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DEVELOPMENTAL DISABILITIES AND FAMILY DYNAMICS

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December 2013

submitted in partial fulfillment of requirements for the degree

MASTER OF ARTS IN CLINICAL PSYCHOLOGY

at the

CLEVELAND STATE UNIVERSITY

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MEGHAN E. MURRAY

ABSTRACT

Typically developing (TD) siblings of children with an Intellectual or Developmental Disability (IDD) are among those most influenced by their sibling's diagnosis. Factors such as increased family stress, lack of family communication, and negative sibling perception can play a role in leading to internalizing and externalizing problems from the TD child. A limit to the existing sibling relationship literature is that the relationships in families with a child with IDD have only been collected via self-report measures through which respondents have been found to fake their responses to avoid being perceived in certain ways. Conversely, implicit measures, such as the implicit association task (IAT) have been shown to uncover what a person may be feeling without a person having to explicitly report those feelings. This study aimed to bridge this gap in the extant literature by pairing self-report measures with an IAT by examining the association between typically developing youths' relationships with their IDD sibling and the TD youths' psychological adjustment. However, due to lack of sample size these relationships were unable to be examined. Instead, this study explored the links between family stress and the role of parental communication about the IDD sibling's disabilities and how those related to TD child adjustment and TD child perception of their IDD sibling.

Keywords: Developmental Disabilities, Typically Developing Siblings, Parent Communication, Family Stress

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CHAPTER I

INTRODUCTION

According to the Center for Disease Control (CDC), people with intellectual/developmental disabilities (IDD) are defined as a diverse group of individuals who experience behavioral, language, or physical delays due to mental or physical impairments (“Facts about Disabilities”, 2015). In the United States alone, Boyle et al. (2011) approximate that 13.87% of children between the ages of 3 and 17 were diagnosed with a developmental disability between the years of 1997 and 2008. Developmental disabilities have also been found to be twice as common in males as they are in females (Boyle et al., 2011). The cause for many types of developmental disabilities remains largely unknown. While some genetic and environmental factors (e.g., in-utero exposure) have been linked as triggers to some developmental disabilities, these factors are not linked closely enough to prove causation (Finucane, 2012). Intellectual and developmental disabilities occur in individuals of all walks of life. Race, gender, and socio-economic status do not play a factor in enabling the manifestation of a disability.

Families are affected by their child receiving a diagnosis of IDD in several ways, the largest being increased stress (Minnes et al., 1989; Martin, 2001; Hauser-Cram, Warfield, Shonkoff & Krauss, 2001; McCubbin & McCubbin, 1989; Goldberg et al., 1986). The significant impact an intellectual or developmental disability diagnosis can have on families highlights the importance of understanding how diagnoses affect individual family members, particularly any typically developing siblings. Typically developing (TD) siblings of children with an IDD are among those most influenced by the diagnosis as they are the family members that have the longest relationship with their sibling and can even assume care for their sibling later in life (Cicirelli, 1994; Heller & Kramer, 2009; Hodapp, Urbano & Burke, 2010). Having a sibling with an IDD can affect the typically developing sibling by causing several internalizing and externalizing problems that can develop during childhood and continue into adulthood (Petals et al., 2009; Wolfe, Song, Greenberg & Mallick, 2014). These negative adjustment issues in the TD child could also adversely affect the sibling with IDD by causing maladaptive behaviors to be displayed by the affected siblings.

The goal of this study is to examine the relationship between children with IDD and their typically developing siblings. This study also aims to understand parent involvement in this family dynamic. In several instances, the sibling relationship has been shown to have a positive impact on the child with an IDD in helping to further behavioral development and social skills. Despite additional stress on the typically developing sibling, self-report measures show, overall, that their IDD sibling positively influences and affects them emotionally (Kersh, 2007). However, factors such as increased family stress, lack of family communication, and negative sibling perception

can play a role in leading to internalizing and externalizing problems from the TD child. A limit to the existing sibling relationship literature is that the relationships in families with a child with IDD have only been collected through self-report measures. In one study, respondents of self-report measures were found to fake or change their responses in order to avoid being perceived in certain ways (McDaniel et al., 2009). Conversely, implicit measures, such as the implicit association task (IAT) have been shown to successfully uncover what a person may be feeling without a person explicitly having to express those feelings (Greenwald, McGhee, & Schwartz, 1998). This test pairing has been found effective in other populations (McDaniel et al., 2009), however has as of yet not been applied in the context of IDD/TD sibling relationships and family dynamics.

In using a novel IAT created to measure TD sibling's implicit feelings toward their sibling, while pairing this task with self-report questionnaires to measure the TD child's explicit feelings toward their sibling, this study aims to bridge gap in the extant literature on the sibling relationship. The relationship between siblings and parents in families with an IDD child can then be understood in a deeper way by allowing researchers to see if the TD sibling's self-report scores aligned with IAT scores. A correlation might then be found between family stress, family communication and their effects on the TD sibling's perception of their IDD sibling. Understanding the relationship between these factors could allow clinicians and parents to help target these areas in order to prevent internalizing and externalizing problems of the typically developing sibling (Hewitt, Agosta, Heller, Williams, & Reinke, 2013).

Developmental Disabilities

Developmental disabilities are a diverse group of conditions characterized by impairments in several areas. These impairments can be in the form of physical, learning, language, or behavioral, and can vary in severity and/or co-occur. Most diagnoses of developmental disabilities are first given when a child is found to be missing the typical developmental markers for their age. The onset of developmental disabilities can begin at any point in a person's life, but they typically develop prior to the age of 22. Some examples of common IDD disorders are: Autism Spectrum Disorder (ASD), Intellectual Disability/Mental Retardation (ID), and Down Syndrome (DS). These disabilities range from causing mild impairment, as in cases of a learning or speech delay to more serious impairment, as in cases of intellectual disability or autism. Depending on the level of impairment, support needs can be very demanding and the effects of having a child with a disability can be far-reaching.

Autism Spectrum Disorder is as a neurobiological disorder that impacts a person's communication and social interaction skills, and can cause the presence of stereotyped behavior and interests (Benson, 2016). Typically, these impairments develop within the first two years of life, however, a diagnosis may not be made until childhood in some cases. According to estimates from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network about 1 in 68 children have been diagnosed with ASD (Christensen et al., 2016).

Intellectual Disabilities (ID) effect 9.1 out of 1000 in the United States (Katusic et al., 1996). Intellectual Disability/Mental Retardation is defined as sub-average levels of intellectual functioning that impact the ability to function in daily life. Levels of

intellectual functioning can be measured in several ways, most commonly by an intelligence test. Typically, intellectual quotient (IQ) scores of less than 70 are considered deficient and may cause a diagnosis of an ID. If an intelligence test is not viable other measures are used to assess intellectual functioning. ID can range from mild (individuals may function independently or with minimal support to maintain self-care) to severe (individuals are unable to function independently and require significant support to maintain self-care).

Down Syndrome (DS) is a condition that results from a copy of the twenty-first chromosome at birth. This extra copy of the twenty-first chromosome causes changes in the way a baby's brain and body develop. Most babies born with DS have a distinct look about their facial features that includes a flattened face, almond-shaped, upward slanting eyes, a short neck, small ears, and a tongue that tends to stick out of the mouth. "Each year, about 6,000 babies are born with Down Syndrome, which is about 1 in every 700 babies born", according to the CDC. DS also has varying degrees of severity and typically impacts a person's intellectual functioning. That is why a diagnosis of ID is common in children who are also diagnosed with DS.

There are also several syndromes, physical disabilities, or rare chromosomal disorders that can present similar behaviors and delays as the disabilities presented previously. Even though the etiology is known for several of these syndromes, physical disabilities, and rare chromosomal disorders, the behavioral and developmental delays can present just as much of a challenge for families with children with autism, down syndrome, or an intellectual disability. The following is a sample of these genetic syndromes: fragile X syndrome, tuberous sclerosis, Angelman syndrome, Rett syndrome,

fetal alcohol syndrome. A common physical disability that can present pervasive behavioral and developmental issues is Cerebral Palsy. Lastly, rare chromosomal disorders can also present like many developmental disabilities like the more well-known chromosomal disorder, Down syndrome, such as 9p deletion syndrome, Cri-du-Chat syndrome, and Williams syndrome.

Sibling Adjustment

Given that developmental disabilities affect 1 in 6 children of families in the U.S, there is a surprising dearth of studies that explain the effect of having an IDD sibling on their typically developing siblings (Boyle et al., 2011). The extant literature on the topic is mixed, with some finding a negative effect on the TD child's adjustment, while others report positive consequences of having an IDD sibling. For example, Emerson and Giallo (2014) found that siblings of children with an IDD had overall lower well-being than their peers without siblings with an IDD. In a similar vein, several studies found that the TD siblings of children with an IDD reported more behavioral problems, lower-self esteem, and depression in comparison to their peers without a sibling with an IDD (Boyce & Barnett, 1993; Hannah & Midlarsky, 1999; Nixon & Cummings, 1999; Summers, White, & Summers, 1994). Fletcher, Harris, & Wolfe, (2012) found that the TD siblings of children with an IDD have reported lower achievement in school. If the TD sibling develops adjustment problems, this can also have a negative effect on the IDD sibling who will also develop emotional problems (Walton, & Ingersoll, 2015). The adjustment problems have been found to carry on into adulthood. Since adults with an IDD are living to older ages, it is increasing the likelihood that this will affect their TD siblings in some way or another in their adult life (Wolfe et al., 2014). Wolfe, Song,

Greenberg, and Mallick (2014) found that adults with a brother or sister with an IDD were less often married and had higher rates of divorce.

Several studies have also found that having a sibling with an IDD can allow for positive adjustment within the typically developing sibling. Since most diagnoses occur at an early age, some TD children have to adjust to the diagnosis of their IDD sibling. As a result, parents often ask TD children to take on more involved care-giving roles. Many TD siblings have reported that their IDD siblings have positively influenced and affected them emotionally (Kersh, 2007; Hodapp, Urbano, & Burke, 2010). TD siblings also tend to develop positive personality characteristics, such as higher rates of kindness and empathy from the relationship (Cuskelly & Gunn, 2003). TD siblings also tend to be more mature as a result of the increased responsibility when compared to their peers and have also reported higher rates of being more altruistic and tolerant of others (Howlin, 1988). Cantwell & Baker (1984) found that TD siblings tend to go into ‘caring professions’ as an adult, potentially because having an IDD sibling increases benevolent tendencies. McHale et al. (1986) found that TD children’s relationships with their peers were not affected by having a sibling with an IDD. Parents also confirm that problems that arise between the siblings are typically resolvable (Simeonsson & McHale, 1981). McHale et al. (1986) showed that TD children with siblings with ASD and ID were more accepting of others with differences and supportive of others than their peers without a disabled sibling. As a result of having a sibling with an IDD, TD adults have been found to have lower rates of divorce than their peers who do not an IDD sibling (Hodapp et al., 2010).

Explaining The Mixed Literature

These mixed findings raise the question of what factors impact the adjustment of the TD children? The literature points to several risk and protective factors that include family stress, parent communication, and the TD sibling's perception of their sibling with an IDD that may explain the apparent disparities in TD sibling adjustment. With this in mind, I explain the factors further.

Family Stress

Having a child with an IDD diagnosis is very stressful on the family members. Families report experiencing higher levels of psychological stress than families without an IDD child (Baker et al., 2003; Dyson, 1991; Emerson, 2003; Fidler, Hodapp, & Dykens, 2000; Friedrich & Friedrich, 1981; Hastings, 2002; Orr, Cameron, Dobson, & Day, 1993). The additional, contributing stressors can present themselves in a number of ways. For example, the severity of the diagnosis can increase family stress (Minnes et al., 1989). The reason the severity of the diagnosis has a greater negative affect on these families is because the increased severity of the diagnosis leads to higher levels of maladaptive behavior have reported more distress (Baker et al., 2003). As a result of these maladaptive behaviors the parents disengage which ultimately negatively affects the TD child (Martin, 2001).

The age of the child has also been found to induce additional stress on families. Depending on the age of the IDD child, different behavioral problems present themselves leading to increased stress at various stages of development. For example, a study conducted by Hauser-Cram, Warfield, Shonkoff, and Krauss (2001) found that parents with older children with an IDD reported more distress than parents with young children

with an IDD resulting from larger developmental changes occurring. Mawdsley (2010) found a relationship between increased parenting stress and child problem behavior in both mother and father child dyads for the young children age group and a relationship between only the mother child dyad in the older children age group. This is also suggestive that different stages of development can induce stress differently for each member of the family.

The type of diagnosis can also lead to the induction of family stress because different disorders can produce more behavioral challenges than others. For example, Donovan (1988) found that both parents with children with DS and ASD had high levels of stress resulting from issues of raising a special needs child, however it was found that parents with a child with a diagnosis of ASD reported higher levels of stress than parents of a child with DS because of the aggressive behaviors more commonly associated with a diagnosis of ASD. An IDD diagnosis also presents a host of issues that would not otherwise be absent in a family without a child with IDD, such as additional financial costs from medications, respite care, and coordination of services incurred in raising and caring for a child with an IDD.

Unknown etiology is also a very stressful component that adds to the family's stress over and above behavioral problems. Goldberg et al. (1986) found that families with a child with an IDD with an unknown etiology (e.g. ASD) had more family stress than those families with a child with an IDD with a known etiology (e.g. DS). Perry, Harris, and Minnes (2004) corroborated the findings in that parents with a child diagnosed with an IDD of unknown etiology have higher levels of poor family dynamics. This could be due to the family's perception of the diagnosis. For example, families who

receive a diagnosis of ASD are more pessimistic about their child's diagnosis than families who receive a diagnosis of DS as found by McCubbin and McCubbin (1989). This could be because parents with a child with ASD, who presents as mild or "appears" normal, have higher levels of stress because these parents may have uncertainty about the nature of their child's diagnosis (Bristol, 1985).

For the TD child, the additional family stress from having an IDD sibling could also be directly causing internalizing and externalizing problems. Externalizing problems are defined as behaviors indicative of hyperactivity, inattention, and intense negative emotional behaviors, while internalizing problems are defined as behaviors indicative of depression and anxiety. Several studies have indicated that when stressors impact a child early in development it can lead to more behavioral and emotional issues in adulthood (Björkenstam et al., 2015; Catherall, 2011; Byrne, Thomas, Burchell, Olive & Mirabito, 2011; Grant, McMahon, Duffy, Taylor & Compas, 2011). Ostberg and Hagekull (2013) reported that the higher the parental stress levels within families with a child with an IDD, the more internalizing and externalizing problems mothers reported of their TD child.

In comparison to other disabilities, children with ASD siblings were found to have higher levels of internalizing symptoms at a younger age and higher levels of externalizing symptoms at an older age in comparison to children with DS siblings, which could again be due to the maladaptive behaviors typically displayed in children with ASD (Fisman et al., 2000). Ross and Cuskelly (2006) found that TD siblings scored six-times greater in the at-risk clinical range on the CBCL for internalizing and externalizing problem behaviors than their peers. Examples of externalizing problems are

that higher rates of sibling aggression have been found in homes where the sibling perceives parental favoritism toward their other other sibling (Brody, 1998; Noller, 2005; Volling, Youngblade, & Belsky, 1997). Typically developing siblings were found to exhibit more symptoms of hyperactivity over their peers (Farber, 2010). Examples of internalizing problems are that TD siblings have been found to express depressive symptoms over their peers, as well as higher levels of anxiety leading to more negative sibling interactions (Faber, 2010; Pollard, Barry, Freedman & Kotchick, 2013).

Family Communication

Another factor that affects TD child adjustment is the degree to which parents communicate with their TD child about their IDD sibling's diagnosis. While the lines of communication are well understood in families without an IDD child, little is known about families who have a child with IDD. What little research there is has found that parental communication affects TD sibling adjustment (Sgandurra, 2001). For example, they found increased family problem solving communication lead to higher level of self-concept and lower levels of anxiety in the TD child. In a study conducted by Irwin (2002), results suggested that by having open communication, parents were better able to predict their typically developing child's worries about their sibling with an IDD. Despite the lack of knowledge as to the effects on communication within families with a child with an IDD, research has revealed encouraging findings in a related field.

In family studies of chronic illness, research shows that parent communication with the well sibling encourages the well sibling to become more accepting of the illness (Cohen, Friedrich, Copeland, & Pendergrass, 1989). It was also found that parents typically made an effort to teach their typically developing children about their sibling's

disability so they can better understand why they need to help their brother or sister (Kao, Romero-Bosch, Plante, & Lobato, 2012). Parents were also found to focus on either the etiology of the disorder or their disabled child's prognosis in their conversations with their typically developing children (Kao, Romero-Bosch, Plante, & Lobato, 2012). The outcomes of this study were that parents and TD children were in agreement with about the sibling relationship which suggests that the open communication about the IDD sibling's disability led to better family adaptation to the disability (Kao, Romero-Bosch, Plante, & Lobato, 2012; Snell & Rosen, 1997).

Sibling Perception

Negative Sibling Perception

One potential way that family stress and communication might affect the adjustment of a TD child is by influencing the perception that child has toward their IDD sibling. Perception of their IDD sibling has been found to influence how the TD child experiences their stress (Fisman, Wolf, Ellison & Freeman, 2000; Wolf, Fishman, Ellison & Freeman, 1998). These views can play a role in psychological adjustment resulting in positive outcomes or internalizing and externalizing problems. As a result of having a sibling with an IDD, the TD sibling is often asked to care physically or emotionally for their sibling with an IDD, leading to more demands on the TD sibling than are expected of their peers without a sibling with an IDD, leading to feelings of indignation toward their IDD sibling. McHale et al. (1986), found that TD siblings are often asked to perform more chores because of the greater amount of attention required from their parents toward their sibling with an IDD resulting in feelings of neglect. When compared with their peers who do not have siblings with an IDD, the TD sibling perform worse in school

and have more adjustment problems leading them to further blame their IDD sibling (Fletcher, Harris, & Wolfe; 2012).

Between the ages of 8 to 14 years, researchers found that siblings had feelings of resentment toward their sibling due to concerns about restricted social activities as result of their IDD sibling (Kao, Romero-Bosch, Plante, & Lobato, 2012). TD siblings may also feel a self-imposed need to over-achieve to make up for their sibling's deficiencies, which can then lead to further feelings of resentment toward their IDD sibling (Howlin, 1988). Tomeny (2015) found that parent stress and perceived social support shape the typically developing child's views of their sibling. Findings also suggest that parents who are overwhelmed create a more stressful family environment which reduces positive sibling interactions, while a less stressful family environment is linked to better psychological adjustment (Culpepper & Tangela, 2007).

These negative perceptions appear to continue on into adulthood. Orsmond and Seltzer (2009), in a study relating ASD and Down Syndrome, found that adults with siblings with ASD and Down Syndrome were both pessimistic about their sibling's futures, with adults with sibling with ASD more so. Adult siblings also reported feeling that they had to use social capital to provide support to their siblings with IDD after their parents passed away (Kramer, Hall, & Heller, 2013).

Positive Sibling Perception

Not all sibling perception has been found to be negative. A study conducted by Kersh (2007) analyzed the sibling relationship and found that TD siblings felt positively about supportive helping and recreational activities with their sibling, as well as experienced feelings of warmth and concern for their sibling. This study also found that

siblings of the same-sex dyad reported more warmth toward their sibling with an IDD. Birth order was not found to affect status or power within the relationship and conflict was related to externalizing problems (Blacher, 1984). Parents also confirm that TD children tend to accept their sibling with an IDD within the family and problems that arise between the siblings are typically resolvable (Simeonsson & McHale, 1981). McHale et al. (1986) showed that TD children with siblings with ASD and ID were more accepting and supportive than their peers without a disabled sibling.

Even into adulthood, positive perceptions of the TD sibling toward their sibling with an IDD have been found to last. A study conducted by Hodapp, Urbano, and Burke (2010) explored the relationship between adult siblings of individuals with IDD and they found that TD siblings reported close contact with their IDD siblings, positive relationships, overall good health, and other benefits from having a sibling with IDD. Female siblings reported benefiting more from the relationship with their IDD sibling and divorced less often than their male counterparts did (Hodapp, Urbano, & Burke, 2010).

TD siblings with positive perceptions of their sibling may live in a family environment that encourages communication about the IDD siblings' disability as well as any issues or reservations that TD child may have toward their IDD sibling. Having a positive perception could also be the result of having diminished family stressors, such as having an IDD sibling with a milder severity requiring less involvement from family members. These mixed findings highlight the need for research to fill the gap in this area.

Shortcomings in Research

There is one major limit to research about the sibling relationship within families with a child with an IDD and that is that all studies that have been conducted have used

self-report measures. The reason using self-report measures alone is not ideal is participants often times fake or change responses to avoid certain perceptions (McDaniel et al., 2009; Ziegler, Schmidt-Atzert, Buhner & Krumm, 2007). Given these findings, it would seem possible for a family member of a child with an IDD to fake or change responses on self-report measures to avoid showing negative feelings. Particularly, it could be plausible for the typically developing sibling to downplay responses on questions such as, “are you ever embarrassed by your sibling?” out of worry that someone may misconstrue that as meaning they don’t love their sibling. One solution to this problem could be to pair an implicit association task (IAT) with the results of self-report measures to make sure the TD siblings are reporting their feelings toward their IDD sibling accurately.

An implicit association task (IAT) has been found to successfully uncover what a person may be feeling without a person explicitly having to express those feelings (Greenwald, McGhee, & Schwartz, 1998). An implicit association task is designed to measure how quickly a person can categorize words or pictures within a positive or negative sentiment to see a person’s automatic associations about two categories (Greenwald et al., 1998). The task is designed to measure an individual’s implicit biases toward the word or picture categorizations (i.e. flowers and insects). The test involves two speed classification tasks. The first classification looks at targets, which is the concept of interest (i.e. flowers versus insects). The second classification looks at the attributes, which are ways to categorize the targets (i.e. good versus bad). The task is then scored by measuring a participant’s reaction time in associating the target with the different attributes. The faster the reaction time toward a target, the more of a positive or

negative bias the participant has toward the target. McDaniel et al. (2009) found this test pairing effective in other populations.

The Disability Attitudes Implicit Association Task (DA-IAT; Pruett & Chan, 2006) is a form of the original IAT and is designed to measure how quickly a person can categorize words and pictures to measure a person's automatic associations about two groups. This version of the IAT measures implicit attitudes towards individuals with physical disabilities and able-bodied individuals. Researchers found that scores from the DA-IAT reflected participants' implicit attitudes towards people with physical disabilities (Pruett & Chan, 2006). However, the scope of this study was limited to measuring how the general population feels towards individuals with a physical disability. Since the DA-IAT is limited to physical disabilities, there is a need for an IAT that can capture how people feel toward individuals with developmental disabilities.

CHAPTER II

CURRENT STUDY

There has yet to be a study that has combined researching the family dynamic of having a child with an IDD through self-report measures with an implicit association measure to avoid the biases of self-report measures, which is why this pairing is novel and important. Conducting this test pairing on TD children with a sibling with an IDD will allow for more accuracy in understanding their feelings toward their sibling. Depending on the TD child's perception of their IDD sibling, internalizing and externalizing feelings will result. The IAT will be used to corroborate or contradict self-report answers to allow for a more accurate depiction of how the TD child feels about their IDD sibling. Family Stress will also be measured to see if this stress effects the TD sibling's internalizing and externalizing problems as negative stressors over and above sibling perception. Showing that lack of family communication and negative stress can lead to poor downstream effects on the typically developing sibling's perception of their IDD sibling will allow practitioners and families to better understand the importance of

open communication about the IDD child's disability and family stressors ultimately leading to a more positive perception.

This study aims to examine the association between typically developing youths' relationships with their intellectually/developmentally disabled siblings and TD youths' psychological adjustment (see Appendix B for the study model). Further, this study examines the role of parental communication about the IDD sibling's disabilities with the typically developing sibling on the aforementioned relationships. TD youths' (aged 10-17 years) relationships with their IDD siblings will be measured via self-report measures and an Implicit Association Test that examines TD youths' tendencies to view their IDD sibling in a negative light. TD youths' psychological adjustment will be measured through parent-rating scales. Parents' communication with the typically developing child will be measured via self-report questions embedded in the demographic questionnaire. Family stress as a result of the impact the IDD child has on the family will also be measured through parent-rating scales. Further, this study serves to recruit a pilot sample as recruiting families to participate in this study will prove difficult since this is a very select portion of the population. The eventual aim is that this pilot data could support further research on this topic and the validity of the IAT in examining TD children's implicit feelings towards their IDD sibling.

Hypothesis I. Typically developing youths' perception of their IDD sibling (measured via self-report, IAT, and the discrepancy between self-reported and IAT indices) will be significantly correlated with their internalizing and externalizing problems.

Hypothesis II. Parent conversations with their typically developing child about their IDD sibling's diagnoses and family stress will predict the typically developing child's positive perceptions of their sibling on self-report and IAT indices, as well as lower internalizing and externalizing symptoms.

CHAPTER III

METHODS

Participants

Several organizations, persons, and online resources were utilized and contacted for the purpose of recruiting families to participate in this study. In total there were thirty-one recruitment sites contacted each of which was asked to share the study flyer and a brief explanation of the study with families who may be interested in participating. Of these thirty-one recruitment sites nineteen sites were organizations specializing in working with children with developmental disabilities and their families, six were special education schools in the local area, three sites were online resources and support groups, two sites were persons who have a large client base of families with children with an IDD, and one site was a research grant application to gain funding for access to a database that paid families to participate in research studies. Please see Appendix C for the recruitment chart.

The organizations, schools, and persons were contacted via email or phone call. Some of these sites did not return the researcher's inquiries, but the majority responded

and expressed an interest in helping. After information about the study was shared, many sites said they would promote this study to families who they felt would meet the study requirements. Unfortunately, there was a lack of accountability thereafter. While, they expressed an interest to help it is unclear if any of these sites subsequently shared the study flyer. Ultimately five families reached out with interest in completing the study (three of whom completed the study) from contacting these resources.

Upon reaching out to the director of two online support groups for RD siblings and pitching this study to him, the director responded by sending an email blast (containing the study flyer and a description of the study) to several families with whom he was connected, as well as posting the study information to both online support groups. This led to seven emails of interest, only one of whom completed the study, despite being the large amount of potential participant interest. Family members and friends also shared the thesis flyer on Facebook in an attempt to leverage their personal networks. From this resource, three families contacted with interest, all of whom completed the study. Overall, the online resources were found to be the most effective in generating participant interest.

To gain access to more families who might be interested in participating in the study, an online research database was found that would provide access to families who would be willing to participate. However, to gain access to this database, outside funding was needed. Therefore, the researcher applied for a Psi-Chi Graduate Student research grant. Unfortunately, the research grant was not awarded and so access to the research database could not be granted. Nevertheless, after speaking with the director of the database on the phone, she offered to send out an email containing the study information

to families she knew personally she believed would be interested in participating. No families contacted with interest in the study from this resource.

The largest recruitment obstacle appeared to be the phone call required by the IRB to ensure that the researcher verbally received child assent and parent consent before either family member started the online survey. Fifteen families contacted with interest in participating in the survey, but once emailed about setting up a phone call to go over the consent forms, five families did not follow up with completing the study. One mother with whom the researcher was able to schedule a phone call with openly admitted almost not having participated in the study because she did not like to speak to others on the phone, especially to someone with whom she had never met. Scheduling the phone call could also have been a contributing factor as it was hard to find coinciding availability for the researcher and the family members to speak. For either reason, having to speak with families over the phone seemed to be one of the biggest hindrances for families to start the online part of the study.

Participants were from families that have at least one child with a developmental disability, and at least one child considered typically developing (TD). Since this was a pilot study, the number of overall participants was expected to be relatively low (n=8 child participants, n=8 parent participants). Of the TD children, seven participants were male and one participant was female. The average age for the RD participants was thirteen and ages ranged from ten- to seventeen-years-old. All of the parent participants were female and the biological mothers of the TD child participants. As reported by the parents, the ethnicity for seven of the parent-child dyads was white and one parent-child dyad responded as other, but chose not to report their ethnicity specifically. Four parent

participants held graduate degrees, two held Bachelor's degrees, and two had some college education. Seven of the parent participants were married and one was divorced.

Instruments

Parent Measures

Demographics. The demographic questionnaire collects information on relationship to children, marital status, racial & ethnic background, education, and occupation. The questionnaire also asks questions about how often the parents communicate with their typically developing child about their disabled child and what kind of conversations they have with their child. Examples of these questions are, "Do you have conversations about your child's diagnosis with your typically developing child?" and "If YES, how often do you start these conversations?" (See the Appendix D for embedded questions within the demographic questionnaire).

Child's Adjustment. The Achenbach Child Behavioral Checklist (CBCL; Achenbach, 1991) is a parent-report measure designed to examine implicit and explicit behavioral problems for the child (between the ages of 4 to 18) on which they are reporting. There are 118-items and the responses are scored and compared to age and gender norms when raw scores are converted to t-scores. This measure asks about children between the ages of 4 to 18. Parents are to circle 0 every time the item is not true of the child, 1 if the item is somewhat true of the child, and 2 if the item is very true of the child. High reliability scores were previously found for internalizing scale scores ($r = .66$) and externalizing scale scores ($r = .80$) based on responses to items from nine subscales within the checklist. The internalizing subscale is a broadband subscale within the CBCL that measures symptoms of anxiety and depression. The externalizing subscale

is a broadband subscale that measures problematic behaviors of aggression. Only the internalizing and externalizing subscales will be used in this study's analysis to measure TD child adjustment.

Family Stress. Family Impact Questionnaire-FIQ (Donenberg, & Baker, 1993) is a 50-item measure asking parents about the impact their ID/DD child's diagnosis has on family activities and family outings. Response options are: not at all, somewhat, much, and very much. Parents are also asked 2 general questions at the end and are asked to respond on a 7-point scale ranging from much less positive to much more positive. Five scales measure negative impact and one scale measures positive impact on various aspects of the family functioning.

Child Measures

Sibling Perception (Explicit Feelings). The What It's Like to Have a Brother or Sister with a Developmental Disorder Questionnaire? (WHAT; Perry, 1989) is a 24-item survey with responses based on a 4-point Likert scale. There are also two open ended questions. This survey is used to measure child adjustment to having a sibling with a developmental disability. The items to this measure are based on 6 subscales: Competence/Knowledge, Chores/Expectations, School/Friends, Anger/Resentment, Mental Health, and Future Concerns. When scoring the subscales, higher scores are indicative of trouble with adjustment. Based on a small norming sample (n=31), the coefficient alpha found was this measure was .49, which indicates poor reliability. This subscale alone was found to have a coefficient alpha of .61. McHale & Gamble agree that these factors may be the most indicative of poor adjustment (1989).

The Sibling Inventory of Behavior-Adapted Version (SIB; Schafer & Edgerton, 1981; Hertherington, 1999) is a 28-item survey that aims to measure a child's relationship with their siblings. The answers range from 1-5, 1 indicating "never" and 5 indicating "always". The questionnaire focuses on 6 subscales: Empathy, embarrassment, acceptance, anger, unkindness, and kindness. Each subscale was scored based on a normed cutoff score and had high internal reliability with a coefficient alpha ranging from .67 to .99 within a normative sample.

Sibling's Implicit Feelings. An Implicit Association Task (IAT; Greenwald et al., 1998) is designed to measure how quickly a person can categorize words in order to see a person's automatic associations about two categories. This version of the IAT is a test designed to measure an individual's implicit biases toward their friend or their brother/sister. The test involves two speed classification tasks. The first classification looks at targets, which is the concept of interest (i.e. friend versus brother/sister). The second classification looks at the attributes, which are ways to categorize the targets (i.e. good versus bad). Please see Appendix E for IAT instructions and IAT model.

There will be two versions of the IAT and each test is then broken into two blocks. The first test is a neutral IAT, designed to teach participants the structure of the IAT by having them assign good (i.e., peace, and love) and bad (i.e. pain, and terrible) words with the categories of insects and flowers. It is also designed to act as a validity check to make sure the participant is paying attention to the instructions. In the first block of the neutral IAT, good words are paired with the word "flower" and bad words are paired with the word "insect" so the the targets are congruent with the attributes. In the second block of the neutral IAT, the good words will then be paired with the word

“insect” and the bad words will be paired with the word “flower”, making the targets incongruent with the attributes. In the second version of the IAT test, good and bad words will be paired with words associated with friend and brother/sister. In the first block the targets are congruent with the attributes. For example, positive words associated with friend (i.e. trust, loyal, like, understanding, care) are paired with good words. Negative words associated with brother/sister (i.e. annoying, trouble, embarrass, shame, tease) are paired with bad words. In the second block, the responses are incongruent, meaning that the positive words associated with friend are paired with bad words and negative words associated with brother/sister are paired with good words. Participants are asked to match the words associated with brother/sister and friend with words associated with the categories of good and bad, by responding as fast as possible on the computer and pressing the corresponding key on a keyboard.

The results provide researchers with an index to measure the response rate at which participants make these associations. The reaction times are measured in seconds. The faster the reaction time towards words or categories the more of a bias the participant has toward that category. This measure helps to show implicit feelings towards their friend or brother/sister that may be contrary to what is reported in self-report measures. For example, if we see that the typically developing sibling is reacting faster to “good” words towards the “friend” category and “bad” words towards the “brother/sister” category then we can see that the participant has a positive bias towards their friends and a negative bias toward their sibling. These results could be contrary to what the typically developing sibling reported in their self-report measures. For example, they could have responded that they were never embarrassed or frustrated by their brother or sister. If they

show that there is negative bias toward their sibling, this suggests that the typically developing sibling is not accurately reporting how they feel.

Procedure

First, IRB approval was received to recruit families to participate in the study. Participants were recruited via a flyer and a brief description of the study dispersed through online databases and given to organizations pertaining to developmental disabilities. The research flyer contained a brief description of the study and the study requirements. The brief description of the study contained details of the research being performed and explained why research was needed in this area. Organizations and online databases that were contacted included the Erie County Board of Developmental Disabilities, Sibshops, and typically developing sibling support groups on Facebook. The flyer instructed qualifying families to contact the researcher if they were interested in participating. Once the families reached out to the researcher, they were asked to set up a time to speak over the phone with the researcher to review the consent documents and to answer any questions about the study. Prior to the call participants were sent the consent documents via an online survey link. Once on the phone with the researcher, participants reviewed the consent documents and the researcher obtained verbal consent from the minor TD child participant. Thereafter, participants were sent separate online survey links and asked to complete all measures via Qualtrics, a secure online survey site. The total time of completion for the surveys took no longer than one hour and thirty-five minutes for the parent participant's survey and twenty-five minutes for the child participant's survey. Each parent/child participant dyad was given an ID number so that their names were not linked to their responses to maintain confidentiality and to enable

the researcher to recognize each parent/child pair. After participants completed their separate surveys they were thanked for their time.

General Analysis

After all participant data was collected statistical analysis were completed using IBM SPSS Statistics (IBM Inc., 2013). For each survey, mean, standard deviation, and range were gathered. Spearman's correlations were then run for each subscale embedded within the CBCL, FIQ, WHAT, SIB, and demographic questionnaire, as the data within these subscales was rank ordered.

Hypothesis I

The previous analytical plan for the data was to collect and calculate scores on the self-report measures and IAT statistics and transform those scores into a Z-score distribution. Then, differences between self-report and IAT Z-scores were to be calculated. These scores were meant to reflect discrepancies between self-report and implicit measures. These discrepancies were intended to predict internalizing & externalizing problems in a series of regression models. However, due to lack of sample size the analytical plan for this hypothesis was altered as the IAT data, discrepancy scores, and regressions could not be calculated. The new analytic plan, used to explore the relationships within Hypothesis I, involved calculating total scores on the self-report measures and internalizing and externalizing problems and analyzing any relationship associations through Spearman's correlations. The goal of this analysis was to highlight any trends between TD child adjustment and the TD child's perception of their IDD sibling.

Hypothesis II

Previously, to analyze hypothesis II, regressions were to be used to examine the effects of parent communication and family stress on the discrepancy scores noted in Hypothesis I. If these effects were found to be significant and if discrepancy scores predicted adjustment problems a mediation analysis was to be conducted to examine whether or not the effects of parent communication and family stress on adjustment were mediated via TD youths' perceptions. However, as there was a lack of sample size the previous analytic plan could not be implemented. The new analytic plan involved analyzing the relationship between parent communication and family stress to determine whether these variables were linked to TD youth's adjustment or perceptions through Spearman's correlation analysis.

CHAPTER IV

RESULTS

Descriptive Information

All eight of the parent and TD child participants completed the self-report measures. The parent participants reported, through the demographic questionnaire, that the average number of children within the families with a child with a developmental disability was three and the range was from two to six children per family. Parent participants reported that one of IDD child used sign language to communicate, one used some sounds to communicate, two used single words, three used short phrases, and four used full sentences or picture exchanges. On average, the parent participants responded that their children with an IDD sometimes interacted socially with others, the range of possible responses being interacting very often, sometimes, rarely, and never ($M=2.1$, $SD=.64$). The parent participants also responded that, on average, their children with IDD were mostly independent, the range of possible responses being entirely independent, mostly independent, rarely independent, and never independent ($M=2.4$, $SD=.92$). Five of the parent participants responded that their children with an IDD were diagnosed with

autism, two were diagnosed with intellectual disabilities, two were diagnosed with language delay, two were diagnosed with learning disabilities, one was diagnosed with down syndrome, and four were diagnosed with a developmental disability not listed including: Inverted Duplicated 8P Syndrome, Chromosome 9 Deletion Syndrome, Fetal Alcohol Syndrome, and Sensory Processing Disorder. The age of diagnosis ranged from prenatal to 14 years old.

All parent participants responded that their TD child participating in this study knew of their disabled sibling's diagnoses and that they had conversations with their TD child about the diagnoses. The average age at which the parent participants began having conversations with their TD children about their disabled sibling's diagnosis was six years old and the range was from three- to fourteen-years-old. Parent participants responded that, on average, they initiated conversations with their TD children once to a few times monthly given the possible responses of: once to a few times weekly, once to a few times monthly, once to a few times every few months, and once to a few times per year ($M=1.8$, $SD=1.0$). On average, the parent participants responded that they felt these conversations were very important ($M=4.5$, $SD=.54$). The response options for the importance of the conversations ranged from not at all important, not too important, somewhat important, very important, and extremely important. The topics of these conversations included discussing that everyone is unique and has a different purpose, that everyone should be accepted no matter who they are, that everyone should be loved, that they (the TD children participants) should support their siblings because "that's what families do", and that the IDD sibling's brain works differently and explaining the differences. Following are several examples of the responses:

Participant 8: “The talks are how we should help him, what our goals are for him. How she feels about his special attention, why she feels jealous. What she wants to do for his future, how she wants to protect him. What she sees his doing to self or other siblings.”

Participant 6: “Ways in which to support her sister with challenges, help her grow independently, help her remember to ask for help, praise her when she completes a task start to finish without help, how to coach her through upset, ways to make her feel appreciated, ways to give her personal space when she needs it, ways to make sure everyone is treated equitably.”

Participant 2: “How we travel, how to cope with others, being a family with everyone being an important piece in the family and that their brother is not the heart of the family, but a part of it just as they are-even though he requires more care and he has to rely on others for his day to day activities.”

Participant 1: “Everyone has their strengths and weaknesses. All people have their own special gifts. All people have a purpose in this world.”

On average the parent participants reported that their TD children initiated the conversations about their disabled sibling once to a few times monthly ($M=1.8$, $SD=1.0$). The possible response options for this question were one to a few times weekly, once to a few times monthly, once to a few times every few months, and once to a few times per year. This data may suggest that the parent participants felt it was important to have conversations with their TD children about their disabled sibling’s diagnosis and the

topics of these conversations often contained messages of love and equality, despite differences.

Hypothesis I. *Do Typically Developing Children's Perceptions of their Intellectually/Developmentally Disabled Siblings Affect their Adjustment?*

With respect to TD child internalizing adjustment problems and how they are related to the TD child perception of their IDD sibling, elevated scores on the WHAT chores/expectations subscale significantly correlated internalizing symptoms $r = .88, p < .05$ on the CBCL. Furthermore, the externalizing adjustment problems subscale was not found to correlate with any of the TD child perception subscales on either the WHAT or the SIB. This suggests that the extra amount of chores and expectations put on the TD child participants compensating for the additional attention required for the IDD child was related to parents' perceptions of the TD child's emotional difficulties. Please see Table I for the TD Adjustment/Perception Correlations table.

Hypothesis II. *Does parental communication and family stress affect the typically developing child's adjustment and in turn affect how the typically developing child perceives their intellectually/developmentally disabled sibling?*

First, parent conversation with their TD child about their IDD sibling's diagnosis was viewed in terms of how often the parents spoke with their TD child and how important they felt these conversations were to have. These parent conversation components were found to be uncorrelated with one another, $r = .538, p = .169$. Second, the role of parental communication on the TD child participants' adjustment was analyzed and were not found to be linked via correlational analyses. How often parents spoke to their TD child about their IDD sibling's diagnosis was to be unrelated to both

internalizing $r = .041$, $p = .924$, and externalizing $r = -.106$, $p = .803$ problem subscales on the CBCL. How important parent felt about having these conversations with their TD was also found to be uncorrelated with both internalizing $r = .396$, $p = .331$ and externalizing $r = .442$, $p = .273$ subscales. Please see Table II for the Parent Communication/Family Stress Correlations table.

Third, parent communication was examined in relation to TD child's perceptions of their IDD sibling. The parent participants' belief in the importance of having conversations with the TD child participants was associated with elevated anger that the TD child participants felt toward their IDD siblings, $r = .67$, $p = .07$. Furthermore, the frequency of these interactions was inversely related to the TD child participants' levels of anger toward the IDD sibling, $r = -.63$, $p = .097$. In a similar vein, the parent participants reported the need to frequently speak with the TD child participants as a function of the TD child participants' tendencies to act unkindly toward their IDD siblings (e.g., teasing), $r = .71$, $p = .05$. These findings suggest that as parents had more frequent conversations with their TD child about their IDD sibling's diagnosis, the TD child's level of anger felt to their IDD sibling diminished. Furthermore, when their TD child's level of anger toward their IDD sibling did increase, parents felt it was very important to have these conversations with their TD child. However, the more often parents had these conversations with their TD about their IDD sibling's diagnosis did not diminish how unkindly the TD children felt toward their IDD sibling, which is very likely due to the siblings having a typical sibling relationship.

Fourth, family stress was examined separately from parent communication to see how functions of stress were alone related to TD child adjustment. The functions of

family stress were viewed in terms of the negative attitudes felt of their current family situation, negative social impact, financial burdens, negative impact on the sibling relationship, and the overall degree to which the IDD child impacted the family. With respect to TD child adjustment, the parent participants' reduced capacity to facilitate social activities correlated with worse externalizing problems, $r = .85, p < .05$. However, all functions of family stress were found to be uncorrelated with internalizing symptoms. These findings suggest that when the TD children are prevented from partaking in a social activity because of their IDD sibling they become aggressive and lash out because they are upset, but this does not worsen any existing anxiety or depressive symptoms. Please see Table II for the Parent Communication/Family Stress Correlations table.

Last, the relationship between family stress and TD child perception of their IDD sibling was analyzed. The results imply that the more financial adversity faced by the family from the increased needs of the IDD siblings, the more the TD child participants felt anger toward their IDD siblings ($r_s = .64$ to $.65, p_s = .08$ to $.09$), however the need to act unkindly toward their IDD siblings decreased ($r = -.80, p = .031$). These findings suggest that the TD children feel anger toward their IDD sibling when they know of their family's financial burden caused by the increased needs of their IDD sibling because they may be quick to lash out in anger, but on some level know it is not their IDD sibling's fault so do not deliberately act unkindly toward their IDD sibling. Further, higher levels of negative social impact and overall negative impact of the IDD siblings were also associated with decreased feelings of unkindness and future concerns ($r_s = -.64$ to $-.80, p_s = .03$ to $.09$). This again suggests that the TD children participants were able to recognize that the increased degree of impact and social burden is not the fault of their IDD

siblings, the TD child participants were able to refrain from feeling or acting unkind or overly worried for their IDD siblings.

CHAPTER V

DISCUSSION

This study aimed to examine the associations between TD youths' relationships with their IDD siblings and TD youths' psychological adjustment. Further, this study aimed to examine the role of parental communication about IDD siblings' disabilities with TD siblings on the aforementioned relationships. Family stress was also meant to be measured to see if this stress effected TD siblings' internalizing and externalizing problems as negative stressors over and above sibling perception. Another aim of this study was to show that lack of family communication and negative stress could lead to poor downstream effects on TD siblings' perceptions of their IDD siblings. This study was intended to serve as a pilot sample, as recruiting families to participate in this study was likely to be difficult due to the narrow definition of the population. The eventual aim of this study was that the pilot data collected could support further research on this topic and the validity of the IAT in examining TD children's implicit feelings towards their IDD siblings'.

Typically developing youths' perceptions of their IDD siblings (measured via

self-report, IAT, and the discrepancy between self-reported and IAT indices) were predicted to be significantly correlated with their internalizing and externalizing problems. Parent conversations with their TD children about their IDD siblings' diagnoses were also predicted to positively influence the TD children's perceptions of their siblings on self-report and IAT indices, lower internalizing and externalizing symptoms, and minimize the effects of family stress. Unfortunately, the biggest limitation of this study was the lack of sample size leading to a lack statistical power. The IAT data was also unusable due to the low number of responses meaning little meaningful analysis could be performed. Furthermore, the TD child participants' implicit feelings could not be measured or compared to their self-report responses through Z-score discrepancies. Finally, regression analyses were not possible and therefore could not be used to determine the relationship between parent communication, family stress, and discrepancy scores.

Hypothesis I Discussion

While the number of families who completed the study was insufficient to gain any meaningful quantitative data, enough families participated to indicate some success in the directionality of the study in analyzing the family dynamics present in multi-child families raising a child with an IDD. In Hypothesis I, the relationship between the TD child participants' perceptions of their IDD siblings and the TD child participants' adjustment was explored. As previously noted, the TD child participants' appraisals of their IDD siblings was measured via the WHAT and the SIB. Results indicated that the extra amount of chores and expectations put on the TD child participants to compensate for the additional attention required for their IDD siblings related to greater emotional

difficulties reported by the parent participants. This is consistent with previous findings that TD children more negatively perceived their IDD siblings because they were assigned more chores and were held to higher expectations, this in turn leading to an increase in negative behaviors (McHale et al., 1986). Furthermore, TD children's perceptions of their IDD sibling were not influenced by any externalizing behaviors reported by the parents.

Hypothesis II Discussion

Hypothesis II sought to explore the relationships between parent conversations with their TD children, various functions of family stress, TD child adjustment, and TD children's perceptions of their IDD siblings. Parent conversation was viewed in terms of frequency and importance across the various aspects of adjustment and perception. First, parent conversation was examined with regard to both internalizing and externalizing adjustment subscales on the CBCL and were not found to be linked via correlational analyses. This suggests that how frequent or important parents felt these conversations were to have with their TD children had no effect on adjustment, which is neither a good or bad thing, simply they were unrelated.

Second, parent communication was examined in relation to TD child's perceptions of their IDD sibling. These findings suggest that as parents had more frequent conversations with their TD child about their IDD sibling's diagnosis, the TD child's level of anger felt to their IDD sibling diminished. Furthermore, when their TD child's level of anger toward their IDD sibling did increase, parents felt it was very important to have these conversations with their TD child. However, the more often parents had these conversations with their TD about their IDD sibling's diagnosis did not diminish how

unkindly the TD children felt toward their IDD sibling, which is very likely due to the siblings having a typical sibling relationship. Meaning that as siblings typically tease one another, the unkindness reported is more likely a function of the typical sibling relationship, while the anger reported is more likely circumstantial and can be diminished when talked through. This is somewhat contrary to what the literature states, which is that TD siblings become more accepting of their IDD siblings when more conversations about their IDD siblings' diagnoses occur (Cohen, Friedrich, Copeland, & Pendergrass, 1989; Kao, Romero-Bosch, Plante, & Lobato, 2012).

Third, family stress was examined separately from parent communication to see how functions of stress were alone related to TD child adjustment. These findings suggest that when the TD children are prevented from partaking in a social activity because of their IDD sibling they become aggressive and lash out because they are upset, but this does not worsen any existing anxiety or depressive symptoms. This is consistent with extant literature in that TD siblings have been found to report increased feelings of resentment toward their IDD siblings due to concerns about restricted social activities (Kao, Romero-Bosch, Plante, & Lobato, 2012).

Last, the relationship between family stress and TD child perception of their IDD sibling was analyzed. These findings suggest that the TD children feel anger toward their IDD sibling when they know of their family's financial burden caused by the increased needs of their IDD sibling because they may be quick to lash out in anger, but on some level know it is not their IDD sibling's fault so do not deliberately act unkindly toward their IDD sibling. Further findings suggest that the TD children were able to recognize that the increased degree of impact and social burden is not the fault of their IDD siblings

and could then refrain from feeling or acting unkind or overly worried for their IDD siblings. As the literature suggests, despite concerns and stressors that arise, families are able to resolve these conflicts, particularly conflicts among the siblings (Simeonsson & McHale, 1981).

Completion Problems

There are several reasons why families may have had difficulties in completing this study. As it is well known, having children is no easy task and many families lead very busy lives. Parents have career requirements to attend to on top of juggling their children's schedules of school, sports practices, doctor's appointments, etc.... As this study has discussed previously, raising children is stressful let alone raising a child with a developmental disability. The families wishing to take part in this study may have had the best intentions but could understandably not find the time to do so. Busy schedules aside, there may have been a few other reasons families struggled to complete this study.

Disability Severity

The severity of the diagnosis for the disabled child may have also been a contributing factor in inhibiting families from completing the study. As also previously discussed, increased disability severity leads to increased demands on the family's time and resources, leading to increased stress. Families with increased demands on their time as a result of a severe diagnosis, on top of routine family demands, could have led to further difficulties in families completing the various parts of this study.

Age

The age of the TD child participants at the time of this study could also have proven to be a contributing factor in inhibiting the TD child participants from completing

the child survey. Between the ages of ten and seventeen significant developmental changes occur causing a large disparity in the maturity of seventeen-year-olds and ten-year-olds. For example, when a parent asks their seventeen-year-old child to sit down and take a short survey online the seventeen-year-old is much more likely to be capable of sitting down, following the command, and completing the survey when asked. However, a ten-year-old will most likely have a much harder time in sitting down and completing this survey in one sitting. The ten-year-old may have also needed parental reminders to finish the survey (which may not have been provided in a busy household). Since the child survey required the child to follow directions to an additional link and to allow the upload of the IAT, the older children may have had a much easier time following these instructions and completing this secondary task, while the younger children may have had a harder time following these directions and, as a result, did not attempt to ask for parental help when they could not get the IAT started.

Technology

As mentioned above, the child survey required the children to follow a link directing them to another platform in order to upload and run the IAT. The instructions were very straightforward and were shown to be effective in leading to its completion as demonstrated by some of the TD child participants. However, there were several glitches that arose as a result of technological limitations. One of these obstacles was pop-up blocking software. Many families' issues related to pop-up blocking software preventing important windows from opening. Several families were able to disable the pop-up blocking software, which allowed the IAT to run. However, once some families encountered this obstacle they did not follow through and finish this part of the survey.

The second obstacle that arose was computer freezes. Some families had difficulties with getting the IAT program to run on their home computers. They reported that the task would freeze several times and subsequently crash preventing them from accessing the IAT program. Unfortunately, this was not an obstacle that could not feasibly be solved between the researcher and the family over the phone or via email, therefore after freezes families were thanked for their participation in completing the self-report surveys. The third obstacle families faced was a failure in downloading the IAT software. Some families reported that after following the link the IAT software did not begin to download preventing them from completing the task. As with the computer freezes, this technological obstacle that could not be overcome by the researcher over the phone or through email. Families were again thanked for their completion of the self-report surveys.

Looking to The Future

One purpose of this study was to explore how TD siblings implicitly feel toward their developmentally disabled siblings at different ages and during stages of development. This study answers an important research question, which is how TD siblings truly feel, despite what they may say on self-reports. This answer can in turn lend insight into how parents of a child with a developmental disability can strengthen the sibling relationship and also have a better idea of how their child is feeling toward their sibling at different ages. Another purpose of this study was to explore how parental conversations about their IDD children's diagnoses with their TD children affected the sibling relationship. Answering this research question could also shed light on the relative importance or unimportance for parents to have these conversations with their TD

children. In understanding these processes, families could be counseled about how to best cultivate positive family dynamics. While this study ultimately served as pilot data due to lack of participants, it does lend understanding on a topic that is under-researched and should be pursued further.

To further explore this topic in the future, several things can be done to eliminate some of the recruitment and completion obstacles that arose during data collection. One way the recruitment and completion obstacles can be overcome is to administer the study in person. This can be accomplished by fostering a stronger connection with a children's hospital or an organization pertaining to developmentally disabled children and their families. Having a better in-road with a hospital or organization can allow the researchers to meet the families in person, explain their roles in the study, as well as be present to answer any questions that arise while each family member is completing their part of the survey. The parent surveys could be completed by hand, while the researcher assists the TD children in completing their part of the survey on a secured computer. This would also eliminate some of the technological, age, and severity obstacles that arose during the study. In having the TD children complete the IAT on a computer that is known to work, the data can successfully be collected. The age of the TD children and the severity of their siblings' diagnoses would also no longer be a concern as the researcher would be there to ensure completion of the study and to assist in any issues that arise.

If the study cannot be administered in person and must be administered online, then it is recommended that the phone call part of the consent process be eliminated. The scheduling of the phone call proved to be the largest hindrance to families partaking in the study. Parents should be trusted to read the consent forms and to have their TD

children read the assent form before starting the survey. The researcher's contact information would be provided so that parents could ask any questions they might have before starting the survey. In eliminating this step of the consent process, this study can be uploaded to online-only research interfaces (e.g., research match) to collect a larger sample of families. An online-only version of this study would not eliminate some of the technological/age/severity issues of completion, but it would quickly and effectively promote the study to a larger sample of participants, some of which would successfully be able to complete the survey, overall encouraging more useable data.

As this study attempted to answer important questions about the interplay of family dynamics within families who have a child with a developmental disability, several recruitment and completion obstacles arose that prevented a sufficient amount of data to be collected in order to interpret anything meaningful from the results. In letting this study serve as an example of what not to do, future studies can learn from the mistakes of this study. Future studies should consider the above recommendations to more successfully collect a larger amount of responses from this specific subset of the population. If in future studies, the IAT proves to successfully uncover how TD children feels toward their IDD siblings, this would answer an important research question and yield novel results. Despite the many pitfalls of this study, pursuit of this research should be highly encouraged to further understand the family dynamics involved in raising a child with a developmental disability.

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APPENDICES

Table I. *TD Child Adjustment/Perception Correlations*

		CBCL- Externalizing Symptoms	CBCL-Internalizing Symptoms
	Mean, Standard Dev.	M=21.13, SD=4.61	M=18.5, SD=3.07
SIB-Embarrassment	M=9.88, SD=1.25	$r=-.267, p=.522$	$r=-.471, p=.238$
SIB-Anger	M=9.75, SD=2.6	$r=-.210, p=.618$	$r=.063, p=.882$
SIB-Unkindness	M=9.5, SD=1.93	$r=-.506, p=.201$	$r=.144, p=.734$
SIB-Empathy	M=19.75, SD=2.12	$r=.059, p=.889$	$r=-.047, p=.911$
SIB-Kindness	M=18.88, SD=3.04	$r=-.506, p=.201$	$r=-.200, p=.635$
SIB-Acceptance	M=23.25, SD=3.73	$r=-.218, p=.604$	$r=.068, p=.872$
WHAT-Anger	M=7.25, SD=1.83	$r=-.360, p=.381$	$r=-.013, p=.976$
WHAT-Embarrassment	M=10.5, SD=1.51	$r=.137, p=.747$	$r=-.439, p=.276$
WHAT-Chores	M=8.5, SD=.756	$r=.466, p=.244$	$r=.877, p=.004^{**}$
WHAT-Knowledge	M=7.12, SD=1.64	$r=.110, p=.795$	$r=.220, p=.600$
WHAT-MentHeal	M=8.13, SD=.99	$r=-.139, p=.743$	$r=.068, p=.074^*$
WHAT-Future Concerns	M=9.5, SD=1.93	$r=-.328, p=.473$	$r=-.156, p=.712$

* $p < .05$ significance value, ** $p < .01$ significance value

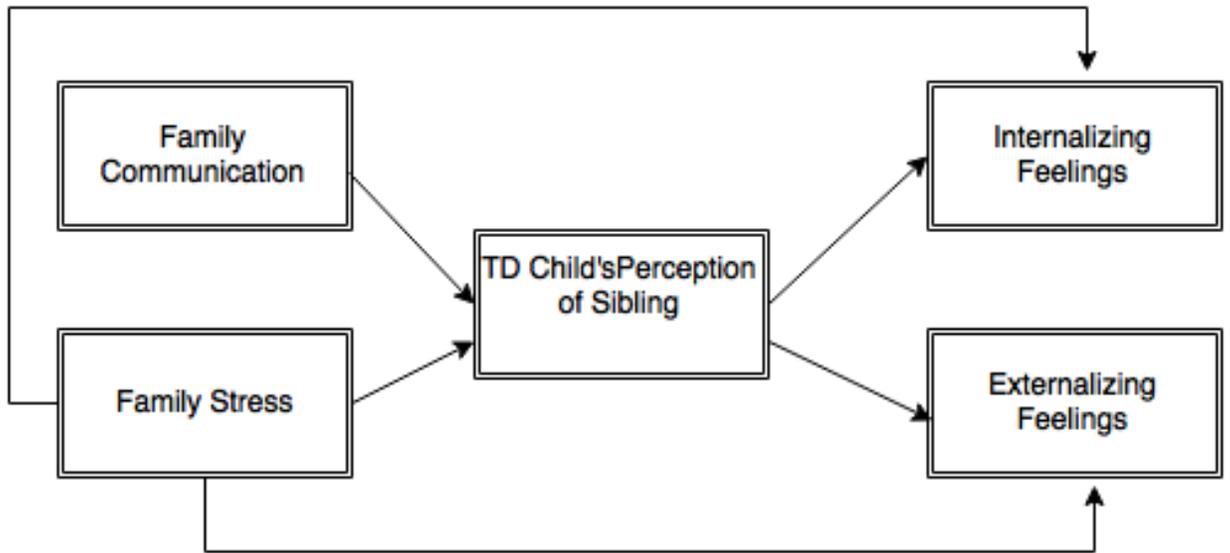
Table II. *Parent Communication/Family Stress Correlations*

	How often Convo.	How important Convo.	FIQ- Attitudes	FIQ- Social	FIQ- Financial	FIQ- Sibling	FIQ-Degree
CBCL Intern.	$r=.041$ $p=.924$	$r=.396$ $p=.331$	$r=.412$ $p=.359$	$r=.412$ $p=.359$	$r=.317$ $p=.444$	$r=.548$ $p=.160$	$r=.590$ $p=.123$
CBCL Extern.	$r=-.106$ $p=.803$	$r=.442$ $p=.273$	$r=.442$ $p=.272$	$r=.847$ $p=.016^{**}$	$r=.352$ $p=.393$	$r=.335$ $p=.417$	$r=.420$ $p=.300$
SIB-Embarras.	$r=-.188$ $p=.655$	$r=.000$ $p=1.00$	$r=-.500$ $p=.207$	$r=-.273$ $p=.554$	$r=.099$ $p=.816$	$r=-.361$ $p=.380$	$r=-.110$ $p=.795$
SIB-Anger	$r=-.267$ $p=.522$	$r=.671$ $p=.069^*$	$r=-.196$ $p=.641$	$r=-.018$ $p=.969$	$r=.638$ $p=.089^*$	$r=.566$ $p=.144$	$r=.244$ $p=.560$
SIB-Unkind.	$r=.706$ $p=.05^*$	$r=-.387$ $p=.344$	$r=.248$ $p=.553$	$r=-.800$ $p=.031^{**}$	$r=-.376$ $p=.359$	$r=-.236$ $p=.574$	$r=-.639$ $p=.088^*$
SIB-Empathy	$r=.243$ $p=.562$	$r=.359$ $p=.383$	$r=.230$ $p=.584$	$r=-.433$ $p=.332$	$r=.171$ $p=.686$	$r=.262$ $p=.530$	$r=-.170$ $p=.688$
SIB-Kindness	$r=-.185$ $p=.661$	$r=.387$ $p=.344$	$r=-.267$ $p=.523$	$r=-.436$ $p=.328$	$r=.279$ $p=.504$	$r=.311$ $p=.454$	$r=-.145$ $p=.733$
SIB-Accept.	$r=-.131$ $p=.757$	$r=.384$ $p=.347$	$r=.054$ $p=.899$	$r=-.321$ $p=.482$	$r=.169$ $p=.690$	$r=.451$ $p=.262$	$r=-.036$ $p=.933$
WHAT-Anger	$r=-.625$ $p=.097^*$	$r=.394$ $p=.334$	$r=-.704$ $p=.051^*$	$r=.145$ $p=.756$	$r=.648$ $p=.082^*$	$r=.127$ $p=.765$	$r=.479$ $p=.230$
WHAT-Embarra.	$r=.007$ $p=.987$	$r=-.169$ $p=.690$	$r=-.086$ $p=.839$	$r=-.185$ $p=.691$	$r=-.235$ $p=.576$	$r=-.373$ $p=.362$	$r=-.196$ $p=.641$
WHAT-Chores	$r=-.173$ $p=.682$	$r=.315$ $p=.447$	$r=.173$ $p=.682$	$r=.538$ $p=.213$	$r=.436$ $p=.281$	$r=.220$ $p=.601$	$r=.577$ $p=.134$
WHAT-Knowle.	$r=.345$ $p=.402$	$r=.222$ $p=.597$	$r=.537$ $p=.170$	$r=-.400$ $p=.374$	$r=-.098$ $p=.818$	$r=.363$ $p=.377$	$r=-.267$ $p=.523$
WHAT-Ment Heal	$r=.093$ $p=.827$	$r=-.359$ $p=.383$	$r=-.348$ $p=.399$	$r=-.060$ $p=.899$	$r=.059$ $p=.890$	$r=-.565$ $p=.145$	$r=.156$ $p=.711$
WHAT-Fut. Con,	$r=.488$ $p=.21$	$r=-.221$ $p=.599$	$r=.067$ $p=.875$	$r=-.685$ $p=.090^*$	$r=-.212$ $p=.614$	$r=-.255$ $p=.543$	$r=-.458$ $p=.254$

* $p < .05$ significance value, ** $p < .01$ significance value

Appendix B

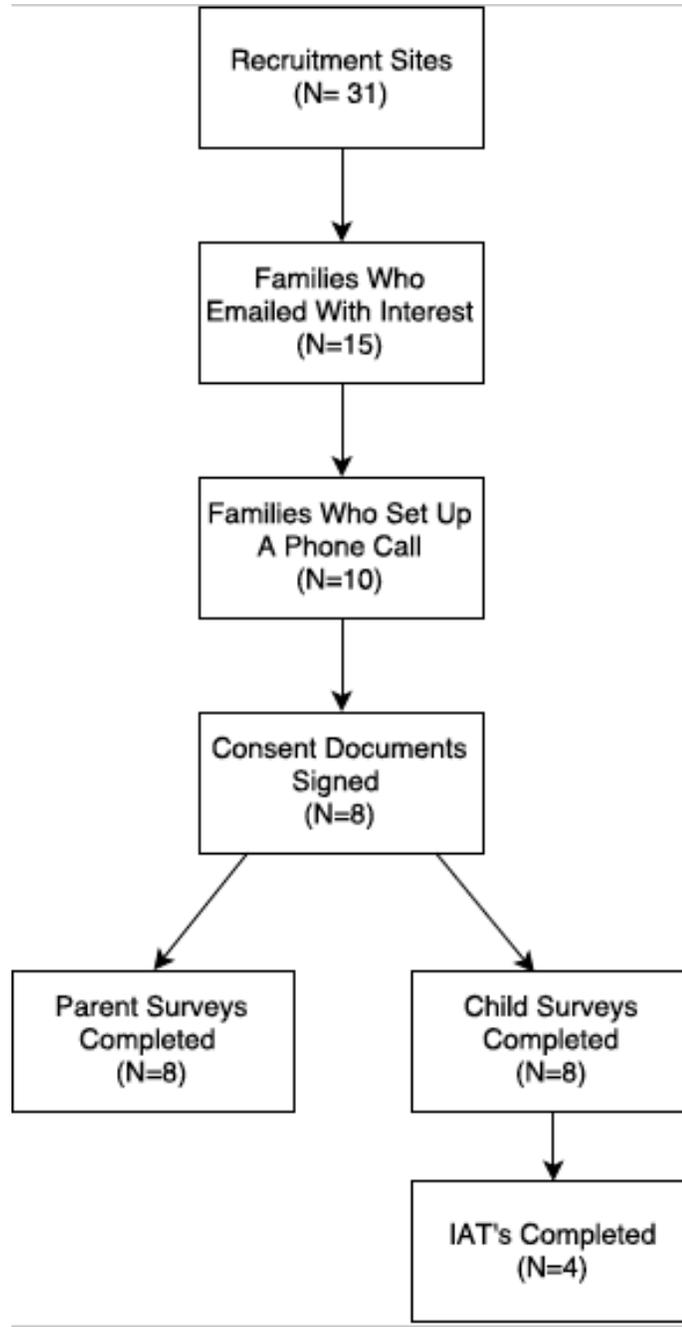
Study Model



This model shows the possible downstream effects of family communication and family stress have on how the TD child perceives their IDD sibling resulting in positive or negative feelings towards their sibling.

Appendix C

Recruitment and Completion Results



This model shows the number of recruitment sites that were contacted to the amount of surveys that were completed in order to illustrate the difficulties of conducting a study requiring families from a specific subset of the population.

Demographic Questionnaire

I: Basic Information

Relationship to the participant (the adolescent child participating in this study) (Circle one):

Mother

Father

Stepmother

Stepfather

Legal Guardian

Marital Status (circle one):

Never Married

Married

Separated

Divorced

Widowed

Race (circle all the apply):

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Other Pacific Islander

Two or more races

Other (please indicate): _____

Ethnicity (circle one):

Hispanic

Non-Hispanic

Highest Level of Education Achieved (Circle one):

Some High School

High School Graduate

Some College

Associates Degree

Bachelor's Degree

Some Graduate Education

Professional Degree (list): _____

Advanced Degree (list): _____

Current Occupation (list):

Current Occupation of Spouse (if applicable) (list):

II: Family Profile

Number of Children in Family: _____ Total (_____ sons _____ daughters)

Please list the birth order of your children (#1 oldest, up to #10 youngest). Please include their first name and age:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

Which developmental disability has your child/children been diagnosed with? (Circle one or more if more has received more than one of these diagnoses. Also indicate which child has received what diagnosis by writing their name next to the diagnosis, if more than one child has received a diagnosis)

Autism Spectrum Disorder (Autistic Disorder, Asperger's, PDD-NOS)

Intellectual Disability

Language Delay

Learning Disability

Down's Syndrome

Cerebral Palsy

Attention Deficit Hyperactivity Disorder

Developmental Disability not listed above:

At what age was he/she first diagnosed? _____

List any other current diagnoses (medical or psychological):

How does he/she primarily communicate? (Circle all that apply):

No Communication

Gestures only

Sign Language

Some Sounds

Verbal Communication- Single Words

Verbal Communication- Phrases

Verbal Communication- Full sentences Picture Exchange (PECS, etc)

Alternative Device

Other (list): _____

How often does he/she interact socially or play with others? (Circle one):

Very often

Sometimes

Rarely

Never

How independent is he/she with daily activities (bathing, homework, etc)? (Circle one):

Entirely Independent

Mostly Independent

Rarely Independent

Never Independent

Please answer the following questions about your typically developing child participating in this study:

Has this child ever received a medical or psychological diagnosis that is not related to a developmental disability? (Circle one): Yes No

If YES, please describe:

Has this child ever been under the care of a therapist? (Circle one): Yes No

If YES, please describe:

Does this child know about their sibling's diagnosis? (Circle one): Yes No

Do you have conversations about your child's diagnosis with your typically developing child? (Circle one): Yes No

If YES, at what age did you start having these conversations?

If YES, how often do you start these conversations? (Circle one):

1. Once to a few times weekly
2. Once to a few times monthly
3. Once to a few times every few months
4. Once to a few times every year

If YES, do you feel it's important to have these conversations? (Circle one):

1. Not at all
2. Not too much
3. Somewhat
4. Very much
5. Extremely much

If YES, what are the content of some of your conversations? (example being: how this impacts your family? Or how we accept individuals from all walks of life.)

How often does your typically developing child initiate these conversations about their sibling?

1. Once to a few times weekly
2. Once to a few times monthly
3. Once to a few times every few months
4. Once to a few times every year

Does your typically developing child talk to their sibling about the diagnosis? (Circle one):
YES NO N/A

If, YES how often?

1. Once to a few times weekly
2. Once to a few times monthly
3. Once to a few times every few months
4. Once to a few times every year

Appendix E IAT Description

Instructions:

For the next portion of this study, you will be asked to classify words into the categories of “Friend” and “Brother or Sister”, as well as words related to “Good” and “Bad”. The words related to each of the categories are shown below. When the word in the center corresponds to the category on the left, you will use the "e" key, and when the word in the center corresponds to the category on the right, you will use the "i" key. Classify the words as quickly as possible while making as few mistakes as possible.

Brother or Sister	Friend	Good	Bad
annoying	like	peace	pain
trouble	trust	pleasure	terrible
embarrass	understanding	love	rotten
shame	care	joy	nasty
tease	loyal	wonderful	sad

Screenshot of Implicit Association Mood Test

