

Running Head: PERCEIVED ROLES OF NON DISABLED SIBLINGS

Understanding Perceived Roles:
Non-Disabled Siblings of Individuals with Developmental Disabilities

Raquel A. Buchanan

Hanover College

Abstract

Despite the prevalence of developmental disabilities in the United States, very little attention has been paid to the subjective experiences of siblings of individuals with developmental disabilities. In the present study, this issue was addressed by conducting open ended interviews with ten participants who have a sibling with a developmental disability. A matched group of ten participants who have a sibling without a developmental disability were also interviewed. Interviews from both groups were audio-recorded, transcribed, and analyzed. Specifically, using the Interpretative Phenomenological Approach, four clusters and eleven themes were found. Clusters included Perceived roles, Factors Influencing Role Portrayal, Involvement Over The Life Span, and Responsibilities. Through comparing the two groups of individuals, this study is able to contribute to a holistic understanding of the experiences of individuals who have a sibling with a developmental disability.

Understanding Perceived Roles:
Siblings of Individuals with Developmental Disabilities

I come from a large family. I have with three brothers and one sister, and I middle child. Each relationship between my siblings and I is distinct in the roles we play in each other's lives. As we all age, the roles we play in each other's lives have changed. With my older siblings and I, their roles have changed from being my supervisor, (e.g., making sure I had all my belongings to get to the bus stop on time) to a friend who I can call in times of emotional need. I see this transition in the relationship between my youngest sibling and I, where I am moving from supervisor to a friend as he becomes more self sufficient. I have seen that the roles my siblings and I have in each other's lives seem to be common in other sibling relationships. However, there is a unique circumstance in my sibling relationship: one of my younger brothers was born with a developmental disability. I feel this has altered our sibling relationship, particularly the roles I take on in our relationship.

My brother James was born with two developmental disabilities, Autism and Mental Retardation, as well as several physical disabilities. During the past 13 years, I have experienced a range of emotions about my brother's disabilities and have spent countless hours thinking about the caretaker role I play in my brother's life. Being eight years old and the baby of the family when James was born I was not aware of the responsibilities my family and I would face. As James and I got older, I realized our relationship as siblings would be far different from most sibling pairs. James' developmental disability affected his ability to verbally communicate: he is not able to use words to express how he feels. Unlike in other sibling relationships, I cannot get a direct response of how my sibling is feeling; instead I must work to find out the root problem. The presence of Autism and Mental Retardation prohibit him from expressing his feelings, which requires paying careful attention to behaviors to relieve any discomforts. As a non-disabled sibling to a disabled sibling, I worry about his future care which is not a great concern of mine for

my other siblings. For example, if I were to expire, I am confident that my older and younger non-disabled sibling would be able to provide for themselves in the future. However, I worry about James because he would not be able to take care of himself without the help of another person. I can only attribute the care taker role I feel I must embody to the presence of the developmental disabilities in James.

After examining my perceived roles in James' life, I began to think about my youngest brother George, who is 4 years younger than James. I began to think about how my youngest brother feels about having a sibling with a developmental disability and what roles he feels he must embody. Does George feel he must play the roles that I feel I must take on in James' life? Reflecting on my perceived roles, and the ones George might feel he plays, the thought sparked my interest in other non disabled/disabled sibling pairs. I began to think, "Do other non disabled siblings feel they must take on the same roles I feel I am obligated to fulfill in their disabled sibling's life?"

To date, very little attention has been paid to the experiences of non-disabled siblings of individuals with developmental disabilities. In fact, one recent review of the literature revealed that only 21 empirical studies have been published to examine the psychosocial impact of having a sibling with a disability. Moreover, only three of these studies used non-disabled siblings as the primary informant. Instead, most asked mothers about how the non-disabled siblings fared (Dew, Balandin, & Llewellyn, 2008). In doing so, response from these studies may not accurately reflect the feelings of the non-disabled sibling. The importance of studying non-disabled siblings is two-fold. First, several studies suggest that non-disabled siblings may be more positive in their reports about their relationships with disabled siblings than is suggested by reports from their mothers (Dew, Baladin & Llewelyn 2008). In fact, several studies which examined the sibling

relationship from the parents perspective did not align with the actual expectations and attitudes the non-disabled sibling held toward their disabled sibling. Vadasy and colleagues (1984) found, only 41% of parents thought non-disabled siblings would care for disabled siblings while 68% of siblings reported that they would assume responsibility for their disabled siblings in the future. Findings from several studies suggest that non-disabled siblings consistently report more positive outcomes, expectations and attitudes in their relationship than the accounts from their parents. Second, when a child with a disability enters the family, most of the focus is on the relationship between parents and the disabled child, overlooking the relationship between siblings. Special attention should be paid to non-disabled siblings because the length of the relationship between siblings typically exceeds the relationship between parents or primary caretakers. Understanding non-disabled siblings' feelings and expectations toward a disabled sibling is important, as non-disabled siblings may often need to become a primary caretaker. Understanding this relationship may be helpful in aiding a smooth transition into tasks which may be presented to a non-disabled sibling in later life.

Several studies suggest that relationships between disabled and non-disabled siblings differ from typical sibling relationships in the roles and interactions they engage in. In a study by Minnett, Vandell, and Santrock (1983), naturalistic observations were conducted to analyze play initiation and roles taken during play between siblings. Through the Sibling Interaction Scale, a device used in recording sibling interaction, researchers found significant differences in role portrayals and play initiation based on birth order and age spacing. Their results showed older siblings initiated play while portraying leadership roles. However, these results did not apply to sibling pairs where one sibling is affected by a life-long disability. In two studies, both using the Sibling Interaction Scale, Knott, Lewis and William (2007) and Caro and Deverensky (2007)

showed play initiation and leadership role portrayal was performed by a non-disabled sibling regardless of birth order or age spacing. Their study concluded that non-disabled siblings portrayed more directive behaviors and engaged in managing roles while disabled siblings were more likely to engage in less directive roles (Caro & Deverensky 1998). Research using Sibling Interaction Scales has been important in identifying roles taken on by non-disabled siblings in disabled-non-disabled sibling pairs. The results provided from studies using the Sibling Interaction scales revealed that interactions between siblings where one individual had a disability varied from interactions between non-disabled siblings. The uniqueness of these results calls for further investigation of sibling relationships where one individual is affected by a disability. More work needs to be done to better understand non-disabled siblings' perceptions and attitudes toward the roles they take on with their disabled siblings.

In the current study, interview methods will be used to gain a holistic understanding of an individual's perceived roles toward their sibling relationship. Two groups of participants (one group who have a sibling with a disability and another who do not have a siblings with a developmental disability) will be interviewed to compare and contrast themes found in both groups to better understand the psychosocial impact of having a sibling with disability. In the case of the relationship where one individual has a disability, the study will following recommendations by Dew et al. (2008) in their review of the existing literature, where the non-disabled siblings will be the primary informant. Interview methods are important insofar as they allow participants to express their feelings and incorporate their personal experiences into their responses. The study being conducted by an interview is able to identify and interpret motives which strictly quantitative studies like the sibling interaction scale are not able to identify. The study will attempt to find

commonalities across participants' responses which will assist in understanding the perspectives of non-disabled siblings and ultimately aid in improving the well being of both siblings.

The disability of primary focus in disabled/non-disabled sibling pairs will be developmental disabilities, due to the rising prevalence developmental disabilities and the wide range of affected individuals. The U.S Department of Health and Human Services (2010) defines developmental disabilities as:

A diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime. (The U.S Department of Health and Human Services 2010)

Developmental disabilities which fall into this outlined category include Autism Spectrum Disorders, Cerebral Palsy, Down Syndrome, Mental Retardation, and Spina Bifida. Due to the variability of gender, age, and socio economic status's, which have potential to influences an individuals perceived roles regarding their sibling with a developmental disability. Variables which may influence perceived roles will be identified at the beginning of the study through a demographics questionnaire [See Appendix B]. The amount of involvement an individual has with their disabled sibling may influence the roles they feel they must embody (LeClere 1994). With the advice of LeClere (2004), a Lickert Scale will be used to accesses the individuals amount of involvement which may influence the results of the study.

This study uses Interpretative Phenomenology, a subjective approach based on multiple perspectives on a shared phenomena (Willig, 2001). The phenomena under investigation is the psychosocial impact of having a sibling with a developmental disability. In this case,

sibling pairs without an individual with a disability lack the psychosocial impact that the disabled/ non-disabled sibling pairs have. This means that non-disabled sibling pairs have not experienced the same social environment and interactions associated with a sibling who has a disability which can influence in role portrayals depicted in Sibling Interaction Scales (Dew, Balandin & Llewelyn 2008). Using Interpretive phenomenology in data analysis can allow researchers to gain a better understanding of findings in previous quantitative studies. Responses from the interview process will be examined for reoccurring themes in the responses. Ideally, the study will conclude a collective theme in a non disabled siblings perceived roles. The research questions include: How do college-age adults perceive their role regarding their disabled sibling? How has their role changed over time and how do they expect it to change in the future? How do individual experiences change role perception?

Method

Participants

Individuals were recruited through a popular internet networking site and personal contacts, resulting in 18 participants. Nine participants had a sibling with a developmental disability. To qualify as having a developmental disability, disabled siblings had to meet the requirements outlined in the Developmental Disabilities Assistance and Bill of Rights Act (2000). The

comparison group included 8 individuals whose sole requirement was to have a sibling. A detailed description of the participant is illustrated in Figure 1.

Figure1 : Participant Demographics Chart

	With Disabled Sibling	Without Disabled Sibling
Number of Participants	9	8
Male	1	4
Female	8	4
Number of Siblings (not including self)		
1	3	4
2	3	2
3	2	0
4	0	1
5	1	0
7	0	1
Socio -Economic Status *		
<\$10,000	1	0
\$10,000-\$24,000	2	1
\$25,000-\$44,000	3	3
\$50,000-\$74,000	1	1
\$75,000 +	1	2
Parent's Marital Status		
Married	6	5
Single	2	2

	With Disabled Sibling	Without Disabled Sibling
Widowed	0	1
Separated	1	0

*Two individuals, one in each group did not indicate SES

Procedures and Materials

Several weeks before the interviews took place, an advertisement was placed on a popular networking site asking individuals who have a sibling with a developmental disability to participate in an interview based study. Simultaneously, another advertisement was posted recruiting individuals with siblings to participate in the study. The individuals who chose to participate were asked to send a confirmation email back to the researcher. Interview dates were then set to best fit with the participant's schedule.

Upon arrival, participants were given an informed consent which was signed by the participants and returned to the researcher [Appendix A]. Prior to the interview, a brief demographic sheet and questionnaire was given to the participants to assess socio-economic status and family involvement by using a Lickert Scale [See Appendix B]. The item used to assess socio-economic status asked participants to report their annual family income, with values ranging from less than \$10,000 dollars to greater than \$90,000. The item used to assess participants' involvement with their sibling included a 5 point scale where 1 indicates no involvement and 5 indicates constant involvement. The Global Assessment of Functioning was given to participants who had a sibling with a developmental disability to better understand the severity of each siblings' disability [Appendix E]. The Global Assessment of Functioning is a numeric scale scored 0 to 100 used to help clinicians assess the social, occupational, and psychological capabilities of individuals with mental illnesses. There are ten categories on the Global Assessment of Functioning survey and

each category is rated 0 to 10. A rating of 0 would indicate that impairments in this category are the most severe and a rating of 10 indicates that the individual has no impairments listed in the category. Score from each category are totaled and reveal the severity of the mental illness.

Scores are as follow:

0-21: Impairments are severe, the individual is in danger of harming themselves or others. There is an inability to function in all areas (social, occupational, psychological).

22-50: Some impairment with severe impairments in few areas.

51-70: Symptoms are moderate and only create difficulty in few areas of life.

71-80: If symptoms are present, they are only onset my psychosocial impressers with no more than slight impairment in social, occupational and psychological functioning.

81-90: Absent or minimal symptoms, good functioning in all areas of life with no more concern than everyday problems

91-100: No symptoms with superior functioning in a wide range of activities.

(Kupfer, Narrow, & Regier 2010)

Participants who had a sibling with a developmental disability were asked to complete the Global Assessment of Function Scale to allow the researcher to gain a better understanding of their sibling's disability. Descriptions and procedure were included on the survey to assist the participants in completion. The scores from the survey were compiled and put into a response table [Appendix F].

Semi- structured interviews, based on pre-determined questions [Appendix D] were conducted with each of the 18 participants. The interviews were conducted at a location designated by the participant. The interviews on average were 30-45 minutes in length. To ensure the participants' comfort, interview questions were structured in a conversational manner in which participants were instructed that they could share as much or as little as they choose. The interview protocol was constructed in such a way that allowed the participant to express the psychological experience of their sibling relationship. The participants were asked to describe their sibling's, and participants who had a disabled sibling disability were asked to include a short description

about their sibling's disability. All participants were asked to relay their feelings regarding their sibling through interview questions that attempted to identify perceived roles in their relationship. The structure of questions identified perceived roles as they are in current and past times as well as expectations of for the future. A set of questions focused on the future relationship between the siblings examining the roles the participants feel they will play in their sibling's future and to identify whether they feel their role is constant or changing. The researcher was interested in sibling relationships and how the psychological experience of having sibling with a developmental disability impacted sibling relationships.

This study, being an interview based study will use phenomenological methods to analyze the transcripts. In phenomenological research, the language used during interviews is believed to be an attempt by the participant to communicate their individual experience. The data analysis is modeled after the Interpretative Phenomenological Approach, where analysis is a "co-construction between participant and analyst" in that it emerges from analyst's interpretation of language presented in the participant's account (Osborn & Smith 1998). To begin, transcripts are read one by one while identifying themes in a single participant's response, while researcher noted questions or reactions to each interview. Themes identified within each participant's interview were then examined in relation to the others. Themes that were representative all of participants were formed into clusters. Individual differences in the clusters yielded themes. These clusters helped identify how the phenomena has impacted all individuals who have experienced it, while clusters allow individual experiences to be recognized (Willig, 2008).

Results and Discussion

Descriptions of Themes and Clusters

The Response Tables show the frequency and distribution of comments pertaining to each cluster and theme. Response Tables demonstrate qualitative findings, therefore tables are used in organizing thematic data but are not indicative of statistical significance. The findings yielded 4 clusters and 11 themes. The four clusters which emerged from the analysis included: ‘Involvement’, ‘Responsibility’, ‘Roles’ and ‘Influencing Roles’. [See Appendix C]

The first cluster, Roles, identify the perceived roles participants hold in their relationship with their sibling. Themes included Friend/Sibling, Caregiver/Parent, Supporter and Protector. These themes arose from a list of role words given to the participant during the interview process. Role portrayal was investigated through out the course of the relationship including perceived roles in the past, present and future.

The second cluster, Influencing Roles, cover descriptions of what or whom is influencing the roles they feel they play in the relationship with their sibling. The themes in this cluster include: Family and Innate Feelings. The theme of Family was created when participants directly identified a family member influencing their role portrayal. The next theme, Innate Feelings were a result of participants not identifying a particular individual but demonstrating the implicit need to fulfill their specified roles.

The third cluster, Involvement, was based on responses from a survey the participants completed prior to the interview. On the survey, the participants were asked to rank the amount of involvement they had with their sibling on a Likert scale, 1 indicating “No Involvement” to 7 indicating “Constant Involvement.” Then participants were asked to describe interactions that explained their noted involvement. Within this cluster, participants’ responses on interaction was condensed into three different activity types that served as themes. The themes included: Expressive, Instrumental, and Affective. The theme of Expressive Activities include activities

which are mutually satisfying and self-fulfilling. Expressive activities are ones in which the participant and sibling are equally satisfied and both expresses enjoyment. The theme of Instrumental Activities are associated with helping or teaching and are often of physical nature. The last theme in the cluster is Affective Activities, they are categorized by emotional interactions and support. Though many of these interactions in affective activities can be associated with helping and teaching, these activities differ from instrumental activities do not require physical elements.

The final cluster, Responsibilities, are directly related to the responsibilities the participants felt they must take on in their sibling relationship. The cluster for Responsibilities was only looked at in the present and future. The themes in this clusters included instrumental activities and affective activities. Again, Instrumental Activities are associated with helping or teaching as means rather than an end and include physical aid while Affective activities relate to emotional interaction not necessarily with a physical presence.

Emerging Insights

Roles

Participants in this study identified particular roles from a given list that best explained their perceived roles in their relationship. For responses on role portrayal in the past, two participant with a disabled sibling indicated roles. In the present, all participants who had a sibling with a developmental disability believed they fulfilled the caretaker-parent role in their descriptions. Although, only 55% (5 of 9) of the individuals responded directly with this term when asked, while 22% (2 of 8) of participants whose sibling was not disabled indicated this role. The sibling-friend role was indicated by 77% (7 of 9) non-disabled siblings and only 22% (2 of 8) of participants who did not have a disabled sibling indicated this role. The supporter role was equally identified by both groups. Lastly, the protector role was identified by 22% (2 of 8) parti-

participants who did not have a disabled sibling and 11% (1 of 9) of participants who did have a disabled sibling. For expectations of future role portrayal 77% (7 of 9) participants with a disabled sibling believed they would take on the caretaker-parent role in their relationship. No other roles were specified in the future for this group. Expectations for role portrayal in participants who did not have a disabled sibling included 22% (2 of 8) taking on the friend-sibling role, 12% (1 of 8) taking on the supporter and protector role.

It is important to note that the perceived roles of the participants varied over time and across scenarios. One participant noted, "I think it [is] a constantly moving role. I don't think there was ever one specific role because we were kinda everything to each other." Perceived role change in individuals who have a disabled sibling can be due to developmental changes during life spans and changes in parental interaction. Yirmiya and colleagues (2006) reported that in the first 14 months of development in children, there are no difference in cognitive or motor development between developmentally disabled and typically developing children. Using the findings from that study, it is possible that similar cognitive abilities allowed the non-disabled siblings had taken on the sibling-friend role. When cognitive abilities are the same, directive roles are not needed at this time in the relationship resulting in equal natured roles. On the other hand, parental involvement can affect can role perception. One participant commented on the change from sibling to caretaker by stating, "When I was younger, I was six when he was born. He was this little baby, and babies were fragile any way, but then my mom, she'd never taken care of a child with a disability, so she was really protective of him." During the disabled and non-disabled individuals' childhood, parents provide most of the care for the disabled sibling which does not illicit a need for a sibling to take on caretaker roles, so they are not pressed to be anything more than a sibling or friend.

A study by Caro and Deverensky (1997) on sibling roles suggested that perceived roles siblings hold derive from their interactions with one another. Though both sets of participants identified themselves as fulfilling similar roles in the relationship with their siblings, the explanation of how they implemented these roles varied. A majority of participants perceived their roles to be a caretaker-parent role at some time in their relationship. Out of nine participants who had a sibling with a disability, seven perceived their role in the future to be a caretaker. The caretaker role specified by this group was implemented through instrumental activities. In contrast, two of eight individuals who did not have a disabled sibling identified themselves as taking on the caretaker role. In their responses of how they fulfilled the caretaker role these individuals indicated more affective activities. Their perceptions of this role included responses like, "I'd probably say caretaker [because] she always comes to me with advice and stuff, I taught her how to drive, I taught her how to act in relationships, she'll always come to me if she needs something." For this group, when the individuals indicated the caretaker roles had instrumental elements, the instrumental interactions had a designated end; the sibling accomplishing the task. Often times, tasks associated with the caretaker role were only implemented at a designated period. The caretaker role did cease at some point in non-disabled sibling relationship. In comparison, the caretaker role was noted by individuals with a disabled sibling to be an ongoing role and can be summarized by one participant who stated, "I gotta do this no matter what point of time, when I get older I'm still gonna have to do it, that's just how I feel."

As far as the sibling-friend role, both groups believed they took on this role. When portrayed by non-disabled sibling pairs, roles composed of affective activities. Interestingly enough, when specified by non-disabled siblings regarding their disabled sibling, responses did not correspond with expected interactions typically thought of in this role. Many of the interactions that

were met in this role were of instrumental nature. One non-disabled sibling commented on the sibling-friend in her disabled siblings life by saying, “If she ever needs help in the shower. I have to do that. I have to get her ready. And I have to do these roles, but I’ve always thought about them as my sisterly roles. So other people would see them as a caregiver role, but I would think of them as my sisterly.” This participants statement shows that having a sibling with a disability has affects the way in which she perceives her world. It is possible that perceptions of other participants with disabled siblings have been influenced by the psychosocial impact of having a sibling with a disability creating alternate views toward the role they play in the relationship with their sibling.

Findings in this cluster were consistent and supported results found in previous studies using Sibling Interaction Scales. Non-disabled siblings in this study, regardless of birth order or age spacing, identified their role toward their disabled sibling as the caretaker-parent role which was indicative of directive activities while the disabled sibling portrayed passive roles (Caro & Deverensky 2007). One participant, a younger female sibling commented on her role in the relationship with her disabled sibling, “I play the caretaker and teacher role. I play the caretaker role..I fix her supper and do her laundry a lot. The teacher role comes into play when she is reading or trying to do something she doesn’t understand....Sometimes she needs extra guidance.” These interactions are similar to the ones recorded in naturalistic observations. Responses from this cluster consistently show that non-disabled siblings perceive their role to be a more directive role regardless of their sibling’s birth order. Similar to other results in the Sibling Interaction Scales, two participants who reported on their older sibling who were not disabled expressed the passive role they took on in their sibling relationship as younger siblings. One participant’s account on her role in the relationship entails, “I definitely in our relationship take on the protect-

ee...For her, in my life, she would be my teacher and protector.” Results from this cluster show the presence of a disabled sibling influenced role portrayal between non-disabled/ disabled sibling pairs and typical sibling relationships.

With in this cluster, the distribution of individuals identifying themselves as taking on particular roles in their relationship was more frequent in individuals who had a sibling with a developmental disability. These individuals maybe more inclined to think about their roles in their sibling relationship. Since one sibling has a developmental disability, which affects learning and self help, the role that the non-disabled sibling takes on is more obvious. The disability having an impact on a siblings abilities may not allow the siblings to hold equalitarian roles. By default, the disabled sibling must assume subservient roles which encourages non-disabled siblings to take on directive roles (Caro & Deverensky 1997). However, the sibling’s disability was not the influenced that served as motivation for role portrayal.

Influencing Roles

The next insight into sibling relationships are the influences that are motivating individuals to embody roles in their sibling relationship. Four individuals who did not have a sibling with a developmental disability indicated that there was a source encouraging them to portray their identified roles. While all participants who have a disabled sibling identified a source pushing them to portray their indicated roles. These two sources created two themes including family members and innate attitudes. Family members as a source of influence were directly identified by the participants. The theme of innate feeling in regards to role portrayal was identified when the participants indicated that the roles weren’t influenced but were portrayed because of instinct. These collective themes by both groups were expressed but varied in responses. The figure below, Figure 2 depicts the indicated responses. Both groups identified family members as sources

influencing them to portray their indicated roles. However, the family members that encouraged each participant’s designated role varied between the two groups. Four individuals with a disabled sibling that indicated a family member was influencing their roles, all four of those individuals relayed that their parents were the primary enforcer. Within the four individuals without the disabled sibling who identified a family member being an influence, only two cases indicated the parents were the source of influence. Lastly, Five individuals who had a disabled sibling stated that their role portrayal was due to innate feelings and attitudes.

Figure 2: Sources Influencing Role Portrayal

Cluster	Theme	Participants with Disabled Sibling (out of 9)	Participants Without Disabled Sibling (out of 8)
Influencing Roles			
	Family	5	4
	Parents	4	2
	Other	1	2
	Innate Attitudes	5	0

Five individuals who had a sibling with a developmental disability identified their role portrayal being influenced by innate attitudes. Innate attitudes were ones in which the participants expressed that the role they played was self satisfying, nothing that was outwardly encouraging role portrayal but the desire came from within. One participant revealing her innate source said, “ I feel I should...Nothing’s really pushing me to, other than myself and I feel it’s right.” Another participant noted, “[My role] was never pushed on me because I don’t think it needed to be. It was never anything out of the norm for me.” Participants with non-disabled sibling did not identify their role portrayal was a result of innate desires. The presence of innate in-

fluences only in disabled-non-disabled sibling pairs lead me to believe that the unique experiences in their relationship have impacted their belief systems. The results in this theme give insight into the psychosocial phenomena that is experienced by individuals with disabled siblings. It possible that individuals with disabled siblings have been affected by their phenomena and have created different attitudes toward their relationship with their sibling.

Four non-disabled siblings identified that their parents were influencing their role portrayal. Dyson and colleagues (1989) proposed that parental attitudes are an indirect influence on the roles and demands that parents place on non-disabled siblings. When a parent asks the non-disabled child to provide care for their disabled sibling, the non-disabled sibling gains more directive roles. In this case, the four participants who identified their parents as the influence stated that the parents have outwardly expressed expectations in the relationship. A participant in this group said, “ If it’s not asking me or telling me, it’s just like already expected, because that’s what they expected of me years ago. They’ve always expected me to take this roles taking care of him, and being somewhat of like a caretaker.” This participant wasn’t the only individual who felt a push from their parents to portray certain roles in their sibling relationship. The four participants who identified their parents as the explicit influence all responded with similar statements pertaining to the question. Though not all non-disabled siblings identified their parents expectations as the primary source influencing role portrayal, all of these individuals noted that the death of their parents impacted the roles they do and will play in their relationship. When one participant was asked if there were any outside influences that encouraged her to take on the caretaker role she specified, she answered, “ [My parents passing away] That definitely does, I think that’s my main one...If anything ever does happen then I would have to step up and be a mom pretty much and just take over.” All non-disabled siblings expressed concern for their sib-

lings well being when their sibling's primary caretaker was no longer able to care and noted they would assume the caretaker role once the primary caretaker was not able to provide for their disabled sibling. The loss of primary caretakers deemed some roles for the non-disabled siblings as inevitable. In comparison, one individual identified the death of his parent as source of influence on his role toward his non-disabled sibling. Though the death of his parent had immediate impact on his roles in his sibling relationship, the roles resulting from the death were not long term roles. This participant goes on to say, "I feel as she gets older she's not really needing my help because she's learning stuff on her own and she's able to have her own sense of judgement." In this case, the death of the parent prompted his protector role in where he had to take on affective and some instrumental activities but in the long term, the death of his parent did not significantly impact future interactions.

Five individuals without a disabled sibling noted that their family had an impact on the roles they played in their sibling relationship. However, there was more variation in the family members who were identified as an influence. Two individuals in a non-disabled sibling relationship targeted their parents as an influence but stated that the expectations their parents placed on role portrayal were subtle. Unlike the individuals with disabled siblings, these participants did not state that their parents had appointed roles or set precise expectations. Another participant identified his sibling influences his role in the relationship because of the expectation that his sibling placed on him. In this case, his sibling influenced the supporter role because he wanted to prove to his sibling that he could rise to the expectations his sibling had placed on him; being a mentor for his niece. The sibling was not directly influencing role portrayal but implicitly promoted role portrayal. Similarly, participants with a disabled sibling did mention that their roles were also influenced by their sibling, however these statements were not answered in the ques-

tion on “sources influencing role portrayal,” but were revealed in other parts of the interview. For example, participants noted their sibling “can’t do much” which lead to certain responsibilities that created directive roles. Caro and Deverensky (1997) stated that the presence of a disabled sibling affects role portrayal in non-disabled siblings. The absence of some abilities in the disabled sibling provoke passive roles and influence non-disabled siblings to take on directive roles. This influence, though not mentioned by participants in the “sources of influence” question, is an apparent influence which is demonstrated through involvement and responsibilities.

Involvement

All participants indicated their level of involvement in a previous questionnaire and were asked to report activities that made up their involvement with their sibling. The noted activities were condensed into three activity themes which included expressive activities, instrumental activities, and affective activities. All participants indicated a shift in their level of involvement and a change in the type of activities they have or will engage in through out their life time. In the present, 75% of participants without a disabled sibling and 77% of participants with a disabled sibling said they engaged in expressive activities that composed their involvement. The biggest difference in the present and future involvement with their sibling is found in instrumental and affective activities. In the present, 37% of individuals who do not have a disabled sibling reported engaging in instrumental activities while 88% of individuals with a disabled sibling reported to engage in activities which fell in this category. For instrumental activities in the future, 25% of individuals without a disabled sibling reported they will be engaging in these activities and 55% of individuals with a disabled sibling plan to have instrumental interactions in the future. Finally, affective activities in the present and future between an individual with a disabled sibling were reported much lower than non-disabled sibling pairs. In the present time, 75% of

individuals with a non-disabled sibling reported affective interactions while 33% of individuals with a disabled sibling report affective activities. In the future, only 11% of individuals with a disabled sibling plan to engage in affective activities and 87% of individuals without a disabled sibling plan to participate in affective activities.

The two groups were very similar in their indicated involvement and indication of expressive activities. In the present, 77% of individuals with a disabled sibling and 75% of individuals who did not have a disabled sibling reported engaging in expressive activities. Expressive activities listed by the two groups included playing video games, shopping and hanging out with the same group of friends. These types of activities when described by participants were discussed in a way that revealed the interactions to be mutually satisfying and engaging to both siblings. However, Cleveland and Miller (1997) found in their study that expressive activities when performed with handicapped siblings often became instrumental activities. For example, one participant with a disabled sibling mentioned her involvement was based on expressive activities but included, "I teach her how to play new video games. I teach her how to play other games as well, like cards and board games." Most participants who had a sibling with a disability did not indicate the change from expressive activities to instrumental, but without observation, this possibility cannot be overlooked. It was found that both groups expected less of expressive activities with their sibling in the future but an increase in other activity types.

Studies by Orsmond and Seltzer (2007) and Greenberg et al. (1999) found that there is a relationship between residential proximity and activity type in sibling relationships. In non-disabled sibling relationships, siblings report more instrumental and affective activities when they live in a close proximity to each other. However, for siblings of individuals with impairments, proximity was related to instrumental but not affective involvement (Orsmond & Seltzer). Find-

ings in this study align with the previous research. Many participants who did not have a sibling with a disability attributed the decrease in expressive activities to less contact with their sibling. In many instances of non-disabled sibling pairs, participants noted that the frequency of contact would decrease because of their own future plans and goals. The onset of affective activities was due to both siblings leaving the shared house and beginning independent lives. Decreased proximity began the onset of affective activities, the most common affective activities included talking to their sibling on the phone and sharing life experiences. In the case of individuals who have a disabled sibling, expressive activities may cease because of an increase in instrumental activities. Non-disabled siblings reported that their level of involvement would increase in the future due to their disabled sibling sharing the same household. The need to engage in affective or expressive interactions diminishes because non-disabled sibling will then be responsible for their sibling's daily activities. Though there was a decrease in participants who mentioned they would be fulfilling instrumental activities in the future, the participants who did identify these activities in their involvement reported there would be responsible for more instrumental activities.

Affective activities were more frequently reported in non-disabled sibling relationships. Individuals who did not have a disabled sibling engaged in similar affective activities dealing with emotional interaction, for example using their experience to give their sibling advice in new situations. In the present, affective activities were a result of other relationships that were being established by their sibling. The participants were often emotional outlets who became an active listener while offered wisdom and words of encouragement. Activities that made up affective involvement were consistent in the present and future. Individuals who had a disabled sibling participated in affective activities but these activities were not sought out by the disabled sibling. The individuals with a disabled sibling who identified themselves engaging in affective activities

were prompted by ridicule and teasing toward their disabled sibling. One participant said, “There was always kids who didn’t understand him, that was picking on him and stuff like that, and he wasn’t gonna tell my parents stuff like that, but I saw it and I kinda felt it was my responsibility to help him through that and protect him to make sure he was okay with that.” The affective activities that non-disabled siblings participated were all noted to be of similar nature and impacted both individuals. Non-disabled siblings deeply empathized with their disabled sibling resulting in affective involvement with did not have an end.

Responsibilities

The final emerging insight was the participants’ responsibilities pertaining to their sibling. The responsibilities were clustered into two activity types; instrumental and affective. The majority of participants who had a sibling with a disability indicated that their responsibilities are composed of instrumental activities while participants who did not have a disabled sibling indicated that their responsibilities are affective activities. In both the present and future 37% of individuals without a disabled sibling indicated they are responsible for instrumental activities as compared to 77% of individuals with a disabled sibling feel their responsibilities are instrumental in the present and future. As far as affective responsibilities, 75% of participants who did not have a disabled sibling indicated that they are responsible for these activities in the present as compared to 33% of individuals who had a disabled sibling. Concerning affective responsibilities in the future, 67% of participants who did not have a disabled sibling reported they will have affective responsible while no participants who had a disabled sibling planned to have affective responsibilities in the future. The differences in the type of activities engaged in, instrumental or affective, are due to the extra help disabled siblings need (Cleveland and Miller 1977). The type of responsibilities that participants have are largely determined by their sibling’s capabilities.

When a sibling is affected by a developmental disability, the disabled sibling often has trouble with self-help and needs assistance. However, typically developing siblings are able to provide for themselves but may experience more emotional struggle and seek out emotional guidance.

In the present and future, participants who have a sibling with a disability report more instrumental interactions within their responsibilities. The major responsibility in the future mentioned by all participants was providing a home for their sibling. All participants revealed that when their sibling's primary caretaker is no longer able to support them, their sibling would be living with them. The presence of the disabled sibling in the non-disabled sibling's home would require the non-disabled sibling to perform more hands on activities, which is supported Orsmond and Seltzer (2007) and Greenberg et al. (1999). One participant captured all of the assumed responsibilities that participants mentioned by stating, "She was gonna end up living with me, I would take care of her, I would be purchasing her medical supplies, monitoring her, making sure she gets to her doctors appointments. And probably, I'm certain that guardianship would be written over to me."

The percentage of individuals with a disabled sibling that reported engaging in instrumental activities did not fluctuate within in from the present to past. However, these participants did reveal that more responsibilities would be taken on in the future. The increase in responsibilities can be summarized by one individual who said, "I feel like there's a lot more that I'd have to take on." In the future, participants who believed they would be living with their disabled sibling acknowledged that responsibilities were much more than providing a home for their sibling. One participant discussing her responsibilities stated, "I just feel like I have to take on another persons life. Not only my life, but his life too." Non-disabled siblings in this study reported face additional responsibilities because they intend to make medical decisions for their sibling as well

as managing their sibling's finances. Increased amounts of instrumental activities could explain the decline in affective activities from the present to future in their relationship. Individuals who have a sibling with a disability may be more concerned about their instrumental responsibilities than affective because their disabled sibling requires more physical than emotional assistance. Responsibilities through out the non-disabled have shown to be constant in their demands.

Participants who did not have a disabled sibling reported more affective responsibilities in the present and future. Many participants in this group stressed the importance of providing emotional support and deemed this support as their responsibility. Their responsibility of emotionally supporting their sibling comes into effect when they and their sibling build lives separate from each other. Fewer participants in this group felt they had to take certain responsibilities because as their sibling aged, their sibling could provide for themselves. One participant commented on the change responsibilities her sister for her saying, "I've grown up so much, the responsibility of teaching and protecting is no longer there." This participant clearly demonstrates that as siblings get older, the responsibilities that the individual has decreases.

Conclusion

In conclusion, I'd like to end with a quote from one participant whose disabled sibling had passed away several years ago. She states, "I couldn't remember a time without her until she was really gone, I mean it was kind of mind boggling because I was so used to the routine of taking care of her. I mean there's a lot less responsibility now that she's gone but it doesn't come with eases, you know less responsibility comes with that sharp end of the knife, that's like 'Ya, you don't have those responsibilities but she's not there for the good times either.'" This participant clearly demonstrates that having a sibling with a developmental disability had changed her

life. She recognizes that her experience was distinct and required additional responsibilities not experienced by typical sibling pairs.

It is important to study the non-disabled siblings perceptions and attitudes to aid a smooth transition into tasks presented throughout the sibling relationship. When a disabled child enters the family, little attention is given to the sibling relationships. Most emphasis is put on the parent-child relationship, offering assistance and parenting programs to assure that the parent has a stable support group. The non-disabled sibling is often overlooked and no attention is paid to their relationship when in fact non-disabled siblings are likely to have more contact with their disabled sibling than any other person (Brown 2003). Through out the non-disabled sibling's life, these individuals often share the same experience as their parents (Doherty 1992).

To gain a better understanding of why siblings perceive their roles to be the ones which were indicated, we can look at other areas of their relationship. With the findings in the clusters Involvement and Responsibilities, it is possible that the themes within those clusters influence role perception. The understanding of how role perceptions are formed in sibling relationships are better understood after exploring other areas of their relationship and the interactions between siblings.

Insight was gained into the experiences of sibling pairs but also found how the presence of a disabled sibling has an impact on the relationship. Individuals who had a sibling with a developmental disability shared similar views, especially regarding their roles in the future. Despite the variation in individual experiences there were collective responses in this group. From the similarities found in each cluster, I am lead to believe that the psychosocial impact of having a sibling with developmental disability have some influence on the perceptions of individuals who experience this phenomena. Other finding from this study reveal differences between typical sib-

ling relationships and relationships where one sibling is affected by a developmental disability. These differences were found in interactions and activity types, expectations and responsibilities. After recognizing that there are differences within the two experiences, findings from this study can prompt support groups for siblings of individuals with developmental disabilities. Integration of the findings presented in this study along with previous research contributes to a holistic understanding of the experience of non-disabled siblings.

Limitations

Previous studies have found that there are gender effects in sibling relationships. Specifically, Orsmond and Seltzer (2007) found that the gender of the sibling affects caregiving and involvement. Their study found that sisters overall are most likely to be involved in sibling relationships and closest to their disabled sibling. They proposed that sisters often grow up with the expectation that they will take on additional caregiving and household responsibilities for their sibling in the future (Orsmond & Seltzer 2007). The majority of individuals who had a sibling with a developmental disability in this study were female. The findings in relation to role portrayal and activities in involvement could have been influenced by the participants gender who had a predisposition for attitudes revealed in the interviews. These results cannot be generalized to the entire population of individuals who have a disabled sibling because findings only represent the perspectives of a few individuals.

The way in which the study was conducted may yield limitations. Interviews being conducted by the researcher who was not familiar with the participants could influence responses. In future, research may benefit from multiple interviews with the individual participants to strengthen participant-researcher relationship. Multiple interviews with a participant would build rapport and perhaps encourage disclosure and aid in our analysis of the interviews. The study's

design does not allow the researcher to make to make causal conclusions or directional inference due to extraneous variables. It is unknown whether the sibling's role is a result of their interactions or the role they hold influences interactions.

Appendix A: Consent Form

This research is being conducted by Raquel Buchanan as a senior sequence project at Hanover College. The research is being overseen by Dr. Ellen Altermatt, associate professor of psychology at Hanover College. The study in which you are asked to participate is qualitative study in which an individual's relationship with their sibling who has a disability will be explored. You will complete a demographics questionnaire then participate in a 20-30 minute interview where questions about sibling interaction and family structure will be asked. The interview will be audio taped. After you have participated in the interview, you will be debriefed.

The study will not take more than 50 minutes. There are no known risks involved in being in this study, beyond those of everyday life. The information you provide during the study is will be treated confidentially; the audiotape will be kept in a secure location and your name will not be associated with the responses you give. If you have any questions about what you will be

doing in the study or about the study itself, feel free to ask them now or at any other time during your participation.

If you have any questions after the study, please contact Raquel Buchanan at BuchananR13@Hanover.edu or Ellen Altermatt at altermattel@hanover.edu.

I acknowledge that I am participating in this study of my own free will. I understand that I may refuse to participate or stop participating at any time. Incomplete participation will not result in credit for participating, but I may complete an alternative assignment of equal time commitment in order to receive credit. If I wish, I will be given a copy of this consent form.

Signature

Date

Appendix B: Questionnaire

Demographics

1. Gender: Male Female

2. Age: _____

Approximate Annual Income of Family:

< \$10,000 \$10,000- \$24,900 \$25,000- \$44,900 \$50,000-\$74,000 \$75,000+

Parents' marital status

Single Married Divorced Widowed

Number of Children in Family

1 2 3 4 5 6 7 8 9 10+

Age of sibling: _____

Your amount of involvement with sibling:

No involvement	Very little	Moderate	Some	Constant Involvement
1	2	3	4	5

Appendix C: Interview Protocol

Present Time

Demographics of sibling

1. Describe your sibling, as much or as little as you like.

According to involvement scale

2. What activities do you participate in that explain involvement with your sibling?

After given list of “role” words

- 3. Which role do you feel take on in the relationship between you and your sibling?
- 4. Are there outside influences that make you feel you must take on the specified role?

Past

- 5. How has your involvement changed over time?
- 6. As a child, did you feel a need to take on certain responsibilities when it came to your sibling?
- 7. What role did you take as a child? (if there is a change) Why?

Future

- 8. As you and your sibling age, what roles do you feel you will take on?
- 9. What responsibilities do you feel you will accommodate for?
- 10. How much involvement do you feel you will have in you siblings future?

Appendix D: Response Tables

Past:

Cluster	Theme	Participants with disabled sibling	Participants without disabled sibling
Roles			
	Sibling/Friend	11%	0%
	Caretaker/Parent	11%	0%
	Supporter	0%	0%
	Protector	0%	0%
Involvement			

Cluster	Theme	Participants with disabled sibling	Participants without disabled sibling
	Expressive Activities	33%	25%
	Instrumental Activities	11%	0%
	Affective Activities	33%	50%

Present:

Cluster	Theme	Participants with disabled sibling	Participants without disabled sibling
Roles			
	Sibling/Friend	77%	25%
	Caretaker/Parent	55%	25%
	Supporter	22%	25%
	Protector	11%	25%
Involvement			
	Expressive Activities	77%	75%
	Instrumental Activities	88%	37%
	Affective Activities	33%	75%
Responsibilities			
	Instrumental Activities	77%	37%
	Affective Activities	33%	67%

Future:

Cluster	Theme	Participants with disabled sibling	Participants without disabled sibling
Roles			
	Sibling/Friend	0%	25%
	Caretaker/Parent	77%	0%

Cluster	Theme	Participants with disabled sibling	Participants without disabled sibling
	Supporter	0%	12%
	Protector	0%	12%
Involvement			
	Expressive Activities	33%	25%
	Instrumental Activities	55%	25%
	Affective Activities	11%	87%
Responsibilities			
	Instrumental Activities	77%	37%
	Affective Activities	0%	67%

Appendix E: Global Assessment of Functioning

The Global Assessment of Functioning (GAF) is a numeric scale (0 through 100) used by mental health clinicians and physicians to subjectively rate the social, occupational, and psychological functioning of adults, e.g., how well or adaptively one is meeting various problems-in-living. Please rate each category on a 0 to 10 scale. A rating of 0 indicates chronic symptoms while a rating on 10 indicates no symptoms.

91 - 100 Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities. No symptoms.

81 - 90 Absent or minimal symptoms (e.g., mild anxiety before an exam), good functioning in all areas, interested and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns (e.g., an occasional argument with family members).

71 - 80 If symptoms are present, they are transient and expectable reactions to psychosocial stressors (e.g., difficulty concentrating after family argument); no more than slight impairment in social, occupational, or school functioning (e.g., temporarily falling behind in schoolwork).

61 - 70 Some mild symptoms (e.g., depressed mood and mild insomnia) OR some difficulty in social, occupational, or school functioning (e.g., occasional truancy, or theft within the household), but generally functioning pretty well, has some meaningful interpersonal relationships.

51 - 60 Moderate symptoms (e.g., flat affect and circumstantial speech, occasional panic attacks) OR moderate difficulty in social, occupational, or school functioning (e.g., few friends, conflicts with peers or co-workers).

41 - 50 Serious symptoms (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) OR any serious impairment in social, occupational, or school functioning (e.g., no friends, unable to keep a job).

31 - 40 Some impairment in reality testing or communication (e.g., speech is at times illogical, obscure, or irrelevant) OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).

21 - 30 Behavior is considerably influenced by delusions or hallucinations OR serious impairment, in communication or judgment (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) OR inability to function in almost all areas (e.g., stays in bed all day, no job, home, or friends)

11 - 20 Some danger of hurting self or others (e.g., suicide attempts without clear expectation of death; frequently violent; manic excitement) OR occasionally fails to maintain minimal personal hygiene (e.g., smears feces) OR gross impairment in communication (e.g., largely incoherent or mute).

1 - 10 Persistent danger of severely hurting self or others (e.g., recurrent violence) OR persistent inability to maintain minimal personal hygiene OR serious suicidal act with clear expectation of death.

Appendix F: Global Assessment of Functioning Scores

GAF Categories	0-21	22-50	51-70	71-80	81-90	91-100
Number of disabled siblings indicated	0	4	5	0	0	0

Range: 23 - 64
 Mean : 49

References

- Brown, E. (2003) *Loss Change and Grief*. London: David Fulton
- Dew, A., Balandin, S., & Llewellyn, G. (2008). The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental and Physical Disabilities*, 20(5), 485-507. doi:10.1007/s10882-008-9109-5.
- Doherty, J. (1992) A sibling remebers. *Candlelighters Childhood Cancer Foundation Quarterly Newsletter*, 16, 14-16.
- Dyson, L., Edgar, E., & Crnic, K. (1989). Psychological predictors of adjustment by siblings of developmentally disabled children. *American Journal on Mental Retardation*, 94, 292-302.
- Greenberg J.S., Seltzer M.M., Orsmond G.I & Krauss M.W. (1999) Siblings of adults with mental illness or mental retardation: current involvement and expectations of future caregiving. *Psychiatric Services* 50, 1214-19.
- Knott, F., Lewis,C. & Williams,T. (2007) *Sibling Interaction of Children with Autism: Development Over 12 Months*. Springer Science.
- Kupfer, D., Kuhl, E., Narrow, W., Regier, D., & McHugh, P. (2010). Updating the Diagnostic and Statistical Manual of Mental Disorders. *Cerebrum* 2010: Emerging ideas in brain science (pp. 81-102). Washington, DC US: Dana Press. Retrieved from PsycINFO database.
- LeClere, Felicia B. "Disability in the Family: The Effects on Children's Well-Being." *Journal of Marriage and Family*. 1994: 457-468.

Minnett, A.M, Lowell Vandell,D. & Santrock, J.W (1983). The Effect of Sibling Status on Sibling Interaction: Influence of Birth Order, Age Spacing, Sex of Child, and Sex of Sibling. *Child Development*, 54, 1064-1072.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.

Yirmiya, N., Gamliel, I., Pilowsky, T. et al. 2006. The Development of children with Autism at 4 and 14 months: social engagement, communication, and cognition. *J Child Psychiatry* 47:511-523.

