Title

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In Their Own Words: Using Siblings’ Meanings about Daily Family Interaction to Understand the Influence of a Child with a Developmental Disability on the Sibling Experience

By

Tahl Sendowski

A dissertation submitted in partial satisfaction of the

requirements for the degree of

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Committee in charge:

Professor Susan Holloway, Chair
Professor Stephen Hinshaw
Professor Laura Sterponi

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In Their Own Words: Using Siblings' Perspectives to Understand the Influence of a Child with a Developmental Disability on the Sibling Experience

by

Tahl DeBoer Sendowski

Abstract

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Doctor of Philosophy in Education

University of California, Berkeley

Professor Susan Holloway, Chair

This study examined daily experiences of stress and coping among adolescent siblings of children with developmental disabilities. Early studies of this population have assumed that living with a disabled sibling is inherently stressful due to changes in the availability and allocation of familial resources. While recent work suggests that only a minority of nondisabled youth experience considerable stress related to family interactions involving a disabled sibling, few studies offer an understanding of how nondisabled siblings make meaning of their experiences and their attempts to cope with them. As such, we have a poor understanding of why some nondisabled siblings struggle while others do not. To address this gap in the literature, I drew on models of stress and coping to conduct a qualitative exploration of the cognitive appraisals used by nondisabled siblings during stressful family interactions. I conducted in-depth individual interviews with 11 nondisabled siblings (aged 10 to 17 years old) to elicit their descriptions of daily family interactions. The interviews were composed of audio-recorded dinner conversations and emotion maps as well as open-ended questions to elicit candid and detailed accounts of family life.

Analyses of participants' appraisal processes addressed the following questions: which aspects of daily family interactions they experienced as stressful and why they were appraised as stressful, how the participants attempted to manage these stressful interactions and why they chose particular coping behaviors and resources, and how their coordination of these appraisals were associated with their subsequent distress. The findings present three important clinical and research implications, including the importance of considering nondisabled siblings' appraisals of stressful family interactions in clinical practice and research, the need to expand nondisabled siblings' coping behaviors and resources for managing daily family-related stress, and the role of parents in nondisabled siblings' experiences of stress.

Dedication

This dissertation is dedicated to all of the siblings whose voices deserve to be heard, and in particular those who were brave enough to share their stories with me. Your stories are important, within your families and within our society. You have shaped my thinking about and work with families, and I hope that this research will shape the thinking of others.

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Chapter 1: Introduction and Review of the Literature

Developmental and family scholars consider sibling relationships to play a key role in individual development through processes of mutual socialization and support (Dunn, 2015; McHale, Updegraff, & Whiteman, 2013). For many individuals, sibling relationships are the longest-lasting relationships experienced during their lifetime, and research suggests that they influence development across the lifespan (Cicirelli, 1995). Due to the importance of sibling relationships for lifelong development, it is crucial to broaden research in this area to include the experiences of children in diverse contexts, including children who have a sibling with a developmental disability, referred to in this study as nondisabled siblings. For the purposes of this study, a developmental disability is defined as a severe and chronic disability with onset at birth or during childhood that is lifelong and hinders the individual's ability to function across several developmental areas (106th Congress, 2000). Overall, the literature on families with children with developmental disabilities suggests that many of these families face heightened stressors due to changes in the availability and allocation of familial resources, a reality that is believed to influence both parents and siblings (Hanson, 2013).

Studies of nondisabled siblings have historically held the view that disability-related family stressors affect siblings in the form of less time and attention from parents, increases in time spent engaged in sibling caregiving, and limited options for family activities due to a disabled siblings' condition or behavior (Hanson, 2013). Investigators have assumed that growing up with a developmentally disabled sibling has inherent negative psychological consequences for nondisabled siblings as a result of these stressful experiences (Hodapp, Glidden, & Kaiser, 2005; Stoneman, 2005; Stoneman & Berman, 1993). However, research findings regarding psychological outcomes for nondisabled siblings are mixed. Some studies indicate poorer psychological functioning among nondisabled siblings, as compared with siblings of typically developing children, while others find nondisabled siblings to fare better than or as well as siblings of typically developing children (Rossiter & Sharpe, 2001; Schuntermann, 2007; Stoneman, 2005).

Interestingly, studies of the experiences of nondisabled siblings have identified notable within-group variability in regard to their evaluation of their family relationships (Dunn, 1992; Stoneman, 2005; Stoneman & Berman, 1993; Taylor, Burke, Smith, & Hartley, 2016). Results from several recent qualitative studies of nondisabled siblings indicate that small subsets of this population experience significant difficulties, such as severe and negative feelings towards their siblings and other family members (Corsano, Musetti, Guidotti, & Capelli, 2017; Goodwin, Alam, & Campbell, 2017; Opperman & Alant, 2003; Stalker & Connors, 2004), or less warmth and closeness along with more conflict and animosity in their sibling relationship (McHale, Sloan, & Simeonsson, 1986; Pollard, Barry, Freedman, & Kotchick, 2013). The research also links these unfavorable experiences with diminished wellbeing. For instance, Pollard and colleagues (2013) found that nondisabled children who reported poor relationship quality with their siblings with autism spectrum disorder (ASD) also reported symptoms of greater anxiety. Overall, these studies indicate that a minority of nondisabled siblings experience considerable stress as a result of their experiences with a disabled sibling, with concomitant impact on their development and psychological wellbeing.

Moving away from a sole focus on possible negative effects of having a disabled sibling, other researchers have attempted to identify positive as well as negative experiences afforded by being a nondisabled sibling (Corsano et al., 2017; Goodwin et al., 2017; Mascha & Boucher, 2006; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008; Okashah, Schoch, Hooper, Shashi, & Callanan, 2015; Rossetti & Hall, 2015; Ward, Tanner, Mandleco, Dyches, & Freeborn, 2016). Overall, these studies seek to address questions about the processes and mechanisms by which the positive and negative experiences associated with being a nondisabled sibling in turn influence child development (Green, 2013; Hastings, 2016; Saxena & Adamsons, 2013). A gap in the literature persists in terms of understanding how stress actually manifests in family interactions and why some nondisabled siblings experience more severe and pervasive stress than others.

In this chapter I offer a summary of the literature on nondisabled siblings. The summary begins with a brief overview of the two primary theoretical frames that characterize the research in this field, followed by a discussion of empirical findings. I conclude the chapter with a description of the elements of family systems theory and the stress and coping model of stress that I used in this study. I then describe the questions that guided my study and identify the potential contributions I hope to make to this field.

Use of Theory in the Study of Nondisabled Siblings

Overall, family systems theory is the most commonly referenced theoretical framework in individual studies of nondisabled siblings. Scholars have typically used family systems theory to place nondisabled siblings within the context of the family, allowing for an open set of potential familial influences on nondisabled sibling outcomes (Stoneman, 2005). In addition, scholars' use of family systems theory has allowed for the coordinated consideration of the influence of multiple family relationships and multiple family members at once on the experiences of nondisabled siblings (Taylor et al., 2016). Within the family systems framework, system inputs (i.e., family and individual characteristics) are transformed into system outputs (i.e., family functions or roles) by means of family interactions (Hanson & Lynch, 2013). However, the construct of family interactions does not explicitly posit how inputs actually become outputs, especially at the level of the individual family member. For example, from a family systems perspective, it is unclear how the "input" characteristic of a child's birth order manifests in family interactions in order to produce particular experiences and outcomes.

In addition to the family systems approach, scholars have used concepts from the stress and coping literature, primarily derived from the work of Lazarus and Folkman (1984) and McCubbin and Patterson (1983). Scholars have argued that it is important to study sources of stress and coping in this population because this work allows for identification of areas in which we can intervene to support nondisabled sibling development (Giallo & Gavidia-Payne, 2006). These studies begin with the assumption that having a disabled sibling presents unique stressors for a child (e.g., in the form of less time with, and attention from, parents) and then investigate nondisabled siblings' perceptions of these stressors and their responses to these stressors in order to understand variability in their adjustment and wellbeing. More specifically, investigators have identified particular sources of stress for nondisabled siblings (Gamble & McHale, 1989; Ross & Cuskelly, 2006) as well as their coping strategies (Cox, Marshall, Mandleco, & Olsen, 2003; Gamble & McHale, 1989; Opperman & Alant, 2003; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006; Smith, Elder, Storch, & Rowe, 2015).

In the following section, I discuss the empirical literature in this field, and note the ways in which theoretical considerations have guided the work. However, much of this work has been guided less by theory and more by clinical observations of nondisabled siblings and assumptions about the negative effects of having a disabled sibling. Saxena & Adamsons (2013) discussed the impact of this lack of theory on our understanding of nondisabled siblings: "what we do know about the development of such siblings in terms of their cognitive, social, psychological, and emotional outcomes is mostly descriptive and has come from research that is largely cross-sectional and atheoretical. This approach has created an accumulation of piecemeal findings with inadequate cohesion, consistency, or organization and little sense of the bigger picture to which any given piece belongs" (p.300).

Effects of having a Disabled Sibling

Generally guided by clinical observations of nondisabled siblings and assumptions about the negative influence of having a disabled sibling, scholars have explored the effects of having a disabled sibling on various aspects of child development as well as on nondisabled siblings' experiences within their families. Among the developmental outcomes most frequently included in this literature are psychological functioning, social competence, school performance, and self-concept. Within these studies, the investigators inferred that nondisabled siblings experienced stress in relation to the presence of a disabled sibling if they were presented with problems in these developmental areas (Gamble & McHale, 1989). Other studies were more explicitly focused on investigating a range of experiences including sibling relationship quality, sibling role relationships, nondisabled siblings' perceived quality of life, perceived parental differential treatment, and sources of stress and coping responses. These outcomes were assumed to indicate the presence of environmental difficulties that could in turn influence nondisabled siblings' developmental outcomes.

Studies focusing on developmental outcomes. In regard to effects on development, scholars have most often studied the psychological functioning of nondisabled siblings, typically operationalized as internalizing and externalizing behavior problems. Nondisabled siblings are believed to be at greater risk for both internalizing and externalizing behavior problems due to the stress that a disabled child places on the family system. Some scholars found increased internalizing and externalizing behavior problems among nondisabled siblings as compared to those raised without a disabled sibling (e.g., Cuzzocrea et al., 2014; Goudie et al., 2013; O'Neill & Murray, 2016), while others found no differences (e.g., Emerson & Giallo, 2014; Hastings & Petalas, 2014; Neely-Barnes & Graff, 2011). It is important to note that many of the former studies have also found the rate of behavior problems among nondisabled siblings to be within the average range of the general population (Hastings, 2016; Stoneman, 2005). A meta-analysis by Rossiter and Sharpe (2001) concluded that behavioral differences between nondisabled siblings and comparison groups of siblings are "small at best" (p.71). Based on these findings, Hastings (2016) asserted that negative outcomes are not a universal experience for nondisabled siblings.

As I noted earlier, some studies have focused on a small group of nondisabled siblings who evidence serious psychological harm as a result of having a disabled sibling (Stoneman, 2005). Results of these studies, which were mostly focused on interview data from small samples, capture reports from some siblings of strong and pervasive negative feelings, including rejection, resentment, or a sense of persecution within the family (Corsano et al., 2017; Goodwin et al., 2017). In other studies, nondisabled siblings offered negative appraisals of having a disabled sibling (Opperman & Alant, 2003; Stalker & Connors, 2004) and parents reported that nondisabled sibling displayed significant distress and social maladjustment (Corsano et al., 2017). In response to these findings of variable experiences and outcomes, McHale and colleagues (2016) emphasized the need for more studies that examined within-group variations in the experiences of nondisabled siblings, as opposed to conducting between-group comparisons with children who do not have a sibling with a disability.

In contrast to the research focusing solely on negative outcomes, other scholars have proposed that the experience of living with a disabled sibling can promote the development of prosocial abilities. According to a review of the literature by Heller and colleagues (2008), nondisabled siblings report having high levels of empathy and altruism as a result of having a disabled sibling. Similar findings emerged in a synthesis of 28 qualitative and quantitative studies of nondisabled siblings' perceptions of living with either a sibling with Down syndrome or a sibling with ASD (Mandleco & Webb, 2015). This review indicated that both groups of nondisabled siblings reported better self-concept than typically developing siblings, displayed higher levels of caring, kindness, and helpfulness than typically developing siblings, and were more patient and accepting than typically developing siblings. In addition, several qualitative studies of nondisabled siblings have indicated that these siblings learn empathy, increased social awareness, compassion, and tolerance as a result of living with a disabled sibling (Corsano et al., 2017; Goodwin et al., 2017; Gorjy, Fielding, & Falkmer, 2017).

Studies focusing on nondisabled sibling experiences and perceptions. Many studies have explored sibling relationship quality among nondisabled siblings due to its importance for child socialization and wellbeing (Rivers & Stoneman, 2003; Stoneman, 2005). Sibling relationship quality is measured on the dimensions of warmth/closeness and animosity/conflict by means of sibling relationship scales originally developed for research on sibling groups that do not include a child with a disability. Sibling relationships marked by high animosity/conflict and low warmth/closeness are considered problematic for child development, while opposite relationships are considered supportive of child development. Studies that have compared ratings of sibling relationship quality across groups of nondisabled siblings and siblings of typically developing children, have generally found similar ratings of sibling relationship quality across the two groups (e.g., McHale et al., 1986). These authors propose that perceived sibling relationships quality is similar across these two groups of children. While the content of their activities may be different (e.g., more interactions characterized by caretaking among nondisabled siblings), similar rates of positive and negative interactions appear to arise across the two groups.

A subset of studies in this field have attempted to identify the aspects of living with a disabled sibling that are perceived by children as stressful, as well as their reported coping responses to these stressors. Mandleco and Webb (2015) proposed that by exploring nondisabled siblings' accounts of daily family stressors and their coping responses, we can illuminate potential reasons for why relationships may exist between the presence of a disabled sibling and nondisabled sibling outcomes. Gamble and McHale (1989) used Lazarus and Folkman's (1984) stress and coping model to inform their study of the mediating role of stress, appraisal, and coping responses between the presence of a disabled child and siblings' psychological wellbeing and perceived sibling relationship quality. The authors operationalized appraisal as "children's affective reactions to stressful events" (p.356). One aspect of this study was the authors' investigation into the nature, frequency, and affective intensity of daily stressors that nondisabled siblings face in the context of their relationship with their disabled sibling. Affective reactions were measured using a stress and coping inventory developed by one of the authors, and only the single affect of anger was measured. The participants were presented with seven types of stressful events (e.g., being teased by their sibling or their sibling taking their toys) and were asked to rate the frequency with which they experienced each type of event in their relationship with their disabled sibling, as well as the degree of anger that they experienced in association with each type of event. The authors found that the total frequency of stressful events experienced by nondisabled siblings was not related to their ratings of wellbeing (although it was associated with their reports of sibling relationship quality). Instead, the intensity of participants' affective reactions to these events was associated with wellbeing. In other words, when the participants reported experiencing more significant anger in response to stressful events, their ratings of wellbeing declined. These results suggest that siblings' appraisals of stressors are more important than the number of stressors experienced on a daily basis.

Recently, the field of nondisabled sibling research has seen an influx of qualitative studies on nondisabled siblings' perceptions of daily life in their families. While each study takes a slightly different look at the nondisabled sibling experience, as a whole the purpose of these studies is to elucidate the components of family life that are salient to the experience of being a nondisabled sibling. The result of this work is a more nuanced understanding of the components of daily life that are perceived as stressful by nondisabled siblings, along with the components that they perceive as supporting them in managing this stress. Through semi-structured interviews with nondisabled siblings, several studies have captured nondisabled siblings' reports of feeling guilt, shame, grief, embarrassment, anger, self-blame, etc. in relation to their disabled sibling (Corsano et al., 2017; Goodwin et al., 2017; Opperman & Alant, 2003). Across these studies, one of the components of family life that has been identified to trigger negative feelings is the experience of reduced parental attention along with some degree of marginalization of nondisabled siblings' own needs (Cridland, Jones, Stoyles, Caputi, & Magee, 2016; Goodwin et al., 2017; Ward et al., 2016). Nondisabled siblings tend to report some degree of understanding regarding why they experience reduced parental attention, but struggle to balance this understanding with feelings of anger and resentment that their sibling is always the parents' priority.

Several studies have also captured nondisabled siblings' reports that the reactions of other people, within and outside of the family, to their disabled sibling triggers them to feel negative emotions (Corsano et al., 2017; McHale et al., 1986; Opperman & Alant, 2003; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Stalker & Connors, 2004). These siblings reported feeling a mixture of protectiveness toward their sibling along with negative feelings (e.g., anger and embarrassment) when they perceived other people to judge or mistreat their disabled sibling. In addition, studies have captured nondisabled siblings' worry about the future with their disabled sibling (Corsano et al., 2017; Goodwin et al., 2017; McHale et al., 1986; Petalas et al., 2012; Rossetti & Hall, 2015). Worry about the future appears to include both worry about the disabled sibling's future abilities, opportunities, and needs, as well as the nondisabled siblings' role in their sibling's future. These findings highlight nondisabled siblings' attunement to their disabled sibling and his or her needs.

In terms of nondisabled siblings' coping responses to family stressors, Gamble and McHale (1989) described a categorization system born out of the stress and coping literature that is similar to how other studies in this field have conceptualized nondisabled siblings' coping responses. Gamble and McHale (1989) categorized coping responses by rating them along two dimensions: their reported functions (i.e., environment-focused vs. self-focused) and their reported modes of expression (i.e., direct action/behaviors vs. cognitions). Coping responses were then considered to be in one of four categories: environment-focused actions (e.g., seeking social support), environment-focused cognitions (e.g., thinking about the situation or other people), self-focused actions (e.g., distracting oneself by doing something), or self-focused cognitions (e.g., trying to calm oneself down). The authors correlated nondisabled siblings' coping response styles with their reports of wellbeing and sibling relationship quality. Based on their analysis, only two coping response styles were consistently associated with the outcome variables. When nondisabled siblings reported coping with family stressors by reasoning about another person (e.g., thinking their disabled sibling was just annoying, or wondering why the disabled sibling acted a certain way) they reported more depression and anxiety symptoms, along with lower self-worth and decreased prosocial attitudes and behaviors toward their disabled sibling. However, when nondisabled siblings reported coping with family stressors by using self-directed cognitions (e.g., telling themselves to calm down or ignore the problem) they reported less depression symptoms and rated their sibling relationship as more positive. The authors hypothesized that the latter coping strategy reflected stronger self-regulation skills and was therefore more effective, whereas the former reflected the nondisabled siblings' inability to deal with their emotional reactions in stressful situations. It is important to note that Gamble and McHale (1989) included a comparison group of siblings of typically developing children in their study. Their analysis of the comparison group's data indicated the same two associations between coping response styles and reported wellbeing and sibling relationship quality.

Findings across several studies of nondisabled siblings' coping responses have indicated the importance of having access to social support in and/or outside of the family (Gorjy et al., 2017; Jones et al., 2019; Moyson & Roeyers, 2012; Opperman & Alant, 2003; Taylor et al., 2016). Results from these studies indicate that it is important for nondisabled siblings' wellbeing to feel supported by family members as well as others outside of the family. Several qualitative studies have also captured nondisabled siblings' reports that they need and want space to be alone within the context of the family (Goodwin et al., 2017; Gorjy et al., 2017; Moyson & Roeyers, 2012). Goodwin and colleagues (2017) found that the participants in their study reported withdrawing from their family to allow for their disabled sibling to be prioritized, as well as withdrawing because they felt overwhelmed by certain situations or because they felt that they could not express their frustrations (i.e., this would be selfish). In addition, studies of nondisabled siblings indicate that the majority of study participants accept their family situation as normal, including that their disabled sibling receives more time and attention than they do (Goodwin et al., 2017; Gorjy et al., 2017; Moyson & Roeyers, 2012; Petalas et al., 2012; Stalker & Connors, 2004). In other words, nondisabled siblings typically report that their family dynamics are acceptable and normal to them.

Overall, qualitative studies in this field assert that being a nondisabled sibling is a mix of positive and negative experiences, with feelings of both annoyance and empathy or anger and gratitude toward the disabled sibling (Corsano et al., 2017; Goodwin et al., 2017; Mascha & Boucher, 2006; Mulroy et al., 2008; Okashah et al., 2015; Rossetti & Hall, 2015; Ward et al., 2016). Results from a study by Goodwin and colleagues (2017) illustrate this finding well. The authors explored nondisabled siblings' perceptions of managing life as a sibling of an individual with 22qII.2 deletion syndrome (i.e., a specific genetic condition characterized by physical, intellectual, and behavioral symptoms), perceptions of changes in themselves over time, and expectations for the future. The authors conducted semi-structured interviews with five young adult siblings and found the participants to oscillate between positive and negative feelings about their disabled sibling's diagnosis and their disabled sibling's role in the family as the priority. They expressed anger, guilt, and resentment regarding their disabled sibling's diagnosis and role in the family, but also expressed gratitude toward their disabled sibling for the positive experiences and life lessons that they attributed to their disabled sibling (e.g., learned patience and compassion). While all of the study participants reported making sacrifices for their disabled sibling, they also reported focusing their energy on making positive meaning out of their experiences with their sibling. Several additional qualitative studies have also indicated that nondisabled siblings often try to make positive meaning out of their experiences in their families (Gorjy et al., 2017; Ward et al., 2016). In doing so, these nondisabled siblings tend to report that their disabled sibling has made them a better person.

The literature on nondisabled siblings' experiences and perceptions in their families has produced nuanced findings regarding the influence of having a disabled sibling on daily family life. We have a sense of the stressors that nondisabled siblings experience along with the ways in which they cope with this stress. However, the processes by which nondisabled siblings experience stress, and therefore why some struggle more than others, remain unclear. In other words, we do yet not have an understanding of how stressors and coping responses actually manifest and interact in the daily lives of nondisabled siblings to produce variable outcomes. This level of understanding is necessary in order to design appropriate and effective interventions to support the nondisabled siblings who are struggling.

In the following section, I discuss the sociodemographic and family relational variables that have been studied as factors that may influence children's experiences of stress when they have a disabled sibling.

Family Factors That Condition the Effects of Being a Nondisabled Sibling

Guided by family systems theory, studies have explored the influence of a range of child and family sociodemographic characteristics and relationships on nondisabled siblings' experiences and developmental outcomes (Schuntermann, 2007; Stoneman, 2005). I review the findings from this literature in this section, beginning with research on the influence of family sociodemographic characteristics and concluding with a look at the influence of familial relationships.

In studies examining the association between the sociodemographic characteristics of the family and nondisabled siblings' well-being, investigators have sometimes hypothesized that SES-related characteristics are associated with a lack of resources for managing the needs of a disabled child. Other studies have examined the influence of family constellation factors such as disability type, severity of the disability, family size, birth order, and age and gender of each sibling (Hastings, 2016; Heller et al., 2008; Schuntermann, 2007; Stoneman, 2005; Taylor et al., 2016). In this work, researchers have hypothesized that these family factors may influence parents' expectations of the nondisabled sibling and therefore affect sibling role relationships within the family. For example, Mandleco and Webb (2015) noted that many researchers have hypothesized that nondisabled sisters experience more caregiver burden than brothers. In studies of disability type and severity, scholars have hypothesized that certain diagnoses (e.g., ASD) and behaviors (e.g., aggression) are associated with decreased wellbeing among nondisabled siblings due to their effects on the disabled sibling's ability to build and maintain relationships (Mandleco & Webb, 2015).

Overall, reviews of the literature suggest that the association between these sociodemographic variables and nondisabled sibling outcomes is relatively weak across most studies (Hastings, 2016; Heller et al., 2008; Schuntermann, 2007; Stoneman, 2005; Taylor et al., 2016). One consistent correlation is that nondisabled siblings reared in higher SES families tend to have fewer psychological problems (Emerson & Giallo, 2014; Giallo & Gavidia-Payne, 2006; Mulroy et al., 2008). Other studies have found that nondisabled children with more typically developing siblings tend to present with fewer psychological problems than those with fewer typically developing siblings (McHale, Sloan, & Simeonsson, 1986; Moyson & Roeyers, 2012; Taylor et al., 2016; Walton, 2016). The most often replicated finding suggests that nondisabled siblings tend to have fewer behavior problems and better sibling relationship quality when the disabled sibling has less severe behavior problems (Hastings, 2016; Hastings & Petalas, 2014; Heller et al., 2008; Jones et al., 2019; Lovell & Wetherell, 2016; Mascha & Boucher, 2006; McHale & Harris, 1992; Shivers, Deisenroth, & Taylor, 2013; Stoneman, 2005; Taylor et al., 2016). Interestingly, several studies have also demonstrated a correlation between disability type (i.e., ASD vs. Down syndrome) and sibling relationship quality, with poorer sibling relationship quality reported for sibling pairs in which one has ASD than sibling pairs in which one has Down syndrome (Mandleco & Webb, 2015; Pollard et al., 2013; Taylor et al., 2016).

Due to a general lack of consistent evidence regarding the influence of these sociodemographic variables, Stoneman (2005) writes that findings related to these variables "are often spurious (i.e., a finding only occurs for younger brothers of girls with one type of disability when reported on by fathers, but not mothers) and are seldom replicated" (p.344). Stoneman (2005) further argues that these inconsistent findings reflect the complex nature of studying nondisabled siblings. Each of these sociodemographic characteristics may influence a nondisabled sibling in some way, but it is almost impossible to determine the influence of each one in isolation. In the following subsection, I briefly summarize study findings regarding the influence of family relationships on nondisabled sibling outcomes. These studies have produced more nuanced findings regarding why some nondisabled siblings may struggle more than others, and how we may be able to intervene to support them.

The influence of family relationships on nondisabled siblings. Studies of correlations between family relationships and nondisabled sibling outcomes have investigated the influence of the following independent variables: the presence of marital or family stress, parenting behaviors and practices, the quality of sibling relationships, and the roles that siblings take in relation to each other. Studies that explore these relational variables are generally guided by family systems theory. In addition, several of these studies explicitly report utilization of theories of family stress and coping (e.g., Cuzzocrea, Larcan, Costa, & Gazzano, 2014; Giallo & Gavidia-Payne, 2006) or individual stress and coping (e.g., Rivers & Stoneman, 2003). Overall, two themes emerge from this literature in terms of family relationships that influence nondisabled sibling outcomes. These themes include the salience of family stress and conflict as a predictor of nondisabled siblings' wellbeing, as well as the importance of nondisabled siblings' perceptions of parenting behaviors.

Findings from studies that include typically developing sibling comparison groups suggest that nondisabled siblings may be more sensitive to family relational issues such as parent stress and family conflict than are children who do not have a disabled sibling (Schuntermann, 2007; Stoneman, 2005). Scholars hypothesize that anything that reduces the resources of the family may impact nondisabled siblings more significantly than siblings of typically developing children because the family resources are already taxed by the presence of disability. A study by Rivers and Stoneman (2003) found that when nondisabled siblings' parents reported higher levels of marital stress, nondisabled siblings described less satisfaction regarding their relationship with their disabled sibling with ASD, and they were observed to direct more negative and fewer positive behavior toward their disabled sibling. These results were supported by another study finding that when parents and nondisabled siblings report low family conflict, nondisabled siblings tend to report more positive sibling relationships, increased self-concept, and fewer behavior problems (Stoneman, 2005).

One family relationship variable that has received a great deal of attention is that of parental differential treatment, defined by Stoneman (2005) as "…within-family differences in parenting experienced by siblings" (p.342). Scholars have consistently found this construct to have a meaningful relationship with children's responses to having a sibling with a disability (Schuntermann, 2007; Stoneman, 2005). In general, parents who have disabled and nondisabled children divide their time and attention asymmetrically between their children in favor of the disabled child. This finding has been replicated across studies of nondisabled siblings; however, few studies find a consistent effect of asymmetric treatment *per se* on the psychological functioning of nondisabled siblings or the quality of their sibling relationships. Rather, it appears that this relationship is moderated by the nondisabled sibling's perception of the fairness or appropriateness of the differential treatment (Gamble & McHale, 1989; McHale & Gamble, 1989; McHale & Pawletko, 1992; Richmond, Stocker, & Rienks, 2005; Schuntermann, 2007; Taylor et al., 2016). For example, McHale and Pawletko (1992) found that disabled sibling's special needs were perceived by nondisabled siblings as a valid reason for parental differential treatment, and therefore moderated the influence of parental differential treatment on psychological functioning.

Overall, the literature on nondisabled siblings suggests that family relationships may play a role in moderating the relationship between disability-related stressors and nondisabled sibling outcomes and experiences. In this study, I embrace the premise that families operate as systems and that family interactions play a mediating role between inputs and outputs. In addition, I utilize a model of stress and coping to understand *how* family interactions facilitate this process. The model that I developed for use in this study is described in the following section.

A Model of Individual Family Member Stress, Appraisal, and Coping

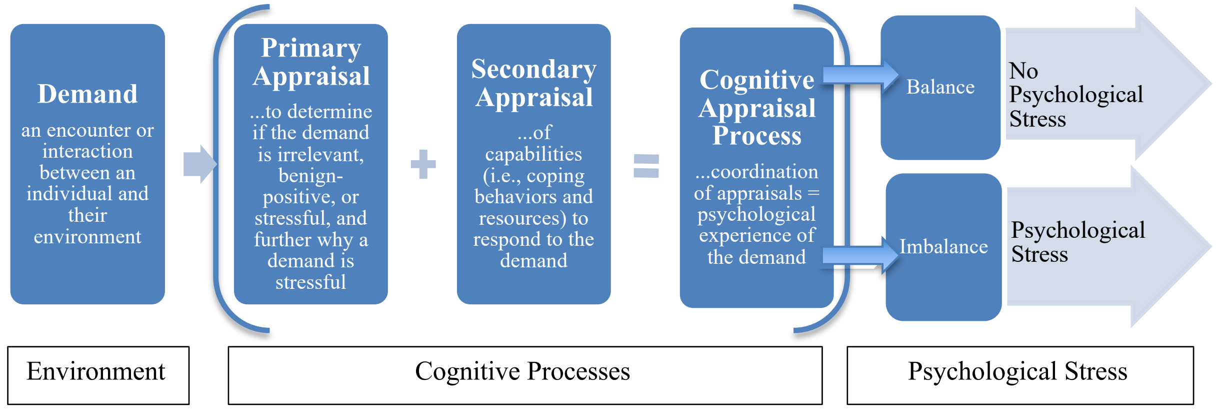
As discussed previously, a general lack of theory utilization in the study of nondisabled siblings has hindered the identification of significant aspects of the nondisabled sibling experience, as well as offering an account of how or why documented associations exist (Saxena & Adamsons, 2013). My study takes a theoretical approach to understanding nondisabled siblings' daily family interactions in an attempt to advance our understanding of this population. I used constructs from the Stress and Coping model (Lazarus & Folkman, 1984), and, in particular, I focused on the construct of cognitive appraisal, which refers to an "evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful" (Lazarus & Folkman, 1984; p.19). I additionally used constructs from the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988, 1993, 2002) to develop an approach for exploring how individual family members experience and understand stressful circumstances associated with living with a child who is disabled (see Figure 1). I hypothesize that my framework allows for the exploration of what is perceived by nondisabled siblings as stressful or supportive, and, more importantly, why these experiences are perceived a certain way and why siblings choose to respond the way that they do.

The stress and coping model developed by Lazarus and Folkman (1984) was groundbreaking for its emphasis on individuals' cognitive understandings or appraisals during the process of experiencing and coping with psychological stress. In their model, Lazarus and Folkman defined psychological stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." (1984, p.19). In order to understand how stress is experienced differently across individuals, the authors proposed the process of cognitive appraisal (i.e., one of the processes that mediates the person-environment relationship). The cognitive appraisal process is thought to consist of two parts. Faced with a demanding circumstance, the individual conducts a primary appraisal to identify the nature and possible cause of the demand followed by a secondary appraisal to identify available resources and possible response options. The individual's coordination of these two appraisals constitutes the individual's overall cognitive experience of the encounter.

In developing the FAAR model, Patterson (1988) expanded key ideas from Lazarus and Folkman to explain stress and coping at the level of the family rather than the individual. The original goal of the FAAR model was to describe, explain, and predict how characteristics of the family system were linked to the wellbeing of individual family members (Patterson, 1988). She proposed that during family interactions, a family uses its resources and coping behaviors to meet perceived demands (i.e., stimuli or conditions that cause or call for change in the system). By managing perceived demands, the family attempts to maintain equilibrium or homeostasis. A central claim of the FAAR model is that a family's ability to maintain equilibrium is a function of the meaning that each family member attaches to a demand. For example, one parent may view a child's developmental disability as damaging to the family's reputation while another individual may appraise the illness as unfortunate but not catastrophic. In the FAAR model, each family member also conducts an assessment of the family's capabilities. This secondary appraisal takes into account the family's resources, such as social support, as well as available forms of coping. If family resources and coping options are not sufficient to deal with the demand as appraised by the family members, then the family experiences problems in their functioning, such as lack of cohesion and ineffective communication. The FAAR model uses the term "family meaning" to refer to the ways that family members coordinate their primary and secondary appraisals or, in other words, of their understandings regarding the balance between demands and family capabilities.

Patterson (1988) uses the term 'adjustment phase' to describe a time of relatively strong system stability during which the general structure and organization of the family does not change. Family members work to maintain equilibrium, or ameliorate felt stress associated with demands, by attempting to reduce demands and/or increase capabilities either subjectively or objectively. Adjustment then manifests in predictable and stable social interactions between family members. This is the only phase of the FAAR Model considered in this study because the participants were interviewed during times of relative family stability. It is these predictable and stable family interactions that are under investigation.

Figure 1. Theoretical model of individual family member stress, appraisal, and coping (as developed for this study)



Definitions of relevant theoretical constructs. Figure 1 is a visual representation of the theoretical framework that I developed for this study. In this section I define the core constructs of my model and describe the ways in which they interact with each other. These core constructs include demands and primary appraisal of those demands, capabilities (i.e., coping behaviors and resources) and secondary appraisal of those capabilities, and their coordination in the cognitive appraisal process. Constructs from Lazarus and Folkman (1984) and Patterson (1988) were blended to create this model. I found this blending to be possible because both frameworks share several core theoretical constructs (e.g., primary and secondary appraisals), and emphasize the role of cognitive appraisal in the experience of stress.

Demands and the primary appraisal process. According to Lazarus and Folkman (1984), an individual's experience of psychological stress begins with "a transaction or series of transactions between the person and the environment" (p.19). These person-environment transactions are appraised in a subjective manner by the individual within the context of previous experiences. According to Lazarus and Folkman (1984), there are three conclusions that can result from the primary appraisal process. A transaction can be perceived as presenting no implications for wellbeing, as being benign or positive in the sense of enhancing wellbeing, or as being stressful in the sense of involving possible harm/loss, threat, and/or challenge.

Within the FAAR model, Patterson (1988) refers to these transactions as demands, which she defines as conditions that cause or call for change in the family system. A demand can take the form of a specific stressor that occurs and produces a felt need for change in the system, a strain that is an ongoing presence and is associated with a need to get rid of it, or a relatively minor daily hassle (Patterson, 2002). When a demand occurs, it is "consciously or unconsciously interpreted from the context of prior experience" (Patterson, 1988; p. 221), a process she refers to as "primary appraisal." She further noted that family response to a demand is best understood within the context of all of the demands being placed on the family at any one time point, a concept termed "pile-up" (Patterson, 2002). Like Lazarus and Folkman (1984), Patterson (1988, 1993, & 2002) uses the term primary appraisal to describe the initial cognitive analysis of the presenting stressor; however, unlike them she focuses exclusively on appraisals of stress rather than considering benign appraisals.

In this study I equate the concept of a person-environment transaction, as proposed by Lazarus and Folkman (1984), to the construct of demand from Patterson (1988). Both concepts capture the triggering event in the experience of stress. For clarity I use the term demand to denote the triggering event in an experience of stress. Stressfully appraised demands are the focus of this study as the goal is to better understand variability in the experience of psychological stress across nondisabled siblings. My use of the construct of primary appraisal is therefore not to understand whether a demand is stressful, but why it has been perceived as stressful. Rather than attempting to categorize the participants' appraisals as referring specifically to harm/loss, threat, and challenge, I focus on the participants' own narratives, including the words they use to characterize the stressful demands that they face during family interactions.

Capabilities and the secondary appraisal process. As previously noted, the term "capabilities" in the FAAR model refers to the resources and coping behavior that families can use to meet the demands that they face (Patterson, 2002). Patterson (1988) proposes that, when presented with a demand, family members evaluate their resources and coping behaviors in a subjective process of "meaning making" that she terms "secondary appraisal." Patterson's concept is similar to that of Lazarus and Folkman (1984), who use the same terminology, secondary appraisal, to mean an individual's evaluation of what he/she might be able to do in response to the person-environment transaction. One form of capability relates to available resources, which can derive from an individual, the family as a whole, or the community. Of most relevance to my research are the resources available at the individual level. Individual resources include characteristics, traits, and competencies, including intelligence, acquired knowledge and skills, personality traits, physical and emotional health, a sense of mastery, and self-esteem. For instance, a key resource for a nondisabled sibling may be an understanding of the sibling's disability, such as knowing that they have a sensitivity to sound. A second form of capability pertains to coping behaviors, which are specific strategies (either behavioral or psychological) that family members can use to try to reduce or manage a demand. According to Patterson (1988), coping behaviors by one or more family members can be effective in mitigating the demands placed on the family system, or can themselves become a source of demand if they are maladaptive. For example, a nondisabled sibling may acquire behavioral management techniques that diffuse a disabled sibling's behavioral outbursts in the short run, such as giving the sibling what he/she wants, but these may ultimately lead to more behavioral outbursts when the disabled sibling learns that they can get what they want by misbehaving. For the purpose of this study, I define 'secondary appraisal' as individuals' evaluation of their capabilities (i.e., coping behaviors and resources) to meet a demand they have appraised as stressful.

The overall cognitive appraisal process. In the FAAR Model, Patterson (2002) seeks to emphasize the ways in which family members respond to demands by not only appraising the demand and the family's capabilities, but also by reasoning about the coordination of these two components. She refers to this coordination process as "situational meaning making," which are said to include "the family's subjective definitions of their demands, their capabilities, and of these two factors relative to each other" (Patterson, 1988; p. 220-221). Patterson (1988) proposes that the family experiences stress and enters a crisis phase if they determine that their capabilities are insufficient for meeting the perceived demand. This proposed meaning making process is similar to Lazarus and Folkman's cognitive appraisal process. Cognitive appraisal, as defined by Lazarus and Folkman (1984), is an evaluative process "that determines why and to what extent a particular transaction or series of transactions between the person and environment is stressful" (p.19). This evaluative process includes primary appraisal of the person-environment transaction, along with secondary appraisal of what the individual might be able to do in response. The result of this cognitive process is an explanation of the individual's subsequent emotional reaction to the situation. For the theoretical model proposed in this study, I use the term "cognitive appraisal process" to capture an individual's coordination of their primary and secondary appraisals in a given situation.

The Present Study

The primary research objective guiding this study is to understand the kinds of family interactions that nondisabled siblings perceive as stressful, particularly those related to being a nondisabled sibling as opposed to those that may be present in the life of an individual who does not have a disabled sibling. To answer this question, I explore nondisabled siblings' retrospective accounts of their cognitive appraisal processes within the context of daily family interactions. I focus on those interactions that they appraise as having been stressful at the time they occurred, and probe deeply into the reasons these interactions are experienced as stressful, as well as ways in which the nondisabled siblings understand the resources and coping behaviors available in particular situations.

My exploration of participants'cognitive appraisal processes is guided by the following research questions: (a) what kinds of nondisabled sibling-related family interactions elicit negative feelings/emotions, and why are they perceived as negative?; (b) what resources and coping behaviors are considered and used by nondisabled siblings during these stressful interactions, and why are they mobilized?; and (c) What themes arise in terms of the experience of stressful nondisabled sibling-related family interactions for these participants? The goal of the first research question is to identify the types of stressful demands experienced by nondisabled siblings during family interactions, as well as to understand why these demands are appraised as stressful. The purpose of the second research question is to explore the coping behaviors and resources utilized by nondisabled siblings in response to demands perceived as stressful, and better understand why specific capabilities are chosen in response to specific stressful demands. My final research question aims to explore themes and patterns across participants' coordination of primary and secondary appraisals (i.e., cognitive appraisal processes). Overall, the purpose of these questions is to elucidate the cognitive processes utilized by nondisabled siblings in the context of family interactions in order to find areas of appropriate intervention in the experience of psychological stress for this population of children. The following chapter provides a detailed description of the methods developed for, and utilized in, this study.

Chapter 2: Methods

Research Design Overview

Previous research on nondisabled siblings has produced minimal leads regarding salient sociodemographic characteristics that can help us to understand variability within the experience of being a nondisabled sibling. Furthermore, any leads (e.g., severity of behavior problems of the disabled sibling) are not well understood. More promising is the research on aspects of family relationships that may influence the experiences of nondisabled siblings, such as nondisabled siblings' perceptions of parental differential treatment and the presence of parental, marital, or family stress. Overall, scholars recognize that there are complex and poorly understood relationships between previously studied independent variables and nondisabled sibling outcomes, and that our shallow understanding of these relationships is in large part due to a lack of theoretical guidance (Cridland et al., 2014; Hastings, 2016; McHale et al., 2016; Schuntermann, 2007; Stoneman, 2005). In other words, the literature to date has generally focused on potential correlations and not processes, or the questions of how and why documented associations exist. This study is structured to be a theoretically-driven, in-depth exploration of the perceptions and appraisals of nondisabled siblings regarding the day-to-day stressful interactions that they encounter in the context of their family. I contend that careful qualitative analysis of nondisabled siblings' perceptions of stressful family interactions can move the field forward by illuminating their subjective cognitive processes of making meaning regarding these events and the relevant family relationships. By highlighting the cognitive appraisals that nondisabled siblings create in relation to their family interactions, we can better understand how various family variables come together to influence the development of the sibling. This will help us to understand the uneven research findings that characterize this field and guide future research and interventions for nondisabled siblings going forward.

I developed three broad research questions to guide my study: (a) what kinds of nondisabled sibling-related family interactions elicit negative feelings/emotions and why are they perceived as negative?; (b) what resources and coping behaviors are considered and used by nondisabled siblings during these stressful interactions, and why are they mobilized?; and (c) what themes arise in terms of the experience of stressful nondisabled sibling-related family interactions for these participants? To answer these questions, I wanted to hear directly from nondisabled siblings about why, when, and with whom they experience family-related stress on a daily basis. To do this, I developed a semi-structured interview protocol (see interview protocol in Appendix C). Inspired by the work of other qualitative researchers, I adapted several different interview methods into a three-part interview protocol. Broadly, the purpose of each part of the interview was to elicit accounts of family interactions and create a picture of the family system. The interview was comprised of the following three parts: (a) creation of an emotion map, (b) discussion of a previously recorded family dinner conversation, and (c) administration of open-ended interview questions. During the emotion map activity, I asked participants to sketch a map of their home and then to recall three emotionally laden interactions from the week or two leading up to the interview. I asked the participants to use stamps with emotion faces on them (i.e., emoticon stamps) to record who participated in each interaction, where each interaction occurred, and what emotions each participating family member experienced in each interaction. We then discussed each of the three interactions in detail. In order to conduct the discussion of a previously recorded family dinner conversation, I asked participants to audio record a family dinner during the week leading up to the interview and send it to me using a smartphone. During the interview, we then listened to the recording together and discussed interactions that I found notable through previous analysis of the recording. In the final portion of the interview, I asked the participants a series of open-ended questions about their knowledge of their sibling's disability, relationships within the family, and family roles and responsibilities.

The semi-structured interviews that I developed for this study produced a large amount of data. I made two major analytic decisions in order to (a) logistically manage the quantity of the data and preserve the quality of the analysis, and (b) theoretically clarify and focus my analysis. My first decision was to focus my analysis solely on family interactions that the participant appraised as stressful (i.e., during which they experienced a negative emotion). My second decision was to focus my analysis on family interactions that were relevant to the participants' role in the family as a nondisabled sibling.

As described in the previous chapter, I created a theoretical model of stress and coping for this study by pulling from the work of Lazarus and Folkman (1984) and Patterson (1988). I then used this theoretical model to develop a list of deductive codes (i.e., a provisional list of codes created prior to fieldwork; Miles, Huberman, & Saldana, 2014). The purpose of the coding scheme was to identify recurring sources of stressful demands, coping behaviors, and resources, as well as participants' cognitive appraisals of stressful family interactions. I used methods from Miles, Huberman, and Saldana's (2014) qualitative methods sourcebook to conduct my analysis. For my analysis, I conducted two rounds of first cycle coding. In other words, I went through each interview transcript twice to assign codes to chunks of the data. I used a combination of holistic (i.e., applying a single code to a large unit of data) and provisional (i.e., applying my deductive codes) coding methods during this first cycle of coding. I then used second cycle coding techniques to group my codes "into a smaller number of categories, themes or constructs" (p.86). I analyzed each interview for themes regarding the participant's perceived stressful demands, coping behaviors and resources, and cognitive appraisals. The purpose of this analysis was to identify the important dimensions of each individual's experience of family stress. I then explored these themes across interviews to assess for variability and similarity in the nondisabled sibling experience.

Study Participants

Researcher. My interest in studying the experiences of nondisabled siblings developed out of clinical interactions with families who have a child with a developmental disability, within family homes and assessment settings. One of my early clinical and research mentors, Bryna Siegel, Ph.D., believed that this population deserved a voice and more consideration within the field of developmental disabilities than they were given (Siegel & Silverstein, 1994). This belief, along with my experiences as a school psychologist trainee, shaped my own perception of this population. It is my perspective that children with developmental disabilities have a pervasive influence on the daily lives of their family members, both in positive and negative ways. Furthermore, typically developing siblings are not always purposefully and meaningfully included or considered in assessment and treatment of the child with a disability.

My first-hand interactions with, and observations of, nondisabled siblings likely enhanced my understanding of the non-disabled sibling research literature and influenced the formation of the research questions that guide this study. While my experiences with this population provided me with the asset of familiarity with the broad difficulties that these children may face, it was also important that I continuously and systematically reflect on and recognize my own personal assumptions and biases so that they did not unduly influence my research. I attempted to do so through regular consultation with my advisor and other members of my advisor's research lab, who helped me to identify my preconceived notions and to then use them as analytic tools. In addition, I grounded myself in the results of the published literature on nondisabled siblings in an attempt to manage the potential influence of my personal and clinical experiences.

It is additionally important that I recognize the similarities and differences in my background to that of the participants. These similarities and differences may have influenced the manner in which I engaged with them, as well as their level of comfort engaging with me. I am a White, Jewish, native English-speaking researcher from a middle-class family, who identifies as female. I do not have a sibling with a developmental disability, but I do have a sibling who was diagnosed with a chronic illness in adolescence. I grew up in the same geographical region as the participants, and my economic and racial background is similar to that of the majority of the participants. My familiarity with the region and its services and service providers for children with developmental disabilities likely helped parents and siblings to feel more comfortable talking to me. It is possible that my gender was a barrier for male participants in terms of their level of comfort in discussing personal experiences with me. It is also possible that my racial and linguistic background was a barrier for the racial and linguistic minority participants in this study. One participant in particular was from an immigrant family that was primarily Spanish speaking. While I tried to be respectful and conscious of cultural differences, our disparate backgrounds likely influenced data collection. Throughout data collection, I was keenly aware of potentially being perceived as an outsider because I do not have a sibling with a developmental disability. I worked hard to reduce participants' potential self-consciousness or feelings of judgment by accepting their narratives and matching their degree of affect. I also utilized self-disclosures about my own experiences as a sibling when appropriate. I attempted to remain conscious of all of these potential differences and speak to them directly when necessary, recognizing my lack of knowledge and taking an inquisitive stance.

My clinical training in school psychology influenced my interview style, making me both attuned to the participants' emotional experience and providing me with tools to support the participant to access and think about their emotions in a safe space. These skills influenced the development of my interview protocol and my actions as an interviewer in the room with participants. Finally, I feel it important to recognize that being a nondisabled sibling is likely not a participants' only identity. However, by asking them to participate in this study I assigned them this identity and made it salient. While in this role of nondisabled sibling, the participants may have felt the need to protect their sibling and family by not discussing negative interactions, and/or may have felt obligated to recount difficult or stressful family interactions due to a perceived assumption that it must be hard to be a nondisabled sibling. I attempted to create a space during the interview free of assumptions about participants' experiences, as well as one in which they felt comfortable expressing both positive and negative accounts of family interactions.

Participants. Participants in this study were typically developing siblings of children with developmental disabilities, ages 10-17. Requirements for participating in this study were the following: the participant had to (a) live full-time with their developmentally disabled sibling and parent(s), (b) never have received special education services, (c) be 10 years old or older, and (d) have a sibling with a developmental disability. Ten was the minimum age for participation in this study because the interview required participants to analyze and discuss the actions, thoughts, and feelings of family members and themselves, which may not be a developmentally appropriate task for children under the age of 10. Developmental disabilities, as defined within this study, included the following diagnoses: ASD, Down syndrome, intellectual disability, cerebral palsy, Rett syndrome, Fragile X syndrome, Angelman syndrome, Turner Syndrome, Prader-Willi syndrome, Williams syndrome, and Spina Bifida (Rossetti & Hall, 2015). Developmental disabilities were chosen for study, as opposed to other childhood disorders, because it is generally believed that this group of children experience unique difficulties and therefore present unique stressors for families.

The sample size for this study was 11 participants across 10 families. I began the study with the assumption of 10 participants. This sample size was determined to be appropriate by my dissertation committee. After I completed 11 interviews, my preliminary analysis suggested that the themes of interest had surfaced in a deep and interesting way. As such, I halted recruitment at that time. Due to findings from previous empirical studies that sociodemographic characteristics, such as birth order, age, and gender of either sibling do not have a consistently significant relationship with sibling outcomes, I did not set recruitment goals based on these characteristics. Six of the 11 participants in the study identified as male, while five identified as female. Among the disabled siblings, six were identified as male and five were identified as female (one family had twin female disabled siblings). The birth order of nondisabled sibling participants in the sample included four first-born siblings, four second-born siblings, two triplets (i.e., two siblings from a triplet set), and one fourth-born sibling. Ages of the participants in the sample included four participants aged 10 to 11, two participants aged 12 to 13, and five participants aged 15 to 17. The disabled siblings of the participants ranged in age from four to 18 years old. The racial/ethnic makeup of the sample included four participants who identified as Caucasian, three who identified as mixed Caucasian and Asian, three who identified as mixed Latinx and Caucasian, and one who identified as Latinx. All participants were born in the United States, and one came from a family of two immigrant parents. In this household, the parents' native language (i.e., Spanish) was the primary language spoken, but the sibling was reportedly fluent in both English and Spanish.

The primary disability of the siblings of the participants in the study included ASD (six participants), global developmental delay (two participants), Down syndrome and ASD (one participant), cerebral palsy and intellectual disability (one participant), and a Genetic Condition (Dup15Q; one participant). I also collected data on severity of disability through reports of the disabled sibling's current interventions. Finally, I approximated family SES for each participant by looking at parent-reported income range/class and parents' level of education. All of the participants identified as within the middle-class range or above. Five out of 11 of the participants lived in suburban areas, while the rest lived in large urban cities. For more information on participant and family demographics, see Appendix C, Table 1.

Researcher-participant relationship. I had no relationship with any of the participants prior to their participation in this study. Once they were in the study, I met each participant twice, once to discuss the study and conduct consent and once again for the interview. One purpose of the first in-person meeting was to build an initial relationship with the participants. By meeting them, answering their questions, and establishing a positive relationship with their parents, I hoped to make them feel more comfortable going into the interview.

Participant Recruitment

The University of California, Berkeley Committee for the Protection of Human Subjects, approved this study and its recruitment procedures. Prospective participants were initially recruited through a private practice in Northern California that runs Sibshops, which are workshops designed for nondisabled siblings that provide peer support and information (Sibling

Support Project, n.d.). The workshop facilitator agreed to email recruitment materials to parents of children in her practice who participate in Sibshops (see all recruitment materials in Appendix B). Only two sets of parents responded with interest to this wave of recruitment, and both families participated in the study. A second wave of recruitment was conducted through a non-profit program that supports families of children with special needs, also located in Northern California. One of the program directors at this agency sent out recruitment materials via email to the agency listserv. Fifteen families expressed interest in participation, but only eight families met inclusion criteria and were entered into the study. I turned away six families because the nondisabled sibling was either too old or too young to participate in the study. None of the families who expressed interest in the study, and met inclusion criteria, refused to participate or dropped out after consenting into the study.

To reduce potential coercion or undue influence, the two professionals who shared my recruitment materials did not participate in recruitment beyond providing these materials to families. They were additionally not informed about who agreed to participate. All parents and nondisabled siblings who responded to the study recruitment materials with interest were contacted by me directly to discuss the study and its requirements. A parent was typically the initial point of contact due to the fact that the study participants were minors. The 17-year-old participant, who had received the recruitment materials from his father, contacted me directly to participate in the study. After a parent or nondisabled sibling expressed interested in my study, I provided them with a brief overview of the study via email or phone. I then set a date and time with the parent and/or participant to visit their home and discuss the study with them in person, and in more detail. At this time, I obtained child assent and parent permission, and scheduled the interview.

I gave participants a $15.00 gift card to a store of their choosing at the conclusion of the interview. I made no provision for partial payment. I chose this form of compensation to support recruitment and to formally thank participants for volunteering their time for the study. I deemed the monetary amount of the gift card to be small enough to not be coercive, but big enough to be a worthwhile reward for study participation.

Data Collection

My first in-person meeting with the family included the prospective nondisabled sibling participant and at least one parent. In some families, other family members chose to be present for the meeting, but I did not elicit their participation. I made the choice to include at least one parent in this initial meeting in order to support parent buy-in, collect parent permission, schedule the interview, and arrange for the transmission of a family dinner audio recording (i.e., part of the interview process). The study procedures and the participant's rights were described in detail during the consent process. The participant and parent were then asked several demographic questions, including: (a) age of participant currently; (b) gender of participant; (c) participant's self-identified race/ethnicity; (d) age of the sibling with a disability currently; (e) gender of the sibling with a disability; (f) age of the sibling with a disability at the time of diagnosis; (g) current services accessed by the sibling with a disability; h) diagnosis of the sibling with a disability; (i) self-reported income range/class (i.e., "lower," "mid-lower," "middle," "mid-upper," and "upper"); and (k) parent's level of education. A date and time for the interview was then scheduled, allowing for a two-hour block of time for the interview.

Details were then discussed in regard to the recording and transmission of a family dinner conversation to me during the week leading up to the interview. I asked the parent and/or participant to use their smartphone to audio record a family dinner and then to send the audio file to me using WhatsApp. WhatsApp was chosen for transmission of the audio file because it allows end-to-end encryption of files. One participant audio recorded the dinner and sent the file to me; otherwise a parent of the participant sent the file. Once a parent or the participant sent the audio file to me, I transcribed it verbatim and analyzed it to identify moments to pause and discuss a particular family interaction with the participant (a detailed description of this process is provided below). A field note was written following each initial meeting with a participant. These field notes were part of the data corpus, but I did not analyze them directly as part of this study.

Each interview lasted 1-2 hours and was conducted in-person at the participants' home, in a quiet place of the participants' choosing. Only the participant and I were present for the duration of the interview. Verbal consent was obtained from the participant to audio record each interview. One interview had to be conducted in two parts across two days due to scheduling difficulties. The last 15 minutes of the interview were conducted remotely using the Zoom online meeting platform for video conferencing ("Zoom Video Communications, Inc.," 2019). Verbatim transcripts were initially produced for each audio-recorded interview using Temi ("Temi," 2019), an online transcription software. I then reviewed each transcript individually, while listening to the audio, and made corrections for accuracy. In addition, I wrote field notes following each interview. Again, I included these field notes in the data corpus, but did not analyze them as part of this study.

Semi-structured interview. The semi-structured interview developed for this study consisted of three sections: (a) the creation of an emotion map, (b) discussion of a previously recorded family dinner conversation, and (c) administration of open-ended interview questions. A copy of the interview protocol developed and utilized for this study can be found in Appendix B. My goal for the first two sections of the interview was to generate examples of family interactions that could be analyzed for demands and their appraisals, coping behaviors, resources and their appraisals, and the cognitive appraisal process. I solicited family interactions associated with a participant's experience of both positive and negative emotions (i.e., the presence of no psychological stress and the presence of psychological stress); however, I only used those that included a participant's experience of negative feelings and emotions in this study. It is important to note that during these two sections of the interview, I asked participants about family interactions that had already occurred. As such, the participants' accounts and appraisals of the various interactions that they reported were inherently influenced by their experiences since that interaction and hindsight. These accounts and appraisals were considered good enough for the purpose of this study, but I recognize their inherent flaws. In addition, I must acknowledge that discussion of what the participant actually did or felt in response to a specific stressful demand was utilized as a proxy for secondary appraisal. One may argue that this information is more accurately a representation of Lazarus and Folkman's (1984) coping process, but it is the closest I was able to come to the participants' reasoning about their coping resources in the context of stressful family interactions. As such, that is how the data is utilized in this study.

The final section of the interview, the open-ended questions, was designed to gain additional information about family relationships and processes, as well as to capture additional sources of stressful demands and utilized coping behaviors and resources. This section triggered discussion of typical stressful family interactions, as opposed to specific stressful family interactions. These interactions were also analyzed as a part of this study.

Emotion map. The emotion map is a visual participatory tool used to examine the respondent's perception of specific family interactions, with a focus on the perceived emotions experienced by the respondent and other family members (Gabb & Singh, 2015). It is used in both clinical and research settings with individuals or multiple family members "to elicit information on family processes as experienced through interactions, located in the family home" (Gabb & Singh, 2015, p.186). Using the map, a clinician or researcher can get a sense of the variety of interactions and emotions experienced in a family. In this technique, the respondents create a floor plan (i.e., map) of the family home and then identify where specific interactions occurred within a prescribed time frame (e.g., during the last week). Traditionally, each respondent is given a set of stickers depicting a range of emotions. The respondent places the stickers at the site of each interaction to indicate which emotion was experienced by each family member in a given interaction.

For the purpose of this study, participants were asked to create a floor plan of their home and to recall three emotionally laden interactions that occurred sometime during the two-week period prior to the interview. They were then asked to use stamps with emotion faces on them (i.e., emoticon stamps) to record who participated in the interaction, where the interaction occurred, and what emotions each participating family member experienced. If the participant was not sure how a family member had felt during an interaction, they were asked to speculate on the emotion that they perceived the family member to have experienced. I then asked the participant to provide an explanation for why each family member behaved and felt the way that he/she did in each interaction. I asked additional questions when appropriate to get as much information as I could about the participants' primary and secondary appraisals of the interactions. In order to better contextualize each interaction and get a sense of the generalizability of the interaction, I also asked questions about the frequency and relative significance of each type of interaction. Two examples of emotion maps are provided in Appendix D.

Dinnertime audio recording. Dinnertime recordings have been used in a variety of studies on families for different purposes. For example, Sterponi (2009) utilized recordings of family dinner conversations to study family discussions of past events in order to understand how children learn important cultural norms. Ochs and Taylor (1992) analyzed family dinner narratives to study how roles and power within families are constructed. In this study participants and/or parents were asked to use their smartphone to audio record one family dinner during the week prior to the interview. They were asked to start the audio recording when everyone was called to the table, and to stop the recording when everyone left the table. In two cases an interval of two to three weeks occurred between recording a dinnertime conversation and conducting the interview due to scheduling difficulties.

I transcribed each dinnertime audio prior to the interview and identified at least three family exchanges that included the participant. One dinner audio captured a mix of spoken English and Spanish. A fellow researcher, and native Spanish speaker, assisted me in translating this dinner audio for my analysis. It is important to note that this colleague was not from the same country in Latin/Central America as the family. She noted that there may have been some cultural differences in the meanings of certain words or phrases. As such, the participant was asked to translate and clarify meaning when appropriate during the interview. The purpose of transcribing and analyzing these audio recordings was to identify prototypical interactions in the audio to listen to and discuss with the participant during the interview. This process additionally allowed me to outline theories regarding each participant's communicative role or profile during family dinners.

In consultation with Dr. Sterponi, an expert on conversation analysis, I created rough communicative profiles for each participant based on their engagement in the recording. To do so, I generated counts of the participants' total number of communicative turns during the dinner audio. These were then broken down into counts of their communicative initiations vs. responses. The initiations and responses were grouped into categories by analyzing the type of speech act and to whom the act was addressed. I then wrote questions about the participants' amount and type of speech acts during family dinners (e.g., "it seems as though Mom is usually the one who asks you questions about your day; is that right?" "I heard you offer to help your sibling several times during dinner; is that something you typically do?"). In addition, I identified specific interactions in the audio that typified the nondisabled siblings' speech acts. I noted the timestamps for these interactions so that I could play them during the interview. For each of these interactions I also wrote what (i.e., content) and why (i.e., process) questions in order to elicit a robust picture of the participants' experience of the interaction. An "interaction" (i.e., when to start and stop the audio) was defined as a conversation about a specific topic. I was generous in the amount of audio that I played for each interaction in an attempt to capture the entire exchange.

During the interviews, I played the dinner audio recordings on my laptop so that the participants and I could hear it clearly. I also showed the participants how to pause and re-start the audio so that they could pause it if/when they had a comment about something they heard. I let them know that I had listened to the recording before the interview and had picked several moments to pause the audio and ask them questions. I then played the audio from the beginning of the recording. I initially let the audio play until the participant paused it or until we reached the end of the first interaction that I had flagged as an example of a typical speech act. After this, I typically fast-forwarded the audio to the next interaction I had noted before the interview. Whenever I paused the audio, I first asked the participant to tell me about what was happening in the interaction we had just heard (e.g., "what was happening/going on there?"). We then discussed the interaction and I followed up with my previously scripted questions as necessary. Throughout this segment of the interview, I also asked questions to clarify a participant's statements, contextualize the interaction, or elicit further examples.

Open ended questions. For the final portion of the interview, I asked each participant to answer open-ended questions about their experiences as a nondisabled sibling in their family. I asked the participants to reflect on their knowledge of their sibling's disability (e.g., "What is your current understanding of your sibling's disability? How does it affect him/her?"), relationships within the family (e.g., "Do you feel that your parents compare you to your sibling? In what ways?"), and family roles and responsibilities (e.g., "In a crisis, what do you think each person in your family would do?"). The purpose of these questions was to collect more detailed information about the frequency and variety of daily stressful demands experienced by the participants (i.e., demand pileup; Patterson, 1988), build a more nuanced understanding of relationships within the family (e.g., parental differential treatment and family communication), elicit accounts of any additional stressful demands and utilized coping behaviors and resources not discussed in the previous sections, and provide opportunities for the participant to discuss more general family interaction patterns. In addition, several questions (five, six, and 10) were informed by the work of Don Meyer, the founder of Sibshops, who has worked with this population of children for decades (Meyer & Vadasy, 2008). His work highlights the importance of inclusion of nondisabled siblings in family decision making and caretaking related to the child with a disability.

Data Analysis

I coded and analyzed the data using methods described by Miles, Huberman, and Saldana (2014). The software program Atlas.ti (version number 8.4.3, released in 2019) was utilized to code the data and generate segments for analysis. My analysis plan was initially shaped and developed based on my theoretical framework. I updated and altered my analysis plan throughout the analytic process as I created increasingly fine-grained codes and developed a clearer focus on particular dimensions of the data. As noted earlier, I made two crucial choices regarding the parameters of my analysis. The first is that I chose to include only family interactions that the participant appraised as stressful (i.e., during which he/she reported feeling a negative emotion). Logistically, by choosing only stressful interactions I was able to manage the quantity of data produced by the semi-structured interviews and preserve the quality of the analysis. In addition, these interactions included clearly identifiable appraisals of demands and coping behaviors and resources, elements that were not as clearly demarcated in participants' discussions of non-stressful interactions. Theoretically, this choice focused my analysis on variability in the experience of psychological stress across nondisabled siblings. The second important parameter is that I chose to analyze interactions that were clearly related to the participant being a nondisabled sibling either because the disabled sibling was a part of the interaction or because the content of the interaction was related to the disabled sibling. I made this decision in order to manage the quantity of data analyzed, but also to focus the analysis on my primary objective, which was to understand the experience of being a nondisabled sibling.

I broke my primary research question down in to three components. The first component focused on understanding which kinds of nondisabled sibling-related family interactions elicit negative feelings/emotions, and why. I attempted to answer the first research question by analyzing the stressful demands that participants identified during stressful family interactions. I analyzed these demands for their content and the participants' reasoning about them (i.e., primary appraisal). In other words, I explored the participants' perceptions of who or what tended to cause them to feel negative emotions during daily family interactions and why. I then identified themes related to the participants' perceived stressful demands and primary appraisals within and across the interviews. The second research component focused on which resources and coping behaviors were considered and used by nondisabled siblings during these stressful interactions. I addressed this component by analyzing the coping behaviors and resources that the participants reportedly considered and/or utilized in response to stressful demands. I analyzed both the content of the coping behaviors and resources, and the participants' reasoning about their use and efficacy (i.e., secondary appraisal). In doing so, I identified themes related to the coping behaviors and resources that each participant considered and used. I then explored these themes across participants. The third component had a synthesis goal, namely to identify themes or patterns that arose in terms of the ways that participants experienced and coordinated the stressful demands, resources, and coping behaviors. I approached this objective by analyzing the participants' coordination of their primary and secondary appraisals of stressful family interactions. I explored themes related to each individual participant's cognitive appraisals of the stressful interactions reported, and then explored themes across participants' cognitive appraisals of stressful family interactions.

First cycle coding. I conducted two rounds of first cycle coding, as defined by Miles and colleagues (2014), for this study. I developed deductive codes for first cycle coding. The purpose of these deductive codes was to capture salient components of my theoretical model, including stressful demands, coping behaviors, resources, and the overall cognitive appraisal process (i.e., the coordination of primary and secondary appraisals). In addition, I developed codes to label the emotions of relevant family members. Through two rounds of holistic and provisional coding, my deductive codes and their definitions were honed. I then grouped my deductive codes by the type of code (i.e., emotion codes, interaction codes, and cognitive appraisal codes). The final coding scheme, with definitions of each code, can be found in Appendix C, Table 2.

I conducted both rounds of first cycle coding in three steps. First, I holistically coded each discussion of a specific or ongoing stressful family interaction that was related to the role of being a nondisabled sibling as an interaction with stress (i.e., coded as “Interaction W Stress”). Second, I conducted provisional coding within each of these stressful family interactions to label the participants’ perceived coping behaviors, resources, and stressful demands, as well as the emotions that they attributed to each family member in the interaction. Finally, I conducted provisional coding to label instances of cognitive appraisal (i.e., reasons for why a family member behaved or felt a certain way). When I labeled instances of cognitive appraisal, I further indicated to which family member the participant had attributed the appraisal. For example, if the participant reasoned about a disabled sibling’s behavior or emotion, I coded it “Cognitive Appraisal: Disabled Sibling,” whereas, if they reasoned about their own behavior or emotion it was coded “Cognitive Appraisal: Nondisabled Sibling.” I conducted two rounds of first cycle coding in order to perfect the coding system, as well as make sure that all appropriate quotes were identified and that the codes were applied uniformly across the data set. I wrote analytic memos (i.e., “a brief or extended narrative that documents the researcher’s reflections and thinking processes about the data”; Miles et al., 2014; p.95) throughout this process that captured the themes or patterns I observed in relation to the participants’ perceived stressful demands, coping behaviors, resources, and cognitive appraisals.

Second cycle coding. According to Miles and colleagues (2014) pattern coding is conducted during second cycle coding. I took several steps to prepare my data for pattern coding. For each interview, I generated a spreadsheet of quotes by pulling all quotes associated with the code groups “Emotion Codes,” “Interaction Codes,” and “Cognitive appraisal Codes.” I then clustered quotes by the stressful family interaction from which they were taken. I developed matrices for each interview that captured the stressful demand(s), appraisals, emotion(s), coping behavior(s), and resource(s) that the participant discussed in relation to each stressful family interaction that they reported (see Figure 2). In the process of making these matrices, I separated the data captured in participants’’ “Cognitive Appraisal Codes” into primary and secondary appraisals of the interaction. Additionally, I generated pattern codes to categorize demand types. Figure 2 provides an example of what the matrix looked like for one stressful interaction from one participant’s interview.

Figure 2. Example of Second Cycle Coding Matrix

Stressful Demand	Type of Stressful Demand	Primary Appraisals	Negative Emotion	Coping Behavior(s)	Resource(s)	Secondary Appraisals
Disabled sibling teases nondisabled siblings	Disabled sibling behavior	…disabled sibling wants attention all the time, and he teases nondisabled siblings so that nondisabled siblings will give him attention by yelling at him	Frustrated	Ignores, or yells at disabled sibling	None identified	…knows disabled sibling just wants attention, so normally tries to ignore him, but when really frustrated yells at him

Once I completed a matrix for a participant (i.e., all stressful family interactions described by the participant in their interview were broken down into their component parts), I wrote narrative descriptions that captured themes within the participant's experiences of stressful family interactions (i.e., narratives that wove first cycle codes together; Miles et al., 2014). These narratives focused on demand content and reasoning, resources and coping behavior content and reasoning, and overall cognitive appraisals (i.e., the coordination of the participant's primary and secondary appraisals). Upon completion of narrative descriptions for each participant, I began to look for themes across the narrative descriptions. My goal in generating these themes was to uncover patterns within participants' cognitive appraisals that could help us to better understand variability and similarity across the experience of family-related stress within this population. I additionally wrote jottings (i.e., my fleeting and emerging reflections and commentary on themes within the data; Miles et al., 2014) and analytic memos throughout this process to support analysis. In addition, I drafted assertions and propositions (i.e., "…connected sets of statements, reflecting the findings and conclusions of the study"; Miles et al., 2014; p.99) during cross-case analysis. The patterned codes (i.e., themes) that I generated through this second cycle of coding are captured in the analytic matrices discussed in the next chapter, and can be found in Appendix E.

Chapter 3: Findings

As I indicated in Chapter 2, this study focuses on family interactions experienced as negative by nondisabled siblings. I considered reported negative emotions to be indicators of felt psychological stress. Negative emotions experienced by the participants in this study included frustration, anger, annoyance, exasperation, sadness, and confusion. I further limited my analyses to interactions linked to *being* a nondisabled sibling (i.e., ones that involved the disabled sibling explicitly or implicitly, or were related to the role of being a nondisabled sibling). I did not include participant-parent interactions that were unrelated to the disabled sibling, or interactions between participants and other typically developing siblings. As such, only those stressful family interactions relevant to being a nondisabled sibling were included in the analysis.

In this chapter I have organized the results of this study according to the three research questions: (a) which kinds of nondisabled sibling-related family interactions elicit negative feelings/emotions, and why?; (b) which resources and coping behaviors are considered and utilized by nondisabled siblings during these stressful interactions, and why?; and (c) what themes or patterns arise in terms of the ways that the demands, resources, and coping behaviors are experienced? Quotations from the interviews are included in text; further examples can be found in Appendix E.

Question One: What Kinds of Nondisabled Sibling-Related Family Interactions Elicit Negative Feelings/Emotions and Why are They Perceived as Negative?

I found that stressful demands fell into three broad categories: (a) disabled sibling behavior (i.e., a behavior enacted by the disabled sibling), (b) parent behavior (i.e., a behavior enacted by one or both parents), and (c) nondisabled siblings behavior (i.e., a behavior enacted by the nondisabled sibling). Disabled sibling behaviors were the most common source of stressful demands across and within the interviews. All participants reported some form of behavior enacted by their disabled sibling that occurred within a family interaction that they appraised as stressful. Furthermore, while these interactions always included the disabled sibling, there were often additional family members involved in the interaction, such as a mother, father, or another typically developing sibling. Parent behaviors were the next most commonly reported source of stressful demands during family interactions, with all but two participants reporting an instance of felt psychological stress in response to a parent's or both parents' behaviors. These interactions sometimes included the disabled sibling, but not always. The third category of demands was the behavior of the actual participant (i.e., nondisabled sibling's behavior). This was the least common source of stressful demands according to participant interviews, with only three of the 11 participants reporting occurrences of this type of stressful demand. I analyzed participants' primary appraisals of all three types of stressful demands for themes. These themes are discussed below (i.e., see also Appendix E, Table 1).

Themes related to perceived stress caused by disabled sibling behaviors. I identified seven themes that emerged from participants' primary appraisals of their disabled siblings' stressful behaviors: (a) disabled sibling behavior interrupts the nondisabled sibling's activity, (b) disabled sibling behavior elicits concerns about the disabled sibling's wellbeing, (c) disabled sibling damages private property, (d) disabled sibling lacks communication skills, (e) disabled sibling offends/embarrasses nondisabled sibling, (f) disabled sibling behavior leads to family conflict, and (g) disabled sibling behavior leads to parent stress.

Disabled sibling behavior interrupts the nondisabled sibling's activity. Nine of the 11 participants in this study (Ryker, Phillip, Sarina, David, Maya, Luke, Daniel, Scarlet, and

Eleanor) reported feeling negative emotions in response to a disabled sibling behavior that interfered with their ability to engage in or complete a desired activity. These activities included getting ready for school in the morning, getting ready for bed at night, eating dinner as a family, and doing homework. Participants considered multiple components of the contexts in which these disabled sibling behaviors were experienced in their primary appraisals. These considerations included who was present in the interaction, the location of the interaction, the timing of the interaction, the frequency of similar interactions, what occurred before the interaction, etc. It makes sense that the context is salient to participants' primary appraisals of these types of stressful demands considering that the felt stress is stemming from a disruption in the environment (i.e., the participant's desired activity).

An excerpt from the emotion map portion of my interview with Phillip (age 16) illustrates this type of stressful disabled sibling behavior. Phillip is a high-achieving student who discussed his busy daily schedule of school, sports, and homework during the interview. His disabled sister (age 18) was diagnosed with ASD at the age of four. He reported a specific incident during which he tried to start his homework at the end of a long day, and his disabled sister interfered with this activity by turning her music up loud.

> So, this was me trying to do homework, and my sister likes to be very loud with her music. And so, what she'll do sometimes is to like, not really scare me and my parents, but like get our attention, by turning the music really loud. And so, if I'm trying to study, and do homework, it can be a lot sometimes. [Researcher asks what emotion he was feeling during this interaction] I guess it is annoyed, but it's also kind of—I think frustrated, annoyed kind of. Cuz I just came home from a long day at school and sports and everything, and I just ate, and I was ready to put in some hard work, and with that happening, it's kind of hard, you know?

In this quote, Phillip reported feeling a negative emotion (i.e., "frustrated, annoyed") in response to his sister playing her music loudly after dinner. Phillip considered multiple facets of the situation in his appraisal of his sister's behavior. In fact, the appraisal reflects a pile-up of appraised stressful demands, including a long day at school and sports. In other words, he did not describe a habitual response to this sibling behavior, but a coordination of multiple cognitions about the situation in which the behavior occurred.

Several participants reported experiencing a negative emotion when their disabled sibling engaged in a behavior that interrupted family dinner. For example, while discussing his family's recorded dinner audio, David (age 15) reported that his disabled sister (age 15) often "acts out" during dinner by getting up from the dinner table and slamming doors. He appraised this behavior as stressful because it interferes with his ability to have dinner with his parents. David is another high-achieving student who discussed his busy schedule of school and sports during the interview. His disabled sister was diagnosed with global developmental delay at the age of four months. He described his parents as busy and hardworking people. Perhaps as a result of the family's busy schedule, David reported that he particularly values the time at dinner that he has to talk to his parents. In the following quote he describes why he experiences ongoing negative feelings when his disabled sister's behavior interrupts the family dinner.

> She can't really control her emotions, so she just goes and, goes and acts out. And that's just, it's just like: 'come on. We're all sitting down. Don't start slamming the door.' Cuz then one of my parents has to go up and get her. So, it kind of just ruins the dinner for me, cause I'm still trying to have a nice dinner with my parents. I - to be honest I don't really care about eating with my siblings, it's more about being with my parents. Cuz

> that's like, that's like the family time. [Researcher says: And you enjoy that.] Mhm. Cuz I know I can - I have plenty of time to hang out with my siblings and go to the park or whatever, or just after school and stuff. But like, dinner, I know my parents are definitely going to be there. So, that's like, don't take them away.

This excerpt from my interview with David also highlights the multifaceted nature of participants' primary appraisals of demands as stressful because they interrupt desired activities. David's account of this stressful behavior reflects his desire to spend time with his parents, and his feeling of loss when he perceives this opportunity as being taken away. A majority of the participants in this sample (i.e., nine out of 11) appraised disabled sibling behaviors as causing them to feel a negative emotion because the behavior interfered with an activity in which they wanted to, or were trying to, engage.

Disabled sibling behavior elicits concerns about the disabled sibling's wellbeing. Seven participants (Ryker, Phillip, Sarina, Olivia, Mateo, Scarlet, and Eleanor) described the experience of feeling negative emotions (e.g., bad, sad, scared, or worried) in response to their disabled sibling engaging in behaviors that were perceived as potentially dangerous (e.g., running away from home), painful (e.g., engaging in self-harm), or reflective of disability-related deficits (e.g., not being able to participate in cognitively advanced activities). For example, during the emotion map activity, Ryker (age 10) reported that his disabled brother (age 7) engages in the potentially dangerous behavior of "going missing" from the family home. Ryker described one specific incident that occurred the morning of the interview, during which his brother left home on his bicycle and no one knew where he was. In response, Ryker felt scared about his brother's safety: "Well, I don't like being a single child. And…it's dangerous, the world is dangerous. And I don't want any - I almost thought someone kidnapped him or he drowned in the creek. Because he can't swim." Ryker reported that his brother engages in this potentially dangerous behavior every couple of months, and he is not sure why: "I don't know really! Normally I'm inside reading or watching TV or I'm away playing with someone.… So, I'm not really normally sure." Based on Ryker's account of this behavior, it is clear that the threat of harm to his brother causes him to feel psychological stress.

During the emotion map portion of the interview, Eleanor (age 16) described a stressful family interaction that occurred the day before the interview. Eleanor reported feeling a negative emotion during this interaction as a result of her brother's (age 18) potentially risky behavior, along with her uncertainty regarding how to respond to the behavior. Eleanor's brother was diagnosed with ASD at the age of two and later diagnosed with several additional chronic health conditions. At the time of this interaction, Eleanor was ill and did not want to pass her illness along to her brother, whose health is already compromised. Her brother asked for a hug, but she refused despite knowing how much he likes physical affection. She "felt kind of bad" because she did not do what he had asked.

> I wasn't feeling so good…And then [disabled sibling] wanted to give me a hug. And then, but, I didn't—because we have to be careful not to get [disabled sibling] sick, because when he gets sick, he gets really, basically all his symptoms, that he normally has, they basically get worse…. Like he'll get more agitated, he'll feel more anxious. Sometimes he even starts hurting himself. So, we don't want that to happen. So, [disabled sibling] wanted to give me a hug, but I was like: 'no.'… And then I felt kind of bad. I don't know. But at the same time, I was like—but [disabled sibling] just really—[disabled sibling] is very affectionate. He likes giving people hugs and stuff.

Throughout the interview, Eleanor shared how close and in tune she and her brother are with each other. While describing her relationship with her brother, she said: "I think we're pretty closely connected…. I feel like I understand him better than anyone else does." She also generally reported enjoying her disabled brother's affectionate nature; however, in this situation, she found his desire to hug her stressful. Due to the nature of his health conditions, Eleanor and her family members take precautions not to get him sick. In this interaction, Eleanor cognitively balanced her brother's desire for affection (coupled with her desire to reciprocate his affection) with the need to preserve his health. Her decision to disappoint him in the short term in order to support his wellbeing in the long term reflects strong self-regulation skills. The appraisal further captures Eleanor's careful and empathic consideration and recognition of her brother's experience of the situation (i.e., that he will be disappointed), as well as her role as one of his caretakers.

Overall, six participants reported feeling bad, worry, fear, or sadness in relation to a disabled sibling behavior that they perceived as dangerous, painful, or reflective of their deficits. In other words, these disabled sibling behaviors elicited participants' concerns for their disabled sibling's wellbeing. These behaviors often reflected symptoms of the disabled sibling's disability. For example, running away from home (also termed *eloping*) is considered a symptom of ASD.

Disabled sibling damages private property. Four out of the 11 participants in the study (Ryker, Olivia, Luke, and Scarlet) reported experiencing psychological stress as a result of their disabled sibling damaging their belongings (e.g., jewelry), items around the house (e.g., a lamp), or things they had made (e.g., a Lego structure). For example, Ryker reported that his disabled brother engages in several repetitive behaviors (e.g., "galloping around" and "hand flapping") that sometimes cause damage to personal property. Ryker's disabled brother was diagnosed with ASD at three-and-a-half years old. During the emotion map activity, Ryker (age 10) described a specific interaction in which he perceived his disabled brother (age 7) to purposefully break his Lego structure while engaged in a repetitive behavior.

> [Disabled sibling] did this [arm swiping gesture], it was on the table. It was the size of probably, it was about, the floor was about the size of the iPad. It was about THAT tall [gestured to indicate height], and it had a bunch of battling troops. One sweep off the table KABLAMO! Everything's gone.

Ryker further reported that his brother broke his Lego structure "cuz he was goofy, and he needed to go to the bathroom." Upon further questioning, Ryker explained that his brother had a yeast infection which made him "go silly and all, and he giggles around, and he gallops all over the place and wrecking things." When I asked directly about his brother's intentions during this interaction (i.e., "Do you think he did it on purpose? Or he just by accident hit it because he was being silly?"), Ryker reported that his brother's behavior was purposeful: "No, he went 'uuuuuuuh' [gestured flailing arms]. That was on purpose." Ryker's appraisal of his brother's actions during this interaction reflect inconsistency regarding the reasons behind his brother's actions. On one hand, he recognized that his brother's actions were at least partly the result of a physical condition (i.e., a yeast infection), in addition to his fundamental disability. On the other hand, Ryker perceived his brother's behavior as purposeful, in the sense that his brother purposefully knocked over his Lego structure. Like Ryker, other participants struggled to integrate their understanding of their sibling's disability and its ramifications with a sense that the sibling may have acted in a way that was intentional. Even when they could articulate the effects of, for example, the sibling's lack of self-control that stemmed from the disability, these participants reported experiencing anger and frustration in response to the occurrence of the behavior.

Disabled sibling lacks communication skills. This theme captures disabled sibling behaviors appraised by participants as stressful because the behavior interferes with the participant's ability to communicate with their disabled sibling. Four of the 11 participants (David, Maya, Olivia, and Luke) reported ongoing family interactions during which this type of behavior caused them to feel frustration, sadness, and/or confusion. Participants reported the following disabled sibling behaviors as stressful because they interfere with communication: unintelligible speech and poor comprehension skills (Olivia), unwillingness or lack of interest in communicating with the participant (David, Maya, and Luke), and poor pragmatic language skills (David and Maya). For example, Olivia (age 11) reported that she, her parents, and her typically developing brother (age 8), struggle to understand what her disabled sibling (age 15) is saying during family dinner conversations. Olivia's disabled sister had a congenital diaphragmatic hernia that led to a stroke at birth. As a result, she was diagnosed with cerebral palsy and intellectual impairment, among other chronic health conditions. In an attempt to avoid difficult or unpleasant interactions with Olivia's disabled sibling during dinner, family members tend to ignore her attempts to engage in the conversation. Instead, they engage in conversation with each other, and one parent may engage with Olivia's disabled sibling on the side. When we listened to her family's recorded dinner audio, Olivia stated: "the topic changes very often. And there are often two different topics at once. I think [disabled sibling] is still trying to get heard, but we aren't really paying attention." In the following excerpt, Olivia explained why this pattern of family interaction tends to occur during dinner.

> Well, we often find that you don't understand what [disabled sibling] is saying. Like she'll be like, she'll say something, and you don't fully understand, so you kind of ignore it. Because you don't know what to say in turn.… I'm not always like that. With some people, I'll still try to make a reply with some people. Even if I don't fully understand it. [disabled sibling], it's more like even if I'm mid-reply to that, she wouldn't even - I don't know if she understands me. So that's like, if I even made a reply, would she know what I'm saying? Would she understand? Like if I said: 'I don't understand,' I bet you she would understand. But then she would keep trying to talk and say this thing that I don't understand. And then again, do you want to keep hearing someone saying gibberish?

Olivia's appraisal of this situation reflects deep and thoughtful consideration of both her own behavior and that of her sister. She distinguishes her behavior with her disabled sister from her behavior with others. In doing so, she appears to be taking her sister's particular communicative capabilities into account. In other words, Olivia's primary appraisal of this situation indicates that she has a sense of what her sister can and cannot understand, and that she (Olivia) can predict how her sister is going to react if she chooses to engage (i.e., with "gibberish"). Olivia further reported that she enjoys family dinners because this is her time to tell her father about her day. In addition, he shares his research with her, which she enjoys. Although not explicitly referenced as part of her appraisal of this disabled sibling behavior, Olivia may also be considering her desire to talk to her father in her appraisal of her sister's behavior. She may view engaging with her sister during dinner as additionally stressful because it interrupts the desired activity of engaging with her father.

Luke (age 17) described a different stressful disabled sibling behavior that leads to ongoing communication difficulty between him and his disabled sibling. Luke's brother (age 16) was reportedly diagnosed with Down syndrome prenatally, but then experienced a developmental regression at the age of 10 that led to an additional diagnosis of ASD. Luke discussed the impact of this regression on his relationship with his brother several times throughout the interview. In particular, he highlighted the impact of his brother's developmental regression in the area of communication on their ability to sustain a relationship. During the open-ended question portion of the interview, when I asked him about his relationship with his disabled brother, Luke stated:

> …we used to have a better relationship when we were younger because we would play together. I'd try to get him to do things with me, like build a fort, and watch movies in a tent or something. And he'd play a game, he'd run around and do stuff. Whereas now he's very reserved. He doesn't really interact with you, other than yes or no questions. And he won't even speak.… I remember him talking as normal as the other Down syndrome, like boys with Down syndrome his age did. And we'd play tag, and like we'd run around through the house, and do stuff like that. But now, like I said, he like—it almost seems like he regressed. And it's kind of just like: he doesn't say anything, interact much, do anything. If I do try to interact with him, he usually doesn't—he seems like he doesn't want to.

In this passage, Luke reported experiencing his brother's lack of interest in interacting with him as a loss of the sibling relationship that he previously had with his brother. While not stated explicitly, Luke appears to experience this loss with sadness. Olivia and Luke's appraisals illustrate two distinct responses to their disabled sibling's poor communication skills. While Olivia anticipated psychological stress as a result of an unpleasant or difficult interaction with her disabled sibling, Luke described a more generalized feeling of loss triggered when his brother does not interact with him.

Disabled sibling offends/embarrasses nondisabled sibling. Four participants (Ryker, Phillip, Maya, and David) reported family interactions during which they felt or anticipated psychological stress because their disabled sibling engaged in a behavior that offended or embarrassed them. The participants did not attribute malicious intent to these disabled sibling behaviors; nonetheless, they experienced negative emotions in response. For example, during the open-ended question portion of the interview, Maya (age 15) discussed her disabled sister's (age 15) tendency to laugh during crisis situations. Maya's disabled sister was diagnosed with global developmental delay at four months old, but her current diagnosis was not clear to the members of her family. Maya recounted a specific interaction during which her disabled sister laughed when Maya fell and hurt herself.

> …one time I hurt myself so bad, cuz I think—I forgot what it was—it was before the house got remodeled and I was swinging on something in the kitchen, and I fell really badly. And I was just there crying, and she stood over me and started laughing. And I was like—it just made it 10 times worse, cause it hurt! [Researcher asked why her disabled sibling laughs in these situations] …maybe it's cuz she doesn't know how else to react. But I ALSO think that she genuinely just thinks it's funny. Like, 'oh something bad's happening, like, that's funny.' I don't know. I don't know what goes through her head.

Maya reported some confusion regarding why her disabled sister laughs during crisis situations like the one reported. Maya's account reflects an acknowledgment that her sister's cognitive limitations may account for her inability to demonstrate a caring response to Maya's pain and distress. However, she further speculated that her sister may take pleasure in the discomfort of others. The emotions that these competing explanations evoke in Maya are similar to Ryker's response to his brother's destruction of his Lego structure. Both Maya and Ryker reported multifaceted appraisals of their siblings' behaviors that illustrate the complex and contradictory reactions that primary appraisals provoke.

Disabled sibling behavior leads to family conflict. Two participants, Maya (age 15) and Daniel (age 13), reported that their disabled siblings engage in behaviors that cause them to feel psychological stress because they trigger family conflict (i.e., an argument between two or more family members). While only two participants reported appraising disabled sibling behaviors as stressful for this reason, they each reported multiple examples of these stressful behaviors within their respective interviews. Daniel reported his experience of observing conflict between his brother (age 16) and his parents. For example, during the open-ended question portion of the interview, Daniel described feeling psychological stress in response to the family conflict that ensues when his brother, who has a diagnosis of ASD, comes home later than promised.

> When [disabled sibling] comes home late, because he was out with his girlfriend. He does that. He's like: 'Oh yeah, I'll be—at the latest I'll be back by 7:30.' And then he comes home by eight. [Researcher asks: Why does that bug you?] Just cuz there's usually conversation afterwards. Sometimes involves raised voices.

In interactions like this one, Daniel reports the stressful effects of observing conflict among other family members. In comparison, Maya reported incidents in which she was engaged in the subsequent family conflict with her disabled sibling and her parents. Typically, these incidents of family conflict began with her sister reacting negatively to something Maya had done, which in turn prompted their parents to intervene. Maya perceived these interactions with her parents as "unnecessary" conflict. For example, during the open-ended question portion of the interview, Maya described ongoing stressful family interactions during which her disabled sister becomes upset when Maya says she wants to be left alone:

> And also like, it's late at night and I'm trying to brush my teeth and [disabled sibling] comes, and I'm like: 'just go away. Like I just want'—And then, I could just talk to her, but she gets offended very easily. Like she takes everything really seriously. Also, because I think she wants attention. So, she'll just like drop her toothbrush, sprint outside, and then now I have to deal with THIS. And all I wanted to do was brush my teeth alone. So, I don't know. It—she makes a little situation that can just be talked through, a situation where my parents have to come upstairs, scream at me and be like 'oh, well why is [disabled sibling] outside? What did you do to her?' 'Well I just asked her if I could brush my teeth alone.' And so, it makes a whole situation where there doesn't need to be any conflict at all. But it's just like, if I'm like, I'm TIRED and I want to go to bed, I'm like '[disabled sibling] you should go to bed now. Like what are you doing up?" And if I say anything, even with a tiny bit of aggression—I have to say everything so nicely. And I think I'm pretty good at it, but when I don't do it, she gets like—if it makes her mad—she doesn't know how to deal with it.

Maya's primary appraisal of this situation reflects the cognitive coordination of multiple aspects of her own behavior, her sister's behavior, her parents' behaviors, and the context of the interaction. Instead of attributing her felt stress solely to her sister's behavior or her parents' behaviors, she explains that she feels stress because her sister's behavior (i.e., over-reaction to Maya's request) leads to conflict between her and her parents. Maya provides several explanations for her sister's behavior, including "she gets offended easily," "she takes everything really seriously," "she wants attention," and "she doesn't know how to deal with it." These explanations reflect Maya's consideration of the implications of her sister's disability on the interaction. Based on Maya's understanding of her sister's ability to handle stress, she reports making attempts to accommodate her sister (i.e., "I have to say everything so nicely"). However, when Maya does not appropriately accommodate her sister, or tries to and it does not work, family conflict ensues. Maya further considers her own role in this interaction by pointing out that her appraisal of the situation is influenced by the fact that it is late at night and she is tired.

Disabled sibling behavior leads to parent stress. Two out of the 11 participants (Maya and Olivia) reported feeling psychological stress in regard to their mothers' emotional reactions to specific behaviors enacted by their disabled sisters. For example, during the dinner audio portion of the interview, Olivia (age 11) reported that her disabled sister (age 15) often boils water at home. Olivia reported that her disabled sister boils water because "she thinks she's doing something good. She thinks that tea's nice and that she's being helpful, and that mommy likes the tea." However, according to Olivia's appraisal of the situation, her sister's behavior causes their mother to become angry.

> [Disabled sibling] boiling water is more like you don't want another row to come up, or anything like that. [Researcher asks: You don't want another row to come up?] It's not exactly a row, it's more like you don't want mommy to be angry.

In discussion of this ongoing stressful interaction, Olivia explained that tension is often high in her house, which causes family members to lack patience with each other: "...like bad moods can come up from small things.… Like if [disabled sibling] did something wrong, as far as like: '[disabled sibling], what are you doing?' Like it's—patience is kind of short here. Easily cracks." Olivia's primary appraisal of this situation does not focus on possible harm to her sister, or her mother's feelings of concern regarding her sister's wellbeing. Olivia actually points to the prosocial intention of her sister's behavior, implying that her mother does not appreciate or understand that her sister is just trying to be helpful. Ultimately, Olivia's appraisal focuses on the generalized tension among family members. She feels stress when her disabled sibling engages in a behavior that triggers her mother to lose her patience, which is already in short supply.

Themes related to perceived stress caused by parent behaviors. In this section, I describe participants' characterization of the behavior of one or both parents that constituted a source of stress. Parental behaviors experienced as stressful included: (a) parents engage in differential treatment, (b) parents are critical of nondisabled siblings' behavior toward the disabled sibling, and (c) parents do not respond appropriately to disabled sibling behavior.

Parents engage in differential treatment. Five out of 11 participants (Ryker, Phillip, Sarina, Olivia, and Eleanor) reported feeling stress in response to interactions in which they experienced parental differential treatment (i.e., "…within-family differences in parenting experienced by siblings" [Stoneman, 2005; p.342]). The participants typically appraised these stressful parent behaviors as a loss of attention or care. Each of the five participants provided an explanation regarding why their parents treated them differently from their disabled sibling. In addition, they each reported that their parent's behavior was generally justified or appropriate. For example, Sarina (age 12) provided the following account of how she sometimes feels sad when her parents treat her differently from her disabled twin sisters (age 15):

> …when I was little, we would go to the mall with the twins, and whatever the twins wanted, [my parents] would get them. But if I wanted something, they wouldn't get me it, because they would be like: 'oh, we'll get you this next time.' Stuff like that. But they would get the twins stuff. And I would get really sad about it. So yeah, that's the only time I feel like that. [Researcher asks: Okay. But you said you would kind of understand why? Why do you think?] Because they're more high maintenance. So—

> And I already know how to take care of myself. So, I think that my parents already know that I know how to take care of myself. So, they don't need to worry about me as much. But they need to worry about the twins because they don't know how to take care of themselves, or anything like that. But sometimes it just gets to me, and I'm just like, like feeling, I don't know, like sad. Because I feel like they don't give me enough care. But I know they do. And I know that it's, that they give the twins more care because they're more high maintenance.

Sarina acknowledges that, compared to her disabled sister, she is independent and self-sufficient, and also notes that her parents know and respect her competencies in this respect. Similar to other respondents I have already discussed, Sarina is aware that the twins need more support and attention from their parents as a result of their disability. And yet, despite her nuanced appraisal of this complex situation, Sarina also indicates that she sometimes feels sad because she experiences relatively less attention and care from her parents.

Parents do not respond appropriately to disabled sibling behavior. Three participants (David, Luke, and Scarlet) reported experiencing negative emotions following a parent's response to a disabled sibling behavior. These participants described experiencing psychological stress when they appraised their parents as using problematic coping behaviors in response to a stressful disabled sibling behavior. David, Luke, and Scarlet appraised these parent behaviors as problematic because, in their opinion, the behavior supported the continuation of, or did not adequately address, the stressful disabled sibling behavior. For example, David (age 15) described how his parents' response to his disabled sister's ongoing behavior of undressing in the home causes him to feel annoyed.

> It really annoys me sometimes. I feel like they give her too much leeway. Cuz it's just, when I'm in the moment I'm just thinking like logical for myself. Like 'why is she acting like this? She can't behave like this.' Whereas they're like giving her a little leeway, and I'm like 'come on, she still has to get punished for doing something like this. How is she going to learn?'

Overall, the participants' appraisals of this type of stressful parent behavior captured disagreement with their parents in regard to how to cope with a disabled sibling behavior that they had appraised as stressful.

Parents are critical of nondisabled sibling's behavior toward the disabled sibling. Three participants (Sarina, David, and Luke) reported feeling negative emotions due to their parents' critical response to the way they attempted to cope with stressful disabled sibling behaviors. For example, David (age 15) described experiencing his parents' response to the way he copes with his sister's (age 15) poor communication skills as a stressful demand. David's disabled sister was diagnosed with global developmental delay at 4 months old. During the dinner audio portion of the interview, David reported that his disabled sister always wants to ask questions during a conversation and refuses to answer questions asked of her. At times, he persists in trying to get her to answer a question, but, as he noted, "sometimes I'll have the wrong tone and then things will escalate." By escalate, David means that his sister becomes upset and acts out in some way (e.g., runs out of the house, slams doors, etc.). Once the situation escalates, his parents often intervene and become angry at him. David appraises his parents' response in this situation as its own stressful demand.

> …my parents just get mad. They're like: 'you're creating problems.' … And then, I'm always the one who's getting in trouble because—even when I feel like I'm trying to do something that has meaning to me. So that's, that's part of the problem too because I feel

> like I sometimes get unjustly blamed for a lot of the issues. Like I get in trouble when she should also be getting like in equal trouble, but she gets off easy.… Because, that's why they get mad at me. Cause I make it hard for them. But at the same time, it's like: 'eh, I don't want to be the only one getting in trouble.' I'm trying to do something that I think, you know, that I think matters, that—I'm just trying to do something. I don't know why you're getting mad at me for that.… And, I mean, it's like I'm trying to do—I'm just trying to ask her a question. why are you getting mad at me for that? So that's, that's really frustrating to me. Cuz I know she can do it. I know she's really smart. Like I've heard her talk to strangers more easily than me.

This excerpt captures the complexity of David's emotions about his parents' response to his coping behavior. He is frustrated by their response because he believes they are unjustly blaming only him for the situation. By only blaming him, David believes that his parents are underestimating his sister's ability to respond to questions, disregarding his attempts to do something he finds meaningful, and overreacting to his behavior. In addition, by noting that his sister is capable of talking in a mature fashion to "strangers," he implies that his sister has control over her behavior, a factor that further adds to his frustration. Another component contributing to David's response is his perception that his parents become angry because he is making the situation difficult for *them*. David's appraisal that his parents are acting out of concern for their own welfare, rather than his, compounds the frustration that results from his sister's behavior.

Themes related to perceived stress caused by nondisabled sibling's own behaviors. This third broad category of stressful demands captures the participants' emotional response to their own behaviors during stressful family interactions. Three participants (David, Maya, and Luke) highlighted their own behaviors as a cause of psychological stress for one of three reasons: (a) they inconvenienced their disabled sibling (e.g., interfered with the disabled sibling's ability to go to bed), (b) they triggered a stressful disabled sibling behavior (e.g., caused a disabled sibling to act out), and/or (c) they exacerbated an already stressful family interaction (e.g., talked back to their parents). The participants typically reported feeling guilt for what they perceived as their selfish or inconsiderate behavior. For example, Maya (age 15) expressed remorse that her late-night studying keeps her sister (age 15) awake, "Although I do feel bad cuz I stay up really late a lot of the times doing my homework. And I have a light on my desk, and so when I have it on, I'm sure it makes it hard for [disabled sibling] to sleep." Maya further noted that their mother sometimes finds it hard to sleep if her sister is still awake: "which affects my mom, cuz [disabled sibling] doesn't go to bed until I do. And so, she's like, she's up. And my mom gets mad at me, you know. And so, it causes conflict, where there doesn't need to be."

This excerpt from my interview with Maya demonstrates how some of the participants reasoned about their own involvement in stressful family interactions. They appraised their own behavior as contributing to their experience of stress in a given interaction because it caused a problem for their disabled sibling, triggered a stressful disabled sibling behavior, and/or made an already stressful interaction more stressful. Participants typically appraised their own behavior as stressful in the context of multiple stressful interactions and demands.

Research Question One: Summary of findings. The goal of my first research question was to understand the types of interactions that nondisabled siblings experience as stressful, with a focus on the meaning they make regarding their experience of those interactions. In general, I found that they often engaged in surprisingly detailed and nuanced analyses of stressful interactions. They reflected not only on the behaviors of the participants in these interactions but also on their internal motivations, competencies, and emotions. One striking pattern involved their acknowledgment of feeling disappointed, angry, or hurt by a disabled sibling's behavior even while expressing detailed awareness of the intellectual limitations created by the sibling's disability and sympathy for their goals and desires.

By examining the ways that the adolescents in my sample understood and experienced stressful demands that occurred in the context of family interactions, I discovered several important themes regarding sources of stress for nondisabled siblings: themes that have received little attention in the research literature. For example, to my knowledge, little work has specifically focused on the stress that arises for adolescents as a result of their disabled siblings' communication difficulties. In addition, at the level of the family system, these analyses illustrate the perceptions of nondisabled siblings concerning the contribution of disabled sibling behavior to family conflict. In addition, while previous studies highlight the importance of parental differential treatment for the wellbeing of nondisabled siblings, few if any have investigated the complex responses of nondisabled siblings when their parents intervene in sibling interactions. Another provocative theme to emerge out of these analyses pertains to nondisabled siblings' evaluation of their own behaviors during stressful family interactions, particularly with regard to incidents in which they feel their own behavior has been insensitive or immature.

By exploring what and why stressful demands exist for nondisabled siblings, I have also identified potential pathways through which previously identified family relationship variables (e.g., parent stress) may influence the wellbeing of nondisabled siblings. For instance, parent stress may manifest in a family interaction as a parent's critical response to the coping behavior that their nondisabled child uses with the disabled child. This criticism may then be appraised by the nondisabled child as a stressful demand and subsequently influence their wellbeing. Elevated parent stress may also play a role in nondisabled siblings' appraisals of disabled sibling behaviors as stressful because they lead, or could lead, to parent stress.

In addition to providing a deeper understanding of nondisabled siblings' experiences of stress, I believe that examining the ways that nondisabled siblings appraise the various stressful demands presented by life with a disabled sibling allows for the development of more specific and effective interventions for nondisabled siblings. For example, it is well-established in the field that more severe disabled sibling behavior problems are associated with poorer nondisabled sibling wellbeing, but this knowledge alone does not provide sufficient guidance for developing effective interventions. However, having a more detailed account of the specific reasons that these behavior problems are stressful (e.g., they are interrupting desired activities, triggering concerns about the disabled sibling's wellbeing, or causing destruction of private property) should allow for the development of more effective interventions targeted more specifically at the causes of distress.

Question Two: What Resources and Coping Behaviors are Considered and Used By Nondisabled Siblings During These Stressful Interactions, and Why are They Mobilized?

I asked participants what they were thinking and feeling during stressful family interactions and questioned them about the reasons for these thoughts and feelings. In addition, I asked participants what actually happened, or tends to happen, during stressful family interactions and again questioned them about the reasons for these events. I considered all of the data generated from these questions to be information regarding the participants' coping behaviors, resources, and secondary appraisals (i.e., "a judgement concerning what might and can be done" [Lazarus & Folkman, 1984; p.53]) during a given stressful interaction. The findings below are grouped into separate sections for coping behaviors and resources that participants reported considering or using during these stressful interactions (also see Appendix E, Table 2).

Coping behaviors. For the purpose of this study, coping behaviors are defined as specific cognitive or behavioral efforts that the participants use to reduce or manage a stressful demand (Patterson, 1988). I found that participants considered and/or engaged in the following coping behavior types: (a) aggressively respond to disabled sibling, (b) intervene directly with disabled sibling, (c) complain or tells parent(s) what to do, (d) disengage from parents and/or disabled sibling, and (e) internally reason about disabled sibling's and/or parents' behavior. Each coping behavior type reflects a different degree of internal (i.e., cognitive) vs. external (i.e., behavioral) coping. I have heuristically distributed these types of coping behavior along a continuum from most clearly behavioral to most clearly internal or cognitive. I place aggressive behavioral responses on the most external end of the spectrum and internal reflection about others' behavior on the most internal end. The other forms of coping represent a combination of external and internal responses. In this section, I begin by describing coping behaviors that capture participants' more direct and engaged responses to family members, followed by progressively more disengaged or indirect responses to family members.

Aggressively responds to disabled sibling. A little over half of the participants, six out of the 11 (Ryker, Sarina, David, Olivia, Luke, and Daniel), reported responding to a disabled sibling behavior with aggression. These participants reported engaging in the following aggressive behaviors: yelling, shouting, arguing, and/or physically tackling their disabled sibling. Overall, they reported using this coping behavior when their disabled sibling engaged in a behavior appraised as stressful because it interrupted a desired activity, resulted in damage to private property, or was offensive/embarrassing. At times, the participants reported responding aggressively when they observed their disabled sibling to initiate a behavior that could potentially end poorly (e.g., yelling "no" as the disabled sibling reached for a breakable item). Other times, participants reported responding aggressively after their disabled sibling's behavior had already caused some form of damage (e.g., tackling their disabled sibling after he broke their Legos). It appeared as though the participants engaged in aggressive coping behaviors in an attempt to assert some control over the situation. The participants reported reacting aggressively without much reflection on the situation or any other possible coping behaviors. For this reason, an aggressive behavior seemed more like an instinctive reaction than a purposefully chosen coping behavior.

These participants generally reported using aggression in response to regularly recurring stressful disabled sibling behaviors, suggesting that a pattern of interaction had developed between the participant and their nondisabled sibling over time. During the dinner audio portion of my interview with Olivia, she described her appraisal of this type of coping behavior: "It's actually more like instinct. It's more like '[disabled sibling]! No! Don't touch that!' Or like if she's about to mess with something I want to keep together, or I don't want her to touch, it's like: 'no!'" This quote illustrates how Olivia yells at her disabled sister without much forethought when her sister is about to damage something of hers. Olivia's description of the impulsive way in which she engaged this coping behavior was similar to that of other participants.

Sarina (age 12) was the only participant to report that her use of an aggressive coping behavior was effective at reducing a particular stressful disabled sibling behavior. Sarina's twin disabled sisters (age 15) were diagnosed with ASD at 3.5 years old. She reported that they do not sit down to eat dinner with the rest of the family. Instead, they eat dinner with one of their behavior therapists every day in order to learn skills that will allow them to eventually join the family dinner. During family dinners the twins are therefore free to choose what they want to do. According to Sarina, one of the twins often spends time alone, while the other frequently approaches family members to request desired items or activities. During our discussion of her family's dinner audio, I commented that Sarina was the only family member who had not engaged at all with the disabled sister when she approached the dinner table. Sarina explained that she typically does not engage with this sibling during dinner because her sister's requests "bother" her. Sarina further explained that when her sister does approach her during dinner, Sarina yells at her. She then hypothesized that her disabled sister avoids her during dinner because she does not want Sarina to yell.

> Like I said, she doesn't come up to me or anything like that. And ask me for anything, except iPods, or apple juice, or tickling, or something. And like at the dinner table, she usually comes up to my dad first, and then my mom. And then if both of them don't work, then she comes to me. And I think that she doesn't come up to me because I get really annoyed, by her. So, then I like start yelling, and she doesn't want me to start yelling. So, then she just goes to my parents for it.

In this excerpt, Sarina describes an appraisal of the results of her coping strategy; in this secondary appraisal she considers whether yelling works to curb the stressful demand in the immediate situation and to prevent future occurrences. In this episode, it is possible to see how Sarina's primary appraisal of her sister's annoying behavior in turn contributes to her secondary appraisal. In particular, Sarina's comments that her sister "doesn't come up to me or anything like that" suggest that she may not experience these requests as legitimate forms of social engagement, and she implies that her behavior is justified by its success in extinguishing the annoying behavior.

Intervenes directly but non-aggressively with disabled sibling. Eight participants (Ryker, Phillip, David, Maya, Olivia, Luke, Mateo, and Scarlet) reported intervening directly with their sibling when they witnessed some sort of stressful behavior. The participants described engaging verbally and/or physically (but not aggressively) with their disabled sibling to reduce or terminate a disabled sibling behavior appraised as stressful. Overall, participants reported choosing this coping behavior because it sometimes works, or because it is the coping behavior utilized by everyone in the family to respond to the given stressful disabled sibling behavior. During the dinner audio portion of my interview with Mateo (age 11), we listened to a family interaction in which his disabled brother (age 6) was hitting himself and Mateo asked him to stop. I then asked Mateo questions about this specific interaction.

> [Researcher asks: …why did you say: 'please stop banging?'] Why did I say that? Because, because I wanted him to stop banging his head on his hand. [Researcher asks: Okay. Does he ever listen when you say that?] Sometimes if, if you say 'stop' loud enough, or something like that.

Unlike Sarina's focus on her own aversion to the disabled sibling's behavior, Mateo was motivated by a concern that his brother would hurt himself. However, similar to the reasoning articulated by Sarina, the utility of his behavior appears to be the reason Mateo continues to utilize it in situations like this one.

An excerpt from my interview with David (age 15) illustrates how he sometimes attempts to reason with his disabled sister (age 15) in the same way that his parents do. During the emotion map portion of the interview, David discussed how he tries to verbally reason with his disabled sister when she demands to receive the same amount of food as others at the dinner table (a behavior he appraises as stressful).

> It happens a lot. She gets jealous about food a lot, especially at like the dinner table and stuff, sometimes…. If somebody gets seconds and then we have to tell her: ‘oh wait, you might, you might feel full after this actually.’ And then, but she still wants to eat because somebody else got more food than her. Or also just serving proportions as well. She'll look at other people's plates to see if she has as much as them. And then sometimes she'll complain. And that's also frustrating for me, cuz I'm just like: ‘same amount of food, really. Just eat it. You can still get seconds if you feel like it.’ So that's frustrating for me.

This quote captures how David attempts to verbally reason with his disabled sister when she expresses her jealousy about food at the dinner table. He further reported that although his parents respond similarly to this behavior during dinner, verbal reasoning does not work very well to reduce or terminate recurrence of the stressful behavior. David may be using this coping behavior in imitation of his parents rather than because of its efficacy.

Complains or tells parent(s) what to do. In response to both stressful disabled sibling and parent behaviors, several participants (Maya, Olivia, Luke, and Scarlet) reported complaining to their parents or telling their parents what to do. Overall, these participants reported dissatisfaction with their parent’s behavior and responded by giving their parents a direction or complaining about the situation. For example, Scarlet (age 11) reported that she regularly feels disappointed and annoyed when she and her typically developing sister (age 9) try to talk to their mother after school and their disabled sibling (age 4) interrupts them. Scarlet’s disabled brother was diagnosed with ASD about a year prior to the interview. Scarlet reported that the family was still trying to figure out the best treatments and interventions for her disabled brother. During the emotion map portion of the interview, she described an ongoing family interaction that occurs after school and reported that she tells her mother to ignore her disabled brother, but her mother chooses not to.

> …well we usually get home from school, and we're trying to talk to mom about our days and [disabled sibling] keeps repeating the same thing about like what he—keeps interrupting us.… And [mom] tries to like, we tell her to just ignore him, but she always wants to try to engage him. But like, what he's talking about doesn't really matter, cuz it's just like scripting from shows. But she tries to make him say ‘excuse me,’ or—then it just takes more time. And I wish she would just not pay attention. But I guess she wants him to feel like he's still there. But he's not really talking about anything legitimate that we're supposed to be talking about, so...

Although not captured in this quote, Scarlet described her feelings about her brother’s behavior as “annoyed” and “disappointed.” In this excerpt, Scarlet explains that she experiences these negative emotions because her brother interrupts her and her sister. She states that he is *scripting*, which is a term used in the field of ASD to refer to repeating lines from TV shows or movies. She expresses the view that his interruptions are not legitimate in the context of the interaction, characterizing this behavior as not “what we are supposed to be talking about.” Scarlet provides insight into why her mother continues to engage her disabled brother, illustrating an understanding of her mother’s behavior, but still believes that her mother should ignore the disabled sibling behavior. While Scarlet’s coping behavior does not produce the desired outcome, she reports recurring use of the coping behavior in this context. It is interesting to consider why Scarlet and other participants chose to intervene with their parents even though this did not appear to be successful in the instances they recounted in our conversations. It is possible that this coping behavior does result in desired outcomes in other contexts not captured in this analysis. Alternatively, the participants may have attained sense of control over the situation by giving their parent a direction or complaining. Moreover, the participants did not report being reprimanded or scolded by their parents when they used this coping behavior.

Disengages from parents and/or disabled sibling. Nine of the 11 participants (Ryker, Phillip, Sarina, David, Maya, Olivia, Luke, Mateo, and Eleanor) reported disengaging from their disabled sibling or parent(s) in response to or in order to prevent a stressful interaction. These participants reported ignoring, physically moving away from, or avoiding a particular family member. Overall, these participants appeared to utilize disengagement in situations for which they did not have another coping behavior that would allow them to sustain the interaction without felt psychological stress. As such, it seems possible that these participants felt some degree of helplessness or powerlessness in these interactions, and therefore felt that their only option was to disengage. For example, during the open-ended question part of the interview, David (age 15) described isolating himself in his bedroom to prevent anticipated conflict with his disabled sister (age 15).

> But then, I've kind of, I've kind of been experiencing less frustration because I've been just putting myself in my room, cuz I know the one way to get out of all this frustration is just not to experience it, because—but I'll, through my door, I'll always hear [disabled sibling] running around, I'll hear her screaming. And I used to be pretty involved with all that…. Cuz I'd be out in the living room and the dining room cuz that's where—or I'd be doing homework out in the kitchen or something. And I just—now that I have my own room, I've just kind of been in there. And I've been less involved with [disabled sibling] too, just because it just caused me so much frustration in the past. I'm just trying to stop because I don't want to give myself unnecessary stress.

In this excerpt, David discussed how he has gotten into the practice of removing himself from communal family spaces because this allows him to engage with his disabled sister less, and, as a result, feel less frustration. David's reasoning regarding why he disengages in this way draws direct connections between engaging with his disabled sister and experiencing frustration, as well as remaining in his room and experiencing less frustration. He therefore makes the conscious decision to stay in his room, and consequently disengage from his whole family, in order to preserve his wellbeing. David's disengagement from the whole family suggests that the disabled sibling behaviors that he appraises as stressful are pervasive throughout daily family life. David's reasoning regarding his disengagement also implies a belief that the family does not need him, or maybe does not even want him, to engage with his disabled sister. In addition, it implies that he does not possess any effective coping behaviors that would allow him to manage or reduce his frustration and also remain engaged with his family.

In the following excerpt from the same conversation with David, he expresses these beliefs even more explicitly.

> But sometimes I'll—but every, every hour I'll come out of my room and I'll just like, I'll just mess around with everybody. And then I'll kind of just go back in. But whenever I come out, I'll just see [disabled sibling] doing something that it's just like I'm so glad I have my room. I just think to myself: 'I'm just going to go back in my room.'… The thing is when I get involved with disabled sibling, I tend to make the situation worse sometimes. So, it makes it easier for everybody sometimes. Yeah. Easier for me. Easier for my parents. Yeah. [Researcher asks: Okay. Why do you think that is?] [Disabled sibling] is only really perceptive to more gentleness. And I'm a little like rough, I think. For me sometimes, just like no B.S. I just want to like deal with the situation, but that's just not how she rolls. And sometimes I'm just caught up in myself, so I just, I don't

> change the mindset. And then I just end up escalating her because she doesn't really react well to that kind of like—I don't know. She can pick up on moods and stuff. And she gets all frustrated. Yeah. So, it's just best for me just not even to talk to her sometimes, because—just the way I am. Sometimes the way I talk. It just doesn't resonate with her, so she just—it escalates the situation.

It becomes clear with the addition of this second excerpt that David does not believe he possesses the skills necessary to engage with his sister without feeling psychological stress. He blames his own behaviors, and even who he is as a person, for triggering his sister's behavior. In addition, he reports that his engagement with his disabled sibling tends to "make the situation worse for everyone," including his parents. As such, his only option for reducing felt stress for himself and his parents is to disengage from the situation.

A majority of the participants in my study reported utilizing disengagement in response to a parent or disabled sibling behavior that they appraised as stressful. In fact, this was the most commonly utilized coping behavior across the sample. My interpretation of these data is that many nondisabled siblings experience family interactions in which they do not appraise themselves as having the skills necessary to resolve or sustain the interaction without feeling psychological stress. As such, they either respond to the behavior by disengaging or attempt to avoid the interaction altogether.

Internally reasons about disabled sibling's and/or parent's behavior. Six participants (Phillip, Sarina, Maya, Daniel, Scarlet, and Eleanor) reported family interactions during which they used cognitive rather than behavioral coping strategies to respond to a stressful demand. These participants appeared to accept the different facets of the situation (e.g., their parents' behaviors, their sibling's behaviors, their sibling's needs) as unchangeable or possibly not worth the effort to change. As such, their response was to cope internally with their feelings in an attempt to re-appraise the initial demand as not stressful. This coping behavior was frequently used in response to parent engagement in differential treatment. Ultimately, these participants attempted to downplay their own needs while highlighting those of their disabled in order to justify their parents' behavior. However, as I noted earlier, participants who reported this appraisal regarding differential treatment continued to regret the lack of attention that they received from their parents.

An excerpt from my interview with Phillip (age 16) provides an illustration of how the participants used internal reasoning in response to parental differential treatment. During the open-ended question portion of the interview, I asked Phillip about whether his parents treat him and his disabled sibling (age 18) differently. He responded that sometimes they do, and sometimes this differential treatment can be "annoying."

> I mean, sometimes it's annoying, because if I—whether it's in the school or during sports, if I [set a personal record] in a race or I do really good on a test, they'll be like 'oh, nice, okay.' Carrying on. They won't really pay attention to it. Which I get, but at the same time is annoying to me. [Researcher asks: What do you mean by 'I get?' What is there to get?] Cuz they obviously have a lot on their plate, and they can't devote all of their attention towards me at one time. And so, I understand they can't worry, not worry, but they can't congratulate me on every single thing that I do. But with my sister, they kind of have to congratulate her because it builds her confidence and it makes her work harder for whatever she's trying to do.

In this quote, Phillip asserts that he understands why his parents typically don't pay as much attention to his accomplishments as they do to those of his disabled sister. To cope with this potentially stressful demand, he reasons empathically about both his sister's needs, which are different from his own, and his parents' limitations. Despite his ability to reason about and understand his parent's behavior, however, he still finds their behavior "annoying" and would like more recognition of his accomplishments.

Another participant, Maya (age 15), discussed using internal reasoning to manage her frustration concerning her sister's (age 15) communication deficits. Maya's sister was diagnosed with global developmental delay at four months old and struggles to hold back-and-forth conversations with family members. Maya explained that sometimes she can reduce her feelings of stress during a conversation with her sister by reminding herself about her sister's ability level.

> …she can really frustrate me when I try and talk to her, and she doesn't respond, she'll completely ignore me. But also, I've gotten used to the idea of like, well, she doesn't think the same way, so I shouldn't take anything personally.… I've gotten used to being able to live with the fact that she's not always gonna—she's not going to understand me. And like, she's not always going to listen to what I have to say.

Maya appears to perceive this situation with her disabled sister as stagnant and one that is beyond her control to change or improve. By recognizing her disabled sister's cognitive deficits, Maya is sometimes able to re-appraise her sister's behavior that she initially perceived as stressful. Maya's phrasing in this quote (e.g., "I've gotten used to being able to live with the fact…") suggests that she has engaged in a process of coming to terms with the limitations of her relationship with her disabled sister. I wonder how much of Maya's reasoning about this stressful demand reflects her own observations and cognitions about her sister's disability, and how much reflects how her parents or other adults have talked to her about her sister's disability.

Resources. According to Patterson (1988), a resource can be a characteristic, trait, or competency, and can include intelligence, acquired knowledge and skills, personality traits, physical and emotional health, a sense of mastery, or self-esteem. In addition to these individual characteristics, another frequently cited resource is social support from friends, family, or others (Gorjy et al., 2017; Jones et al., 2019; Moyson & Roeyers, 2012; Opperman & Alant, 2003; Taylor et al., 2016). While use of social support can be viewed as either a coping strategy or as a resource, I have included it in the discussion of resources for reasons that I will explain presently. I also made the decision to focus exclusively on those resources that participants explicitly labeled as aiding them in relation to a stressful demand. While some of the participants mentioned sources of strength or resilience that appeared to me to be a resource (e.g., emotional support from a sympathetic adult outside the family), I sought to remain consistent with the phenomenological frame of my research by including only those that were specifically appraised as helpful by the participants.

Across the data set, participants identified the following resources: (a) parents act to provide support to nondisabled siblings, (b) participant has knowledge of parent positive intent, (c) participant has ability to take care of him/herself, and (d) participant has access to own physical space.

Parents act to provide support to nondisabled siblings. Five out of the 11 participants (Ryker, Phillip, Daniel, Scarlet, and Eleanor) reported that their parents acted to terminate a stressful interaction between them and their disabled sibling. Across these five participants, this type of action on the part of the parent was appraised as welcome and effective. They did not report relying on or expecting their parents to intervene, but they also did not report feeling surprised or otherwise bothered by their parents' behavior. In addition, these participants typically reported parent intervention in the context of ongoing conflicts with their disabled sibling and so did not seem to view the possibility of proactively enlisting parent support as a form of coping.

For example, during the open-ended question portion of the interview, Daniel (age 13) described an interaction during which his mother intervened in an argument between Daniel and his disabled brother (age 16). Daniel's brother has a history of several diagnoses, the most recent of which was reportedly ASD. Daniel and his brother share a room, and Daniel reported that his brother often takes a long time to get ready for bed, which frustrates Daniel. In this particular interaction, Daniel's brother was getting ready for a weekend trip and was taking a long time to prepare his clothes and pack his bag. Daniel confronted his brother about this behavior, and they had an argument. Their mother eventually intervened by telling Daniel to sleep in his parents' bed while his brother finished packing. Daniel added that he was not thrilled with the solution but was glad that he could go to sleep.

Participant has knowledge of parent positive intent. Several participants (Phillip, Sarina, Scarlet, and Eleanor) reported an understanding of why their parents engaged in parental differential treatment. They further indicated that they accessed this knowledge while reasoning about their parent's behavior. By engaging this knowledge, these participants were sometimes able to re-appraise their parent's behavior as not stressful or less stressful. For example, during the open-ended question portion of the interview, Sarina (age 12) discussed how she sometimes feels that her parents give her twin disabled sisters (ages 15) more care than they give her. Her twin sisters both have diagnoses of ASD. While Sarina reports that she sometimes feels this way, she also knows why her parents spend more time caring for her sisters.

> But sometimes it just gets to me, and I'm just like, like feeling, I don't know, like sad. Because I feel like [parents] don't give me enough care. But I know they do. And I know that it's, that they give the twins more care because they're more high maintenance.

Sarina can use this knowledge (a resource) to internally reason about her parents' behavior (a coping behavior) to reduce frustration or sadness.

Participant has ability to care for him/herself. Three participants (Phillip, Sarina, and Eleanor) reported that they knew they were able to take care of themselves, unlike their disabled siblings. This resource was often utilized in conjunction with the resource of having knowledge of parent intent (as discussed above). For example, during the open-ended question portion of my interview with Eleanor (age 16), she discussed having to learn how to do a lot of things independently as a result of having a disabled brother (age 18). Her brother was diagnosed with ASD at three-and-a-half years old, and subsequently diagnosed with several chronic health conditions. Eleanor reported that her parents treated her differently from her brother, but expressed the view that this was generally appropriate because her brother has ASD. In addition, she noted that she was able to take care of herself.

> It's like—it's cuz I don't have autism. I'm the normal one. And like, I'm the less demanding one. And I think I've had to learn to do more things on my own. Because of having [disabled sibling] in my life…. And like I have to cook for myself sometimes. That kind of thing. And just, yeah. [Disabled sibling's] the autistic kid, and I'm the normal kid. Basically. And I think maybe, sometimes I feel like I have a little more pressure because of that.

While Eleanor sometimes experiences the pressure to achieve as a stressful demand, she generally does not experience psychological stress when her parents provide more care to her disabled brother because she reminds herself that she can take care of herself when she needs to.

Participant has access to own space. Three participants (Ryker, David, and Luke) reported accessing their own space within the family home to either prevent stressful interactions or escape stressful interactions. Participants utilized this resource in conjunction with the coping behavior of disengagement. For example, Luke (age 17) reported several times throughout our interview that he went to his room to avoid stressful interactions with his disabled brother (age 16) and/or parents. For instance, during the emotion map portion of the interview, Luke reported a stressful interaction that occurred during the week leading up to the interview. In this interaction, his brother, diagnosed with Down syndrome and ASD, reportedly tried to damage Luke's bracelet. Luke yelled at his brother and then went to his room: "well, he started to pull it, and before it ripped, I screamed. I was like: "[disabled sibling]!" And then he let go, and then I went to my room." This incident illustrates how the resource of private space is a key factor in determining participants' choices of coping behaviors.

Research question two: summary of findings. In this section, I identified themes regarding participants' capabilities by types of coping behaviors and resources. I then explored the secondary appraisals made by the participants when they considered and used these coping behaviors and resources. In doing this, I highlighted why the nondisabled siblings in my study chose certain coping behaviors and resources during stressful interactions, as well as the efficacy of their use. This analysis presents a novel contribution to the literature on nondisabled siblings. Previous studies of coping responses among nondisabled siblings have typically focused on coping behaviors and resources and their correlations with nondisabled sibling wellbeing. My analysis integrates previously identified coping behaviors (e.g., disengagement) and resources (e.g., social support) with nondisabled siblings' cognitions about their consideration and utilization of these coping behaviors and resources. As a result, these data capture insight into why nondisabled siblings use and access certain coping behaviors and resources in their attempts to manage and respond to a stressful demand.

The most commonly mentioned active behavioral coping behavior was that of aggression in response to a stressful disabled sibling behavior. The participants reported limited if any cognitive appraisal of the situation before acting aggressively toward their disabled sibling, suggesting that aggression was more a reaction than a consciously reasoned coping behavior. With the exception of Sarina, participants generally acknowledged that this coping behavior was not effective in reducing the occurrence of stressful disabled sibling behaviors. In contrast to coping via aggression, other forms of coping appeared to be undertaken with intentionality as a result of conscious reflection, including intervening by providing information, attention, or comfort to the disabled sibling. The participants appraised this coping behavior as appropriate because it was sometimes successful at reducing or terminating the stressful demand, or because other family members used the coping behavior. This is an important insight because it suggests that nondisabled siblings learn coping behaviors from their parents or other family members.

Another form of coping involved taking direct action but focusing on influencing the parent directly rather than the disabled sibling. While most participants reported that this form of coping was not particularly successful, the fact that they continued using it suggests that it may have reduced their felt stress at least temporarily, or they felt that they had something to gain by using the behavior, such as believing that their parents would eventually see the situation their way. Yet another coping behavior, disengagement, reflected a shift away from direct interactions with family members. Participants chose to disengage from their disabled siblings and/or parents to prevent the occurrence of stressful interactions or in response to stressful interactions. Disengagement was generally appraised by participants as the only tool available to them in a given interaction to manage their feelings of psychological stress. Finally, participants also reported coping by reasoning internally in response to certain stressful disabled sibling and parent behaviors. When participants used internal reasoning, their appraisals typically reflected acceptance of the situation and acknowledgement that it could not be changed or controlled. The purpose of participants' internal reasoning appeared to be to re-appraise the initial demand as not stressful and, like disengagement, sometimes resulted in a distancing from the demands of the disabled sibling.

Participants reported using many of these coping behaviors in the context of recurring stressful interactions, suggesting that the behaviors in these interactions may often be relatively entrenched. If this is true, participants may have often engaged in coping behaviors based on the behavior pattern that has been established within the family for that situation rather than actively reasoning about each particular situation. However, in some situations, participants were able to discuss the reasoning that led to their chosen coping behaviors. In the process of deciding how to respond, participants often cognitively coordinated considerations of their own role in the situation with their perceptions of other family members' roles, reasoning, and intentions. In these considerations, participants also highlighted several resources that they actively engaged to manage their emotions in an interaction. These resources included the knowledge that their parents' actions were intentional and usually benign, their ability to take care of themselves, and the availability of space to be alone. In addition, participants reported that their parents sometimes provided them with support during a stressful interaction with their disabled sibling. While the participants did not elicit this support or report considering the availability of the support in their appraisal of the situation, they appeared to welcome and appreciate the support when it was given.

Question Three: What Themes or Patterns Arise in Terms of the Experience of Stressful Nondisabled Sibling-Related Family Interactions for These Participants?

This section explores the participants' overall cognitive appraisal processes in regard to stressful family interactions. I conceptualize the cognitive appraisal process as a participant's coordination of their primary and secondary appraisals of a stressful family interaction (Lazarus & Folkman; 1984). Participants engaged in this evaluative process to determine why and to what extent an interaction was stressful. In the interviews, this process was communicated via participants' explanation of their emotional experience of stressful family interactions. In this section, I present several themes that characterize the varying ways in which participants coordinated their primary and secondary appraisals of a stressful interaction. I have labeled the themes (a) selecting ineffective coping behaviors, (b) experiencing pile-up of stressful demands, (c) using preventative coping behaviors, and (d) experiencing compounding stressful demands (see Appendix E for examples).

Cognitive appraisal process: selecting ineffective coping behaviors. The most common theme that emerged in participants' cognitive appraisal processes was the use of a coping behavior in response to a stressful demand that was ineffective at preventing felt psychological stress. All 11 participants reported cognitive appraisals characterized by ineffective coping behaviors. I further identify themes that explain why a reported coping behavior was ineffective at managing the perceived stressful demand. One theme captures interactions in which the participant did not know or understand why a family member engaged in the behavior that caused the participant stress. In other words, the participant provided a *shallow primary appraisal* of the demand that he/she had appraised as stressful. It may have been difficult for participants to manage a stressful demand effectively without a functional understanding of it. As such, they experienced psychological stress in these interactions.

More frequently, however, the participants provided reasons for why a family member engaged in a behavior they appraised as a stressful demand. Nevertheless, despite providing a rationale for the behavior, the participants still engaged coping behaviors that were ineffective and ultimately experienced psychological stress. I propose two different themes to explain why participants used ineffective coping behaviors in these interactions. The first theme, *disconnected appraisals*, captures interactions in which the participants' primary and secondary appraisals were not logically connected. In other words, a participant used a coping behavior that was inappropriate relative to their appraisal of the stressful demand and was therefore ineffective. The second theme, *inconsistently effective coping behaviors*, captures interactions in which the participants' primary and secondary appraisals were logically linked but the participant appraised the coping behavior as only sometimes effective. In other words, when the participants used the coping behavior in a specific interaction it was sometimes effective but other times, in the same type of interaction, it was not effective.

Shallow primary appraisal. Seven participants (Ryker, Sarina, David, Maya, Olivia, Luke, and Scarlet) provided accounts of stressful family interactions that were characterized by shallow appraisals of the stressful demand. I define shallow appraisals as those in which the participant reported not knowing why the family member engaged in the stressful behavior. Interactions characterized by shallow primary appraisals typically resulted in the participant using disengagement or aggression to manage the behavior. For example, Luke (age 17) reported that his disabled brother (age 16) often tries to damage Luke's private property, and he does not know why. Luke's brother was diagnosed with Down syndrome prenatally. He experienced a developmental regression when he was 10 years old and was subsequently diagnosed with ASD. Luke reported that he and his disabled brother had a reciprocal relationship before the regression, but since the regression Luke has struggled to interact with and maintain a relationship with his brother. Luke described the following stressful family interaction during the emotion map portion of the interview. In the interaction, he witnessed his disabled brother grabbing something from their mother, and he tried to intervene. Upon intervening, Luke became annoyed when his disabled brother grabbed his bracelet and damaged it.

> I think it was two nights ago, so that would be Monday night. My mom was trying to fan my brother's food, because it was really hot. And then he grabbed the fan, and she was like: 'let go, let go, let go.' So, I came over and I took it out of his hand, and then he grabbed my bracelet and stretched it really far, and it didn't break. But now it's kind of loose, and so that annoyed me because, now my bracelet's loose. And I like my bracelet, and it was expensive… [Researcher asks: Why do you think disabled sibling tried to grab the fan and break it?] He just, he grabs hold of things, and likes to destroy things. So, if you got too close and you have your—like a Hoodie—he'll try to pull the string all the way. In front of him. I don't know. He just tries to break things, or tries to like annoy you, or take things away from you. For some reason. I don't know why. So, Yeah. [Researcher asks: Why did you try to help your mom? Why'd you intervene, I guess?] Because he can be pretty strong. And he just like does this a lot. So, it's like—and she—it seemed like she wasn't in control of the situation. So, I kind of just took it out of his hand. Yeah. [Researcher asks: And how did it all end?] Well, he started to pull it, and before it ripped,

> I screamed. I was like: '[disabled sibling]!' And then he let go, and then I went to my room.

This quote from my interview with Luke illustrates the relationship between a shallow primary appraisal of a stressful demand and use of coping behaviors that may have diminished but ultimately did not prevent the participants' experience of psychological stress. Luke became annoyed when his brother grabbed his private property and tried to damage it. Luke described this stressful disabled sibling behavior as common, and he reported that he does not know why his brother engages in the behavior, although his description implies that the behavior might have malicious intent (e.g., "he tries to annoy you"). In response, Luke is aggressive toward his brother and then disengages from the interaction. Luke does not appear to have more prosocial ways of managing these kinds of interactions with his disabled brother, nor do his chosen coping behaviors prevent recurrence of the behavior. It seems that when participants did not understand the behavior causing them to feel psychological stress, they were then not able to appraise a prosocial coping behavior to use in response.

Logically disconnected appraisals. Each of the 11 participants discussed cognitive appraisals characterized by logically disconnected primary and secondary appraisals. In other words, the participants' reported using coping responses in these interactions that were not linked logically to the reasons they provided for why their family member engaged in the stressful behavior. The participants' coping behaviors therefore appeared nonfunctional and they experienced felt psychological stress. To illustrate this pattern, I return to an incident described earlier, in which Mateo (age 11) reported an interaction from his family's dinner audio in which his disabled brother began hitting himself on the head and Mateo asked him to stop. Mateo's disabled brother (age 6) has been diagnosed with a genetic disorder (Dup15Q) as well as ASD. In the excerpt below, I had just paused the audio and asked Mateo what was going on.

> [Disabled sibling] was hitting himself on the head. [Researcher asks: So, do you help out when he's doing things like that to try to stop him?] Yeah. Cuz it's not good for him. [Researcher asks: Are your parents okay with you helping out in those situations?] Yeah…. [Researcher asks: Why did you say: 'please stop banging?'] 'Your head?' Why did I say that? [Researcher confirms the question] Because I wanted him to stop banging his head on his hand. [Researcher asks: Does he ever listen when you say that?] Sometimes if, if you say 'stop' loud enough, or something like that. [Researcher asks: Why do you think he does that?] I don't know. I think he's just trying to get attention or something. [Researcher asks: How do you feel when he does that?] I feel sad because I'm guessing it probably hurts.

In this quote, Mateo reported that he felt sad when his brother hit himself because it probably hurt, and he reported that he intervened directly because this sometimes works to stop the behavior. Additionally, Mateo reported that his parents do not mind when he intervenes with his disabled brother. Mateo's actions in this interaction initially appear logical: he used a coping behavior that he appraised as sometimes effective at managing his brother's self-harm behavior in the given context. However, Mateo's primary appraisal of the stressful demand is that his brother hits himself to get attention. Considering this appraisal of the stressful demand, the chosen coping behavior is inherently illogical because it provides Mateo's disabled brother with attention. It is also interesting to consider that Mateo's parents were present during this interaction and did not respond directly to the disabled sibling's behavior. In the context of this interaction, the consequence of Mateo's mismatch in appraisals is that he experiences psychological stress.

This cognitive appraisal process may reflect a general lack of coping behaviors in the participants' individual repertoires. Professionals take considerable time and effort to develop and hone their skills for working with children with disabilities. These skills are not always intuitive, and often must be explicitly learned and practiced. It is therefore not surprising that nondisabled siblings would lack skills to cope effectively and functionally with their disabled siblings' behaviors. Participants may then resort to coping behaviors that, while not logical, reflect their only available solution for managing the behavior.

Inconsistently effective coping behaviors. Finally, five participants (Phillip, Sarina, Maya, Olivia, and Eleanor) reported cognitive appraisals in which they chose coping behaviors that they appraised as inconsistently effective for terminating the stressful demand. To illustrate this phenomenon, I return to an excerpt from my interview with Sarina (age 12), whose disabled twin sisters (ages 15) were diagnosed with ASD when they were three-and-a-half years old. During the open-ended questions portion of the interview, she revealed that she sometimes feels sad when she perceives her parents as providing more care to her sisters than to her. She further reported that she understands why her parents provide more care to her sisters, but sometimes it still "gets to" her.

> …when I was little, we would go to the mall with the twins, and whatever the twins wanted, [our parents] would get them. But if I wanted something, they wouldn't get me it, because they would be like: 'oh, we'll get you this next time.' Stuff like that. But they would get the twins stuff. And I would get really sad about it. So yeah, that's the only time I feel like that. [Researcher asks: But you said you would kind of understand why? Why do you think?] Because they're more high maintenance. And I already know how to take care of myself. So, I think that my parents already know that I know how to take care of myself. So, they don't need to worry about me as much. But they need to worry about the twins because they don't know how to take care of themselves, or anything like that. But sometimes it just gets to me, and I'm just like, like feeling, I don't know, like sad. Because I feel like they don't give me enough care. But I know they do. And I know that it's, that they give the twins more care because they're more high maintenance.

In this excerpt, Sarina cognitively reasons about her own capabilities, her parents' perspectives, and her twin sisters' needs and capabilities. In doing so, she attempts to re-appraise an initial stressful demand as not stressful. According to Sarina, this internal reasoning process sometimes works to reduce the psychological stress she feels when she perceives her parents as providing more care to her sisters than to her. However, sometimes this re-appraisal process does not completely remove her wishful desire for a larger share of her parents' care and attention.

Another context in which I identified this cognitive appraisal process was when participants tried to intervene directly with their disabled sibling to manage a stressful behavior, but the stressful behavior persisted. For example, during the emotion map portion of my interview with Phillip (age 16), he reported attempting to reason with his disabled sister (age 18) regarding access to the family television. According to Phillip, his disabled sister, who is diagnosed with ASD, had been watching television for a while and he wanted a turn as well.

> I was trying to chill out and play video games. I think it was last weekend. And my sister didn't want to get off the TV. And so, I was kind of conflicted because I wanted to play my video games… It's more conflicted and like, I was trying to reason with her and try to say like 'you've had it for this amount of time, and you should let other people use it.' And she was like 'no, I wanna keep using it.'… We're both kind of annoyed in the

> moment… Eventually I just told her ‘Ok. You get 10 more minutes and then I'm coming down, and I'm going to use it.’ And she was like ‘Ok.’ And 10 minutes passed, and she didn't want to get off, and then my mom distracted her by saying ‘let's go,’ I think, ‘take a shower’ or something. And she was like ‘oh, ok,’ and then she left, and I got my time. It all worked out… And so, it was, [mother] was probably feeling determined to solve the problem for both of us. And I was trying to solve the problem as well. And trying to reason with [disabled sibling]. But it wasn't really working in my favor at the time. But that's how it, that's how it goes. [Researcher asks: And why do you think she didn't want to turn it over to you, the TV and the video game?] I don't know. It's probably because—well actually I know it's not because she's not done. Because what she likes to do is, she'll watch it on replay. She's never really done. She also doesn't, I don't think she likes people using it when she's not using it, you know? Like, she wants to be there if someone else is using it, whether it's at like a family gathering or someone else's house, she wants to be there when something happens. And so, I feel like that's what happens sometimes…. And also, I think she just, she just loves her shows, you know? It really comes down to that… [Researcher asks; And does your mom usually try to help out when there's conflict like that happening?] Yeah, but usually I can deal with it by myself. I have gotten to that point where I can take control of the situation and—when I was younger, it was a lot more, but now I, I'm pretty good at handling situations like that… Sometimes it works out, sometimes it doesn't.

In this excerpt, Phillip discusses how he initially appraised the stressful demand (i.e., his sister refusing to give up the television) as a challenge; he has learned how to solve conflicts with his sister and prefers to do this independently from their mother. The quote illustrates how Phillip used several behavioral techniques in an attempt to reason with his disabled sister and was “kind of annoyed” when they did not work. However, he then states that this is just “how it goes,” meaning that sometimes he is able to manage his sister’s behavior and sometimes he is not. At the end of the interaction, Phillip’s mother steps in to support him in managing the stressful behavior. Phillip’s mother’s behavior appears to be a resource for Phillip that he does not feel he always needs, but that he appreciates.

Participants who reported stressful family interactions characterized by an inconsistently effective coping behavior generally described their emotional experiences of the interactions as less severe than their emotional experiences of other types of family interactions. I observed this tendency in the participants’ language, such as “kind of annoyed” (Phillip), “sometimes sad” (Sarina), “a little more pressure” (Eleanor), etc. It may be that when participants appraise a stressful interaction as one for which they possess tools to manage the stressful demand, even if the tools are inconsistently effective, their emotional experience of the interaction is less severe than it is when they appraise a stressful interaction as one for which they do not possess tools to manage the stressful demand.

Cognitive appraisal process: experiencing a pile-up of stressful demands. Phillip, Maya, and Olivia reported interactions for which their cognitive appraisals were characterized by a pile-up of stressful demands. While only three participants reported these cognitive appraisals, pile-up of stress reflects a process identified in previous work on stress and coping (e.g., Patterson, 1988). Within the participants’ cognitive appraisals of these interactions, they reported that certain disabled sibling behaviors did not typically bother them, but if they were tired or already feeling “stressed out,” they experienced psychological stress as a result of the behavior. More specifically they reported appraising the stressful demand as “the last thing I want to hear/need." For example, Phillip (age 16) discussed his variable emotional experience of a repeated family interaction in which his sister scripts (i.e., repeats lines from a movie or TV show) during dinner. Phillip and I listened to an example of this family interaction that was captured on his family's recorded dinner audio. In our subsequent discussion of the interaction, he explained why he sometimes finds it bothersome and other times does not.

> [Referring to his disabled sibling scripting] I mean I get why she does it. It's because if there's something she likes, whether it's a movie or a TV show, and there's one specific scene, like locking someone in a bathroom, it's like if she could put herself in their shoes, she would enjoy doing that. You know? Like she enjoys watching it. But she also like wants to be in it. You know what I mean? Like when we were all little, we all were like: 'oh, I want to be in this movie, cuz it would be so fun,' you know? That's what she's thinking, I think.... Sometimes, sometimes it bothers me. If like, if I'm stressed out, that's really the last thing I want to hear because it's just like, it's nonsense. But if I'm neutral, I'm just like: 'okay, yeah.' I'll hear it, I'll listen to it. And then that's it. And then she'll stop talking about it because we'll just move on.

In this excerpt from my interview with Phillip, he explains that he sometimes appraises his sister's scripting as bothersome when he is "stressed out." When he is calmer or less tired, he can reason about his disabled sister's behavior internally and listen to it. On the dinner audio, Phillip was feeling "stressed out" and was bothered by his sister's scripting. These participants generally reported that when they were experiencing heightened stressful demands, usually at school, they struggled to cope with stressful disabled sibling behaviors effectively. It appears as though participants' capabilities are compromised in some way when they are stressed, and, as a result, they are not able to effectively manage their emotional experience of a stressful disabled sibling behavior.

Cognitive appraisal process: using preventative coping behaviors. Seven out of the 11 participants in this study (Phillip, Sarina, David, Maya, Olivia, Luke, and Scarlet) reported engaging in specific behaviors for the purpose of avoiding potentially stressful demands during family interactions (see Appendix E, Table 4 for examples). Several cognitive appraisals involving preventative coping responses emerged in the family dinner audios. Participants' cognitive appraisals of these interactions involved logically linked primary and secondary appraisals. For example, several participants reported using disengagement as a preventative coping behavior. Phillip (age 16) provided an example of this type of cognitive appraisal process in which he utilized disengagement effectively to avoid an "awkward" situation with his disabled sister. He reported that his sister, who was diagnosed with ASD, often repeats private information in public spaces. Phillip finds this situation "awkward" so he purposefully does not discuss much about his personal life at the dinner table in front of his sister. Instead, he talks about things in private with his mother.

> If I say something that's, that's appealing to my sister, she'll remember it and she'll say it at the wrong time. Like if something really bad happens like 'oh this and this happened,' then let's say in a different like on a different day, and I'm with my sister and maybe some other people, she'll randomly blurt this out. This random event that happened, that was bad.

Phillip's account of this interaction implies an acceptance that this stressful disabled sibling behavior is part of the reality of his life with his disabled sibling. As such, he has found a way to cope with this stressful behavior that works for him. Other participants reported preventatively coping with stressful disabled sibling or parent behaviors by yelling at their disabled sibling, having playdates at friends' homes as opposed to their own home, telling parents what to do, or intervening directly with their disabled sibling.

Cognitive appraisal process: experiencing compounding stressful demands. Several participants (Sarina, David, Maya, and Luke) reported cognitive appraisals of family interactions that were characterized by compounding stressful demands. These cognitive appraisals captured the participants' reports of family interactions in which they appraised and responded to two separate but linked stressful demands. The participants reported that the two stressful demands were linked by their own coping response to the initial stressful demand. More specifically, they reported that their coping response to an initial stressful disabled sibling behavior triggered a parent or disabled sibling behavior that they then also appraised as stressful. Most commonly, the participants reported the second demand to be a parent behavior that was appraised as stressful because the parent was being critical of their response to their disabled sibling (i.e., the initial stressful demand). In other words, I observed this cognitive appraisal process most often in participants' reports of interactions in which they were reprimanded by their parents for how they managed a stressful situation with their disabled sibling. All four of the participants reported these family interactions to be recurring, and two (David and Luke) reported strategic preventative disengagement from their families in order to prevent the occurrence of these interactions (see Appendix E, Table 5 for examples).

Two excerpts from my interview with David (age 15) illustrate a cognitive appraisal process characterized by compounding stressful demands. During the dinner audio portion of my interview with David, he discussed an ongoing family interaction in which he appraises his disabled sister's (age 15) communication skills as stressful. When he attempts to intervene directly with his sister, which David admits can sometimes be aggressive, her behavior "escalates" and his parents become angry with him for upsetting her. David appraises his parent's critique of his coping behavior as a second stressful demand. This first quote captures David's appraisal of the initial stressful demand and his coping response.

> [Disabled sibling] doesn't seem to have the ability to answer [questions] or she just—she knows the answer; she just doesn't really say it. She just, she would rather be asking questions. Conversations are hard with her because it's very one-sided. It's, if I'm going to talk to you, you're going to be listening and answering all of my questions about anything. And it's very direct. And when you try to have a conver—she'll get frustrated sometimes if you try to like, if you're the one trying to ask her questions and driving the conversation. So, it's very controlling in a sense. So that's the frustrating part about it for me. And also, the fact that she just doesn't want to ask me the question directly sometimes. [Researcher asks if any family members ever try to get his disabled sister to answer their questions instead of always answering her questions] I do. Because it frustrates me. Sometimes I'm pretty antagonistic. I'm just like 'come on, answer the question.' You know? And sometimes I'll have the wrong tone and then things will escalate… I don't care about getting her angry cuz I'm just like 'she's my sister.' I just see it the same as messing around with my other sister sometimes. But she just—sometimes she can't take it that same way, so it makes it hard. So, I've kind of tried to ease down on that cuz I know, I understand my parents are the ones who are mostly dealing with her… I mean, she's always the one asking questions. So, I'll ask a few questions too. And it's like 'come on. I know you know the answer.' It's kind of like matching her. Because I want her to like, tell me a few things too. I don't want to always be talk—cuz it's annoying for me sometimes. For her to always be asking questions. So that's like my way

> of just being like: ‘yeah, come on.’ Kind of pushing the conversation in a different angle because it gets kind of boring and frustrating. [Researcher asks why he pushes the conversation, instead of just dropping it] It's important because sometimes she just doesn't - she'll just stall, she'll be like: ‘uuuh.’ And then she'll get all frustrated. And that's part of her own, like part of her disability where she has trouble answering. But I feel like a lot of the times she can answer. A lot of times she just—I think she just needs a little push. That's just how I feel. And it's, it's not like I'm really—I just want to talk with her. Like have a more NORMAL conversation. Where, instead of where she's just always asking questions. So, that's why. But sometimes I just, I just do walk away. Sometimes I'm like: ‘you know what? I'm really not in the mood to wait for [disabled sibling] to answer,’ because sometimes she will take a minute to answer a simple question. And then she'll start asking questions right away, and I'm just like: ‘oh my gosh.’ So, I've stopped doing that. And also, because my parents, they like—sometimes it's hard for them because when she gets frustrated then, yeah.… Or also I'll just give up too because she'll tell the answer to my mom. She won't tell me. Even when, even though I'm the one asking the question. And then when she tries to tell me—like she'll tell my mom right away, and then when she tries to tell me she just, she'll just stumble and then I'll be like ‘uh-huh,’ and then I'll have like an off tone and then she'll get frustrated.

In this excerpt from my interview with David, he provides a detailed and nuanced account of his experience of his sister’s communication deficits and why he finds them frustrating. He considers multiple complicated facets of the situation in his cognitive appraisal of the interaction. In his primary appraisal of the stressful disabled sibling behavior, he provides multiple reasons for why his sister struggles to communicate with him, ultimately concluding that she is capable of engaging with him more collaboratively. His primary appraisal of the demand also reflects his reasons for why he wants to be able to communicate more collaboratively with his sister (e.g., he wants to be able to have a more normal conversation with his sister). David’s secondary appraisal of this interaction again reflects consideration of multiple facets of the situation. He discusses why he feels that directly intervening with his disabled sister in order to push her to respond to his questions is important. He also equates this interaction to messing around with his typically developing sister reports and reports that he does not mind that his disabled sister sometimes gets angry when he pushes her. David additionally recognizes how he may be a part of the resulting conflict when his sister “escalates” (e.g., “sometimes I'm pretty antagonistic”), and considers his parents’ experience of the interaction (e.g., “sometimes it's hard for them because when she gets frustrated then, yeah”). David’s account also implies that he does not know how else to interact with his sister. His coordination of these two appraisals is difficult to follow. While he understands that his sister has communication deficits that could make answering questions difficult, he believes that she is capable of more and wants to have a better relationship with her. His solution to confront her, especially when he knows that she does not respond well to this, is therefore somewhat illogical.

In this next excerpt, described earlier in this chapter, David reports that he has recently given up on trying to push his sister to answer his questions because, when he does, his parents “get mad” at him. He appraises this parent behavior as an additional stressful demand.

> So, I've kind of given up on that because my parents just get mad. They're like: ‘you're creating problems.’… And then, I'm always the one who's getting in trouble because—even when I feel like I'm trying to do something that has meaning to me. So that's, that's part of the problem too because I feel like I sometimes get unjustly blamed for a lot of the

> issues. Like I get in trouble when [disabled sibling] should also be getting like in equal trouble, but she gets off easy.… Because, that's why they get mad at me. Cuz I make it hard for them. But at the same time, it's like: 'Eh, I don't want to be the only one getting in trouble.' I'm trying to do something that I think, you know, that I think matters. I'm just trying to do something. I don't know why you're getting mad at me for that.… And, I mean, it's like 'I'm trying to do—I'm just trying to ask her a question. why are you getting mad at me for that?' So that's, that's really frustrating to me. Cuz I know she can do it. I know she's really smart. Like I've heard her talk to strangers like more easily than me.

In this second quote, David reports that if he does choose to push his sister to answer his questions, she becomes upset and his parents get mad at him. According to David, his parents get mad because they have to calm his disabled sister down, which is a "hard" situation for them. While David understands that he has created a difficult situation for his parents, he is upset by their reaction because he feels justified in the coping behavior. In an attempt to avoid the stress that he feels when his parents get mad at him, David disengages from his disabled sister when he feels frustrated by her communication deficits instead of confronting her. David does not appear to have any other capabilities (i.e., coping behaviors or resources) to manage this stressful demand, so he disengages.

I found disengagement to be a theme in regard to how these participants typically responded to the second stressful demand, whether the demand took the form of a disabled sibling behavior or a parent behavior. I perceive this disengagement to reflect an exhaustion of their limited coping resources. When a participant reported an interaction in which the second stressful demand was a stressful disabled sibling behavior, the second demand was typically the disabled sibling engaging in some form of tantrum behavior in response to the participant's initial coping behavior. It is possible that when the second stressful demand was perceived as parent criticism, the situation reflected a disconnect between the parents' expectations of the participants' coping behaviors and the participants' actual coping behaviors in the interaction. It is interesting to juxtapose these interactions with those reported by other participants in which parent support following a participant's ineffective coping behavior and ended the conflict instead of escalating the conflict. It would be interesting to explore why parents chose to respond the way that they did across these two types of interactions.

Research question three: summary of findings. This section explored participants' overall cognitive appraisal processes in regard to stressful family interactions. I conceptualized the cognitive appraisal process as a participant's coordination of their primary and secondary appraisals of a stressful family interaction (Lazarus & Folkman; 1984). I then identified themes that reflected the different ways in which I observed participants coordinating their primary and secondary appraisals of these interactions. These themes capture various ways in which these participants experienced stress during family interactions. To my knowledge, no study has carefully analyzed and explored nondisabled siblings' stressful family interactions in this manner. Whereas most previous studies focus on a single component of this general process, my study illuminated the patterned ways in which components of the appraisal process are linked, thereby having a specific and in many ways predictable effect in terms of how they experience stress in their families.

The processes through which the participants experienced psychological stress were identified as selecting ineffective coping behaviors, experiencing a pile-up of stressful demands, experiencing compounding stressful demands, and using preventative coping behaviors. In this chapter I first focused on the selection of ineffective coping behavior, which I attributed to three possible causes: shallow primary appraisals, logically disconnected primary and secondary appraisals, and inconsistently effective coping behaviors. At times, participants did not understand why their disabled sibling engaged in a stressful behavior, and as a result their primary appraisal of the situation could be considered shallow. In this situation, participants struggled to identify a response that would allow them to manage the situation without disengaging or becoming aggressive. At other times, participants reported secondary appraisals that were not logically connected to their primary appraisals of the situation. In these interactions, the participants experienced psychological stress because their coping behaviors were not an appropriate match for the stressful demand (based on their own appraisal of the demand). Finally, some participants reported interactions in which they used coping behaviors that they appraised as inconsistently effective. Overall, these types of cognitive appraisal processes highlighted for me the significant lack of effective coping options available to participants in the face of family interactions that were often characterized by ambiguity due to uncertainties regarding the disabled siblings capabilities, that took a toll on the energy and emotional wellbeing of all family members, and that were unlikely to improve significantly in the foreseeable future.

Participants also reported complex appraisal processes that emerged when multiple stressful demands were present. A participant's cognitive coping process was termed pile-up of stressful demands if they reported an interaction in which they experienced a family member's behavior as stressful due to a pile-up of stressful demands from other parts of their lives. In other words, when these participants were already feeling stressed at the outset of a family interaction, they experienced certain family member behaviors as stressful that they typically appraised as benign. I also identified coping responses characterized by the use of preventative coping behaviors. In these interactions, participants reported consciously using specific coping behaviors to prevent the occurrence of a stressful demand.

Finally, I identified a family interaction pattern in which participants reported appraising and responding to separate but linked stressful demands. Participants' appraisals of these stressful demands and accompanying coping behaviors suggested that the demands were unique (i.e., each demand manifested as a separate family member behavior) but the appraisals were intertwined. In these interactions, participants experienced an initial stressful disabled sibling behavior, responded to the behavior, and then experienced a second stressful demand in the form of a parent behavior (i.e., parent criticism of their coping behavior) or disabled sibling behavior (i.e., a tantrum believed to be triggered by the coping behavior). Typically, the participants responded to the second stressful demand by disengaging from the situation. I found these interactions and their cognitive appraisals (termed compounding stressful demands) particularly interesting. Not only did the participant experience the first demand as stressful when their coping behavior was ineffective at managing the stress of the demand, they also perceived the coping behavior as a trigger for an additional stressful demand. As such, I understood these coping behaviors as not just ineffective, but themselves stressful.

Chapter 4: Discussion

Scholars across fields consider sibling relationships to play an important role in lifelong development (Cicirelli, 1995; Dunn, 2015; McHale et al., 2013). It is therefore important that we study the influence of sibling relationships across diverse family contexts, such as those in which one or more siblings has a developmental disability. Studies of this population were initially built on the assumption that living with a disabled sibling was inherently stressful due to changes in the availability and allocation of familial resources (e.g., less time and attention from parents and increased time spent in caregiving roles; Hanson, 2013; Schuntermann, 2007; Stoneman & Berman, 1993; Stoneman & Brody, 1993). Findings based on this assumption have been inconsistently replicated across studies. For example, findings from studies that have compared samples of nondisabled siblings to samples of children with typically developing siblings on the dimension of psychological functioning have suggested no differences between the two groups (e.g., Emerson & Giallo, 2014) or increased psychological problems among nondisabled siblings (e.g., Cuzzocrea et al., 2014). Research in this field has also been characterized by a lack of guiding theory. Typically informed by family systems theory and/or concepts from theoretical models of stress and coping, studies have explored the influence of a variety of family sociodemographic variables and family relational variables on nondisabled sibling outcomes without producing many consistently replicated findings. As such, this work has produced limited information regarding what and how family characteristics influence nondisabled siblings' developmental and experiential outcomes.

More recent studies of the daily experiences of nondisabled siblings have highlighted the nuanced and diverse experiences of this population rather than simply linking the status of being a nondisabled sibling to particular psychological outcomes (Green, 2013; Hastings, 2016; McHale et al., 2016). By explicitly exploring aspects of family life perceived by nondisabled siblings as stressful, along with their reported coping responses to these stressors, these studies have produced findings that help us to understand why relationships may exist between the presence of a disabled sibling and either negative or positive outcomes among nondisabled siblings. Using nondisabled siblings' own accounts, their daily lives have been characterized as a mix of both positive and negative experiences. In addition, studies that have taken a careful look at within-group differences have found that a minority of children appear to experience a considerable amount of stress in response to having a disabled sibling (Dunn, 1992; Stoneman, 2005; Stoneman & Berman, 1993; Taylor et al., 2016). My study added to this work by using a hybridized theoretical model of stress and coping to analyze participants' individual cognitive appraisals of daily stressful family interactions that were related to their role as a nondisabled sibling. Through careful and in-depth analysis of these interactions, I provided a look into how 11 nondisabled siblings perceived and experienced daily instances of family stress. In doing so, I also captured potential explanations for why some nondisabled siblings may experience a greater intensity and pervasiveness of stress than others. I discuss these reasons in the sections that follow in this chapter.

Overall, the nondisabled siblings who participated in my study were able to provide detailed, thoughtful, and nuanced appraisals of stressful family interactions. Beyond being able to recall and report on the behaviors of all family members involved in an interaction, they were able to reflect on their own and their family members' emotions, competencies, and motivations during stressful interactions. This level of insight provided rich data for analyzing their cognitive appraisals. I first analyzed participants' primary appraisals of the demands they perceived during stressful family interactions in order to understand the types of interactions that they experienced as stressful. I identified three general sources of stressful demands within family interactions, including the behaviors of disabled siblings, parents, and nondisabled siblings' own behaviors and cognitions. Within these three sources of stressful demands, I further identified themes regarding why the participants appraised these behaviors as stressful.

This analytic process enabled me to identify several themes not previously discussed in the literature. For instance, previous research has highlighted parent engagement in differential treatment as a source of stress for nondisabled siblings (Cridland et al., 2016; Goodwin et al., 2017; Ward et al., 2016). While I too identified this source of stress, I also identified two types of parent behaviors that were reported as stressful. These included parent behaviors perceived as stressful because they were appraised as critical of the participant's own behavior toward the disabled sibling, or because they were appraised as an inappropriate response to a disabled sibling's behavior. More specifically, several nondisabled siblings described feeling angry or upset when their parents criticized them for the way that they had behaved toward their disabled sibling. In addition, a few participants reported experiencing frustration when their parents engaged with their disabled sibling in a way that they believed perpetuated the stressful behavior (i.e., by giving the disabled sibling too much "leeway," or "babying" the disabled sibling). My results also indicated that some nondisabled siblings experienced stress as a result of their disabled siblings' communication difficulties. According to several participants, communication difficulties led to both annoying or irritating conversations and made it difficult for the nondisabled sibling to build a meaningful relationship with their brother or sister with a disability.

An additional contribution of my analysis was the provision of several reasons for why disabled siblings' behavior problems present as stressful demands for nondisabled siblings. Disabled sibling behavior problems have been the most commonly replicated source of stress in the literature, with increases in the severity of behavior problems linked to decreases in nondisabled sibling wellbeing (Hastings, 2016; Stoneman, 2005; Taylor et al., 2016). Based on my analysis, disabled siblings' acting out and tantrum behaviors caused participants to experience stress for a wide range of reasons, including when the behavior was perceived to interrupt a nondisabled siblings' activity, elicit concerns about the disabled sibling's wellbeing, damage private property, embarrass or offend the participant, or trigger family conflict. Another novel theme pertains to nondisabled siblings' evaluation of their own behaviors during stressful family interactions, particularly in relation to incidents in which they felt their own behavior had been insensitive or immature.

Next, I analyzed the participants' accounts of stressful family interactions to identify themes regarding the coping behaviors and resources they considered and used to manage stressful demands. To do this, I explored the participants' secondary appraisals during stressful interactions. These appraisals captured participants' reasons for why they considered and chose certain coping behaviors and resources, along with their perceptions of the efficacy of these responses. Each coping behavior reflected a different degree of internal (i.e., cognitive) vs. external (i.e., behavioral) coping responses. I considered the participants' use of aggressive behavioral responses to be the most external coping behavior because it was coupled with limited to no secondary appraisal cognitions. On the other end of the spectrum was internal reflection about others' behaviors. This coping behavior was considered the most internal because the participants did not report coordination of these cognitions with any external behaviors. The remaining three coping behavior themes were comprised of a combination of external and internal responses. This distinction between external and internal coping responses is reflected in the work of other scholars in this field (e.g., Gamble & McHale, 1989); however, I have not seen any previous work on coping behavior that integrates the two response types.

Overall, the participants considered the effectiveness of the coping behaviors and resources that they used in their reasoning about what coping strategies to use in a stressful interaction. For example, the participants described certain coping behaviors (e.g., intervening directly but non-aggressively with the disabled sibling) as appropriate because they were sometimes effective at reducing or terminating the stressful demand or because they were modeled by other family members. The participants appeared to use other coping behaviors (e.g., complaining or telling parents what to do) not because the behavior terminated the demand, but because it reduced their felt stress in the moment. Disengagement from family members was an interesting coping behavior because the participants often reported using it in response to stressful demands that they experienced as triggering particularly strong negative emotions. Participants reported using disengagement successfully to prevent the occurrence of stressful interactions, as well as to calm themselves down in response to stressful interactions. Previous qualitative studies have similarly highlighted nondisabled siblings' desire or need for withdrawal from their family (Goodwin et al., 2017; Gorjy et al., 2017; Moyson & Roeyers, 2012).

In addition to coping behaviors, participants sometimes referenced cognitive or physical resources that they actively engaged to manage the stress of an interaction. These resources included the knowledge that their parents' actions were intentional and typically benign, the knowledge that they, the participants, were able to take care of themselves, and the availability of a physical space to be alone. Participants' use of cognitive resources to reappraise a stressful demand as benign is consistent with previous findings that nondisabled siblings actively try to make positive meanings out of their family interactions (Gorjy et al., 2017; Ward et al., 2016). In addition, participants reported that their parents sometimes spontaneously provided them with support during a stressful interaction with their disabled sibling. Their reports indicated that they did not explicitly elicit this support, but that it was welcome and appreciated. This resource may be similar to the construct of social support which previous studies have identified as important for nondisabled sibling wellbeing (Gorjy et al., 2017; Jones et al., 2019; Moyson & Roeyers, 2012; Opperman & Alant, 2003; Taylor et al., 2016).

The final piece of my findings reflected my analysis of the participants' overall cognitive appraisal processes in regard to stressful family interactions. In other words, I analyzed participants' coordination of their primary and secondary appraisals of the stressful interactions they reported. I then identified themes that reflected the different ways in which the participants coordinated their appraisals. Ultimately, these themes captured the ways in which the participants experienced stress during family interactions. Most of the previous work on stress and coping among nondisabled siblings has focused on one piece of this general process. By highlighting the ways in which the components of the appraisal process are linked, these results represent a novel contribution to the field. The overall cognitive appraisal processes identified in this study were each characterized by one of the following four themes: the selection of ineffective coping behaviors, the experience of a pile-up of stressful demands, the experience of compounding stressful demands, or the use of preventative coping behaviors.

The first theme pertained to the selection of ineffective coping behaviors. It appeared that one reason for choosing ineffective coping behaviors was that the participant did not know why a family member engaged in a specific stressful behavior, a phenomenon I labeled "shallow primary appraisal." The second theme included cognitive appraisal processes in which there was a pile-up of stressful demands, such that it became impossible for participants to manage a demand that they could typically have handled effectively because of concurrent stressful demands in other parts of their lives. A third type of cognitive appraisal process was one in which the participants reported consciously using specific coping behaviors to prevent the occurrence of a stressful demand. The final cognitive appraisal process captured a pattern of family interaction in which the participants reported appraising and responding to two separate but linked stressful demands. Within these interactions, the participants reported the initial stressful demand to take the form of a stressful disabled sibling behavior. They then described how their coping response to their sibling's stressful behavior triggered either a stressful parent behavior (e.g., the parent was critical of the nondisabled sibling's behavior toward the disabled sibling) or an escalation in the disabled sibling's behavior.

Overall, my analyses of participants' appraisal processes allowed me to create a nuanced picture of (a) what they experienced as stressful in their daily family interactions and why these interactions were appraised as stressful, (b) how they attempted to manage these stressful interactions and why they chose the coping behaviors and resources that they did, and (c) why they ultimately experienced psychological stress in the context of these interactions. When I considered these findings as a whole, I was struck by three important clinical and research implications. These implications include the importance of considering nondisabled siblings' appraisals of stressful family interactions, the importance of expanding nondisabled siblings' coping behaviors and resources for managing daily family-related stress, and the role of parents in nondisabled siblings' experiences of stress. In the sections that follow, I discuss the implications of my findings for both clinical practice and future research. I then discuss limitations of this study and conclude with a final statement.

Implications

The importance of considering nondisabled siblings' appraisals of stressful family interactions. The results of my study suggest that, on a daily basis, nondisabled siblings grapple with the complex and highly interpretive process of navigating stressful family interactions. While the participants experienced the interactions themselves as stressful, it was their cognitive appraisals that explained why they actually experienced psychological stress in any specific interaction. Primary appraisals in particular provided information regarding several pathways through which a demand was perceived as stressful. Overall, the participants discussed a wide range of family member behaviors that they appraised as stressful. These behaviors included some unique to specific families (e.g., enactment of a parent's grief in response to the sibling's diagnosis, or a disabled sibling asking for a hug), and others that were reported by multiple participants (e.g., a disabled sibling having a tantrum, or a disabled sibling engaging in self harm behavior). Importantly, I observed that specific behaviors could be perceived as stressful for different reasons across participants (e.g., repetitive communication patterns were perceived as stressful by some participants because they interrupted a desired activity and by others because they interfered with their ability to hold a conversation with their disabled sibling). In addition, several participants appraised specific types of parent or sibling behaviors as stressful that others did not (e.g., a disabled sibling running around the house naked). By analyzing the reasons behind why behaviors were perceived as stressful, I found homogeneity in the experience of stress across this data set. In addition, my findings indicated that family members' behaviors were not inherently stressful, instead the participants experienced psychological stress as a result of the meanings that they gave to the behaviors during the appraisal process. These findings have important research and clinical implications.

First, when studying or treating nondisabled siblings it is important to focus on why specific behaviors or situations are triggering them to feel stress, as opposed to the behaviors or situations themselves. In addition, the stress pathways that I identified can be used to refine the study of nondisabled siblings by adjusting the focus away from collecting lists of individual stressors, and toward investigation and refinement of these specific pathways. Clinically, it may prove effective to create a holistic picture of the ways in which a nondisabled sibling experiences stress in order to identify overarching patterns that can then be addressed in treatment. In other words, instead of attempting to work on each individual source of stress with a nondisabled sibling, it may be more effective to address the underlying reasons for why the nondisabled sibling is perceiving these interactions as stressful.

Analysis of secondary appraisals provided important information regarding what coping behaviors and resources the participants considered along with why they ultimately chose to use the ones that they did in an interaction. These appraisals provided an explanation of participants' behaviors. Their reasoning and justification regarding certain coping behaviors suggested that they gained these tools in various ways, including through careful consideration of other family members' motivations and competencies, trial and error, and parent modeling. Coping behaviors that reflected minimal cognitive consideration, such as aggressively responding to a disabled sibling, suggested that some coping behaviors were more reactive than thoughtful. In addition, participants sometimes described feeling as though their only choice was to disengage from certain family members, suggesting an exhaustion of other coping responses. The recurring nature of many of the stressful interactions that the participants reported also suggested that nondisabled siblings' behaviors may be part of larger family patterns of interaction. Overall, these nuances in why participants utilized certain coping behaviors and resources provided important information regarding how they learn coping strategies and why they were ineffective.

The major research and clinical implications of these findings regarding secondary appraisals are similar to those stated previously in regard to primary appraisals; when studying or treating nondisabled siblings it is important to understand not just what coping behaviors and resources nondisabled siblings are using, but why they are using them in specific contexts. This information is vital for understanding how coping strategies were adopted, what gaps in coping may exist, and the efficacy of certain strategies within specific contexts. We also need to conduct research to better understand how coping behaviors are learned and adopted by nondisabled siblings. This research would assist in improving effective treatments for nondisabled siblings who are struggling. In addition, research needs to move away from correlating coping types (e.g., external vs. internal coping behaviors) with wellbeing, and toward an understanding of what nondisabled siblings need in order to cope effectively across different family contexts. Clinicians may benefit from identifying ingrained patterns of family interaction that are causing stress for nondisabled siblings, and then working with multiple family members to break these patterns and establish healthier patterns of interaction.

When I explored participants' coordination of primary and secondary appraisals, several themes regarding cognitive appraisal processes emerged that explained why they experienced psychological stress in the interactions they reported. By analyzing the participants' cognitive appraisals in particular, I was able to create specific theories as to why they experienced psychological stress in family interactions. For example, I observed the most common cognitive appraisal process to be characterized by the use of a coping behavior and/or resource that was ultimately ineffective at managing the stressful demand without the experience of psychological stress. By looking closely at the coordination of their primary and secondary appraisals, I was further able to discern several reasons why this appraisal process occurred. In addition, by looking very closely at participants' appraisals, I was able to identify interactions in which the participants reported experiencing two separate but linked stressful demands. Ultimately, I was struck by the participants' general lack of effective and appropriate coping behaviors and resources to manage the various stressful demands that they reported experiencing on a daily basis.

Overall, these findings indicate that in both research and clinical contexts stressors and coping responses should be considered in coordination with, not in isolation from, each other. Without either piece of this puzzle, we cannot fully understand nondisabled siblings' experiences of stress. In other words, we need to consider both what is triggering nondisabled siblings to feel stress and how they attempt to manage this stress in order to understand why they ultimately experience psychological stress during family interactions. Clinically, these findings also highlight the importance of building and using treatment and intervention tools that can be tailored specifically to the individual needs of nondisabled siblings. One participant, Eleanor (age 16) described and justified this practice of individualizing treatment.

> ...everyone's experience is different. Because all our siblings are different. And then also, all our parents are different too…. And if you really want to help a person, listen to them individually. Even though I think there's a lot you can do, just to benefit siblings in general. But like, an important thing is just to—maybe learn more about them and their sibling. And see what they need. Because I think it's different for everybody.

Clinicians can help nondisabled siblings to understand that their experiences within their families are unique in comparison to the experiences of other nondisabled siblings, as well as in comparison to the experiences of other members of their family. They should not expect that all nondisabled siblings, or all of their family members, will react the same way to certain behaviors or interactions. Finally, clinicians and researchers may also want to consider inclusion of other family members in this research and clinical practice in order to more accurately understand the sources of individual nondisabled siblings' stressful demands, along with the most effective ways to develop their coping behaviors and resources (e.g., whether that's through more intentional parent modeling or parent provision of additional cognitive and/or behavioral resources).

The importance of expanding nondisabled siblings' coping behaviors and resources for managing daily family-related stress. As discussed in the last section, when I reflected on the cognitive appraisal processes reported by the participants in this study, I was struck by their lack of effective coping behaviors and resources to manage stressful family interactions. This was particularly evident in the cognitive appraisal processes of ineffective coping behaviors and compounding stressful demands. By using the cognitive appraisal processes that I identified in this study as a starting point, clinicians can investigate nondisabled siblings' appraisal processes in order to identify why and in what contexts their patients are lacking effective coping behaviors and resources to manage the stressful family demands that they face. In particular, clinicians may want to identify and work on nondisabled siblings' coping strategies in the context of interactions characterized by compounding stressful demands because these appeared to be particularly stressful interactions for nondisabled siblings. In addition, clinicians may want to support the development of the following coping behaviors and resources that appeared important to, and effective for, the participants in this study: a designated private space in the home where they can be alone, a designated space in the home to keep their breakable belongings, tools and language for talking to their parents productively about their needs and experiences, a repertoire of skills for intervening directly and effectively with the disabled sibling, and an understanding that it is acceptable to feel negative emotions (i.e., reduce the tendency to engage in self-blame). Clinicians may also want to identify those times during which nondisabled siblings engage reactively in aggressive behaviors and teach some more prosocial and functional coping skills for those moments. Furthermore, clinical research is necessary to explore the effectiveness of interventions that promote the development of these coping behaviors and resources.

Within the participants' cognitive appraisals, I observed that they sometimes chose ineffective coping behaviors and resources even when they provided an understanding of the behavior that they appraised as a stressful demand (i.e., provided a rich primary appraisal). Based on my analysis, this cognitive appraisal process occurred when the participants used coping behaviors that were not logically linked to their primary appraisal of the stressful demand, or when they used a coping behavior that was only sometimes effective at managing the stressful demand. This observation has an important implication for clinicians working with nondisabled siblings, namely that understanding the reason behind a family member's stressful behavior is not always sufficient for choosing and using an effective coping behavior or resource to manage the stressful behavior. As such, understanding of a behavior is only helpful in so much as it is linked to the development of effective coping behaviors and resources. A more supportive approach would likely be providing nondisabled siblings with an understanding of the behavior in coordination with appropriate coping strategies that they can use to manage the behavior.

It is clear from this data set that many of the participants lacked effective coping strategies to manage the kinds of daily stress that they experienced in the context of family interactions. However, it is not clear how they actually developed the strategies that they used (e.g., through parent modeling, explicitly learning skills outside of the family, trial and error, careful consideration of the stressful demand, etc.). As such, we need more research that systematically investigates how nondisabled siblings develop their repertoire of coping behaviors and resources, including both their effective and ineffective coping behaviors and resources. This information will improve our understanding of variability in the experience of being a nondisabled sibling, as well as how best to support the development of effective coping behaviors and resources among nondisabled siblings. For example, if nondisabled siblings primarily develop their coping skills through parent modeling, it stands to reason that when they lack effective coping strategies it is a reflection of the parents' lack of effective coping strategies. In this case, the more effective intervention would likely be to build the parents' or whole family's coping strategies, as opposed to just those of the nondisabled sibling.

Interestingly, two participants reported formally learning coping strategies outside of the family that they then used at home with their disabled sibling. For example, Eleanor (age 16) reported learning skills to work with children with ASD like her disabled brother (age 18) through employment as a camp counselor at a summer camp for children with developmental disabilities. Phillip (age 16) reported learning conflict management skills through an extracurricular club that teaches adolescents how to promote social inclusion on middle school campuses. While Phillip noted that his intervention techniques did not always work to manage his disabled sister's (age 18) behavior that he appraised as stressful, he also reported that this was okay because it was to be expected (i.e., "sometimes it works out, sometimes it doesn't"). His subsequent emotional experiences of interactions in which he unsuccessfully directly intervened with his sister were relatively subdued (e.g., "sort of annoyed"). In addition, he reported continued and varied efforts to intervene directly with his sister. Based on these accounts, nondisabled siblings may benefit from formal training of effective coping strategies. However, these two participants also reported learning about their sibling's disability from their parents, consulting with their parents' when they had questions about their sibling or their sibling's condition, and receiving real-time support from their parents to manage stressful interactions with their siblings. As such, additional research on coping skill development is needed to truly understand the best ways to support nondisabled siblings' development of effective coping behaviors and resources. As Phillip and Eleanor's interviews suggest, the best approach may be a combination of family-based skill development and support, along with formal training in relevant coping skills outside of the family.

Finally, I believe that research is also needed to explore the effects of disengagement, a widely used coping behavior, on nondisabled sibling outcomes. While some level of disengagement from stressful situations or specific family members may be an appropriate and effective coping behavior, pervasive disengagement from the family may lead to other negative developmental outcomes. Children need support from their parents to thrive. If nondisabled siblings are disengaging from their families regularly and for large amounts of time, they may not be receiving the support and guidance they need to develop into healthy adults.

The role of parents in nondisabled siblings' experiences of stress. Parents played an important role in the ways that the participants in this study experienced stress. In particular, I observed two forms of parent intervention during conflictual sibling interactions that resulted in markedly different experiential outcomes for nondisabled siblings. The first form of parent intervention was perceived as a resource by the participants because their parent(s) acted to provide them with support. Several participants reported that their parents intervened during a conflictual interaction with their disabled sibling by either supporting them in obtaining their goal (e.g., distracting the disabled sibling so that the participant could do their homework) or ending the conflict (e.g., physically separating the siblings and giving each directions/consequences). These parent actions were described as supportive and demarcated the end of the conflictual sibling interaction. The second form of parent intervention was reportedly experienced by participants as a stressful demand because they perceived their parents as critical of their behavior toward their disabled sibling (e.g., getting mad at them for upsetting the disabled sibling) or they perceived their parents as responding to the disabled sibling inappropriately (e.g., giving the disabled sibling too much "leeway"). These parent behaviors were commonly reported in the context of cognitive appraisal processes characterized by compounding stressful demands. In these interactions, the parents were perceived to make an already stressful interaction more stressful for the participants.

These two forms of parent intervention clearly had different impacts on the participants' emotional experiences during family interactions. The first type of intervention terminated the conflict, whereas the second escalated the conflict. Continued research is needed to further understand the influences of these two forms of parent intervention on nondisabled sibling wellbeing, as well as to understand why parents in some families intervene one way while parents in other families intervene the other way. Previous research points to a significant relationship between parent stress and nondisabled sibling wellbeing, with increases in parent stress associated with decreases in wellbeing (Schuntermann, 2007; Stoneman, 2005). It is feasible that parents who are experiencing more stress in relation to the child with a disability respond more critically to the nondisabled sibling's behavior and/or are more forgiving of the disabled sibling's behavior in moments of sibling conflict. Whereas, parents experiencing less stress may be able to intervene in a more balanced manner during sibling conflict. If this is the case, parent intervention during sibling conflict may be one pathway through which parent stress influences nondisabled sibling wellbeing. This theory aligns with David's (age 15) insight that his parents become upset with him about the way that he engages with his disabled sibling (age 15) because it causes more problems for them. In addition, referring to his parents' tendency not to reprimand his disabled sister when she misbehaves, he reported: "it feels like sometimes my parents have just given up because they're SO tired." While David reported that he understands that his parents are tired, it upsets him that they give her "leeway" because she does not learn and continues to misbehave. Additional research is needed to explore this theory, along with other pathways through which parent stress may negatively influence nondisabled sibling wellbeing (e.g., in the form of disabled sibling behaviors that are perceived by nondisabled siblings as stressful because they cause parent stress). Clinicians can be sensitive to the presence of parent stress within families, and support the family as a whole to identify interactions during which parent stress is causing additional stress for nondisabled siblings.

Beyond understanding whether or not parent stress is playing a role in these stressful family interactions, it is important to understand why parents choose to engage in these different forms of intervention in the context of these interactions. This understanding allows for more specific and effective family interventions to reduce the occurrence of these interactions. From a stress, appraisal and coping perspective, it may be that conflict arises between parents and nondisabled siblings when they each have conflicting appraisals of either the initial stressful demand (i.e., the disabled sibling behavior) or the best way to manage the initial stressful demand, or both. From this perspective, parent intervention may be perceived by nondisabled siblings as supportive when they share similar cognitive appraisals of the situation. Patterson (1988) posits that stress can emerge in families as a result of conflict in family members' meanings regarding specific demands. In addition, she asserts that inconsistent cognitive appraisals across family members can themselves become stressful demands. It is possible that inconsistency across family members' appraisals of these sibling conflicts explains why the participants experienced their parents' intervention as critical or inappropriate. Clinicians may want to investigate all of the participating family members' appraisals of these types of conflictual interactions in order to identify the source of the conflict. Treatment can then be provided to the whole family to develop shared appraisals of these interactions in order to reduce conflict in similar situations moving forward (e.g., support the family in developing agreed-upon ways to respond to certain disabled sibling behaviors).

The role that parents play in nondisabled siblings' experiences of stress may be one explanation for why a minority of nondisabled siblings report more severe and pervasive negative emotions in relation to their disabled sibling and their family. Interactions characterized by compounding stressful demands were typically described by participants as eliciting more extreme negative emotions. It appeared particularly difficult for participants to cope with a stressful disabled sibling behavior when they did not have the skills to manage the behavior in the moment, and they experienced additional stress when their parents intervened. Another way of conceptualizing these interactions from the perspective of the nondisabled sibling, is that they did not experience their parents as a source of support in dealing with their disabled sibling's behavior. Ultimately, the participants appeared at a loss for how to handle these situations and disengaged. Additional research is needed to further understand the influence of these types of family interactions on nondisabled sibling wellbeing. In addition, clinicians should be aware of and look out for the occurrence of these types of family interactions in order to target them through intervention.

Limitations

There are several notable limitations to this study. The first is the size of the sample. While a sample size of 11 participants is reasonable for an exploratory qualitative study, it is limiting in terms of the diversity of experiences captured and therefore the generalizability of the findings. In addition, the sample included a limited amount of diversity in terms of the participants' SES and race/ethnicity. All of the participants in the sample reported coming from families whose incomes placed them in the middle to upper-middle class ranges. As such, there is a lack of representation in this study of lower SES backgrounds and experiences. This is particularly problematic in that previous research suggests that SES does have a measurable influence on nondisabled sibling wellbeing (Emerson & Giallo, 2014; Giallo & Gavidia-Payne, 2006; Mulroy et al., 2008). I was able to recruit participants from a variety of racial and ethnic backgrounds (i.e., four participants identified as Caucasian, three identified as Asian and Caucasian, three identified as Latinx and Caucasian, and one identified as Latinx), but future studies should include additional voices.

In this project I chose to include only the perspectives of nondisabled siblings, as opposed to also capturing the perspectives of other family members. Without data from other family members there were significant limitations in terms of the inferences that I could make regarding family relationships and family dynamics. For example, I was not able to determine if another family member had actually felt angry or frustrated in a specific interaction as the participant reported. This being said, I was not interested in capturing data that was reliable in this way because I was focused on the participants' perceptions and appraisals. Not having data from other family members allowed me to focus on the participants' accounts of events as their subjective truths. Another major limitation of this study was that I did not analyze interactions in which the participants did not report experiencing psychological stress. A comparison between these two types of family interactions may have provided interesting information regarding differences in nondisabled siblings' perceptions of positive vs. negative family interactions. In addition, I did not explicitly ask participants to recount interactions with their disabled siblings outside of the home. By not including these types of interactions with disabled siblings, I did not include this part of the experience of being a nondisabled sibling in my study.

The lack of quantitative measures of wellbeing and adjustment are another limitation of this study. Inclusion of measures of wellbeing and/or adjustment would have provided more objective data to correlate with the qualitative findings. This data would have allowed me to make more concrete conclusions regarding the effect of stress on siblings' wellbeing. It would be interesting to see this type of correlation in future work. Finally, I recognize that my role as a researcher from UC Berkeley, along with my gender and ethnic/racial background, may have made some of the participants uncomfortable or influenced their responses during the interview process. I attempted to reduce their discomfort by meeting with each of them twice, conducting the interview in a space where they felt comfortable, engaging them in informal conversation throughout the process, and thoughtfully disclosing information about my own background.

Concluding Statement

This study investigated nondisabled siblings' accounts of daily stressful family interactions, and specifically those interactions related to their role as a nondisabled sibling. The goal of this study was to better understand the processes through which nondisabled siblings experience family stress. While the literature indicates that nondisabled siblings generally fare just as well as siblings of typically developing siblings, it also suggests that a minority of nondisabled siblings experience significant and pervasive negative reactions to their disabled siblings and families. Using a hybridized theoretical model of stress and coping that focused on nondisabled siblings' cognitive appraisals of stressful family interactions, I identified several pathways through which nondisabled siblings appear to experience stress, several ways in which they attempt to manage stress, and several explanations for why they experience stress in the context of family interactions. By analyzing nondisabled siblings' cognitive appraisals of stressful family interactions, I provided explanations for why individual differences may exist in terms of the wellbeing of nondisabled siblings. Ultimately, I concluded that nondisabled siblings' cognitive appraisals capture vital information for understanding their experiences of stress, and have argued that scholars and clinicians should focus on the appraisals of their experiences rather than, for example, attending to sociodemographic characteristics as predictors of stress. By understanding more deeply the cognitive lens through which nondisabled siblings construe their daily experiences, clinicians will be better able to support them in developing effective coping behaviors and resources as well as to help other family members understand and respond supportively to nondisabled siblings' experiences of stress.

References

106th Congress. The Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 114 STAT. 1677 (2000). United States.

Cicirelli, V. G. (1995). *Sibling relationships across the lifespan*. New York: Springer.

Corsano, P., Musetti, A., Guidotti, L., & Capelli, F. (2017). Typically developing adolescents' experience of growing up with a brother with an autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, *42*(2), 151–161. doi: 10.3109/13668250.2016.1226277

Cox, A. H., Marshall, E. S., Mandleco, B., & Olsen, S. F. (2003). Coping responses to daily life stressors of children who have a sibling with a disability. *Journal of Family Nursing*, *9*(4), 397–413. doi: 10.1177/1074840703258328

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, *18*(3), 213–222. doi: 10.1177/1362361312472261

Cridland, E. K., Jones, S. C., Stoyles, G., Caputi, P., & Magee, C. A. (2016). Families Living With Autism Spectrum Disorder. *Focus on Autism and Other Developmental Disabilities*, *31*(3), 196–207. doi: 10.1177/1088357615583466

Cuzzocrea, F., Larcan, R., Costa, S., & Gazzano, C. (2014). Parents' competence and social skills in siblings of disabled children. *Social Behavior and Personality: An International Journal*, *42*(1), 45–57. doi: 10.2224/sbp.2014.42.1.45

Dunn, J. (1992). Sisters and brothers: Current issues in developmental research. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 1–17). Hillsdale, New Jersey: Lawrence Erlbaum Associates Publishers.

Dunn, J. (2015). Siblings and socialization. In *Handbook of socialization: Theory and research* (pp. 309–327). doi: 10.4319/lo.2013.58.2.0489

Emerson, E., & Giallo, R. (2014). The wellbeing of siblings of children with disabilities. *Research in Developmental Disabilities*, *35*(9), 2085–2092. doi: 10.1016/j.ridd.2014.05.001

Gabb, J., & Singh, R. (2015). The uses of emotion maps in research and clinical innovation and critical inquiry. *Family Process*, *54*(1), 185–197. doi: 10.1111/famp.12096

Gamble, W. C., & McHale, S. M. (1989). Coping with stress in sibling relationships: A comparison of children with disabled and nondisabled siblings. *Journal of Applied Developmental Psychology*, *10*(3), 353–373. doi: 10.1016/0193-3973(89)90035-X

Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, *50*(12), 937–948. doi: 10.1111/j.1365-2788.2006.00928.x

Goodwin, J., Alam, S., & Campbell, L. E. (2017). 'At the end of the day, it is more important that he stays happy': an interpretative phenomenological analysis of people who have a sibling with 22q11.2 deletion syndrome. *Journal of Intellectual Disability Research*, *61*(9), 888–898. doi: 10.1111/jir.12397

Gorjy, R. S., Fielding, A., & Falkmer, M. (2017). "It's better than it used to be": Perspectives of adolescent siblings of children with an autism spectrum condition. *Child and Family Social Work*, *22*(4), 1488–1496. doi: 10.1111/cfs.12371

Goudie, A., Havercamp, S., Jamieson, B., & Sahr, T. (2013). Assessing Functional Impairment in Siblings Living With Children With Disability. *Pediatrics*, *132*(2), e476–e483. doi: 10.1542/peds.2013-0644

Green, L. (2013). The Well-Being of Siblings of Individuals with Autism. *ISRN Neurology*, *2013*, 1–7. doi: 10.1155/2013/417194

Hanson, M. J. (2013). Families with children with disabilities. In M. J. Hanson & E. W. Lynch (Eds.), *Understanding families: Supportive approaches to diversity, disability, and risk* (2nd Editio, pp. 97–122). Baltimore, MD: Paul H Brookes Publishing Co.

Hanson, M. J., & Lynch, E. W. (2013). *Understanding families: Supportive approaches to diversity, disability, and risk* (2nd Editio). Baltimore, MD: Paul H Brookes Publishing Co.

Hastings, R. P. (2016). *Do Children With Intellectual and Developmental Disabilities Have a Negative Impact on Other Family Members? The Case for Rejecting a Negative Narrative. International Review of Research in Developmental Disabilities* (Vol. 50). Elsevier Ltd. doi: 10.1016/bs.irrdd.2016.05.002

Hastings, R. P., & Petalas, M. A. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. *Child: Care, Health and Development*, *40*(6), 833–839. doi: 10.1111/cch.12131

Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., & Dufresne, D. (2008). The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities, (January), 25. Retrieved from www.siblingsupport.org/sln-white-paper-final-2.pdf

Hodapp, R. M., Glidden, L. M., & Kaiser, A. P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation*, *43*(5), 334–338. doi: 10.1352/0047-6765(2005)43

Jones, E. A., Fiani, T., Stewart, J. L., Sheikh, R., Neil, N., & Fienup, D. M. (2019). When One Sibling has Autism: Adjustment and Sibling Relationship. *Journal of Child and Family Studies*, 1272–1282. doi: 10.1007/s10826-019-01374-z

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities*. doi: 10.1016/j.ridd.2015.11.023

Mandleco, B., & Webb, A. E. M. (2015). Sibling perceptions of living with a young person with Down syndrome or autism spectrum disorder: An integrated review. *Journal for Specialists in Pediatric Nursing*, *20*(3), 138–156. doi: 10.1111/jspn.12117

Mascha, K., & Boucher, J. (2006). Preliminary Investigation of a Qualitative Method of Examining Siblings' Experiences of Living with a Child with ASD. *The British Journal of Development Disabilities*, *52*(102), 19–28. doi: 10.1179/096979506799103659

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review*, *6*, 7–37. doi: 10.1300/J002v06n01_02

McHale, S., & Harris, V. (1992). Children's experiences with disabled and nondisabled siblings: Links with personal adjustment and relationship evaluation. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 83–100). Hillsdale, New Jersey: Lawrence Erlbaum Associates Publishers.

McHale, S M, Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships of children with autistic, mentally-retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders*, *16*(4), 399–413. doi: 10.1007/bf01531707

McHale, Susan M., & Gamble, W. C. (1989). Sibling relationships and adjustment of children with disabled brothers and sisters. *Journal of Children in Contemporary Society*, *25*(3), 421–429. doi: 10.1300/J274v19n03_08

McHale, Susan M., & Pawletko, T. M. (1992). Differential treatment of siblings in two family contexts. *Child Development*, *63*(1), 68–81. Retrieved from http://www.jstor.org/stable/1130902

McHale, Susan M., Updegraff, K. A., & Feinberg, M. E. (2016). Siblings of Youth with Autism Spectrum Disorders: Theoretical Perspectives on Sibling Relationships and Individual Adjustment. *Journal of Autism and Developmental Disorders*, *46*(2), 589–602. doi: 10.1007/s10803-015-2611-6

McHale, Susan M., Updegraff, K. A., & Whiteman, S. D. (2013). Sibling relationships. In G. W. Peterson & K. R. Bush (Eds.), *Handbook of marriage and the family* (Third Edit, pp. 329–352). New York: Springer. doi: 10.1007/978-1-4614-3987-5

Meyer, D. J., & Vadasy, P. F. (2008). *Sibshops: Workshops for Siblings of Cdhilren with Special Needs, Revised Edition* (Revised Ed). Baltimore, MD: Paul H. Brookes Publishing Co., Inc.

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative Data Analysis: A Methods Sourcebook* (Third Edit). SAGE Publications, Inc.

Moyson, T., & Roeyers, H. (2012). "The overall quality of my life as a sibling is all right, but of course, it could always be better". Quality of life of siblings of children with intellectual disability: The siblings' perspectives. *Journal of Intellectual Disability Research*, *56*(1), 87–101. doi: 10.1111/j.1365-2788.2011.01393.x

Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research*, *52*(3), 216–229. doi: 10.1111/j.1365-2788.2007.01005.x

Neely-Barnes, S. L., & Graff, J. C. (2011). Are there adverse consequences to being a sibling of a person with a disability? A propensity score analysis. *Family Relations*, *60*(3), 331–341. doi: 10.1111/j.1741-3729.2011.00652.x

O'Neill, L. P., & Murray, L. E. (2016). Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses. *Research in Developmental Disabilities*, *51–52*, 116–125. doi: 10.1016/j.ridd.2015.12.017

Ochs, E., & Taylor, C. (1992). Family Narrative as Political Activity. *Discourse & Society*. doi: 10.1177/0957926592003003003

Okashah, R., Schoch, K., Hooper, S. R., Shashi, V., & Callanan, N. (2015). Parental Communication and Experiences and Knowledge of Adolescent Siblings of Children with 22q11.2 Deletion Syndrome. *Journal of Genetic Counseling*, *24*(5), 752–759. doi: 10.1007/s10897-014-9806-4

Opperman, S., & Alant, E. (2003). The coping responses of the adolescent siblings of children with severe disabilities. *Disability and Rehabilitation*, *25*(9), 441–454. doi: 10.1080/0963828031000069735

Patterson, J. M. (1988). Families experiencing stress. *Family Systems Medicine*, *6*(2), 202–237. doi: 10.1037/h0089739

Patterson, J. M. (1993). The role of family meanings in adaptation to chronic illness and disability. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 221–238). Baltimore, MD: Paul H Brookes Publishing Co.

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family*, *64*(2), 349–360.

Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder.

Journal of Intellectual and Developmental Disability, *37*(4), 303–314. doi: 10.3109/13668250.2012.734603

Pollard, C. A., Barry, C. M., Freedman, B. H., & Kotchick, B. A. (2013). Relationship Quality as a Moderator of Anxiety in Siblings of Children Diagnosed with Autism Spectrum Disorders or Down Syndrome. *Journal of Child and Family Studies*, *22*(5), 647–657. doi: 10.1007/s10826-012-9618-9

Richmond, M. K., Stocker, C. M., & Rienks, S. L. (2005). Longitudinal associations between sibling relationship quality, parental differential treatment, and children's adjustment. *Journal of Family Psychology : JFP : Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, *19*(4), 550–559. doi: 10.1037/0893-3200.19.4.550

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, *33*(4), 383–394. doi: 10.1023/A:1025006727395

Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability*, *31*(2), 77–86.

Rossetti, Z., & Hall, S. (2015). Adult Sibling Relationships With Brothers and Sisters With Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, *40*(2), 120–137. doi: 10.1177/1540796915592829

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, *10*(1), 65–84.

Saxena, M., & Adamsons, K. (2013). Siblings of Individuals With Disabilities: Reframing the Literature Through a Bioecological Lens. *Journal of Family Theory & Review*, *5*(4), 300–316. doi: 10.1111/jftr.12021

Schuntermann, P. (2007). The sibling experience: Growing up with a child who has pervasive developmental disorder or mental retardation. *Harvard Review of Psychiatry*, *15*(3), 93–108. doi: 10.1080/10673220701432188

Shivers, C. M., Deisenroth, L. K., & Taylor, J. L. (2013). Patterns and predictors of anxiety among siblings of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(6), 1336–1346. doi: 10.1007/s10803-012-1685-7

Sibling Support Project. (n.d.). About Sibshops.

Siegel, B., & Silverstein, S. (1994). *What about me? Growing up with a developmentally disabled sibling*. Cambridge, MA: Perseus Publishing.

Smith, L. O., Elder, J. H., Storch, E. A., & Rowe, M. A. (2015). Predictors of sense of coherence in typically developing adolescent siblings of individuals with autism spectrum disorder. *Journal of Intellectual Disability Research*, *59*(1), 26–38. doi: 10.1111/jir.12124

Stalker, K., & Connors, C. (2004). Children's perceptions of their disabled siblings: 'She's different but it's normal for us.' *Children & Society*, *18*(3), 218–230. doi: 10.1002/chi.794

Sterponi, L. (2009). Accountability in Family Discourse: Socialization into norms and standards and negotiation of responsibility in Italian dinner conversations. *Childhood*, *16*(4), 441–459. doi: 10.1177/0907568209343269

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, *43*(5), 339–350. doi: 10.1352/0047-6765(2005)43[339:SOCWDR]2.0.CO;2

Stoneman, Z., & Berman, P. W. (1993). *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges*. Baltimore, MD: Paul H Brookes

Publishing Co.

Stoneman, Z., & Brody, G. H. (1993). Sibling relations in the family context. In Z. Stoneman & P. W. Berman (Eds.), *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges* (pp. 3–30). Baltimore, MD: Paul H Brookes Publishing Co.

Taylor, J. L., Burke, M. M., Smith, L. E., & Hartley, S. L. (2016). Families of Adolescents and Adults With Intellectual and Developmental Disabilities. *International Review of Research in Developmental Disabilities*, *50*, 195–231. doi: 10.1016/bs.irrdd.2016.04.001

Temi. (2019).

Walton, K. M. (2016). Risk factors for behavioral and emotional difficulties in siblings of children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *121*(6), 533–549. doi: 10.1352/1944-7558-121.6.533

Ward, B., Tanner, B. S., Mandleco, B., Dyches, T. T., & Freeborn, D. (2016). Sibling Experiences: Living with Young Persons with Autism Spectrum Disorde...: Discovery Service para Universitat de Les Illes Balears. *Pediatric Nursing*, *42*(2). PMID: 27254975

Zoom Video Communications, Inc. (2019). Retrieved from https://zoom.us

Appendix Index

Appendix A: Recruitment Materials

Recruitment Flyer

HEY SIBLINGS

WE WANT TO HEAR YOUR STORY

HOW DO SIBLINGS EXPERIENCE THEIR FAMILY?

IF YOU ARE 10 YEARS OR OLDER,
AND HAVE A SIBLING WITH A
DEVELOPMENTAL DISABILITY,
HELP US ANSWER THIS QUESTION
BY PARTICIPATING IN A ONE-
HOUR INTERVIEW!

CONTACT TAHLE
510-209-0363
TSENDOWSKI@BERKELEY.EDU

EARN A $15.00 GIFT CARD!

TAHLE; SIBLING STUDY
510-209-0363
tsendowski@berkeley.edu

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Recruitment Email

Dear Parents,

I am a graduate student in the School Psychology program at UC Berkeley and am writing to see if your family is interested in being included in my doctoral dissertation, which I am conducting under the supervision of Professor Susan Holloway.

A staff member from AGENCY NAME is reaching out to you on my behalf because you have a child with a developmental disability and at least one typically developing child. The purpose of my project is to better understand the experiences and perceptions of typically developing children and adolescents who have a sibling with a developmental disability. The goal of this work is to help professionals, who work with families like yours, to provide effective support to families as a whole, no matter their size or configuration.

If you and your child were interested in participating in my project I would come to your home, at your convenience, for about 30 minutes to discuss the study in more detail and answer any questions or concerns you might have. Then we would arrange a time for me to speak with your typically developing child in person at your home for about an hour about his or her daily family experiences. This informal conversation would be audio recorded so that it is accurately captured. Everything he or she says would be completely confidential and I would not reveal any identifying information about your child or your family. In addition, I would ask that you audio record a family dinner conversation on your cell phone and share this with me for the sole purpose of having something concrete to discuss with your child. I have worked extensively with families who have a child with a disability, and I am trained to talk to children and adolescents about their thoughts and feelings in ways that create a positive and supportive environment.

Your child must be 10 years or older to participate and must be currently living in the home with a sibling with a developmental disability. After completing the interview, your child will receive a $15.00 gift card of their choosing. If your child is interested in participating, or if you would like to hear more about the project, please give me a call or send me an email: 510-209-0363; tsendowski@berkeley.edu). I would love to tell you both more about it!

Your choice to participate in this project or not will have no influence on your family's access to services or relationship with AGENCY NAME.

Thank you for your time, and I hope to hear from you!
Tahle Sendowski
Doctoral Candidate, School Psychology
Graduate School of Education
University of California, Berkeley

Appendix B: Interview Protocol

DEMOGRAPHICS

Age of participant currently:
Gender of participant:
Participant’s self-identified race/ethnicity:
Age of disabled sibling currently:
Gender of disabled sibling:
Age of disabled sibling @ Diagnosis:
Diagnosis:
Current Services Accessed by disabled sibling:
SES: Lower Mid-Lower Middle Mid-Upper Upper
Parent's level of education:

INTRODUCTION

[Bolded information is read aloud to participants]

Families are different for all sorts of reasons, maybe there are 9 children in the family, or a parent has a health condition, or one child in the family has a developmental disability. I asked to interview you because you live in a unique family, in which your sibling has a developmental disability. I think your experience is important because it reflects what it is like to grow up with a sibling who is different than many other siblings. That is why I want to talk to you about your family experiences and hear your story. Parents get to talk about their experience a lot, but sometimes siblings do not, and they have a lot of important things to say too.

The information I collect from you is part of a study that I am doing to explore what families like yours look like from siblings' eyes. I think it is important to learn about your perspective so that professionals can support siblings in the right way, if they need help. Our conversation will take about an hour and a half, and if you are uncomfortable at any point just let me know and we can move on.

I am going to record our conversation and keep the materials that we make during our time together. However, your name will not be attached to any of this information.

EMOTION MAP

1. **I am interested in hearing about your experiences in your family on a day-to-day basis. To do that I am going to ask you to remember some interactions that you had with your family members over the past week or two. But first, I would like you to draw a blueprint of your house.**
2. **Here are some smiley-face stickers in different colors, let's pick out different colors for each member of your family.**
3. **Now, I am going to give you a few minutes to think about times over the last week or two when you felt a strong emotion at home. So think about when you were home over the last few days and you had specific feelings/emotions, meaning maybe you felt sad, happy, frustrated, angry, surprised, excited, or something else. To help me get a sense of what went on, when you are ready, please put some stickers down the map that show**

who was there and what kinds of feelings/emotions each person had.

4. Give 5 minutes to think and put some stickers down. If the participant does nothing in 5 minutes, ask them if they need some help. Encourage the participant to reference at least 3 incidents within the last week or two. If 2-3 were when the individual was alone, ask them explicitly to think about a time when they had an emotion with other family members present.
5. Once each incident is marked: **Tell me a little bit about what was going on during this interaction.**
6. Ask probing questions or make statements/interpretations to get more information. The participant must self-identify what caused the emotion, why the interactors felt and acted the way that they did, and how, if at all, the situation ended or was resolved. e.g., It looks like XX was not involved in any of these incidents. Is there a reason for that?
7. Probe about the frequency and severity of this type of incident in the home.

FAMILY DINNER RECORDING

[Conducted by the family the week leading up to the interview and sent to the interviewer to review before the interview]

Explain activity:

1. **As you know I asked you to record a family dinner this week. I asked you to do that so we could listen to it together and I could get a sense of your thoughts about the different interactions that occurred. I'm also curious about some of the thoughts you were having during dinner. If you want to stop the audio at any time to tell me about what was going on, or for any other reason, please do.**
2. **Before we start, I'm curious if you think it was a typical family dinner? How so?**
3. I will have listened to the recording ahead of time and noted the timing of at least 3 discrete interactions, during which another family member made a direct social overture toward the participant, the participant made a direct social overture toward another family member, and/or there was clear conflict between at least two family members. I will pause at the conclusion of these discrete interactions and ask for information.
4. **Tell me a little bit about what was going on during that interaction. I heard your voice change, what were you feeling? Was it… Was it anything else?** Ask probing questions or making statements/interpretations to get more information (e.g., Who was involved? What happened? How were they feeling? Why did they behave that way?). Participant should self-identify the stressor or reason for the incident/interaction, the feelings of the interactors during the interaction, why they felt that way, and any conclusion to the interaction.
5. Probe about the frequency and severity of this type of interaction in the home.

OPEN-ENDED QUESTIONS

I'm curious about a few more parts of your experience, so I have some questions for you:

1. **Throughout the day, we all have things that bug us or bother us. They can be little things or big things. So that I can learn a little bit about what tends to bother you on a normal day, first think about a typical day you had from this past week. Briefly tell me what happened from the moment you got up until you went to bed. During that day, did anything come up that bugged you? Do those things typically bug you?**
2. **Briefly describe the members of your family. What are their likes/dislikes? What roles do you each play in your family?**

   a. **In a crisis, what do you think each person in your family would do?**
3. **How would you describe, in your own words, your relationship with your sibling?**
4. **What is your current understanding of your sibling's disability? How does it affect him/her?**
5. **Are you generally included in conversations about your sibling's disability?**
6. **Are you involved in any of your sibling's therapies/interventions? If so, how? If not, why do you think?**
7. **Are there any taboo subjects in your home? What are they? Why do you think they are taboo?**
8. **Do you feel that your parents compare you and your sibling? In what ways?**
9. **Do you think your parents treat you and your sibling differently? How so?**
   a. **Are the rules in your home different for you and your sibling? What sorts of things do you get in trouble for? What sorts of things does your sibling get in trouble for?**
   b. **Do your parents praise you for certain kinds of behaviors? Can you give me some examples?** ***Is that different from how they praise your sibling?***
10. **Is there anyone who supports you in your role as a sibling? If so, who, and how?**
11. **Do you think your parents have a good understanding of your experience as a sibling? Why or why not?**
12. **If you have other typically developing siblings, do you think these other siblings experience your family differently than you do? Why?**
13. **On a scale of 1-10 (10 being the best sibling relationship, and 1 being the worst) how would you rate your relationship with your sibling?**
14. **Do you ever think about the future with your sibling?**
15. **Is there anything else that you think I should know about being a sibling of a child with a developmental disability?**

Appendix C: Methods Tables

Table 1 - Participants

Participant and Family Demographics														
Pseudonym	NDS Age	NDS Gender	NDS Race/ Ethnicity*	NDS Birth Order	DS Age	DS Gender	Other Typical Sibling(s) (age)	DS Initial Dx**	DS Dx Age	DS Current Primary Dx**	DS Current Secondary Dx**	DS Current Interventions ***	Income Range/ Class****	Parents' Level of Education
Ryker	10	Male	Caucasian	1st Born	7	Male	None	ASD	3.5 years	ASD	None	In-home ABA (3-9hr/wk); Social skills group (2hr./week); Public school with IEP (mainstreamed with full time aide); RC client	Middle	Dad – Graduate Degree Mom – Bachelor's degree
Phillip	16	Male	Caucasian & Asian	2nd Born	18	Female	None	ASD	4 years	ASD	Epilepsy	Public school with IEP (SDC, SLT, OT, & behavior services); Private SLT; RC client; In-home support services; SSI	Middle	Dad – Bachelor's degree Mom - Bachelor's degree
Sarina	12	Female	Latinx	4th Born	15 & 15	Female & Female	2 Sisters (21 & 25)	ASD	3.5 years	ASD	1 had health problems	Public school with IEPs (SDCs, OT, SLT); In-home ABA (2hr/day)	Middle	Dad – Bachelor's degree Mom – High School Diploma
David	15	Male	Latinx & Caucasian	Triplet	15	Female	1 Sister (15)	GDD	4 months	Unclear	Febrile Seizures	Public School with IEP (SDC, OT, PT, SLT); RC	Middle	Dad – Master's Degree

												client; In-home ABA off and on		Mom - Master's Degree
Maya	15	Female	Latinx & Caucasian	Triplet	15	Female	1 Brother (15)	GDD	4 months	Unclear	Febrile Seizures	Public School with IEP (SDC, OT, PT, SLT); RC client; In-home ABA off and on	Middle	Dad – Master's Degree Mom - Master's Degree
Olivia	11	Female	Caucasian & Asian	2nd Born	15	Female	1 Brother (8)	Congenital Diaphragmatic Hernia (led to stroke at birth)	Prenatal (20 weeks)	CP	Intellectual impairment; Food intolerances; Dysarthria	Private SLT; Public school with IEP (SDC, SLT, OT consult, adaptive PE); RC client	Middle	Dad – Doctoral Degree Mom – Doctoral Degree
Luke	17	Male	Caucasian & Filipino	1st Born	16	Male	None	DS	Prenatal (20 weeks)	DS	ASD	Public school with IEP (Speech, OT Consult, Special day classroom); Regional center client	Mid-Upper	Dad – Bachelor's degree Mom - Bachelor's degree
Daniel	13	Male	Caucasian	2nd Born	16	Male	None	SPD & GDD	4 years	ASD	None	Public school with IEP (Mainstreamed with 1period/day of Resource)	Mid-Upper	Dad – Bachelor's degree Mom - Bachelor's degree
Mateo	11	Male	Latinx & Caucasian	1st Born	6	Male	None	Genetic Condition (Dup15Q)	18 months	Genetic Condition (Dup15Q)	ASD	Public school with IEP (OT, PT, SLT, SDC); Private ABA & PT; Therapeutic	Mid-Upper	Dad – Master's Degree Mom – Doctoral Degree

												swim lessons		
Scarlet	11	Female	Caucasian	1st Born	4	Male	1 Sister (9)	ASD	3.5 years	ASD	None	Public school with IEP (SDC, OT, SLT); Mainstreaming at Head Start PreK with ABA Therapist (3day/week); In-home ABA (1day/week)	Middle	Dad – Bachelor's degree Mom - Bachelor's degree (& teaching credential)
Eleanor	16	Female	Caucasian	2nd Born	18	Male	None	ASD	2 years	ASD	PANS; Epilepsy; Apraxia; Hyper-anxiety; Gastric Issues; Aggression /Self-injury	Non-public school (SDC, SLT, OT); Osteopathy; summer camps for children with ASD	Mid-Upper	Dad – Master's Degree Mom – Doctoral Degree

Demographic information based on parent and subject report

Nondisabled Sibling (NDS); Disabled Sibling (DS)

**Self-identified*

***Autism Spectrum Disorder (ASD); Global Developmental Delay (GDD); Cerebral Palsy (CP); Down syndrome (DS); Sensory Processing Disorder (SPD)*

****Individualized Education Plan (IEP), Occupational Therapy (OT), Physical Therapy (PT), Applied Behavioral Analysis (ABA), Speech and Language Therapy (SLT), Regional Center (RC), Special Day Classroom (SDC), Social Security (SSI), Physical Education (PE)*

*****Parent-identified: Range: Lower, Mid-Lower, Middle, Mid-Upper, Upper*

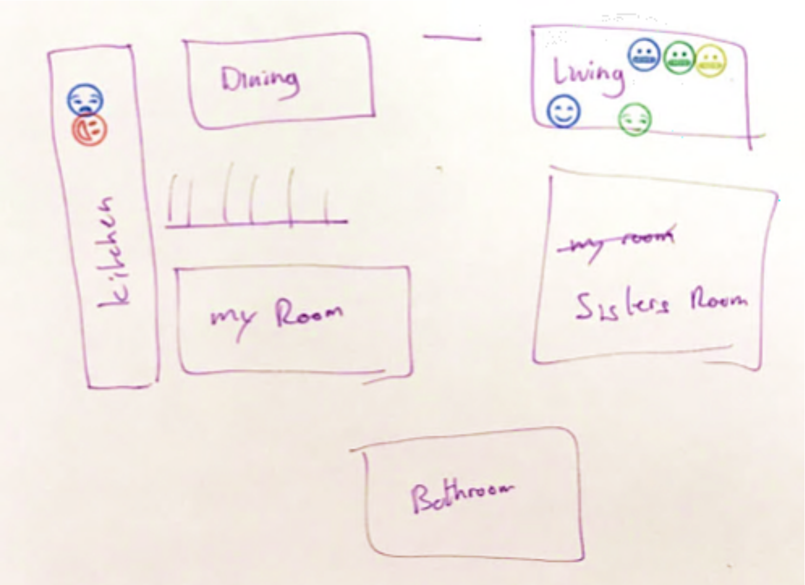
Table 2 – Codes and Definitions

Code Group	Code Name	Definition
None	Interaction W Stress	This code is given to either a *specific* family interaction involving the participant, or to a family interaction involving the participant that was described as *typical or recurring*. The interaction must include the occurrence of a negative emotion/feeling attributed to the participant. These quotes may capture example family interactions that the nondisabled sibling describes, or specific occurrences from the weeks leading up to the interview.
Emotion Codes	Emotion: disabled sibling	This code captures an emotion attributed to the disabled sibling during a family interaction.
	Emotion: Father	This code captures an emotion attributed to the father during a family interaction.
	Emotion: Mother	This code captures an emotion attributed to the mother during a family interaction.
	Emotion: Nondisabled Sibling	This code captures an emotion attributed to the nondisabled sibling during a family interaction.
	Emotion: Parents	This code captures an emotion attributed to both parents as a unit during a family interaction.
	Emotion: Sibling	This code captures an emotion attributed to a typically developing sibling during a family interaction.
Interaction Codes	Coping Behavior	This code indicates that the participant engaged in an action (internal or external) in order to respond to a demand placed on them. This can also include a behavior that is not used in response to a specific interaction but is identified by the participant as something that they use generally to manage demands.
	Resource	This code indicates that the participant used a resource (i.e., something they have) in response to a demand (Patterson, 1988). This can include a characteristic, trait, competency, or means. Resources may include intelligence, acquired knowledge and skills, personality traits, physical and emotional health, a sense of mastery, or self-esteem. This can also include a resource that is not used in response to a specific demand but is identified as something that the nondisabled siblings uses generally to manage a specific type of demand.
	Stressful Demand	This code indicates either: (a) an occurrence that reflects an ongoing tension that causes the participant to feel a negative emotion; or (b) an occurrence that causes the participant to feel a negative emotion. A demand may be a family member's behavior that is an ongoing difficulty, or a specific behavior or reaction of a family member.
Cognitive appraisal Codes	Cognitive Appraisal: Disabled Sibling	This code captures a reason for why the disabled sibling took a particular action or felt a specific emotion in relation to a specific family interaction or a family interaction that is described as typical or recurring. It is likely begun with the word "because." This can include a reason that is phrased as common/frequent or specific to that interaction.
	Cognitive Appraisal: Family	This code captures a reason for why the family as a whole unit, or any sub-unit of two or more family members, took a particular action or felt a specific emotion in relation to a specific family interaction or a family interaction that is described as typical or recurring. It is likely begun with the word "because." This can include a reason that is phrased as common/frequent or specific to that interaction.

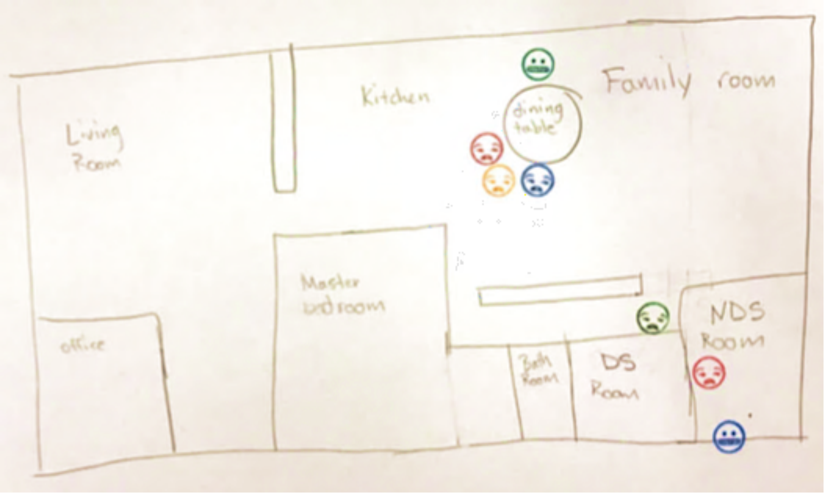
	Cognitive Appraisal: Father	This code captures a reason for why the father took a particular action or felt a specific emotion in relation to a specific family interaction or a family interaction that is described as typical or recurring. It is likely begun with the word “because." This can include a reason that is phrased as common/frequent or specific to that interaction.
	Cognitive Appraisal: Mother	This code captures a reason for why the mother took a particular action or felt a specific emotion in relation to a specific family interaction or a family interaction that is described as typical or recurring. It is likely begun with the word “because." This can include a reason that is phrased as common/frequent or specific to that interaction.
	Cognitive Appraisal: Nondisabled Sibling	This code captures a reason for why the participant took a particular action or felt a specific emotion in relation to a specific family interaction or a family interaction that is described as typical or recurring. It is likely begun with the word “because." This can include a reason that is phrased as common/frequent or specific to that interaction.
	Cognitive Appraisal: Sibling	This code captures a reason for why a typically developing sibling took a particular action or felt a specific emotion in relation to a specific family interaction or a family interaction that is described as typical or recurring. It is likely begun with the word “because." This can include a reason that is phrased as common/frequent or specific to that interaction.

Appendix D: Example Emotion Maps

Emotion Map, David



Emotion Map, Luke



Appendix E: Analysis Tables

Table 1

Stressful Demands and Primary Appraisals

Broad Category of Stressful Demand	**Subcategory of Stressful Demand**	**Participants Affected**	**Examples**
Stressful disabled sibling Behavior	*Disabled sibling behavior interrupts the nondisabled sibling's activity*	Ryker, Phillip, Sarina, David, Maya, Luke, Daniel, Scarlet, Eleanor	• "Cuz we are just trying to eat a normal family dinner and we don't want to talk about the Robin Williams tunnel." (Ryker) • "So, this was me trying to do homework, and my sister likes to be very loud with her music. And so, what she'll do sometimes is to like, not really scare me and my parents, but like get our attention, by turning the music really loud. And so, if I'm trying to study, and like do homework, it can be a lot sometimes." (Phillip) • "So it's almost 10 o'clock, I'm in bed, he's like—I'm like: 'turn off the light.' He's like: 'no, I'm just finishing my boots, NOW I get to go pack my bag.'" (Daniel) • "…well [Sister & nondisabled siblings] usually get home from school, and we're trying to talk to mom about our days and [disabled sibling] keeps repeating the same thing about like what he—like keeps interrupting us." (Scarlet)
	Disabled sibling behavior elicits concerns about the disabled sibling's wellbeing	Ryker, Phillip, Sarina, Olivia, Mateo Scarlet, Eleanor	• "He was hitting himself on the head…. I feel sad because I'm guessing it probably hurts." (Mateo) • "…he's SUPER sensitive when he gets in trouble. And he like starts crying, and he goes like this [puts hand to face] And he like hits himself." (Scarlet) • "…I wasn't feeling so good…. And then [disabled sibling] wanted to give me a hug. And then, but, I didn't—because we have to be careful not to get [disabled sibling] sick, because when he gets sick, he gets really, basically all his symptoms, that he normally has, they basically get worse." (Eleanor)
	Disabled sibling damages private property	Ryker, Olivia, Luke, Scarlet	• [in regard to Lego structure] "[disabled sibling] did this [arm swiping gesture], it was on the table. It was the size of probably, it was about—the floor was about the size of the iPad. It was about THAT tall [gestured to indicate height], and it had a bunch of battling troops. One sweep off the table KABLAMO! Everything's gone." (Ryker) • "He just, he grabs hold of things, and likes to destroy things. So, if you get too close and you have your—like a Hoodie—he'll try to pull the string all the way. In front of them." (Luke)
	Disabled sibling lacks communication skills	David, Maya, Olivia, Luke	• "…she can really frustrate me when I try and talk to her, and she doesn't respond, she'll completely ignore me." (Maya) • "Well, we often find that you don't understand what [disabled sibling's] saying. Like she'll be like, she'll say something, and you don't fully understand, so you kind of ignore it. Because you don't know what to say in turn." (Olivia) • "And it's kind of just like: he doesn't say anything, interact much, do anything. If I do try to interact with him, he usually doesn't, he seems like he doesn't want to." (Luke)
	Disabled sibling offends/embarrasses nondisabled sibling	Ryker, Phillip, Maya, David	• "It's like 'we're all living here. [disabled sibling's] gotta know how to share space the right way.' And like we've told her, so many times, sooo many times. And she just doesn't listen. It's just, to me, it's just like a basic 'f you,' you know? 'I'm going to do whatever I want. And you're going to have to, YOU'RE going to be the one who has to close the door. YOU'RE going to be the one that has to see me walking around in my underwear.' That's how I perceive it." (David) • "If I say something that's, that's appealing to my sister, she'll remember it and she'll say it at the wrong time. Like if something really bad happens like 'oh this and this happened,' then let's say in a different like on a different day,

			and I'm with my sister and maybe some other people, she'll randomly blurt this out. This random event that happened, that was bad." (Phillip)
	Disabled sibling behavior leads to family conflict	Maya, Daniel	• "But my dad came home with my sister, and I had the door locked cuz I guess I was taking a nap, and I lock the door sometimes cuz when [disabled sibling] comes I, I dunno. Anyways, so, so she came to knock on the door. But I had my headphones in cuz I was listening to music, so I couldn't hear it. And I was also just in a bad mood because I'd had a bad day. And so, she knocks on the door and I think she got, she got, she was frustrated by the time that I went to open it. And my dad, I don't remember the full situation, but I think I talked back—like I was being really snarky when he came to ask why [disabled sibling] was being so upset. And I was like: 'well I was gonna open the door for her. But she just got aggravated really quickly.' And then my dad got mad at me cause when I was explaining it to him I was really snapping back at him, and I didn't—it just frustrated me that when they came home they like—cuz I was having a fine time in my room, just relaxing. And then it kind of—a whole fight broke out when they came home." (Maya) • "When [disabled sibling] comes home late, because he was out with his girlfriend. He does that. He's like: 'Oh yeah, I'll be—at the latest I'll be back by 7:30.' And then he comes home by eight." [Researcher asks: Why does that bug you?] "Just cuz there's usually conversation afterwards. Sometimes involves raised voices." (Daniel)
	Disabled sibling behavior leads to parent stress	Maya, Olivia	• "I feel bad for my mom sometimes because my sister's more like HER, like my sister is very orientated with my mother. Like she is always with her, and when she's not she's always asking me about her. And whenever my mom comes home, from work, it's like my sister goes straight to her, bombarding her with questions…" (Maya) • "[disabled sibling] Boiling water is more like you don't want another row to come up, or anything like that." [Researcher asks: You don't want another row to come up?] "It's not exactly a row, it's more like you don't want mommy to be angry." (Olivia)
Stressful Parent Behavior	*Parents engage in differential treatment*	Ryker, Phillip, Sarina, Olivia, Eleanor	• "I mean, sometimes it's annoying, because if I—whether it's in school or during sports, if I PR in a race or I do really good on a test, they'll be like 'oh, nice, okay.' Carrying on. They won't really pay attention to it. Which I get, but at the same time is annoying to me…. But with my sister, they kind of have to congratulate her because it builds her confidence and it makes her work harder for whatever she's trying to do." (Phillip) • "[disabled sibling's] the autistic kid, and I'm the normal kid. Basically. And I think maybe, sometimes I feel like I have a little more pressure, because of that. It's almost as if I'm the only child, but I'm obviously not." (Eleanor)
	Parents are critical of nondisabled sibling's behavior toward the disabled sibling	Sarina, David, Luke	• "Sometimes I say that I'm not comfortable doing something. And then they'll be like: 'why not?' And they'll try to make me do it. And it's just stuff like that. Like they don't understand—or like when I'm feeling sad, or when I'm feeling angry, they'll be like, tell me to stop like: 'why are you angry?' Or something like that. And I don't want to tell them because it's the twins. And then they'll think that it's because I'm growing up, or something." (Sarina) • "…usually I try to get involved. But then my parents don't like it when I get involved. Because then they get mad at ME. Since they're kind of like: 'it's not any of your business.' And also they're like: 'you're too aggressive,' or something like that." (Luke)
	Parents do not respond appropriately to disabled sibling behavior	David, Luke, Scarlet	• "…they baby him a lot. And so I think—like let's say he gets aggressive, or he still, he lashes out, he'll hit you, or do something. And I'm like: 'well he only does that because you let him.'" (Luke) • "Well, it was kind of annoying always having [mom]—But, it was okay because she, I mean, I understand why she was grieving. But it was a little too long, and then she like always had to explain it to us. Like, I don't know, I just—it was not very good." (Scarlet)
Stressful Nondisabled	*Self-Blame*	David, Maya, Luke, Eleanor	• "Although I do feel bad cuz I stay up really late a lot of the times doing my homework. And I have a light on my desk, and so when I have it on, I'm sure it makes it hard for [disabled sibling] to sleep." (Maya) • "I feel like I don't interact as much with my brother as I could." (Luke)

Sibling Behavior			

Table 2

Coping Behaviors, Resources, and Secondary Appraisals			
Capability	**Coping Behavior Type**	**Participants Affected**	**Examples**
Coping Behavior	*Disengages from parents and/or disabled sibling* (e.g., moving away, ignoring, not engaging)	Ryker, Phillip, Sarina, David, Maya, Olivia, Luke, Mateo, Eleanor	• “So when I get really really mad at him, I run out to the backyard and go behind the shed. And this little space between the gate and the shed, I can kinda squeeze through. And I can sit there and maybe either cry or do something, I'll just sit there and wait.” (Ryker) • “I don't feel like there is a point to interact with him, if he's not going to interact back with you. Like he won't respond, he won't—or he'll just get agitated and lash out and hit you. So, I'm like: ‘there's—I don't need that.’ So, I'm just not going to do it.” (Luke) • “And then [disabled sibling] wanted to give me a hug. And then, but, I didn't—because we have to be careful not to get [disabled sibling] sick, because when he gets sick, he gets really—basically all his symptoms, that he normally has, they basically get worse.” (Eleanor)
	Intervenes directly but non-aggressively with disabled sibling	Ryker, Phillip, David, Maya, Olivia, Luke, Mateo, Scarlet	• “I was trying to reason with her and try to say like ‘you've had it for this amount of time, and you should let other people use it.’ …Eventually I just told her ‘Ok. You get 10 more minutes and then I'm coming down, and I'm going to use it.’" (Phillip) • [Researcher asks: …why did you say: ‘please stop banging?’] “Why did I say that? Because, because I wanted him to stop banging his head on his hand.} [Researcher asks: Okay. Does he ever listen when you say that?] “Sometimes if, if you say ‘stop’ loud enough, or something like that.” (Mateo) • “…sometimes it's like if he's annoying me, I'll give him a direction. But usually it's my mom, and I like comfort him after he gets in trouble.” (Scarlet)
	Aggressively responds to disabled sibling (e.g., yelling, shouting, arguing, tackling)	Ryker, Sarina, David, Olivia, Luke, Daniel	• “I screamed. I was like: ‘noooooooooo!’ And I tackled him and shoved him on the couch and punched him in the back.” (Ryker) • “And I started like, kind of yelling at her to put her clothes on.” (Sarina) • “It's actually more like instinct. It's more like ‘[disabled sibling]! No! Don't touch that!’ Or like if she's about to mess with something I want to keep together, or I don't want her to touch, it's like: ‘no!’" (Olivia)
	Internally reasons about disabled sibling’s and/or parent’s behavior	Phillip, Sarina, Maya, Daniel, Scarlet, Eleanor	• “I've gotten used to the idea of like, well, she doesn't think the same way, so I shouldn't take anything personally…. I've gotten used to being able to live with the fact that she's not always gonna—she's not going to understand me. And like, she's not always going to listen to what I have to say.” (Maya) • “I don't feel like I don't get enough attention, because I feel like I actually do get a lot of attention. It's just that [disabled sibling's] problems are bigger. Yeah. And I think my parents make sure that I do get attention. It's just that my problems aren't as big as his. So, they kind of have to deal with his first before they deal with mine, to a certain extent. [Researcher asks: Does that make sense to you? Do you Resent it?] “Yeah, I don't resent it.” (Eleanor)
	Complains or tells parent(s) what to do	Maya, Olivia, Luke, Scarlet	• “…well we usually get home from school, and we're trying to talk to mom about our days and [disabled sibling] keeps repeating the same thing about like what he—like keeps interrupting us.… And [mom] tries to like—we tell her to just ignore him, but she always wants to try to engage him.” (Scarlet) • “And so, I was like: ‘you need to teach him how to sneeze—or how to cover his sneeze.’ Because that's just gross. That's just a normal thing you teach your children, right? Like just certain manners.” (Luke)

Resource	*Parent(s) act to provide support to nondisabled sibling*	Ryker, Phillip, Daniel, Scarlet, Eleanor	• “So [disabled sibling] hits M in the back, tackles me, and pulls A's hair. And then I pick him up and throw him on to the other side of the trampoline. And then, daddy comes out, pulls him out, starts yelling at him…” (Ryker) • “Because we had been arguing over that and [mom] was like: ‘Nope, just [Daniel] you come here, [disabled sibling] you go get ready.’” (Daniel) • “And usually we end up getting to talk to her. But it's usually like when [disabled sibling's] like playing something else, or doing something like that. [Researcher asks: So, will he kind of just leave eventually? Or does your mom redirect him to play something?] “Well my mom has to redirect him. Yeah, my mom usually has to redirect him.” (Scarlet)
	Participant has knowledge of parent positive intent	Phillip, Sarina, Scarlet, Eleanor	• “Because I feel like [parents] don't give me enough care. But I know they do. And I know that it's, that they give the twins more care because they're more high maintenance.” (Sarina) • “And [mom] tries to like—[sister and I] tell her to just ignore [disabled sibling], but she always wants to try to engage him. But like what he's talking about doesn't really matter, cuz it's just like scripting from shows. But she tries to make him say: ‘excuse me,’ or—then it just takes more time. And I wish she would just not pay attention. But I guess she wants him to feel like he's still there. But he's not really talking about anything legitimate that we're supposed to be talking about, so...” (Scarlet)
	Participant has ability to take care of him/herself	Phillip, Sarina, Eleanor	• “Because [the twins are] more high maintenance. So—And I already know how to take care of myself.” (Sarina) • “And I think I've had to learn to do more things on my own. Because of having [disabled sibling] in my life.… And like I have to cook for myself sometimes. That kind of thing.” (Eleanor)
	Participant has own physical space	Ryker, David, Luke	• “And then he let go, and then I went to my room.” (Luke) • “I've kind of, I've kind of been experiencing less frustration because I've been just putting myself in my room, cuz I know the one way to get out of all this frustration is just not to experience it.” (David)

Table 3

Themes Across the Cognitive Appraisal Processes

Cognitive Appraisal Process Themes		**Stressful Demand subcategory (Participant, age)**	**Stressful Demand and Primary Appraisals**	**CB Type**	**Coping Behavior and Secondary Appraisals**	**Resource(s)**
Selecting ineffective coping behaviors (11 out of 11 participants)	***Shallow primary appraisal*** (Ryker, Sarina, David, Maya, Olivia, Luke, Scarlet)	Disabled sibling lacks communication skills (**Maya, age 15**)	"Well she asks a lot of questions. And it takes a lot for me to like think. And they're very repetitive too…. And she keeps going deeper and deeper. And it's like questions that don't really interest me, and it's just like her interrogating me…And also her questions are kind of like, they're very blatant and random. And like: 'oh what was your friend wearing? How many buttons did their shirt have? Why was it red?' And blah, blah, blah. It's like: 'okay, I don't even want to answer your questions.'"	Disengages from parents and/or disabled sibling	"...and I'll answer the first 5, and then after a while I just tune her out…And so, when it's not a real conversation I just kind of, I just drop it. …maybe I should, instead of doing THAT, I should ask her a question. But also, when I do that, she's like: 'good, yeah, yeah.' Like she doesn't want to answer that. She just wants to ask. So, that makes it hard. That dynamic makes it hard to like talk. Because she only wants to ask questions, and so if I ask her a question it's not going to go well.… So, it makes it really easy for me to zone out."	None
		Disabled sibling damages private property (**Ryker, age 10**)	"…Babysitter was there, my mom left.... And THEN [disabled sibling] goes bazooka, and then he's galloping around—he broke a light fixture. And then he threw a ball and cracked it. And he was screaming, and then I was in tears. And then, it was really embarrassing cuz [my friends] arrived just at that moment." [Researcher asks: Why did he go bazooka that time?] "I have no clue. It's just how he does it."	Disengages from parents and/or disabled sibling	"And I like shot out the door."	None
	Logically disconnected appraisals (Ryker, Phillip, Sarina, David, Maya, Olivia, Luke, Daniel, Mateo, Scarlet, Eleanor)	Disabled sibling behavior elicits concerns about the disabled sibling's wellbeing (**Mateo, age 11**)	"He was hitting himself on the head…I feel sad because I'm guessing it probably hurts." [Researcher asks: Why do you think he does that?] "I don't know. I think he's just trying to get attention or something."	Intervenes directly with disabled sibling	[Researcher asks: …why did you say: 'please stop banging?'] "Why did I say that? Because I wanted him to stop banging his head on his hand. [Researcher asks: Okay. Does he ever listen when you say that?] "Sometimes if, if you say 'stop' loud enough, or something like that." [Researchers says: So, do you help out when he's doing things like that to try to stop him?] "Yeah. cuz it's not good for him."	None

		Disabled sibling behavior interrupts nondisabled sibling's activity (**Daniel, age 13**)	"[disabled sibling] was packing to go to the cabin, and I had gone to bed, just gotten in bed. He finished polishing his boots, instead of—And so I was like—he had put all the oil on them. And he's got his steel toed boots that he wears. And so, instead of packing and doing his laundry. So, he had all that stuff on his bed. So, it's almost 10 o'clock, I'm in bed, he's like—I'm like: 'turn off the light.' He's like: 'no, I'm just finishing my boots, NOW I get to go pack my bag.'"	Aggressively responds to disabled sibling	"It's like: 'why didn't you just do that instead of polishing your boots? You can polish your boots any other time!'" [Researcher asked how (disabled sibling) responded] "There was a big argument over it. And so, I just ended up going to my mom's room. And then later she sent me back. [Researcher asks: In the middle of the night?] "Yeah. Because we had been arguing over that and she was like: 'Nope, just Daniel you come here, [disabled sibling] you go get ready.'"	Parent(s) act to provide support to nondisabled sibling
	Inconsistently effective coping behaviors (Phillip, Sarina, Maya, Olivia, Eleanor)	Disabled sibling behavior leads to parent stress (**Olivia, age 11**)	Boiling water is more like you don't want another row to come up, or anything like that. [Researcher asks: You don't want another row to come up?] It's not exactly a row, it's more like you don't want mommy to be angry. And you don't want anything to happen. … But it's like, I guess I feel like [disabled sibling] gets in trouble a lot. But it's not exactly trouble, because she does not understand what she's doing. Either she thinks she's being helpful, like boiling a lot of tea. And she's like letting it sit everywhere. And there's a lot of tea in the house. And she thinks she's doing something good. She thinks that tea's nice and that she's being helpful, and that mommy likes the tea.… [disabled sibling] thinks it's good to boil tea, and I don't really mind it, actually. Because I'm not the one who's having to drink at all."	Intervenes directly with disabled sibling	[Researcher asks: So, you're trying to stop her because you don't want anything to happen?] "Yeah. It's also that sometimes, like bad moods can come up from small things.… Like if [disabled sibling] did something wrong, as far like: '[disabled sibling], what are you doing?' Like it's—patience is kind of short here. Easily cracks.	None
		Parents engage in differential treatment (**Sarina, age 12**)	"…when I was little, we would go to the mall with the twins, and whatever the twins wanted, they would get them. But if I wanted something, they wouldn't get me it, because they would be like: 'oh, we'll get you this next time.' Stuff like that. But they would get the twin stuff. And I would get really sad about it. So yeah, that's the only time I feel like that."	Internally reasons about disabled sibling's and/or parent's behavior	[Researcher asks: But you said you would kind of understand why? Why do you think?] "Because they're more high maintenance. So—And I already know how to take care of myself. So, I think that my parents already know that I know how to take care of myself. So, they don't need to worry about me as much. But they need to worry about the twins because they don't know how to take care of themselves, or anything like that. But sometimes it just gets to me,	Knowledge of parent intent & Has ability to take care of him/herself

					and I'm just like, like feeling, I don't know, like sad. Because I feel like they don't give me enough care. But I know they do. And I know that it's, that they give the twins more care because they're more high maintenance.”	
		Disabled sibling behavior interrupts the nondisabled sibling’s activity (**Phillip, age 16**)	“I was trying to chill out and play video games. I think it was last weekend. And my sister didn't want to get off the TV. And so, I was kind of conflicted because I wanted to play my video games. [Researcher asked why [disabled sibling] would not get off of the TV] “I don't know. It's probably because—well actually I know it's not because she's not done. Because what she likes to do is, she'll watch it on replay. She's never really done. She also doesn't, I don't think she likes people using it when she's not using it, you know? Like, she wants to be there if someone else is using it, whether it's at like a family gathering or someone else's house, she wants to be there when something happens. And so, I feel like that's what happens sometimes…And also, I think she just, she just loves her shows, you know? It really comes down to that.”	Intervenes directly with disabled sibling	“I was trying to reason with her and try to say like ‘you've had it for this amount of time, and you should let other people use it.’ And she was like ‘no, I wanna keep using it.’… Eventually I just told her ‘Ok. You get 10 more minutes and then I'm coming down, and I'm going to use it.’ And she was like ‘Ok.’ And 10 minutes passed, and she didn't want to get off, and then my mom distracted her by saying: ‘let's go,’ I think, ‘take a shower’ or something. And she was like ‘oh, ok,’ and then she left and I got my time.”… “And I was trying to solve the problem as well. And trying to reason with [disabled sibling]. But it wasn't really working in my favor at the time. But that's how it, that's how it goes.” [Researcher asks: And does your mom usually try to help out when there's conflict like that happening?] “Yeah, but usually I can deal with it by myself. I have gotten to that point where I can take control of the situation and—when I was younger, it was a lot more, but now I, I'm pretty good at handling situations like that.”	Parent(s) act to provide support to nondisabled sibling
Experiencing pile-up of stressful demands (Phillip, Maya, Olivia)		Disabled sibling behavior interrupts the nondisabled sibling’s activity (**Phillip, age 16**)	[Referring to disabled sibling scripting during family dinner] “I mean I get why she does it. It's because if there's something she likes, whether it's a movie or a TV show, and there's one specific scene, like locking someone in a bathroom, it's like if she could put herself in their shoes, she would enjoy doing that. You know? Like she enjoys watching it. But she also like wants to be in it. You know what I mean? Like when we were all little, we all were like: ‘oh, I want to be in	Internally reasons about disabled sibling’s and/or parent’s behavior	“Sometimes it bothers me. If like, if I'm stressed out, that's really the last thing I want to hear because it's just like, it's nonsense. But if I'm neutral, I'm just like: ‘okay, yeah.’ I'll hear it, I'll listen to it. And then that's it. And then she'll stop talking about it because we'll just move on.”	None

		this movie, cuz it would be so fun,’ you know? That's what she's thinking, I think.			
	Disabled sibling behavior interrupts the nondisabled sibling’s activity (**Maya, age 15**)	“…[disabled sibling]—actually that always happens. Whenever I'm like—I'll stay up late and I'll like sit on the couch and read or something. And [disabled sibling] will come up, or not come up, but she'll just like come and sit next to me. And then I'll go into my bed, and then she'll go in to the room. It's like she kind of follows me around. And also, same with brushing my teeth. [disabled sibling]—Okay I'm the one that [disabled sibling] copies a lot.” … “And I think it's cute, but I also find it very annoying. So, whenever I go to brush my teeth, and she's already brushed your teeth, she'll come and start brushing her teeth. And like we have two sinks, so it's fine, but it just, it bothers me. I'm like: ‘[disabled sibling] can you not follow me.’ And so sometimes I get frustrated by it. [Researcher asks: Why do you think she does that?] “I think, I'd like to say that she looks up to me. I think that it's good for her to have someone to follow. And she—that's like a way for her to maybe get to know me better, or something. And like be more, not NORMAL, but like know how to do things.… She does it so much that, I don't care anymore, but like...”	Internally reasons about disabled sibling’s and/or parent’s behavior	“When my parents point it out, I'm like: ‘yeah, whatever.’ It does bother me, but I just choose not to care about it. Although sometimes it does frustrate me. [Researcher asks: “Why do you think it frustrates you?] “Well, when I'm in a bad mood and [disabled sibling] does it, I think it's just like the last thing I need.”	None

Table 4

Themes Across the Cognitive Appraisal Process: Using Preventative Coping Behaviors

Cognitive Appraisal Process Themes	**Stressful Demand Type (Participant)**	**Stressful Demand and Primary Appraisals**	**CB Type**	**Preventative Coping Behavior(s) and Secondary Appraisals**
Preventative coping behaviors (Phillip, Sarina, David, Maya, Olivia, Luke, Scarlet)	Parents do not respond appropriately to disabled sibling behavior (**Luke, age 17**)	“But it's just like, my mom will repeatedly ask him the same question, expecting a different outcome.” [Researcher asks why mom keeps asking] “I don't know. Maybe because she thinks that he might respond differently. But I don't know why she would think that, because that's never happened.”	Complains or tells parent(s) what to do	[During dinner audio, nondisabled sibling restates disabled sibling’s response to mom’s question: “That’s a no.”] “And it's like just—like he already gave you his answer, just stop. Stop asking it.” [Researcher asks: So, you were trying to like head-off her asking this question again?] “Yeah. Like ‘that's a no.’ You don't need to ask him again.”
	Disabled sibling behavior interrupts the nondisabled sibling’s activity (**Sarina, age 12**)	[The researcher asks if it’s typical that she does not interact with one of her disabled siblings during dinner] “It's pretty typical, because she doesn't like bother me or anything like that. She doesn't come up to me and ask me for anything. So, I just don't do anything. [Research says: So, you don't initiate contact with her?] “Yeah.” [Research says: How come?] “Like I said, she doesn't come up to me or anything like that. And asks me for anything, except iPods, or apple juice, or tickling, or something. And like at the dinner table, she usually comes up to my dad first, and then my mom. And then if both of them don't work, then she comes to me.”	Aggressively responds to disabled sibling	“And I think that she doesn't come up to me because I get really annoyed, by her. So, then I like start yelling, and she doesn't want me to start yelling. So, then she just goes to my parents for it.”
	Disabled sibling offends/embarrasses nondisabled sibling (**Phillip, age 16**)	“If I say something that's, that's appealing to my sister, she'll remember it and she'll say it at the wrong time. Like if something really bad happens like ‘oh this and this happened,’ then let's say in a different like on a different day, and I'm with my sister and maybe some other people, she'll randomly blurt this out. This random event that happened, that was bad.”	Disengages from parents and/or disabled sibling	“I try to avoid the awkwardness I guess. You know?” [Researcher asks: So, you don't say things in front of her in case she'll remember it and like say it at the wrong time later?] “Yeah, exactly.”

Table 5

Themes Across the Cognitive Appraisal Process: Experiencing Compounding Stressful Demands

Initial Stressful Demand Type (Participant)	**Initial Stressful Demand and Primary Appraisals**	**Initial CB Type**	**Initial Coping Behavior(s) and Secondary Appraisals**	**Second Stressful Demand Type**	**Second Stressful Demand and Primary Appraisals**	**Second CB Type**	**Second Coping Behavior(s) and Secondary Appraisals**
Unspecified disabled sibling behavior (**Sarina, age 12)**	[Unspecified disabled sibling Behavior]	Complains or tells parent(s) what to do	“Sometimes I say that I'm not comfortable doing something.”	Parents are critical of nondisabled sibling’s behavior toward the disabled sibling	“And then [parents will] be like: ‘why not?’ And they'll try to make me do it. And it's just stuff like that. Like they don't understand—or like when I'm feeling sad, or when I'm feeling angry, they'll be like, tell me to stop like: ‘why are you angry?' Or something like that.”	Disengages from parents and/or disabled sibling	“And I don't want to tell them because it's the twins. And then they'll think that it's because I'm growing up, or something.” [Researcher asks: Just puberty, or whatever?] “Yeah. They'll be like: ‘you'll get over it.’ Or something like that. And just like: ‘okay.’”
Disabled sibling offends/embarrasses nondisabled sibling (**David**, **age 15**)	“…seeing her with just her underwear on, running around the house. Or she wears this—sometimes she doesn't even wear underwear, and she just has some blouse, and I'm just like: ‘oh my gosh, I just don't want to see your’—She'll be changing, and she doesn't close her door, and I open my door, but it's like the hall is looking right at each other. So I'll just be like ‘ah, come on!’ And I have to go close the door or something, and it's like ‘come on, what's wrong?’ Or I'll go out and I want to use the bathroom, and I see the door open, and I'm like ‘oh great	Intervenes directly with disabled sibling	“…the thing is when I get involved with [disabled sibling], I tend to make the situation worse sometimes.” [Researcher asks: Why do you think that is?] “[disabled sibling] is only really like perceptive to more gentleness. And I'm a little like rough, I think. For me sometimes, just like no B.S. I just want to like deal with the situation, but that's just not how she rolls. And sometimes I'm just caught up in myself, so I just, I don't change the mindset. And then I just end up escalating her because she doesn't really react well to that kind of like, I don't know. She can pick up	Parents do not respond appropriately to disabled sibling behavior	[Researcher asks: how do you, how do you feel about parents doing it differently?] “It really annoys me sometimes. I feel like they give her too much leeway. Cuz it's just, when I'm in the moment I'm just thinking like logical for myself. Like ‘why is she acting like this? She can't behave like this.’ Whereas they're like giving her a little leeway, and I'm like ‘come on, she still has to get punished for doing something like this. How is she going to learn?’ Cause for me it's just like, she knows she's doing something bad. I know she knows she is doing something bad. At a certain point she knows for sure. And then they're still just being kind of like more	Disengages from parents and/or disabled sibling	“And I just—now that I have my own room, I've just kind of been in there. And I've been less involved with [disabled sibling] too, just because it just like caused me so much frustration in the past. It's just like, I'm just trying to stop because I don't want to give myself unnecessary stress. Especially when I'm so tired. But sometimes I'll—but every, every hour I'll come out of my room and I'll just like, I'll just mess around with everybody. And then I'll kind of just go back in. But whenever I come out, I'll just see [disabled sibling] doing something that it's just like I'm so glad I have my room. I just think to myself: "’I'm just going to

	nobody's in there.’ And then I just see that she, she's just, she's on the toilet and she just left the door open and I was like ‘oh my gosh.’" [Researcher asks why this behavior bothers David] “Basic decency. Yeah, I'm just like ‘come on.’ It's like ‘we're all living here. You gotta know how to share space the right way.’ And like we've told her, so many times, sooo many times. And she just doesn't listen. It's just, to me, it's just like a basic ‘f you,’ you know? ‘I'm going to do whatever I want. And you're going to have to, YOU'RE going to be the one who has to close the door. YOU'RE going to be the one that has to see me walking around in my underwear.’ That's how I perceive it. Just like when I'm thinking normally. But when I like really think about it from her perspective, I'm like ‘oh maybe she just’—Cuz I know she has a hard time with moral standards sometimes. And I'm just like I know she doesn't understand, but it's still		on moods and stuff. And she gets all frustrated.”		calm with her. And I'm just like ‘oh my gosh.’ I mean there has to be some reprimandation or something. Cuz—and it feels like sometimes my parents have just given up because they're SO tired. And I totally understand that. But, for me, I still feel, in my own like righteousness or sense of righteousness, like ‘why, why is she able to get away with something like this?’ And then I end up being the one who gets reprimanded sometimes. So that's, that's why it really frustrates me when they behave—when they interact with her differ—or try to deal with the situ—when they deal with the situations differently like that. Because sometimes I just, in the moment I just fail to understand that—the difference in how you HAVE to deal with somebody like her, like with her situation. Yeah. How they—cuz, when you try to, when you're kind of rough with her, yelling makes the situation worse. You have to be calm. So, I know, I mean when I think about it, I know they're doing the best, they're doing the absolute best thing to calm [disabled sibling] down. But it's just—like I said earlier, in the moment, it's just I can't,		go back in my room.’… So it's just best for me just not even to talk to her sometimes, because—just the way I am. Sometimes the way I talk. It just doesn't resonate with her, so she just—it escalates the situation.… By distancing myself from her has also made it harder for me to be more understanding in a sense. Like Maya, she sleeps in the same room with [disabled sibling]. But with me it's like I'm just trying to be as far away as possible sometimes because I know I'll just get frustrated. It's like, it's like my mindset. Because I just realize, for me, I'm psyching myself out. I'm just thinking "oh I know I'll just be frustrated when I try to do something like this. What's, what's the point?" And then when I go and try to interact it's just like: ‘see this is exactly what, this is exactly what's happening.’”

	really frustrating for me because it's just like all of us have to do this, so you're not exempt from it.”				I fail to understand that. And it just really frustrates me. I want something different. So, come on. It's been this way for too long. Yeah, sometimes I feel like I'm the only one thinking that. And that's also why I feel kind of like isolated sometimes too. It's frustrating.”		
Disabled sibling lacks communication skills (**David, age 15**)	“She doesn't seem to have the ability to answer [questions] or she just—she knows the answer; she just doesn't really say it. She just, she would rather be asking questions. Conversations are hard with her because it's very one-sided. It's, if I'm going to talk to you, you're going to be listening and answering all of my questions about anything. And it's very direct. And when you try to have a conver—she'll get frustrated sometimes if you're try to like, if you're the one trying to ask her questions and driving the conversation. So, it's very controlling in a sense. So that's the frustrating part about it for me. And also, the fact that she just doesn't want to ask me the question directly sometimes.”	Intervenes directly with disabled sibling	[Researcher asks: Does anyone kind of push back with her and try to get her to answer their questions instead of just always answering her questions?] “I do. Because it frustrates me. Sometimes I'm pretty antagonistic. I'm just like ‘come on, answer the question.’ You know? And sometimes I'll have the wrong tone and then things will escalate.… I don't care about getting her angry cuz I'm just like ‘she's my sister.’ I just see it the same as messing around with my other sister sometimes. But she just—sometimes she can't take it the same way, so it makes it hard. So, I've kind of tried to ease down on that cuz I know, I understand my parents are the ones who are mostly dealing with her.… I mean, she's always the one asking questions. So, I'll	Parents are critical of nondisabled sibling’s behavior toward the disabled sibling	“So, I've kind of given up on that because my parents just get mad. They're like: ‘you're creating problems.’… And then, I'm always the one who's getting in trouble because—even when I feel like I'm trying to do something that has meaning to me. So that's, that's part of the problem too because I feel like I sometimes get unjustly blamed for a lot of the issues. Like I get in trouble when she should also be getting like in equal trouble, but she gets off easy.… Because, that's why they get mad at me. Cause I make it hard for them. But at the same time, it's like: ‘Eh, I don't want to be the only one getting in trouble.’ I'm trying to do something that I think, you know, that I think matters, that—I'm just trying to do something, I don't know why you're getting mad at me for that.… And, I mean, it's like I'm trying to do—I'm just trying to ask her a question. why are you	Disengages from parents and/or disabled sibling	“Just leave the situation as it is. And just go cool down.”

			ask a few questions too. And it's like ‘come on. I know you know the answer.’ It's kind of like matching her. Because I want her to like tell me a few things too. I don't want to always be talk—cuz it's annoying for me sometimes. For her to always be asking questions. So that's like my way of just being like: ‘yeah, come on.’ Kind of pushing the conversation in a different angle because it gets kind of boring and frustrating.” [Researcher asks why he pushes the conversation] “It's important because sometimes she just doesn't—she'll just stall, she'll be like: ‘uuuh.’ And then she'll get all frustrated. And that's part of her own, like part of her disability where she has trouble answering. But I feel like a lot of the times she can answer. A lot of times she just—I think she just needs a little push. That's just how I feel. And it's not like I'm really—I just want, I just want to talk with her. Like have a more NORMAL conversation. Where instead of where she's just always asking		getting mad at me for that? So that's, that's really frustrating to me. Cuz I know she can do it. I know she's really smart. Like I've heard her talk to strangers like more easily than me.”		

			questions. So, that's why. But sometimes I just, I just do walk away. Sometimes I'm like: ‘you know what? I'm really not in the mood to wait for [disabled sibling] to answer,’ because sometimes she will take a minute to answer a simple question. And then she'll start asking questions right away, and I'm just like: ‘oh my gosh.’ So, I've stopped doing that. And also, because my parents, they like—sometimes it's hard for them because when she gets frustrated then, yeah.… Or also I'll just give up too because she'll tell the answer to my mom. She won't tell me. Even when, even though I'm the one asking the question. And then when she tries to tell me—like she'll tell my mom right away, and then when she tries to tell me she just, she'll just stumble and then I'll be like ‘uh-huh,’ and then I'll have like an off tone and then she'll get frustrated.”				
Disabled sibling behavior interrupts nondisabled sibling’s	“…she copies like everything I do. And I think it's cute, but I also find it very annoying. So whenever I go to brush	Intervenes directly with disabled sibling	“… if I'm TIRED and I want to go to bed, I'm like: ‘[disabled sibling] you should go to bed now. Like what are you doing up?’ And if I say	Disabled sibling behavior leads to family conflict	“And then, I could just talk to her, but she gets offended very easily. Like she takes everything really seriously. Also because I think she wants attention.	Complains or tells parent(s) what to do	“‘Well I just asked her if I could brush my teeth alone.’ And so like, it makes a whole situation where there doesn't need to be any conflict at all.”

activity (**Maya, age 15**)	my teeth, and she's already brushed her teeth, she'll come and start brushing her teeth…And so sometimes I get frustrated by it.” [Researcher asked why [disabled sibling] does this] “I think—I'd like to say that she looks up to me. I think that it's good for her to have someone to follow. And she—that's like a way for her to maybe get to know me better, or something. And like be more, not NORMAL, but like know how to do things.” [Researcher asks: Why do you think it frustrates you?] “Well, when I'm in a bad mood and [disabled sibling] does it, I think it's just like the last thing I need.”		anything, even with a tiny bit of aggression—I have to say everything so nicely. And I think I'm pretty good at it, but when I don't do it, she gets like, if it makes her mad, she doesn't know how to deal with it."		So, she'll just like drop her toothbrush, sprint outside, and then now I have to deal with THIS. And all I wanted to do was brush my teeth alone. So, I don't know. It—she makes a little situation that can just be talked through, a situation where my parents have to come upstairs, scream at me and be like: ‘oh, well why is [disabled sibling] outside? What did you do to her?’”		
Disabled sibling damages private property (**Luke, age 17**)	[Example disabled sibling behavior: “*My mom was trying to fan my brother's food, because it was really hot. And then he grabbed the fan, and she was like: ‘let go, let go, let go.’ So, I came over and I took it out of his hand, and then he grabbed my bracelet and stretched it really far, and it didn't break. But now*	Aggressive response & Disengages from parents and/or disabled sibling	[Example nondisabled sibling response: *“Well, he started to pull it, and before it ripped I screamed. I was like: "[disabled sibling]!" (Yeah.) And then he let go, and then I went to my room.”*]	Parents are critical of nondisabled sibling’s behavior toward the disabled sibling	“Yeah, usually I try to get involved. But then my parents don't like it when I get involved. Because then they get mad at ME. Since they're kind of like: ‘it's not any of your business.’ And also, they're like: ‘you're too aggressive,’ or something like that. They're like: ‘can you be nicer to your brother?’ Like I'm surprised my dad didn't say anything when I screamed [disabled sibling], because	Complains or tells parent(s) what to do	“I'm like: ‘well if he wants to break things, then like—I mean’—I don't—I think my parents baby him too much, is what I think.”

	it's kind of loose, and so that annoyed me because, now my bracelet's loose. And I like my bracelet, and it was expensive." … [Researcher asks: Why did you try to help your mom? Why'd you intervene, I guess?] "Because he can be pretty strong. And he just like does this a lot. So it's like—and she—it seemed like she wasn't in control of the situation. So I kind of just took it out of his hand."]				he pulled it, so that was my reaction. So, I screamed '[disabled sibling]!' But yeah, that was like a one-time thing where my parents didn't say anything."		