicate how participants were currently perceiving the family situation and how it may have influenced family interactions. Also, based on the length of some of the interviews, it appeared that most participants were comfortable talking about their perceptions and experiences.

Given the current findings, “longitudinal research is needed to gain more insight into the sibling experience” (McHale et al., 2012, p. 5). Extending this research study over a lengthier duration would enable a researcher to look at different aspects of the phenomenon of inquiry such as the development of the relationship and over different developmental periods (Creswell, 2007; Hays & Singh, 2012; Merriam, 2009). It could also be interesting to examine the continuity or discontinuity of certain variables over time, such as frustration felt

by the sibling over not being able to participate in activities with their brother and/or sister.

Further research about sibling relationships of children with a DD should also focus on the trajectory of the sibling relationship over time when one sibling has a DD (Seltzer et al., 2009). This type of research would enable researchers to look at modifications that might arise over time, and therefore provide patterns of observations and information about each individual (Seltzer et al., 2009). Certainly, it would provide further information about the family system and functioning for these families. Finally, literature suggests the need to include demographically disadvantaged families in studies as most available research uses demographically stable samples (Seltzer et al., 2009).

### **Implications for Practice**

This phenomenological study contains several implications for practice. Overall, the findings from the present study indicate that having a sibling with a DD is associated with both positive and negative aspects of the sibling relationship. There is a body of work demonstrating that consistent, and individualized parental attention, providing ongoing information about a sibling's DD, open communication, and opportunities for interaction are all fruitful avenues for fostering a positive relationship between siblings when one has a DD (Feinberg et al., 2012; National Quality Standard Professional Learning Program [NQSPLP], 2012). With effective guidance from parents, interactions between siblings can be facilitated, at least in some cases (NQSPLP, 2012). Giving simple instructions, as well as providing praise for appropriate play interactions are simple skills that can be taught to children that might enable them to engage in playful interactions (NQSPLP, 2012). Parents might also be able to attend workshops where they could learn strategies for teaching their children how to give their sibling attention and simple instructions, and tips on how to praise play/exchanges (NQSPLP, 2012). This could in turn improve the relationships within a nuclear family. In considering that PDT had been linked to less positive sibling relationships, as this study



illuminated, several changes could be considered to improve relationships as a whole within a nuclear family. Responding to the aforementioned problems, it is essential for clinicians to place an emphasis when implementing child and family programs (Feinberg et al., 2012; NQSPLP, 2012). When deemed appropriate, the possible negative consequences of PDT should also “be explained to parents, with support for monitoring and disrupting such processes” (Feinberg et al., 2012, p. 15). Given that such issues are not likely to be resolved promptly, it would be important, in the meantime, to explain what the DD is to siblings in developmentally appropriate terms, and ensure that every child is a fully integrated member of the household. Furthermore, parents also should be conscious of the influence their own parenting may have and how it could affect their children’s relationships.

### **Conclusion**

This study reveals some of the challenges a family may be facing while raising a child with a DD. In the present study, semi-structured interviews and questionnaires were used to gain insight about parental differential treatment and sibling relationships regarding their interactions, and the type of social play in which the siblings engage. The semi-structured interviews allowed parents and siblings to share their unique knowledge and experience about the topics of interest. The questionnaires sometimes generated results confirming other data regardless of the disparities and differences in data collection techniques, analysis, and interpretation (Harris & Brown, 2010). Both forms of assessment generated new hypotheses about the sibling relationships of children with a DD. In addition, they contributed essential insights about the type of relationship the siblings have with one another. This phenomenon needs further analysis but shows promise as an important area of investigation. The implications of the findings suggest that professionals may be able to implement, introduce, and teach methods to parents so that they can take an active role in fostering a positive relationship between their children.

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Appendix A  
Consent/Assent Forms



## INFORMATION AND CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Study Title:** Parental Differential Treatment and Sibling Relationship Quality in Families with a Child with a Developmental Disability

**Researcher:** Marie-Michèle Truchon

**Researcher's Contact Information:**

A. Email: [marymichelle.truchon@gmail.com](mailto:marymichelle.truchon@gmail.com)

B. Telephone: 514-267-6279

**Faculty Supervisor:** Dr. Nina Howe

**Faculty Supervisor's Contact Information:**

A. Email: [nina.howe@education.concordia.ca](mailto:nina.howe@education.concordia.ca)

B. Telephone: 514-848-2424 ext. 2008

**Source of funding for the study:** Not Applicable

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

### A. PURPOSE

The first purpose of the research is to identify how parents believe that they interact with both of their children and if their typically developing child thinks this is fair or not. The second objective is to examine how the typically developing sibling views their interactions with their brother or sister. Finally, the last purpose of this study is to assess whether and how the sibling relationship might be impacted when one of the siblings has a developmental disability.

### B. PROCEDURES

Each family will be asked to participate in a session in their home environment that will last between 60 minutes and 90 minutes. Both parents and only the typically developing child will be interviewed, but not the child with a disability. All the interviews will be audio-recorded. To participate in this study, the participant sibling (between the ages of 8 and 12 years old) will be asked to do the following:

A. Complete 1 questionnaire

- A short questionnaire that asks children about the kind of interactions they have with their sibling (e.g., 16 questions, for example how often they play together, have disagreements).

B. Participate in an interview with me that should last between five and ten minutes. The interview will be adapted to an appropriate level for the child by me to ensure the child understands my questions. For example, I am interested in asking your child

about the relationship he or she has with the sibling with a developmental disability. I am also interested in asking about their perceptions of their mother and father's parenting (e.g., rules in the house). Finally, I am going to be asking them about whether they think these experiences with their parents are fair or not in comparison to their sibling.

In addition, each parent/guardian is asked to do the following:

- A. Complete 3 questionnaires
  - A short demographic questionnaire on your family
  - A short questionnaire asking about the similarities and differences in how you parent your two children.
  - A questionnaire that asks you to rate the quality of your children's sibling relationship.
  
- B. Participate in an interview with me that should last between fifteen and twenty minutes. For example, I am interested in asking about you about your children's relationship.

### **C. RISKS AND BENEFITS**

There is no foreseeable risk of any harm to participants and others.

There are no direct benefits for the individuals participating in this study. However, the participants may be contributing indirectly by increasing the knowledge about sibling relationship quality in families with a child with a developmental disability. In addition, they might gain knowledge about the pertinent issues by asking questions throughout the process and by reading a short report of the findings that will be sent after the completion of the study.

### **D. CONFIDENTIALITY**

We will gather the following information as part of this research: demographic information, your parenting styles with the two children, your rating of the quality of the sibling relationship, and your child's view about how they interaction with their sibling.

By participating, you agree to let the researchers have access to information about the topics listed above. This information will be obtained from both parents and your typically developing child.

We will not allow anyone to access the information, except myself and my supervisor because only we are directly involved in conducting the research, and except as described in this form. We will only use the information for the purposes of the research described in this form.

We will protect the information by storing electronically on a password-protected computer in Dr. Howe's research office the data collected, consisting of audio-recording tapes, and transcript/notes. The questionnaires will be stored in a locked filing cabinet in Dr. Howe's research office. This material will be treated with great care in order to protect the confidentiality of the participants by assigning a number to each participant. The only people

who will have access to this information are the researcher, and the participants themselves. Once the study is completed all data will be destroyed.

We intend to publish the results of the research. However, it will not be possible to identify you in the published results. If quotes are used from the interviews the participant's number or a pseudonym will be used.

In certain situations we might be legally required to disclose the information that you provide. This includes situations, such as child abuse or an imminent threat of serious harm to specific individuals. If this kind of situation arises, we will disclose the information as required by law, despite what is written in this form. My supervisor, Dr. Nina Howe and my committee member, who is also a licensed psychologist, Dr. Harriet Petrakos would be consulted to apply any legal requirements.

#### **E. CONDITIONS OF PARTICIPATION**

You do not have to participate in this research. It is purely your decision. If you do participate, you or your child can stop at any time. You can also ask that the information you provided not be used, and your choice will be respected. If you decide that you don't want us to use your information, you must tell the researcher 1 week following the meeting. In a situation where a participant chooses to withdraw, all their information and data will be destroyed.

If participants are being offered compensation:

As a thank you for participating in this research, each child in the family will receive an age appropriate book of their choice. There are no negative consequences for not participating, stopping in the middle, or asking us not to use your information.

#### **F. PARTICIPANT'S DECLARATION**

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. A parent's signature in the space provided below indicates their family's consent (including the sibling's) to participate in this research study. The typically developing sibling will also be asked to provide verbal assent to participate on the day of the meeting.

**MOTHER'S NAME** \_\_\_\_\_  
(please print)

**SIGNATURE** \_\_\_\_\_

**FATHER'S NAME** \_\_\_\_\_  
(please print)

**SIGNATURE** \_\_\_\_\_

**DATE** \_\_\_\_\_

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514-848-2424 ext. 7481 or [oor.ethics@concordia.ca](mailto:oor.ethics@concordia.ca).



### Sibling Verbal Assent Script

Hi (name of the child)! I am Miss Marie-Michèle. I am doing a project for school on how brothers and sisters get along and I am asking you to help me.

If you agree to help, you and I would spend some time talking together at your home, just the two of us. I will be asking you some questions about your feelings and how you get along with (name of brother or sister with special needs). I am also going to be asking you some questions about the ways in which you think your mother and father parent you and (name of brother or sister with special needs), for example what kind of rules are in your house. Lastly, I am going to ask you to compare your experiences with those of (name of brother or sister with special needs) and to tell me if those experiences are fair or not. I will audio-record what you tell me so that I don't forget (I will be showing the child the recorder apparatus I will be using).

If you get tired you can take a break and then we can try again, if you want. You may decide to stop at any time. You do not have to answer any questions that you do not want to. Everything that you say is private and will be kept between you and me. I will not tell your parents or anyone else unless I think that you are not safe and you need help. Then I will have to tell an adult.

Do you have any questions? Do you understand what we will be doing?

Do you want to help me with this project by answering some questions about how you get along with (brother or sister)?

If yes, thanks for helping me out.

If no, that's ok.

Appendix B

Ethics Forms



## SUMMARY PROTOCOL FORM (SPF)

Office of Research – Research Ethics Unit – GM 900 – 514-848-2424 ext. 7481 –  
<mailto:oor.ethics@concordia.ca> – [www.concordia.ca/offices/oor.html](http://www.concordia.ca/offices/oor.html)

### IMPORTANT INFORMATION FOR ALL RESEARCHERS

Please take note of the following before completing this form:

- You must not conduct research involving human participants until you have received your Certification of Ethical Acceptability for Research Involving Human Subjects (Certificate).
- In order to obtain your Certificate, your study must receive approval from the appropriate committee:
  - Faculty research, and student research involving greater than minimal risk is reviewed by the University Human Research Ethics Committee (UHREC).
  - Minimal risk student research is reviewed by the College of Ethics Reviewers (CER; formerly the “Disciplinary College”), except as stated below.
  - Minimal risk student research conducted exclusively for pedagogical purposes is reviewed at the departmental level. **Do not use this form for such research.** Please use the Abbreviated Summary Protocol Form, available on the Office of Research (OOR) website referenced above, and consult with your academic department for review procedures.
- Research funding will not be released until your Certificate has been issued, and any other required certification (e.g. biohazard, radiation safety) has been obtained. For information about your research funding, please consult:
  - Faculty and staff: OOR
  - Graduate students: School of Graduate Studies
  - Undergraduate students: Financial Aid and Awards Office or the Faculty or Department
- Faculty members are encouraged to submit studies for ethics by uploading this form, as well as all supporting documentation, to ConRAD, which can be found in the MyConcordia portal.
- If necessary, faculty members may complete this form and submit it by e-mail to [oor.ethics@concordia.ca](mailto:oor.ethics@concordia.ca) along with all supporting documentation. Student researchers are asked to submit this form and all supporting documentation by e-mail, except for departmental review. Please note:
  - Handwritten forms will not be accepted.
  - Incomplete or omitted responses may result in delays.
  - This form expands to accommodate your responses.
- Please allow the appropriate amount of time for your study to be reviewed:
  - UHREC reviews greater than minimal risk research when it meets on the second Thursday of each month. You must submit your study 10 days before the meeting where it is to be reviewed. You will normally receive a response within one week of the meeting. Please confirm the deadline and date of the meeting with the staff of the Research Ethics Unit.
  - CER reviews, and delegated reviews conducted by UHREC generally require 2 to 4 weeks.
- Research must comply with all applicable laws, regulations, and guidelines, including:
  - The [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#)

- The policies and guidelines of the funding/award agency
- The [Official Policies of Concordia University](#), including the *Policy for the Ethical Review of Research Involving Human Participants, VPRGS-3*.
- The Certificate is valid for one year. In order to maintain your approval and renew your Certificate, please submit an Annual Report Form one month before the expiry date that appears on the Certificate. You must not conduct research under an expired Certificate.
- Please contact the Manager, Research Ethics at 514-848-2424 ext. 7481 if you need more information on the ethics review process or the ethical requirements that apply to your study.

### **ADDITIONAL INFORMATION FOR STUDENT RESEARCHERS**

- If your research is part of your faculty supervisor's research, as approved, please have him or her inform the Research Ethics Unit via e-mail that you will be working on the study.
- If your research is an addition to your faculty supervisor's study, please have him or her submit an amendment request, and any revised documents via e-mail. You must not begin your research until the amendment has been approved.

### **INSTRUCTIONS FOR COMPLETING THIS FORM**

- Please make sure that you are using the most recent version of the SPF by checking the OOR website.
- Please answer each question on the form; if you believe the question is not applicable, enter not applicable.
- Do not alter the questions on this form or delete any material. Where questions are followed by a checklist, please answer by checking the applicable boxes.
- The form can be signed and submitted as follows:
  - Faculty research submitted on ConRAD will be considered as signed as per section 16.
  - SPFs for faculty research submitted via the faculty member's official Concordia e-mail address will also be considered as signed as per section 16.
  - Both faculty and student researchers may submit a scanned pdf of the signature page by e-mail. In this case, the full SPF should also be submitted by e-mail in Word or pdf format (not scanned).
  - If you do not have access to a scanner, the signature page may be submitted on paper to the OOR.

### **ADDITIONAL DOCUMENTS**

Please submit any additional documents as separate files in Word or PDF format.

## I. BASIC INFORMATION

**Study Title:** Parental Differential Treatment and Sibling Relationship Quality in Families with a Child with a Developmental Disability

**Principal Investigator:** Marie-Michèle Truchon

**Principal Investigator's Status:**

- Concordia faculty or staff
- Visiting scholar
- Affiliate researcher
- Postdoctoral fellow
- PhD Student
- Master's student
- Undergraduate student
- Other (please specify):

**Type of submission:**

- New study
- Modification or an update of an approved study.
- Approved study number (e.g. 30001234):

**Where will the research be conducted?**

- Canada
- Another jurisdiction:

## 2. STUDY TEAM AND CONTACT INFORMATION\*

Role	Name	Institution <sup>†</sup> / Department / Address <sup>‡</sup>	Phone #	E-mail address
Principal Investigator	Marie-Michèle Truchon	Department of Education/1455, de Maisonneuve Blvd. W. Montreal, Quebec, H3G 1M8	514-267-6279	Marymichelle.truchon@gmail.com
Faculty supervisor <sup>§</sup>	Dr. Nina Howe	Department of Education/1455, de Maisonneuve Blvd. W. Montreal, Quebec, H3G 1M8	514-848-2424 Extension: 2008	Howe.nina@gmail.com
Committee	Dr. Harriet	Department of	514-848-	hpetrakos@education.concordia.ca

member <sup>l</sup>	Petrakos	Education/1455, de Maisonneuve Blvd. W. Montreal, Quebec, H3G 1M8	2424 Extension: 2013	
Committee member <sup>l</sup>	Dr. Miranda D'Amico	Department of Education/1455, de Maisonneuve Blvd. W. Montreal, Quebec, H3G 1M8	514-848- 2424 Extension: 2040	miranda@education.concordia.ca

Additional Team Members <sup>o</sup>				
Not applicable	Not applicable	Not applicable	Not applicable	Not applicable

## Notes:

\* If additional space is required, please submit a list of team members as a separate document.

†For team members who are external to Concordia only.

‡For individuals based at Concordia, please provide only the building and room number, e.g. GM-910.03.

§For student research only.

lFor research conducted by PhD and Master's students only.

<sup>o</sup>Please include all co-investigators and research assistants.

### 3. PROJECT AND FUNDING SOURCES

Please list all sources of funds that will be used for the research. Please note that fellowships or scholarships are not considered research funding for the purposes of this section.

Funding Source	Project Title*	Grant Number <sup>†</sup>	Award Period	
			Start	End
Not applicable	Not applicable	Not applicable	Not applicable	Not applicable

## Notes:

\* Please provide the project title as it appears on the Notice of Award or equivalent documentation.

† If you have applied for funding, and the decision is still pending, please enter "applied".

### 4. OTHER CERTIFICATION REQUIREMENTS

Does the research involve any of the following (check all that apply):

- Controlled goods or technology
- Hazardous materials or explosives

- Biohazardous materials
- Human biological specimens
- Radioisotopes, lasers, x-ray equipment or magnetic fields
- Protected acts (requiring professional certification)
- A medical intervention, healthcare intervention or invasive procedures

*Please submit any certification or authorization documents that may be relevant to ethics review for research involving human participants.*

Not applicable

## **5. LAY SUMMARY**

Please provide a brief description of the research in everyday language. The summary should make sense to a person with no discipline-specific training, and it should not use overly technical terms. Please do not submit your thesis proposal or grant application.

This qualitative study seeks to examine the associations between parental differential treatment and sibling relationship quality during the period of middle childhood in families in which there is a child with a developmental disability.

Past research demonstrates that children raised in the same family are distinct from one another in terms of personality traits and diagnoses of psychopathology. In fact, theorists argue that siblings who are raised in the same nuclear family may be as different from one another as those children who are brought up in different families. One important family factor that may contribute to this variation is parental differential treatment. Parental differential treatment is defined as the within-family differences in parenting experienced by siblings, which, in turn, is associated with the quality of sibling relationships.

Children are often concerned about whether parents treat their sibling(s) more favourably than they are treated. Starting at a young age, children start to monitor their parents' behaviours towards themselves and their sibling(s) to potentially detect any differential treatment (e.g., attributing more attention to one child than the other). Indeed, recent evidence suggests that parental differential treatment is related to greater sibling conflict, poor sibling relationships, and less affection between siblings when one child perceives his/her own treatment as less favourable compared to the sibling. For instance, Hetherington (1988) found that siblings were more likely to behave in an aggressive, rivalrous, avoidant, and unaffectionate manner toward their sibling when parents treated one child with less warmth and affection and more coercion, punitiveness, irritability, and restrictiveness than the other child. On the other hand, when children justified the unequal treatment due to age differences and a difference in personal attributes, parental differential treatment was not associated with poor sibling relationships. In fact, parental differential treatment was only related to poor sibling relationships when the children interpreted the differential treatment as unfair.

Previous research on parental differential treatment has focused primarily on typically developing children and has neglected how parental differential treatment applies to families in which there is a child with a developmental disability. The term developmental disability includes diagnoses such as Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, which are now replaced by one umbrella term: Autism Spectrum Disorder. In the present study, I will be examining the issue of differential parental treatment

in families with a child with special needs, but am focusing only on the parents' views and those of the typically developing sibling.

Children with a developmental disability require more attention from parents, which adds another layer of complexity that is not found in other families. Studies in which siblings of children with a developmental disability participated failed to include the perceptions of these typically developing siblings (e.g., perceived fairness), which may be in part responsible for the links between differential treatment and poor sibling relationships. It is essential to incorporate siblings' self-reports in order to fully capture all the effects of differential treatment on children and integrate such results into broader applications.

While a large body of literature has investigated parental differential treatment, focusing primarily on maternal and combined (i.e., maternal and paternal) parenting, little attention has been paid to siblings' differential experiences with their fathers. Investigating the father's role could provide a more complete picture of the functioning of family systems.

Thus, the aim of the present study is to examine the effect of parental differential treatment on the quality of sibling relationships when one sibling has a developmental disability, and the other sibling does not. Specifically, this study will examine whether, in the presence of perceived parental differential treatment, typically developing siblings tend to regard their sibling with a developmental disability as a rival or in more positive terms. Perceived rivalry and positive feelings will be assessed by analyzing the extent of negative sentiments such as anger, jealousy, and resentment and the extent of positive feelings such as warmth and affection that are expressed by the typically developing sibling towards their sibling with a developmental disability. This will then serve to examine how the sibling relationship is impacted. In the present study, only the typically developing sibling will be interviewed and the child with special needs.

## 6. SCHOLARLY REVIEW

As part of the research, will participants be exposed to risk that is greater than minimal?

*Minimal risk means that the probability and magnitude of the risks are greater than those to which participants would be exposed in those aspects of their daily lives that are pertinent to the research.*

Yes

No

Has this research received favorable review for scholarly merit?

*For faculty research, funding from a granting agency such as CIHR, FQRSC, or CINQ is considered evidence of such review. Please provide the name of the agency.*

*For student research, a successful defense of a thesis or dissertation proposal is considered evidence of such review. Please provide the date of your proposal defense. Scholarly review is not required for minimal risk student research.*

Yes      Funding agency or date of  
defense:



Friday, November 7<sup>th</sup>, 2014

- No
- Not required

If you answered no, please submit a Scholarly Review Form, available on the OOR website. For studies to be conducted at the PERFORM Centre, please submit the Scientific Review Evaluator Worksheet.

## 7. RESEARCH PARTICIPANTS

Will any of the participants be part of the following categories?

- Minors (individuals under 18 years old)
- Individuals with diminished mental capacity
- Individuals with diminished physical capacity
- Members of Canada's First Nations, Inuit, or Métis peoples
- Vulnerable individuals or groups (vulnerability may be caused by limited capacity, or limited access to social goods, such as rights, opportunities and power, and includes individuals or groups whose situation or circumstances make them vulnerable in the context of the research project, or those who live with relatively high levels of risk on a daily basis)

a) Please describe potential participants, including any inclusion or exclusion criteria.

A total of 10 English and French speaking families will be selected. The selection criteria for participants will involve families with the following characteristics: multiple children within the age range of 9 and 13 years, at least one child with a developmental disability, and geographically situated on the island of Montreal or the surrounding area within a 50 km radius. Siblings of children with a developmental disability may be younger or older, and if there is more than one typically developing sibling, the one closest-in-age will be asked to participate. The child with a developmental disability may have one of the following diagnoses: Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder, however this child will not participate in the study. Only the typically developing child and both parents will be asked to participate.

b) Please describe in detail how potential participants will be identified, and invited to participate. Please submit any recruitment materials to be used, for example, advertisements or letters to participants.

Participants will be recruited through snowball, convenience, and criterion sampling methods (e.g., word-of-mouth, community centers, and relevant organizations).

c) Please describe in detail what participants will be asked to do as part of the research, and any procedures they will be asked to undergo. Please submit any instruments to be used to gather data, for example questionnaires or interview guides.

Participants will first be presented with a short description of the study and asked if they would be interested to participate. If participants agree to participate in the study, the researcher will communicate with them, and arrange a convenient time to meet (e.g., week

nights and/or weekends). An information letter with the description of the study, the consent forms, the demographic questionnaires, and the Sibling Inventory of Differential Experiences (SIDE-R), a questionnaire that assesses parental differential treatment, will be sent to the participants prior to the study. The participants will be given a choice to complete the demographic questionnaires prior to, during or after the study. The participants will be asked to return the SIDE-R prior to the meeting given that this questionnaire will be used to assess perceived differential parental treatment. A self-addressed return envelope will be provided. Families that will be participating will be interviewed in their home environment. The home visit will last between sixty minutes and ninety minutes in length (to be determined after piloting the measures). After receiving the proper consent from the parents, the researcher will be responsible for conducting an individual interview with each parent and the sibling of the child with a developmental disability. The study will be explained to the typically developing child and they will be asked to give verbal assent to participate.

Parents will be required to complete one questionnaire: (a) Parental expectations and perceptions of Children's Sibling Relationships Questionnaire, which looks at parental perceptions of sibling relationships. Separate forms of the questionnaire will be provided for mothers and fathers to answer privately and separately. Once the questionnaires are completed, parents will be individually interviewed in a counter balanced order across families. Each interview should last between fifteen and twenty minutes. The parents' interviews will consist of answering fourteen semi-structured, predetermined questions. Both parents will be asked the same set of questions. These will be designed using a variety of question types to gain insight about their family dynamics, the relationship between themselves and their children, and the relationship between their children.

Prior to beginning any meetings with the typically developing child, the researcher will establish rapport by engaging in a casual discussion to make him/her at ease. Children will start the process by completing one questionnaire, Sibling Relationship Questionnaire, which measures perceptions of the quality of interactions with one's sibling. A short version of the questionnaire will be used (16 items). That questionnaire will aim at gathering data on parental differential treatment and sibling relationship quality. The questionnaire will be read aloud to the child if requested/needed, and following this, the child will be interviewed privately. The interview will consist of answering seventeen semistructured, predetermined questions. It will last between five and ten minutes and will focus on parental differential treatment and sibling the relationship. The researcher may ask follow-up and/or probing questions to the child to further engage the participants and to get a more thorough understanding of their experiences.

d) Do any of the research procedures require special training, such as medical procedures or conducting interviews on sensitive topics or with vulnerable populations? If so, please indicate who will conduct the procedures and what their qualifications are.

Not applicable

## **8. INFORMED**

a) Please explain how you will solicit informed consent from potential participants. Please submit your written consent form. In certain circumstances, oral consent may be appropriate. If you intend to use an oral consent procedure, please submit a consent script containing the same elements as the template, and describe how consent will be documented.

*Please note: written consent forms and oral consent scripts should follow the consent form template available on the OOR website. Please include all of the information shown in the sample, adapting it as necessary for your research.*

On the day of the meeting, the children's parents will be required to provide parental consent by signing the parental consent document for their own and their children's participation. The typically developing sibling will also be asked to provide verbal assent to participate.

b) Does your research involve individuals belonging to cultural traditions in which individualized consent may not be appropriate, or in which additional consent, such as group consent or consent from community leaders, may be required? If so, please describe the appropriate format of consent, and how you will solicit it.

Not applicable

## **9. DECEPTION**

Does your research involve any form of deception of participants? If so, please describe the deception, explain why the deception is necessary, and explain how participants will be de-briefed at the end of their participation. If applicable, please submit a debriefing script.

*Please note that deception includes giving participants false information, withholding relevant information, and providing information designed to mislead.*

There will be no deception used in this study.

## **10. PARTICIPANT WITHDRAWAL**

a) Please explain how participants will be informed that they are free to discontinue at any time, and describe any limitations on this freedom that may result from the nature of the research.

The individuals taking part in this study will be informed about this matter in the consent form, which I will be reviewing with each of them prior to participating in this study. Furthermore, both parents and children will be reminded verbally of their right to withdraw from this study at any time on the day of the observation.

b) Please explain what will happen to the information obtained from a participant if he or she withdraws. For example, will their information be destroyed or excluded from analysis if the participant requests it? Please describe any limits on withdrawing a participant's data, such as a deadline related to publishing data.

In a situation where a participant chooses to withdraw, all their information and data will be destroyed.

## **11. RISKS AND BENEFITS**

a) Please identify any foreseeable benefits to participants.

There are no direct benefits for the individuals participating in this study. However, the participants may be contributing indirectly by increasing the knowledge about parental differential treatment and sibling relationship quality in families with a child with a developmental disability. In addition, they might gain knowledge about the phenomenon of interest by reading a summary of the findings that I will send after the completion of the study, and by asking questions throughout the process.

- b) Please identify any foreseeable risks to participants, including any physical or psychological discomfort, and risks to their relationships with others, or to their financial well-being.

There is no foreseeable risk of any harm to participants and others.

- c) Please describe how the risks identified above will be minimized. For example, if individuals who are particularly susceptible to these risks will be excluded from participating, please describe how they will be identified. Furthermore, if there is a chance that researchers will discontinue participants' involvement for their own well-being, please state the criteria that will be used.

Not applicable

- d) Please describe how you will manage the situation if the risks described above are realized. For example, if referrals to appropriate resources are available, please provide a list. If there is a chance that participants will need first aid or medical attention, please describe what arrangements have been made.

Not applicable

## 12. REPORTABLE SITUATIONS AND INCIDENTAL FINDINGS

- a) Is there a chance that the research might reveal a situation that would have to be reported to appropriate authorities, such as child abuse or an imminent threat of serious harm to specific individuals? If so, please describe the situation, and how it would be handled.

*Please note that legal requirements apply in such situations. It is the researcher's responsibility to be familiar with the laws in force in the jurisdiction where the research is being conducted.*

According to my knowledge, it is very unlikely that my research could reveal a situation that would have to be reported to appropriate authorities. However, if such circumstances were to arise, my supervisor, Dr. Nina Howe and my committee member, who is also a licensed psychologist, Dr. Harriet Petrakos would be consulted to apply any legal requirements.

- b) Is there a chance that the research might reveal a material incidental finding? If so, please describe how it would be handled.

*Please note that a material incidental finding is an unanticipated discovery made in the course of research but that is outside the scope of the research, such as a previously undiagnosed medical or psychiatric condition that has significant welfare implications for the participant or others.*

According to my knowledge, there is no such risk in this study.

## 13. CONFIDENTIALITY, ACCESS, AND STORAGE

- a) Please describe the path of your data from collection to storage to its eventual archiving or disposal, including details on short and long-term storage (format, duration, and location), measures taken to prevent unauthorized access, who will have access, and final destination (including archiving, or destruction).

The data collected, consisting of audio-recording tapes, and transcript/notes will be stored electronically on a password-protected computer in Dr. Howe's research office. The questionnaires will be stored in a locked filing cabinet in Dr. Howe's research office. This material will be treated with great care in order to protect the confidentiality of the participants by assigning a number to each participant. The only people who will have access

to this information are the researcher, and the participants themselves. Once the study is completed all data will be destroyed.

b) Please identify the access that the research team will have to participants' identity:

I will assign a number to each family and participant and I will be the only person who has access to this information. The list of family name and number will be kept on a password-protected computer in Dr. Howe's research office.

<input type="checkbox"/>	Anonymous	The information provided never had identifiers associated with it, and the risk of identification of individuals is low, or very low.
<input type="checkbox"/>	Anonymous results, but identify who participated	The information provided never had identifiers associated with it. The research team knows participants' identity, but it would be impossible to link the information provided to link the participant's identity.
<input type="checkbox"/>	Pseudonym	Information provided will be linked to an individual, but that individual will only provide a fictitious name. The research team will not know the real identity of the participant.
<input type="checkbox"/>	Coded	Direct identifiers will be removed and replaced with a code on the information provided. Only specific individuals have access to the code, meaning that they can re-identify the participant if necessary.
<input type="checkbox"/>	Indirectly identified	The information provided is not associated with direct identifiers (such as the participant's name), but it is associated with information that can reasonably be expected to identify an individual through a combination of indirect identifiers (such as place of residence, or unique personal characteristics).
<input checked="" type="checkbox"/>	Confidential	The research team will know the participants' real identity, but it will not be disclosed.
<input type="checkbox"/>	Disclosed	The research team will know the participants' real identity, and it will be revealed in accordance with their consent.
<input type="checkbox"/>	Participant Choice	Participants will be able to choose which level of disclosure they wish for their real identity.
<input type="checkbox"/>	Other (please describe)	

c) Please describe what access research participants will have to study results, and any debriefing information that will be provided to participants post-participation.

The participants will be sent a short summary of the general findings of the study following their participation and once the study is complete.

d) Would the revelation of participants' identity be particularly sensitive, for example, because they belong to a stigmatized group? If so, please describe any special measures that you will take to respect the wishes of your participants regarding the disclosure of their identity.

The identity of the participants will never be revealed. If quotes are used from the interviews in my thesis or any ensuing publications, the participant's number or a pseudonym will be used.

e) In some research traditions, such as action research, and research of a socio-political nature, there can be concerns about giving participant groups a "voice". This is especially the case with groups that have been oppressed or whose views have been suppressed in their cultural location. If these concerns are relevant for your participant group, please describe how you will address them in your project.

Not applicable

#### 14. MULTI-JURISDICTIONAL RESEARCH

Does your research involve researchers affiliated with an institution other than Concordia? If so, please complete the following table, including the Concordia researcher's role and activities to be conducted at Concordia. If researchers have multiple institutional affiliations, please include a line for each institution.

Researcher's Name	Institutional Affiliation	Role in the research (e.g. principal investigator, co-investigator, collaborator)	What research activities will be conducted at each institution?
Not applicable	Not applicable	Not applicable	Not applicable

#### 15. ADDITIONAL ISSUES

Bearing in mind the ethical guidelines of your academic or professional association, please comment on any other ethical concerns, which may arise in the conduct of this research. For example, are there responsibilities to participants beyond the purposes of this study?

According to my knowledge, there are no other ethical concerns, which may arise in the conduct of this protocol.

#### 16. DECLARATION AND SIGNATURE

Study Title: Parental Differential Treatment and Sibling Relationship Quality in Families with a Child with a Developmental Disability

I hereby declare that this Summary Protocol Form accurately describes the research project or scholarly activity that I plan to conduct. I will submit a detailed modification request if I wish to make modifications to this research.

I agree to conduct all activities conducted in relation to the research described in this form in compliance with all applicable laws, regulations, and guidelines, including:

- The [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#)
- The policies and guidelines of the funding/award agency
- The [Official Policies of Concordia University](#), including the *Policy for the Ethical Review of Research Involving Human Participants, VPRGS-3*.

**Principal Investigator Signature:** Marie-Michèle Truchon

**Date:** Thursday, November 13<sup>th</sup>, 2014

**FACULTY SUPERVISOR STATEMENT (REQUIRED FOR STUDENT PRINCIPAL INVESTIGATORS):**

I have read and approved this project. I affirm that it has received the appropriate academic approval, and that the student investigator is aware of the applicable policies and procedures governing the ethical conduct of human participant research at Concordia University. I agree to provide all necessary supervision to the student. I allow release of my nominative information as required by these policies and procedures in relation to this project.



**Faculty Supervisor Signature:** \_\_\_\_\_

\_\_\_\_\_

**Date:** \_\_\_\_\_ Dec 5, 2014 \_\_\_\_\_



Appendix C  
Demographic Questionnaires

## Family Questionnaire #1

**ID:** -----

**Date:** -----/-----/-----

**Please circle or fill in the appropriate answer**

1.     Parent #1     Age   \_\_\_\_\_                      Gender   \_\_\_\_\_
   
       Parent #2     Age   \_\_\_\_\_                      Gender   \_\_\_\_\_
  
2.     What is your current marital status?
  - a)     Single
  - b)     Divorced
  - c)     Married
  - d)     Separated
  - e)     Widowed
  - f)     Would rather not say
  
3.     How many children are there in your family?
  - a)     1
  - b)     2
  - c)     3
  - d)     4 or more
  
4.     What is the highest level of education each parent (i.e., #1, #2) has completed?
 

a)     Some high school	f)     Bachelor's Degree
b)     High school or equivalent	g)     Master's Degree
c)     Vocational/Technical School	h)     Doctoral Degree
d)     Some college	i)     Professional Degree (MD, JD, etc.)
e)     College graduate	j)     Other _____
  
5.     Parent #1: Do you work outside of your home?    YES   NO
 

If so, what do you do? \_\_\_\_\_

Parent #2: Do you work outside of your home?    YES   NO

If so, what do you do? \_\_\_\_\_
  
6.     Please circle the combined yearly income level your family falls in.

- |                              |                              |
|------------------------------|------------------------------|
| a) Under \$20,000            | e) Between \$50,000-\$74,999 |
| b) Between \$20,000-\$29,999 | f) Between \$75,000-\$99,999 |
| c) Between \$30,000-\$39,999 | g) Over \$150,000            |
| d) Between \$40,000-\$49,999 | h) Would rather not say      |

7. Please circle your family's religious affiliation

- |                     |                |
|---------------------|----------------|
| a) Atheist/Agnostic | d) Jewish      |
| b) Christian        | e) Muslim      |
| c) Buddhism         | f) Other _____ |

**Thank you for your time!**

## Family Questionnaire #2

**ID:** -----

**Date:** -----/-----/-----

Thank you for agreeing to participate in this study. Please complete the following questionnaire.

1. What is the gender of your child with a developmental disability?

- Male     Female

2. When was your child with a developmental disability born? ...../...../.....

3. What is this child's position in the family?

- First  
 Second  
 Third  
 Forth  
 Fifth  
 Sixth

4. What would you describe the level of your child's developmental disability (Please tick the one you consider the closest description)?

- Requiring very substantial support     Requiring substantial support     Requiring support

5. What is the nature of your child's disability?

- Autistic disorder  
 Asperger's disorder  
 Pervasive developmental disorder  
 Other \_\_\_\_\_

Specify if:

- With accompanying intellectual impairment  
 With accompanying language impairment  
 Associated with a known medical or genetic condition or environmental factor  
 Associated with another neurodevelopmental, mental, or behavioral disorder  
 With catatonia

Other \_\_\_\_\_

6. Does your family receive any support caring for your child with special needs within the home?

Yes    No

If yes, please specify the type of support received

---



---

7. Does your family receive any support caring for your child with special needs outside the home (such as community resources)?

Yes    No

If yes, please specify the type of support received

---



---

### **Sibling Information**

1. What is the gender of your child participating in this study?

Male    Female

2. When was your child who is participating in this study born? ...../...../.....

3. What is this child's position in the family?

First

Second

Third

Forth

Fifth

Sixth

4. Is the child participating in this study older or younger than your child with a developmental delay or disability?

Older    Younger

5. Does your child with a developmental delay or disability attend the same school as his or her sibling?

Yes    No

6. Is your child currently a member of a sibling support group?

Yes    No

If yes, please specify the type of support received

---

---

7. Has your child been a member of a sibling support group in the past?

Yes    No

If yes, please specify the type of support received and also the duration of involvement in this group.

---

---

8. Would you like to tell us anything else, or do you have any other comments?

---

---

---

**Thank you for your time!**

## Appendix D

### Sibling Inventory of Differential Experiences - Revised (SIDE-R)

ID: \_\_\_\_\_

Date: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

### Your Relationship With Your Mother/Father

These questions are about relationships with your mother/father and your sibling's relationship. Please respond to these questions thinking about how things were generally in your family while you were growing up.

If both of you were treated about the same, circle the number "3".

If you were treated a particular way more often, circle "4" or "5", depending on how much more.

If your sibling was treated a particular way more often, circle "1" or "2", depending on how much more.

**Example:** The first question asks if your mother/father was stricter with you or with your sibling. If she/he was much more strict with you, circle "5". If she/he was much more strict with your sibling, circle "1". If she/he was about the same towards both of you, circle "3".

Much more with me	A bit more with me	About the same	A bit more with my sibling	Much more with my sibling
1	2	3	4	5

1. Our mother/father was strict with us

1    2    3    4    5

2. Our mother/father was proud of the things we did

1    2    3    4    5

3. Our mother/father enjoyed doing things with us

1    2    3    4    5

4. Our mother/father was sensitive to what we thought or felt

1    2    3    4    5

5. Our mother/father punished us for our misbehaviour

1    2    3    4    5

6. Our mother/father showed interest in the things we liked to do

1    2    3    4    5

7. Our mother/father blamed us for what another family member did



1      2      3      4      5

8. Our mother/father tended to favour one of us

1      2      3      4      5

9. Our mother/father disciplined us

1      2      3      4      5

ID: -----

Date: -----/-----/-----

### Your Relationship With Your Children

**In a household with 2 children it may be difficult to spend the same amount of time with both children. The following questions ask you to think about whether you do some things more or less often with “name of the child” than with “name of the child”. Using the following scale, please indicate whether the following items were done more so with “name of the child”, “name of the child”, or both equally over the past month.**

Much more with	A bit more with	About the same	A bit more with	Much more with
1	2	3	4	5

1. Have been strict with him/her

1      2      3      4      5

2. Have been proud of things he/she does

1      2      3      4      5

3. Have enjoyed doing things with him/her

1      2      3      4      5

4. Have been sensitive to what he/she thinks and feels

1      2      3      4      5

5. Have punished him/her for conflict

1      2      3      4      5

6. Have shown interest in the things he/she likes to do

1      2      3      4      5

7. Have blamed him/her for what another family member may have done

1      2      3      4      5

8. Have tended to favour him/her

1      2      3      4      5

9. Have disciplined him/her

1      2      3      4      5

Appendix E

Sibling Relationship Questionnaire (SRQ)

ID: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

For each question, check the answer that is best for you.

---

1. Some brothers and sisters do nice things for each other a lot, while other brothers and sisters do nice things for each other only a little. How much do both you and your brother/sister do nice for each other?

Hardly at all  
 Not too much  
 Somewhat  
 Very much  
 Extremely much

2. Who usually gets treated better by your mother, you or your brother/sister?

My brother/sister almost always gets treated better  
 My brother/sister often gets treated better  
 We get treated about the same  
 I often get treated better  
 I almost always get treated better

3. How much do you show your brother/sister how to do things he/she doesn't know how to do?

Hardly at all  
 Not too much  
 Somewhat  
 Very much  
 Extremely much

4. How much does your brother/sister show you how to do things you don't know how to do?

Hardly at all  
 Not too much  
 Somewhat  
 Very much  
 Extremely much

5. How much do you tell your brother/sister what to do?

Hardly at all  
 Not too much  
 Somewhat  
 Very much  
 Extremely much

6. How much does your brother/sister tell you what to do?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

7. Who usually gets treated better by your father, you or your brother/sister?

- My brother/sister almost always gets treated better
- My brother/sister often gets treated better
- We get treated about the same
- I often get treated better
- I almost always get treated better

8. Some brothers and sisters care about each other a lot while other brothers and sisters don't care about each that much. How much do you and your brother/sister care about each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

9. How much do you and your brother/sister go places and do things together?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

10. How much do you and your brother/sister insult and call each other names?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

11. How much do you and your brother/sister like the same things?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

12. How much do you and your brother/sister tell each other everything?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

13. Some brothers and sisters try to out-do or beat each other at things a lot, while other brothers and sisters try to out-do or beat each other only a little. How much do you and your brother/sister try to out-do or beat each other at things?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

14. How much do you admire and respect your brother/sister?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

15. How much does your brother/sister admire and respect you?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

16. How much do you and your brother/sister disagree and quarrel with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

17. Some brothers and sisters cooperate a lot, while other brothers and sisters cooperate only a little. How much do you and your brother/sister cooperate with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

18. Who gets more positive attention from your mother, you or your brother/sister?

- My brother/sister almost always gets more positive attention
- My brother/sister often gets more positive attention
- We get about the same amount of positive attention
- I often get more positive attention

19. How much do you help your brother/sister with things he/she can't do by himself/herself?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

20. How much does your brother/sister help you with things you can't do by yourself?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

21. How much do you make your brother/sister do things?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

22. How much does your brother/sister make you do things?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

23. Who gets more positive attention from your father, you or your brother/sister?

- My brother/sister almost always gets more positive attention
- My brother/sister often gets more positive attention
- We get about the same amount of positive attention
- I often get more positive attention
- I almost always get more positive attention

24. How much do you love your brother/sister?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

25. How much does your brother/sister love you?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

26. Some brothers and sisters play around and have fun with each other a lot, while other brothers and sisters play around and have fun with each other only a little. How much do you and your brother/sister play around and have fun with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

27. How mean are you and your brother/sister to each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

28. How much do you and your brother/sister have in common?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

29. How much do you and your brother/sister share secrets and private feelings?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much



30. How much do you and your brother/sister compete with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

31. How much do you look up to and feel proud of this brother/sister?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

32. How much does your brother/sister look up to and feel proud of you?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

33. How much do you and your brother/sister get mad at and get into arguments with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

34. How much do you and your brother/sister share with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

35. Who does your mother usually favor, you or your brother/sister?

- My brother/sister almost always is favored
- My brother/sister is often favored
- Neither of us is favored
- I am often favored
- I almost always am favored

36. How much do you teach your brother/sister things that he/she doesn't know?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

37. How often does your brother/sister teach you things that you don't know?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

38. How much do you order your brother/sister around?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

39. How much does your brother/sister order you around?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

40. Who does your father usually favor, you or your brother/sister?

- My brother/sister almost always is favored
- My brother/sister is often favored
- Neither of us is favored
- I am often favored
- I almost always am favored

41. How much is there a strong feeling between you and your brother/sister?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

42. Some kids spend lots of time with their brothers and sisters, while others don't spend so much. How much free time do you and this brother/sister spend together?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

43. How much do you and your brother/sister bug and pick on each other in mean ways?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

44. How much are you and your brother/sister alike?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

45. How much do you and your brother/sister tell each other things you don't want other people to know?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

46. How much do you and your brother/sister try to do things better than each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

47. How much do you think highly of your brother/sister?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

48. How much does your brother/sister think highly of you?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

49. How much do you and your brother/sister argue with each other?

- Hardly at all
- Not too much
- Somewhat
- Very much
- Extremely much

Appendix F

Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire

(PEPC-SRQ)

ID: -----

Date: -----/-----/-----

**PEPC-SRQ****WHAT I SEE AS A GOOD SIBLING RELATIONSHIP BETWEEN CHILDREN**

Imagine a family – not necessarily your own – in which two children get along very well. Others describe them as having a very good sibling relationship. These children are the same ages and gender as your children. How frequently do you think each of the following occurs in this kind of relationship?

	Never	Rarely	Sometimes	Usually	Always
1. Physical aggression (hitting, pushing, etc.)	1	2	3	4	5
2. Sharing	1	2	3	4	5
3. Jealousy	1	2	3	4	5
4. Playing together in a single activity	1	2	3	4	5
5. Competition	1	2	3	4	5
6. Respecting each others' property	1	2	3	4	5
7. Rivalry	1	2	3	4	5
8. Sharing worries or concerns	1	2	3	4	5
9. Angry feelings	1	2	3	4	5
10. Loyalty or sticking up for one another	1	2	3	4	5
11. Arguing	1	2	3	4	5
12. Comforting one another	1	2	3	4	5
13. Fighting over territory or space	1	2	3	4	5
14. Protectiveness – looking out for each other's welfare	1	2	3	4	5
15. Feeling proud of one another	1	2	3	4	5
16. Fighting where the problem never gets worked out	1	2	3	4	5

17. Talking to each other, having conversations	1	2	3	4	5
18. Fighting over objects (games, toys, clothes, TV)	1	2	3	4	5
19. Helping one another	1	2	3	4	5
20. Threatening one another	1	2	3	4	5
21. Teaching (how to play a game, etc.)	1	2	3	4	5
22. Affection (hugging, kissing, saying "I love you," etc.)	1	2	3	4	5
23. Trying to control each other's behaviour using phrases like "Don't do that," "Stop it," or "Leave me alone"	1	2	3	4	5
24. Being kind or nice to one another	1	2	3	4	5
25. Going to each other for advice/support	1	2	3	4	5
26. Sharing inner secrets and feelings with each other	1	2	3	4	5
27. Teasing or annoying each other	1	2	3	4	5

## HOW I SEE MY CHILDREN'S SIBLING RELATIONSHIP

Please circle the number that best fits your feelings about the following aspects of your children's relationship during the past 2 weeks.

<b>How frequently would you say each of the following occurs in your children's relationship?</b>	<b>How much would you say this is a problem?</b>	<b>If this is a problem, how easy would it be for you to improve this if you wanted to?</b>	<b>How much would you like help with this?</b>
<b>1. Physical aggression (hitting, pushing, etc.)</b>			
(1) Never	(1) It's not a problem	(1) Very difficult	(1) No help
(2) Rarely	(2) It's a small problem	(2) Difficult	(2) A little help
(3) Sometimes	(3) It's a big problem	(3) Neutral	(3) A lot of help
(4) Usually	(4) It's a very big problem	(4) Easy	
(5) Always		(5) Very easy	
<b>2. Sharing</b>			
(1) Never	(1) It's not a problem	(1) Very difficult	(1) No help
(2) Rarely	(2) It's a small problem	(2) Difficult	(2) A little help
(3) Sometimes	(3) It's a big problem	(3) Neutral	(3) A lot of help
(4) Usually	(4) It's a very big problem	(4) Easy	
(5) Always		(5) Very easy	
<b>3. Jealousy</b>			
(1) Never	(1) It's not a problem	(1) Very difficult	(1) No help
(2) Rarely	(2) It's a small problem	(2) Difficult	(2) A little help
(3) Sometimes	(3) It's a big problem	(3) Neutral	(3) A lot of help
(4) Usually	(4) It's a very big problem	(4) Easy	
(5) Always		(5) Very easy	
<b>4. Playing together in a single activity</b>			
(1) Never	(1) It's not a problem	(1) Very difficult	(1) No help
(2) Rarely	(2) It's a small problem	(2) Difficult	(2) A little help
(3) Sometimes	(3) It's a big problem	(3) Neutral	(3) A lot of help
(4) Usually	(4) It's a very big problem	(4) Easy	
(5) Always		(5) Very easy	



**How frequently would you say each of the following occurs in your children's relationship?**

**How much would you say this is a problem?**

**If this is a problem, how easy would it be for you to improve this if you wanted to?**

**How much would you like help with this?**

5. Competition

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

6. Respecting each other's property

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

7. Rivalry

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

8. Sharing worries or concerns

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

**How frequently would you say each of the following occurs in your children's relationship?**

**How much would you say this is a problem?**

**If this is a problem, how easy would it be for you to improve this if you wanted to?**

**How much would you like help with this?**

9. Angry feelings

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

10. Loyalty or sticking up for one another

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

11. Arguing

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

12. Comforting one another

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

13. Fighting over territory or space

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

**How frequently would you say each of the following occurs in your children's relationship?**

**How much would you say this is a problem?**

**If this is a problem, how easy would it be for you to improve this if you wanted to?**

**How much would you like help with this?**

14. Protectiveness—looking out for each other's welfare

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

15. Feeling proud of one another

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

16. Fighting where the problem never gets worked out

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

17. Talking to each other, having conversations

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

**How frequently would you say each of the following occurs in your children's relationship?**

**How much would you say this is a problem?**

**If this is a problem, how easy would it be for you to improve this if you wanted to?**

**How much would you like help with this?**

18. Fighting over objects (games, toys, clothes, tv)

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

19. Helping one another

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

20. Threatening one another

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

21. Teaching (how to play a game, how to read, etc.)

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

**How frequently would you say each of the following occurs in your children's relationship?**

**How much would you say this is a problem?**

**If this is a problem, how easy would it be for you to improve this if you wanted to?**

**How much would you like help with this?**

22. Affection (hugging, kissing, saying "I love you", etc.)

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

23. Trying to control each other's behavior using phrases like, "Don't do that," "Stop it," or "Leave me alone"

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

24. Being kind or nice to one another

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

25. Going to each other for advice/support

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

**How frequently would you say each of the following occurs in your children's relationship?**

**How much would you say this is a problem?**

**If this is a problem, how easy would it be for you to improve this if you wanted to?**

**How much would you like help with this?**

26. Sharing inner secrets and feelings with each other

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

27. Teasing or annoying each other

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always

- (1) It's not a problem
- (2) It's a small problem
- (3) It's a big problem
- (4) It's a very big problem

- (1) Very difficult
- (2) Difficult
- (3) Neutral
- (4) Easy
- (5) Very easy

- (1) No help
- (2) A little help
- (3) A lot of help

Overall, how well would you say your children get along with one another?

1  
very poorly  
well

2

3

4  
neutral

5

6

7  
extremely

Appendix G  
Interview Questions

### Parent Interview Questions

- a) Please tell me about your relationship with (name of the child with a developmental disability)?
- b) Please tell me about your relationship with (name of the typically developing child)?
- c) How would you describe the relationship between (name of the child with a developmental disability) and (name of the typically developing child)?
- d) Does having a child with special needs affect your other children? If so, how?
- e) Do you receive any type of support for your other children? If so, what kind of support has been most helpful to you and your family?
- f) Do you receive any type of support for your child with special needs? If so, what kind of support has been most helpful to you and your family?
- g) Do you feel that there are any rewards of having a child with special needs? If so, what are the rewards of having a child with special needs?
- h) Are there any challenges that you experience while raising a child with special needs? If so, what challenges do you experience?
- i) What fears do you have as a parent with a child with a developmental disability, and how do you address them?
- j) Is there anything else you want to tell me?



### Sibling Interview Questions

- a) Please tell me about your relationship with (name of the sibling with a developmental disability)?
- b) What are the best parts of being a brother or sister to (name of the sibling)?  
  
Prompt: Can you tell me more?
- c) What are some of the not so good parts/challenges you face on a daily basis of being a brother or sister to (name of the sibling with a developmental disability)? How does having a sibling with a developmental disability affect your activities and/or friendships?  
  
Prompt: Can you tell me more?
- d) What helps you handle the difficult situations?
- e) Can you think of other things that have helped you?
- f) How did you become aware of your sibling's developmental disability (e.g., autism, Asperger, or pervasive developmental disorder)? Did someone explain it to you? What did they tell you?
- g) Is there anything you don't understand about his or her developmental disability? What else would you like to know?
- h) What kind of "special time" or "special activities" do you have with your parents (e.g., bedtime story, movie, etc)? How often does this happen? How do you feel when you have special time with your parents?
- i) Has his or her (sibling) developmental disability prevented you from doing an activity you want to do?
- j) In what ways has having a sibling with a disability meant extra responsibilities (e.g., caring for your sibling) for you? If so, are you okay/happy with the extra responsibilities or do you wish that you didn't have to do them? Why?
- k) What kind of rules are in your house? Do you think they are fair for both you and (name of sibling)? Why or why not?
- l) Does your sibling attend a special program or school? Have you been included in any of these programs in any way?

- m) Are you ever worried about (name of the sibling)? Tell me how or what worries you?  
If not, why not?
- n) Tell me about a time about when you were proud of your sibling?
- o) Is there any thing else you want to tell me?