

PERCEPTIONS OF TYPICALLY DEVELOPING CHILDREN IN INDIA  
ABOUT THEIR SIBLINGS WITH DISABILITIES

BY

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THESIS

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## ABSTRACT

In India, people with disabilities often struggle to access various opportunities and resources. Because of the Indian culture around acceptance of disabilities, family members may face social, financial, and emotional difficulties or hardships. Having a child with a disability in the family may lead to strained sibling relationships. Often siblings have little knowledge about disabilities, and may feel ostracized by friends, extended family members, and neighbors. The purpose of this study was to examine the knowledge and attitudes of 12 Indian children regarding their younger siblings with disabilities, including their perceptions about disabilities against the backdrop of societal attitudes and perceptions. Siblings of children with disabilities were interviewed to understand their knowledge about their siblings' disabilities, to examine their relationships with their siblings, and to assess how the school and society played a role in influencing their perceptions about disabilities. Results from this exploratory study can help parents and other family members understand how disability shapes relationships between children. The findings also provide Indian policy makers and program directors with information that might help them better support families.

*Key words:* siblings, disabilities, India, sibling relationships

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## CHAPTER 1

### INTRODUCTION

According to the Indian Census (2011), which contains data from 2001 (the most recent census available), the number of individuals with disabilities is 21 million, which represents 2.1% of the total population. The census also reveals that individuals with disabilities tend to live in more rural than urban areas. Across the groups of individuals with disabilities in India, only 35.29% have access to school (Janardhana, Muralidhar, & Raghavendra, 2015). Janardhana et al. (2015) also noted that the situation for people with disabilities in India is extremely difficult, especially in rural areas and among lower socio-economic populations. These researchers emphasized how the stigma attached to disabilities affects both the individuals with disabilities and their family members. Often people with disabilities are confined to their homes and denied basic amenities such as education, employment, and opportunities for outdoor recreation (Janardhana et al., 2015).

Although India is developing economically and improving in various social sectors, there are very few services for individuals with disabilities. These individuals face significant discrimination and have limited access to education and employment. Additionally, for individuals with physical disabilities, the roads and buildings are often inaccessible. One important obstacle facing individuals with disabilities is a lack of awareness among the people in the Indian community. Stigma attached to disability is more prevalent for people with intellectual disabilities than physical disabilities; negative attitudes affect not only the individuals with disabilities but their families as well. For example, Gupta, Mehrotra, and Mehrotra (2012) examined parental stress associated with having a child with a disability in India, and found that parents of children with developmental and disabilities felt more stressed compared to parents

whose children had medical disabilities. The authors indicated that parents in the former group often encountered social, emotional, and economical stress.

Sari, Baser, and Turan (2006) examined the stress level of mothers of children with Down syndrome in the USA. These parents noted that having a child with Down syndrome affected their typically developing children. The parents stated that their typically developing children struggled academically and became introverted due to having a sibling with Down syndrome. Orsmond and Seltzer (2009) noted that there was more research on how mothers of children with autism adjusted to having a family member with a disability, compared to how siblings adjusted. Many studies exist regarding siblings' wellbeing, adjustment, and their experiences with having a brother or sister with disabilities; however, these studies typically have been conducted in the context of Western societies (Lobato, Kao, & Plante, 2005; Raghuraman, 2008; Sage & Jagatheesan, 2010). Nielsen, Mandelco, Roper, Cox, Dyches, and Marshall (2012) noted that previous studies examined the impact of having a sibling with a disability and mostly focused on problems and experiences rather than focusing on sibling relationships.

Some researchers found that having a sibling with a disability had a negative impact on sibling relationships (Sari et al., 2006), while other researchers suggested that there was no negative impact (Raghuraman, 2008). There is a need to understand the impact on typically developing siblings of children with disabilities, in order to determine if interventions are needed. Also it is important to investigate if variables such as gender, age, and type of disability impact sibling relationships. Hodapp, Urbano, and Burke (2010) examined the male and female siblings of individuals with disabilities, and found that female siblings reported it was advantageous to have a brother or sister with disabilities. Similarly, Skotko, Levine, and Goldstein (2011) found

that having a brother or sister with a disability had a positive influence on typically developing siblings. On the other hand, Neece, Blacher, and Baker (2010) found that typically developing siblings reported a negative impact when a brother or sister has a disability, especially if the sibling has behavior problems. Many researchers studied parents' perceptions about sibling relationships, however all of these studies were done in the USA, where most of the schools were inclusive settings and the sample consisted of mostly Caucasian Americans. Little is known about the siblings of children with disabilities in India, where it is common for extended family members to live together. In such cases, siblings often take care of their brothers or sisters with disabilities even after the typically developing child gets married. If children do not have positive perceptions or attitudes about their siblings with disabilities, it may lead to low expectations for the individuals with disabilities and limited opportunities for inclusion across all aspects of life.

## CHAPTER 2

### LITERATURE REVIEW

The literature on which this study was based focused on different aspects of sibling relationships. Typically, siblings spend a great deal of time together at home and therefore they can influence each other in many ways. Studies have either explored similarities in relationships between siblings of children with disabilities and siblings of typically developing children, or differences in relationships between siblings with and without disabilities. Some researchers studied the warmth and closeness of relationships and perceptions about disabilities, while other researchers explored factors that influenced sibling relationships. Research also has been conducted on how siblings participate in their brother's or sister's interventions, as well as how having a brother or sister with a disability has affected typically developing siblings.

To conduct the literature review for this study, articles were found in the ERIC database, and in the *siblingleadership.org* database. Keywords included: *siblings' perceptions of disability*, *siblings and disability*, and *impact of having siblings with a disability*. A total of 72 articles were found from the above-mentioned sources. After reading the abstracts, 38 were excluded for their purpose was different from the current study. The remaining 34 studies fulfilled the required focus, but they were further filtered to 11 articles on the basis of the age of the participants, and the research methodology (see Appendix A). Only few articles were available, which concentrated only on elder typically developing siblings who have a younger brother or sister with disabilities. So the researcher included those 11 articles where at least a few typically developing elder siblings participated in the studies. The criterion for selecting articles were: the studies had to be done in English; one of the siblings had a disability; the participants were

typically developing siblings; the research was conducted in the USA between 2000- 2015; and interview/survey/observation methodology was used.

### **Siblings' experiences, relationships, attitudes, and perceptions about disabilities**

While different cultures have different values toward individuals with disabilities, it is interesting to see how family members, especially siblings perceive their brother's or sister's disability. Sage and Jagatheesan (2010) conducted a study to examine the perceptions that siblings from Asian American and European American families had about their brother or sister with autism. They conducted in-depth case studies of two families living in the USA, who each had sons with autism and a typically developing elder son. Data were collected primarily by interviewing the typically developing siblings using "visual methodologies," questioning the parents, observing family interactions, and video-recording the siblings playing and interacting with each other.

Findings indicated that in the European American family the typically developing sibling asserted that his younger brother with autism was "unique" and "special" because he had autism. He described his younger brother as a "happy boy" who smiled when he was surrounded with other people. He also said his sibling was smart and capable of doing many things. This sibling noted they were very happy when they were home together and the authors summarized their relationship as warm, close, and caring. The typically developing sibling also reported that he understood his brother with autism better than their parents. Regarding awareness and understanding autism, the authors noted that the older sibling had a good sense of what autism was. These feelings and attitudes of the older sibling were reflected through his drawings and interviews.

The authors also found that in the Asian American family the typically developing sibling had much less awareness and knowledge about his younger brother with autism. The authors reported that the older sibling was not aware of his brother's condition, and attributed it to tantrums and a lack of good listening skills. This sibling developed an understanding of autism based on his brother's behavioral and communication patterns. In his drawings, the sibling did not draw his brother's ears because he thought his brother did not have ears to listen. The drawings also revealed that the typically developing brother had mixed feelings about his brother with autism, such as anger and frustration, but he put a smile on his own face because his mother instructed him to do this. The authors observed that there was tension during sibling interactions. They concluded that the two siblings from two different backgrounds had different attitudes and perceptions about their brothers' disabilities. Limitations of the study included a small number of participants, with only one family from each cultural background. While this study represents two families, it does not represent their whole cultures. Thus the conclusions cannot be generalized to a larger group of Asian American or European American families.

Rivers and Stoneman (2003) examined sibling relationships when a child has disability in the context includes marital stress and support coping. The authors recruited 50 families with a child with autism in the USA. Participants included the parents, typically developing siblings and children with autism from each family. The age of the typically developing sibling ranged between 7 and 12 years old and the children with disabilities were between 4 and 12 years old. Mothers were between 30 and 49 years old. Participants completed by self- report inventories and questionnaires.

Findings indicated that the typically developing siblings and their brothers or sisters with autism had positive relationships. The authors also mentioned that the age of the siblings, the age

between the siblings, parents' education level, family income, and the severity of the autism did not impact the sibling relationships. Limitations of the study included most of the families were Euro-American and the authors did not observe the participants' interactions.

Lobato et al. (2005) examined the knowledge and understanding of Latino siblings about their brothers' or sisters' developmental disabilities. Twenty non-Latino and 20 Latino families from similar socioeconomic backgrounds were recruited for participation. Parents and siblings of children with disabilities were interviewed. Findings indicated that Latino siblings had relatively less accurate knowledge about disabilities compared to non-Latino siblings, but siblings from both groups shared similar understandings about the cause of their siblings' disabilities. According to the authors, the typically developing siblings responded differently to their brother or sister, depending on the significance that each respective culture attributed to the sibling relationships. The authors mentioned that Latino culture places a strong emphasis on sibling relationships and siblings caring for each other.

When it comes to the knowledge and perceptions that typically developing siblings have toward their brothers or sisters, Raghuraman (2008) conducted a study to examine variables such as closeness, warmth, conflict, depression, perceptions of parental attention, responsibilities, and sibling activities. He interviewed 35 siblings of children who were hard of hearing and 35 siblings of typically developing children. The siblings were interviewed about their perceptions and relationships, and parents were interviewed and asked to complete a child behavior checklist. Raghuraman (2008) found that positive and negative feelings that siblings harbored toward each other remained unaffected by the fact that one of the siblings had a disability. The author predicted that the reason for limited differences between these two groups might be the result of parental communication, adjustment, the age of the siblings. Another prediction was that sibling

relationships and perceptions might change over time. The author also found that sisters from both groups had more positive interactions with their younger siblings than older brothers. The primary limitation of this study was that most of the participants were Caucasian (28 of 35 families).

Orsmond and Seltzer (2007) examined emotional involvement in the relationships of adult siblings who had brothers or sisters with Autism Spectrum Disorder (ASD) or Down syndrome. The authors gathered and compared data from two longitudinal studies of 77 adult siblings of individuals with ASD and 77 adult siblings of individuals with Down syndrome. Overall they found that siblings of adults with ASD described less positive emotional relationships and fewer personal interactions and contact than the adult siblings of individuals with Down syndrome. The authors also noted that siblings of individuals with ASD were less optimistic about their brother or sisters' future than siblings of individuals with Down syndrome. The researcher indicated that more positive and closer relationships existed if the siblings of individuals with ASD did not have higher educational degrees, lived close to each other and if the individuals with ASD were less dependent on their siblings.

Orsmond and Seltzer (2009) examined the wellbeing of brothers or sisters with ASD, using data gathered from questionnaires. In this study, the authors focused on 57 adolescent participants, who were between 12 and 18 years old and their mothers. The authors noted that only one third of the siblings reported depressive symptoms, however they found that girls who had siblings with ASD reported more depressive and anxiety symptoms compared to boys who had siblings with ASD.

Smith, Ronski, and Sevick (2013) examined the role of communication and interaction patterns on the quality of sibling relationships when one sibling had a developmental disability.

The authors recruited 30 sibling dyads to participate in their study. Among the typically developing sibling participants, there were 18 boys and 12 girls ranging in age from 10 to 17 years old. All participants had siblings with disabilities younger than them, but within a 4 year age gap. The authors conducted home visits and observations, concluding that communication skills did not influence the sibling relationships in terms of warmth, closeness, conflicts and rivalry. The authors also noted that the typically developing siblings engaged more in teaching, and helping their siblings with disabilities. These behaviors resulted in the relationships being unequal or asymmetrical.

Angell, Meadan, and Stoner (2012) examined the experiences and of siblings of individuals with autism spectrum disorders (ASD). Twelve siblings were interviewed for this study, aged between 7 and 12 years old. The authors noted that the participating siblings were somewhat engaged in their siblings' education. The researchers also mentioned that the siblings played roles of caregivers, entertainers, and helpers in the lives of their brother or sister with ASD. The authors reported that from the interviews they explored the caring nature, compassion, affection, and patience the typically developing siblings had for their brothers or sisters with ASD.

Overall these studies indicated that sibling relationships were affected by the type of disability, the siblings' age, and how the family prioritized the sibling relationship. Siblings' perceptions depended on how much information they received from their parents about their brothers or sisters' disabilities. The more knowledge the siblings had, the better their perceptions and relationships were about their brothers or sisters with disabilities.

### **Research on sibling-mediated interventions**

Often siblings take part in the interventions conducted with their brothers or sisters with disabilities. The training to provide an intervention is usually guided by family members or professionals. Some researchers have studied how siblings of children with disabilities could help enhance their brother's or sister's communicative and interactive skills and other aspects of treatment. For example, Trent-Stainbrook, Kaiser, and Frey (2007) conducted a study to teach "responsive interaction strategies (mirroring and verbal responding)" (p. 274) to typically developing older siblings and to examine the outcomes of the sibling- implemented intervention during play sessions with their younger siblings with Down syndrome. The authors recruited three sibling dyads for this study and trained the typically developing older siblings on non-verbal mirroring and verbal responsiveness. Sessions occurred in the children's homes for 30- 60 minutes each. A total of 12 to 15 sessions were conducted with each dyad. The researchers videotaped play sessions between the siblings and found that the elder siblings learned the responsive communication strategies quickly and implemented them during interactions with their siblings with Down syndrome. Results also revealed that the communicative skills of siblings with Down syndrome increased in terms of making comments without prompting from others. The researchers concluded that if typically developing elder siblings knew "how to interact" with their younger siblings who had disabilities, they would enjoy their interactions to a greater extent. Also the siblings with Down syndrome benefitted from increased communication with their typically developing siblings. Similarly, Smith et al. (2013) suggested that teaching new methods of interaction to the siblings of children with developmental disabilities could positively impact their interactions.

Kresak, Gallagher, and Rhodes (2009) examined the perceptions of families about the inclusion of typically developing siblings of children with disabilities. Both quantitative and

qualitative data were collected. The study consisted of 87 parents who had a child registered in Part C early intervention services in one state. The findings from this study suggested that parents believed that siblings were an important part of young children's early intervention programs and played an integral part in the learning opportunities for children with special needs in the community and within family settings. Forty-eight percent of the participants reported they would like to have goals for their typically developing children on the Individualized Family Service Plan, especially related to play and communication.

### **The impact of a disability on typically developing siblings**

Many researchers have studied the impact of having a brother or sister with intellectual and developmental disabilities on siblings. While a disability can assume different manifestations (e.g., psychological, emotional, and psychosocial), one of the consistent significant concerns is the financial responsibility and caretaking role that a sibling might assume. Orsmond and Seltzer (2007) reported that many adult siblings of individuals with autism or Down syndrome were expected to take on responsibility for their siblings in the absence of their parents however, it can become challenging to be involved in their siblings' lives when they have their own families and responsibilities. The authors discovered that siblings of adults with ASD might face more difficulties after their parents die, may not be able to take on the role of primary caregiver, or may have less emotional attachment and less positive feelings about their siblings' future compared to siblings of individuals with Down syndrome.

Cox, Marshall, Mandelco, and Olsen (2003) studied how 46 elder siblings of children with disabilities coped with daily stressful events. These researchers conducted home visits and had siblings' verbally complete sentences consisting of real and hypothetical stressful situations. The researchers concluded that 65% of participants were proactive in responding to the stressful

situations and used a problem- solving rational and/or a physical approach (e.g., walk away, run, and talk about it). The authors found that 19% of siblings reported that they would use interactive approaches to solve stressful situations by seeking out another person for social support. Also, 13% of siblings' responses were internally reactive (e.g., they engaged in thought processes and expressed emotional feelings to stressful situations, such as "Get mad," or "Get frustrated," they thought of silly things that they could do etc.). The authors also noted that proactive responses had a positive impact not only on the individuals but also on family members and society. They suggested that taking extra responsibility for having a brother or sister with a disability made the typically developing siblings personally more responsible. A noteworthy fact is that the authors only explored daily stressful events, not the long- term impact of the siblings living with brothers or sisters with disabilities.

Neece, Blacher, and Baker (2010) examined the impact on siblings of children with intellectual disabilities in their daily lives. The authors studied the siblings at the ages of 5-8 years across a three-year period of time. The authors indicated that the 114 parents reported a more negative impact on their other children when they had siblings with disabilities than the parents of siblings of typically developing children. The authors suggested that siblings who assumed more family responsibilities, or were embarrassed about their sisters'/brothers' behavior did not enjoy their siblings' company, which led to a stronger negative impact. The authors also found a negative impact if a sibling had behavior problems, regardless of whether the child had intellectual disabilities.

In contrast to the aforementioned findings, there are studies, which suggest positive outcomes when a child has a brother or sister with disabilities. Hodapp et al. (2010) examined 1,160 adult brothers and sisters of individuals with disabilities through a web-based survey that

included 163 survey questions. Questions focused on the relationships between siblings with and without disabilities. The authors indicated that the siblings shared positive relationships and had close contact. The authors also found that only a few participants reported negative impacts from having a sibling with a disability. Over 39% of participants rated their health as “very good” and 29% rated it as “excellent” (p. 55). Respondents noted that they seldom experienced depressive symptoms. Another finding from this study was that the Caucasian, highly educated American female siblings of individuals with disabilities married late in life, which was not observed in male siblings. The primary limitation of this study was the lack of diversity among the participants as most of the participants were Caucasian Americans and highly educated. It would have been a stronger study if participants were included from different racial and ethnic backgrounds, educational levels and socioeconomic levels.

Skotko et al. (2011) examined the perceptions of 822 siblings of individuals with Down syndrome. Findings from this survey study suggested that most of the siblings loved their brother or sister with Down syndrome. The results also showed that the participants’ love and pride for their siblings was not impacted by the severity of the brother’s or sister’s disability. Participants who were high school students identified themselves as better people as a result of having a brother or sister with Down syndrome. Another positive finding from this research was that the participants reported that they could appreciate the differences in human beings in a better way and they gained deeper perceptions about life as a consequence of having a sibling with Down syndrome. A small percent of participants did feel sorry themselves as a result of having a sibling with Down syndrome, especially one with learning disabilities. The primary limitation of this study was that in-depth interviews were not conducted, and survey data not provide a thorough understanding of the perceptions of siblings of individuals with Down syndrome.

Overall several researchers have shown that having a brother or sister with a disability impacts siblings. Findings revealed that this impact varies depending on the disability and on the typically developing siblings.

### **Cultural and family influences on siblings' knowledge, perceptions, and relationships**

Culture influences us in many ways, for example the way we dress, the way we talk or even the way we perceive things. In some studies, it has been shown that depending on ones' cultural background, parents have an important role to play in building relationships between their children. Bat-Chava and Martin (2002) examined the sibling relationships of children who were hard of hearing. These authors interviewed 37 parents of siblings of children who were hard of hearing. In-depth interviews focused on their children's social life in order to understand the relationship between the siblings. The authors concluded that sibling relationships were gratifying but indicated that when families who had only 2 children made negative comparisons between their deaf child and their typically developing children, sibling relationships were more negative. Similarly, Raghuraman (2008) stated that siblings' perceptions of their own behavior and temperament in the context of having a brother or sister with disabilities tended to reflect their parents' views and was related to how accurate the information was that their parents shared with them.

Bellin and Rice (2009) examined family, individual and peer factors related to the quality of sibling relationships for youth with Spina Bifida. Participants included 224 siblings and their parents. The siblings completed a survey of 140 questions measuring their attitudes towards the disability, the quality of relationships, peer supports, and family functioning. The parents provided information about the severity of the disability and other family demographics. The authors concluded that there was a strong connection between family functioning and sibling

relationships. They also indicated that the family played a more important role than peer relationships in influencing the siblings' interactions and relationships with their brother/sister with a disability.

Sage and Jegatheesan (2010) indicated that religious and cultural views influenced family members' beliefs and understanding about disability, which in turn impacts their child-rearing practices. The authors mentioned that the older son in the European-American family did not have extra responsibilities for his sibling with a disability, in contrast to the son from an Asian American family. Also the Asian American family felt ashamed of their child's disability and did not share information with their typically developing son for almost two years after the diagnosis. The authors stated that cultural practices and religious beliefs put a lot of expectations on the older sibling, which caused frustration and anger by the typically developing sibling in the Asian-American family. The authors suggested that since parents are the first and most important teachers in their children's lives, they play a significant role in nurturing sibling relationships.

Lobato et al. (2005) pointed out that Latino cultures believe that collectivism and "familism" are strong cultural parts of all subgroups. The authors also noted that cultural values were reflected in the quality of sibling relationships of Latino and non-Latino groups, and that Latino groups placed significant importance on sibling relationships.

Cultural background shapes the priorities and responsibilities in different relationships. Families from different cultures have varying views about the siblings' duties and responsibilities toward their brothers and sisters with disabilities. It is difficult to draw conclusions about cultural influences or how different cultures view disabilities from the limited numbers of empirical studies that addressed this topic. However, it is clear that disability is viewed as stigmatizing in many cultures.

## **Gaps in the literature**

Most of the literature used in this review, examined the relationships between siblings in the context of Western societies; only a few studies examined this topic from a more global perspective. Few researchers have explored the role that family members play in sibling relationships. It was hard to find any literature about families in India, including the perceptions that siblings of children with disabilities have about disability, and how society reinforces family attitudes toward disability. In India as a whole, religion plays a very important role in people's lives, however India's traditional culture with its roots in different religions is unique. Yet how Indian cultures influence the attitudes of family members (especially siblings) of children with disabilities is an under researched topic. No studies were found which explored this aspect of special education.

## **Statement of the Problem**

In Indian societies, having a disability is still taboo. People with intellectual and other developmental disabilities are not readily included in most community settings, and have very limited access to schools, and employment opportunities. The families of children with disabilities go through various struggles including financial, social, and emotional ones. India is culturally and religiously diverse; so the impact of disability can vary extensively between Southern and Northern India, urban and rural areas, and across religious and socio-economic classes. In rural areas and sometimes even in urban settings, the family structure is very different from western society. For example, extended family members often live together under one roof, in joint families, which may include grandparents, uncles, aunts, and cousins. In this system, each family member influences the others. Sonawat (2001) noted that the caste, family, and community are the core structures of Indian societies. This author also described that on one

hand, the family influences the life of the individuals, while on the other hand the community and socio- religious beliefs and practices have an immense impact on Indian families. Therefore, if a child has a disability it can affect all of the family members.

Among all family members of a child with disabilities, parents and siblings are most profoundly affected. The parents who typically function as primary caregivers may receive support through various types of groups; but often the siblings have little access to information or support in understanding a disability and its impact. Parents may choose not to talk about their child's disabilities with their other children, and in some cases they may not even have a clear idea about the disability themselves therefore making it difficult to share information. Often parents are unable to discuss such matters with other community members due to a fear of social rejection. A further complication is that after the parents pass away it is common in Indian societies that siblings take on the responsibility for individuals with disabilities. For that reason typically developing siblings need to have sufficient knowledge about disabilities from a very young age as this will not only help them understand their siblings better, it will provide them with background information to support their siblings in the future.

It is also important to know how a child's disability impacts the relationship between siblings and the family structure. A sibling's knowledge and relationship with his or her brother or sister usually reflects the family's perceptions and attitudes towards disability. Clear understanding and knowledge can help siblings cope with insensitive questions and comments from friends and neighbors, and can help them deal with uncomfortable stares from strangers. This knowledge might positively impact the social and emotional lives of typically developing siblings, especially in their formative years. This study provides a window into how some members of an Indian society perceive disability.

## **Purpose of Research**

The purpose of this exploratory study was to examine the knowledge and attitudes that children of Indian families have regarding disability, particularly their perceptions of a sibling with a disability. Additionally, siblings' understanding of the impact that a disability has on the family structure and relationships, including their perceptions of disability in the context of their schools and society were examined. The following research questions were explored:

1. What are the perceptions of typically developing children toward their siblings with disabilities, *and* what is the impact of a disability on the sibling relationship?
2. How do children feel about the way their siblings with disabilities are perceived in school and in the community?

## CHAPTER 3

### METHODS

The focus of this study was to examine children's perceptions about their younger siblings with disabilities. Interview methodology was used to gather data so that participants could explain their perceptions and views in detail. The interviews consisted of open-ended questions, which helped the researcher gain important information from the participants, beyond the researcher's own perceptions or data from past research (Creswell, 2012). Once IRB approval was granted (see Appendix B), and receiving parent approval, participants were interviewed in-person, and the conversations were recorded for later transcription.

#### **Participants**

The site for this study was a South Indian city, Hyderabad, the capital of Telengana State. According to the 2011 Census in India the population of Hyderabad city was 6,731,790 and the area was 217.00 sq. kms. The literacy rate in Hyderabad city was 83.26% and the total number of children (birth-6) was 799,397. The ratio of males to females was 1000:922 (Census of India, 2011). In Hyderabad, there are approximately 15 schools exclusively meant for children with physical and intellectual disabilities. Among them, there is a school in the center of the city that is free of charge for students with disabilities. For the purpose of this study, the school will be called Shikshayatan School and pseudonyms were given to the participants. The main reason for choosing Shikshayatan School was that most of the students and their family members speak Hindi, unlike many of the schools in Hyderabad, where the primary language spoken by the students and their families is Telegu. The researcher is fluent in Hindi but does not speak Telegu. Potential participants were contacted through Shikshayatan School.

Table 1

## Participant demographic information

Participants	Age	Gender	Child with Disabilities	Age	Gender	Type of Disability	No. of Children in family
Suhana	12	F	Kamala	7	F	Down syndrome	10
Jahnavi	9	F	Arati	7	F	Down syndrome	2
Soha	14	F	Muhammad	6	M	Intellectual Disability	4
Farzana	12	F	Omkar	7	M	Intellectual Disability	4
Rukmini	11	F	Ruma	5.5	F	Autism	5
Soma	16	F	Hanifa	7	F	Developmental delays	3
Fardeen	10	M	Zaib	5	M	Down syndrome	3
Shehnaz	13	F	Somaya	8	F	Down syndrome	3
Akshar	13	M	Rani	8	F	ADHD	3
Arbaz	11	M	Abrar	7	M	Autism	3
Bhanu	10	M	Bhavesh	8	M	Developmental delays	2
Sohan	16	M	Shakeeb	8	M	Intellectual Disability	3

Originally, 13 parents agreed to have their children participate in this exploratory study, however; one child declined the request for an interview as he was fasting during that time for religious purposes and was too tired to take part in the study. Therefore, 12 siblings, seven girls and five boys and their parents participated in the study (see Table 1). Two of these participants had also participated in a class project with the same researcher six months earlier. All participants were between nine and sixteen years old ( $M = 12.2$ ) and they all had a younger brother or sister with disabilities, between five and eight years old ( $M = 6.9$ ). Among the children

with disabilities, half were female and half were male. The types of disabilities as reported by parents, included Down syndrome, Autism Spectrum Disorder, Speech delays, Attention Deficit Hyperactive Disorder, Developmental Disabilities, and Intellectual disability. Four parents described their children's disability as Down syndrome, two parents said their children had Autism, and the other six families described their children as having an Intellectual disability, Speech Problems, Developmental delays, and or ADHD. Across the participants, the average number of children in the home was 3.7, with a range of 2-10. The researcher described the criterion for the participants' age to the parents, and if a family had more than one typically developing child between the ages of 8-16, then the parents selected which typically developing child would participate in the study.

### **Setting**

All interviews were conducted in person in the participants' homes. The interviewer called the parents to ascertain the best time to talk to the participants. The interviewer then called back 24 hours before the interview and asked the participants whether they were able and willing to participate in an interview the following day. If a participant agreed, then the interviewer went to the home and conducted the interview. All interviews were audio recorded. It was assumed that interviewing participants in their homes with their parents present would help the children feel more comfortable yet would maintain their privacy.

### **Instruments**

The participants and their parents were interviewed in Hindi, their first language (see Appendix C). The researcher selected interview questions based on the literature review. First, parents were asked five questions to gather demographic information, such as how many children they had, their ages, which grades they were in, and whether they discussed their child's

disability with their typically developing children. Questions for sibling' interviews were adapted from Benderix and Sivberg (2007) and Lobato et al. (2005). Benderix and Sivberg (2007) conducted a study to examine siblings' past and present experiences with their brothers or sisters with autism or a moderate intellectual disability. These authors developed some questions related to the time siblings spent together and whether their friends knew that their brothers or sisters had a disability. Lobato et al. (2005) conducted a study to examine the knowledge and perceptions of siblings about their brothers or sisters with disabilities, and looked into cultural influences on a sibling's understanding of disabilities. Since the topics of both studies were similar to this study, some questions were adapted for use in the current study. The development of the instrument also was informed by feedback from two professors with expertise in interview methodology.

Interview questions were divided into three parts. After agreeing to participate in the study but before interviewing the participants, the researcher gathered demographic information from the parents during an informal discussion. After learning about the child's disability and determining if the parents talked about it with their other children, the researcher interviewed one sibling per family. The first section of the child interview focused on the siblings' relationship. This section of the interview included three questions: 1) What kinds of things do you like to do with (child's name)? 2) What kinds of things is (child's name) good at? and 3) What do you like most about (child's name)? The second section focused on siblings' perceptions about their brother or sister with disabilities and included two questions: 1) Tell me about (child's name) disability, and 2) What special things does (child's name) require because of his/ her disability?

The third section addressed participant understanding of society's perceptions of disability (i.e., school, friends etc.), and how this impacted them. This section included several

questions: 1) Do you have opportunities to do a lot of things with your friends? What do your friends know about (child's name)'s disability? 2) What happens when you bring your friends to your home? 3) How do they interact with (child's name)? 4) Tell me about a time when you took (child's name) with you when you spent time with your friends? 5) What do your neighbors say about (child's name)? 6) Describe how the children in your neighborhood play with (child's name). What things do they like to play with him or her? Or why do you think they do not play with (child's name)? 7) Have you ever been teased for having a brother/sister with disabilities? Tell me about it. 8) Have you ever noticed other people teasing your brother or sister about his/her disability? If yes, what did they say or do? 9) What worries or concerns do you have about your sibling (child's name)? 10) Finish these sentences for me: a) In 5 years I think my brother or sister will... b) One dream I have for (the child's name) is ... c) One dream I have for myself is ... and 11) Is there anything else you would like to share with me? After interviewing the siblings, the researcher asked the parents several debriefing questions such as whether they wanted to clarify anything their child mentioned, whether they wanted to add anything, and whether they thought their child had forgotten to mention anything.

A class project, done in Spring 2016 set the stage for this study. For the class project, the researcher conducted interviews with 8 typically developing siblings of children with disabilities, upon receiving signed consent letters from their parents. The eight participants were between 10 and 20 years old. The participants' brothers or sisters with disabilities were between 3 and 10 years old. All participants were recruited from the city of Hyderabad, India; the interviews were conducted over the phone and audio recorded. Based on this class project, changes were made to the interview procedures and protocol including: interviewing participants in person, interviewing parents to gather demographic information, and debriefing with parents after the

sibling interview.

## **Procedures**

The researcher volunteered at a school for children with special needs in Hyderabad for 6 months in 2012. Because of this, the researcher was familiar with the principal. After getting the IRB approval from Institutional Review Board, University of Illinois, Urbana- Champaign, the researcher contacted the principal of Shikshayatan School to obtain permission to contact teachers who shared the flyers and consent forms with parents. The principal of Shikshayatan School introduced the researcher to the teachers at a staff meeting during which the researcher explained the study and distributed flyers. The teachers were asked to identify families who had children with special needs between 3 and 8 years of age because this study focused on young children with disabilities as the researcher had strong interests and expertise in early childhood special education. Typically developing elder siblings, between 8 and 16 years old, were targeted as interviewees as it was felt that children of this age could verbally express their views. The teachers distributed the flyers to families who met the criterion. After getting the flyers back from the parents, the researcher called the parents and scheduled a time to meet them individually to explain the study and their children's role as a participant. According to the classroom teachers 18 consent forms were distributed (See Appendix D). Depending on parental preference the researcher met the parents at the school or their residence to discuss the study. The researcher gave parents the option of sending the consent forms back to the school or signing the consent form and giving it to her immediately. The researcher obtained some signed consent forms from the teachers, while others were obtained directly from families at the time of the interview. If the consent forms were not received within two weeks from the date of sending them out, the researcher contacted the teachers who were asked to resend the forms.

After receiving approval from the parents, the researcher called them to schedule a time for the interview. She also introduced herself to the child participants over the telephone and informed them about the interview time. On the day of interview, the participants and their parents were informed about their right to: a) withdraw consent, b) refuse to participate in the project, or c) decline to answer any particular questions during the interview. Prior to interviewing each child, the parents were asked a few questions (see Appendix C, Section I) to gather some background information about the family. During ten of the interviews only the mother of the child was present during the entire interview, while during the other two interviews both parents were present.

Parents were first asked five questions about their family demographics. The researcher also asked the parents whether it would be all right to ask questions to the participants about their sibling's disability. All parents said yes, therefore the researcher proceeded with interviewing the 12 child participants (see Appendix C, Section II). Prior to beginning each interview, the participants were informed that if they wanted, they could ask their parents or another adult to be with them during the interview. All 12 participants requested their parents' presence. The participants also were informed about the project in a simplified way by the researcher and asked for their permission to audio-record the interview. Next the researcher asked the participants whether they were comfortable and ready for the interview. Once they said "yes," the researcher began the interview. During the interview if the participants were unable to answer a question, the researcher repeated the question a second time. The researcher spoke slowly and calmly to enunciate each word so that questions were clear. If a participant did not appear to understand a question after it was repeated, the researcher went on to the next question. After finishing the

interviews, the researcher thanked all participants for their time and valuable comments, and gave them a university pen in appreciation for their participation.

Participants' responses were audio recorded using an I-phone. After each interview, the researcher listened to the audio- recording and transcribed it. Since the participants were interviewed in Hindi, the interview data were transcribed into English. While transcribing, the researcher typed the interviewer and interviewees' comments in different colors to identify them easily while analyzing the data. Pauses and laughter also were included in the transcribed data (Creswell, 2012). After the interviews with participants, the researcher debriefed the interview with their parents (see Appendix C, Section III). It gave the parents an opportunity to clarify any facts or add anything that their child forgot to mention. The average interview time was 15.42 minutes (range of 10.04-21.27 minutes). The total number of transcript pages was 98 and the range was 6-11 pages per participant.

The researcher explained to the parents and to participants who were between 13-16 years old, ( $n=5$ ) that she would send them a summary of the themes by email to give them an opportunity to check the accuracy of the data. This particular age for the participants was chosen as it was assumed that they could remember what they said during the interview and compare that with the themes that emerged. These participants were asked to email any corrections or ideas to the researcher however, when these five participants were called only two participants' parents answered the phone. The parents reported that the children were busy with exams and would not be able to check the accuracy of the data.

### **Data analysis**

The answers acquired from the 12 interviews constitute the data for this study. To explore the data at an initial level, the researcher and her advisor read through each of the

(English) transcriptions. The researchers read the transcriptions multiple times to gain an in-depth understanding of the information acquired from the interviewees. The data were coded and then organized into potential themes. A table was created to organize the data, with each participant's information initially placed in a separate column on the table to create different codes of the data. Based on these codes, detailed descriptions of siblings' perceptions emerged as the data were combined across participants, categories began to emerge within each theme. All data within a potential theme was read and discussed to verify if it belonged under that theme. Consensus was reached as some responses were moved around to different categories and some categories were redefined or combined. After that, the major themes were clearly defined to present the data in a more systematic way.

### **Data verification**

After transcribing the interviews, the researcher reached out to a few Indian graduate students studying at the University of Illinois at Urbana- Champaign who knew Hindi well. The researcher's advisor chose four transcripts randomly, which were given to one Indian student whose native language was Hindi. He listened the interviews and checked the accuracy of the transcripts. Next the researcher's advisor sent the edited transcripts completed by the native speaker and the original ones completed by the researcher to a Master student in Special Education to calculate the accuracy of transcription. The accuracy for one transcription was 97% accurate, while the other three were 99% accurate.

### **Researcher's Reflection**

Being born and raised in India, the researcher has her own perceptions about how individuals with disabilities are looked upon in Indian society. While earning a Masters in Medical and Psychiatric Social Work, the researcher volunteered at a school for children with

special needs. During that time she saw firsthand how excluded children with special needs were from general education settings, and how the children were required to attend segregated schools. Children with disabilities and their parents were often blamed for the disability based on factors such as actions in their past lives (in Hinduism this is called 'karma'), or they were stigmatized. Having a relative with Down syndrome, the researcher has seen how individuals with disabilities can be excluded from mainstream society, and many times that person and his or her family are not able to participate in social functions due to the fear of not being accepted by other members of the community. This social isolation can have a devastating impact on members of a family. The researcher also talked to many parents of students in the segregated school where she used to volunteer. These parents reported that they rarely took their children to parks or participated in other community activities because parents of typically developing children would complain about the presence of the children with disabilities. Thus some of the questions asked of participants in this study were based on the researcher's personal and professional experiences in India.

## CHAPTER 4

### RESULTS

This study focused on Indian children's perceptions of having a younger sibling with a disability *and* the impact of a disability on the sibling relationship. Children's feelings about the way their siblings with disabilities were perceived in school and in the community also were explored. Data addressing each of these three research topics follows. However, before exploring the research questions it is important to note that when participants were asked to explain their siblings' disabilities or their siblings' struggles, all 12 participants were able to verbalize something about their siblings' condition but only five participants were able to name the disability. Two of these 5 participants correctly identified their siblings as having Down syndrome while the others gave more general descriptions (i.e., special needs, developmental delays) or partial descriptions (i.e., speech delays). Interestingly, seven of the 12 participants reported that they wanted to see their siblings get cured or become 'normal' in the future.

#### **Participants' perceptions about their siblings with disabilities**

The first research question focused on the perceptions of typically developing children toward their younger siblings with disabilities. Participants' responses were divided into six categories: communication, motor, cognitive, medical, behavior, and adaptive (see Table E.1 in Appendix E). Seven of the 12 participants reported that their siblings struggled to communicate. For example, three of the four participants with siblings who had Down syndrome, and both participants whose siblings had autism, mentioned communication as being problematic.

Six participants noted that their siblings struggled with motor skills. This category included responses such as Akshar's comment about his 8-year old sister Rani, "She can talk, but sometimes falls down while she walks." In a similar vein, 13-year old Shehnaz noted that her 8-

year old sister "...tries to jump but she falls and sometimes she cannot jump. She can't balance as well. She cannot walk...she cannot run, jump or walk fast."

Some participants ( $n = 4$ ) also mentioned their siblings' struggles with cognitive issues, noting that they were slower in grasping information, could not write, or could not follow the rules when playing games. Three participants mentioned that their siblings had behavioral problems; two of these participants had siblings with autism. For instance when describing her younger sister with autism, Rukmini stated, "Normal children do not make that noise/sound, she screams and hits her head on the ground." Finally, medical issues, such as seizures were noted as struggles for some children with disabilities, as well as adaptive issues such as eating independently.

To understand typically developing children's perceptions about their siblings with disabilities, the researcher also asked them about their siblings' strengths. These data were divided into four categories: motor skills and playing, daily living skills, social-emotional skills, and cognitive skills (see Table E.2 in Appendix E). All 12 participants reported that their siblings had strengths, highlighting the fact that in addition to concerns about their siblings' limitations, all participants had positive perceptions about their siblings. For example, seven participants reported that their siblings had good motor skills and played sports such as cricket. Nine-year old Jahnvi talked about her sister Arati's improvements in developing motor skills, "My sister is good at throwing the ball, I mean throwing the ball correctly. Nowadays she is doing this but before she could not do so."

Participants ( $n = 6$ ) also focused on daily living skills when they discussed their siblings' strengths. For instance Akshar, whose younger sibling had ADHD, said "She works at home, she sweeps the floor, and sometimes brings food when we sit to eat." Additionally, participants

highlighted their siblings' strengths in the area of social-emotional development, with comments such as: "Talks well, replies promptly," shared by Soha about Muhammad who had an intellectual disability; and "She never hurts or scolds me. If I say something, she will understand that and I also understand her. She helps me while I do my homework. She helps everyone. If I am writing, and I forget something, she will bring it to me" mentioned by Shehnaz in regard to Somaya who had Down syndrome. Three participants mentioned their siblings' cognitive skills as strengths, including the ability to follow directions as noted by Fardeen about his younger brother with Down syndrome. Also, 12-year Farzana highlighted her 7-year old brother's reading skills with this comment: "good at reading Quran, praying to Allah."

To understand the participants' knowledge about their siblings' disabilities, the researcher asked them what special things their siblings required. Their responses were coded into three categories: intervention, support, and nothing (see Table E.3 in Appendix E). Eight participants reported that their siblings required interventions, which included medicine, physiotherapy, a good doctor, and speech therapy. For example Shehnaz stated, "She should be like us. She should run, jump and walk. She should do everything like us. She should practice," while Akshar stated, "She has problems while walking. It's good she comes to this school [special school]. It is good for her. She disturbs others a lot. She screams a lot and laughs out loudly."

The second category that emerged from the responses to this topic was shared by five participants and focused on support. For instance when talking about her 7 year old sister with Down syndrome, 12 year old Suhana stated that her sister's "brain needs to be cured by prayers," while Jahnvi reported about her sister, Arati, who had Down syndrome "Needs support from all of us." Similarly Soha said, "He likes dancing, so I want to help him to be a dancer. And for that

I need parents' support as well. That's what he wants to be also." The final category focusing on special things required of the siblings with disabilities, was reported by one participant; Bhanu noted that his sibling needed nothing. Interesting, Bhanu's brother recently started going to a special school, as he had previously attended his brother's school. The teachers at that school were concerned about him, suggesting that the family take him to a doctor, who diagnosed Bhavesh with developmental delays. These events might have led Bhanu to think that his brother did not need any other special supports.

To understand the perceptions of typically developing siblings, the participants also were asked about their worries and dreams for their brother or sister with disabilities. Eleven participants shared their worries about their siblings; the researcher forgot to ask this question to Farzana. Participants' responses were coded into 4 categories: being normal, being independent and having a good future, going to school, and other (see Table E.4 in Appendix E). The first category, being normal, included comments from four participants. For instance, Soma said, "Like she should get back her speech. That's the main worry," whereas Shehnaz stated, "She should do everything like us. And be a respectable person in society like us. She should never do any mistake and be normal person."

The second category that emerged from the responses to this topic was being independent and having a good future, which was addressed by three participants. This category included comments such as "Yes. Like what will she become, what will happen to her, all these" (Jahnavi), and "But only thing if he understands his life, then his future will be secured. He should have a good career, that's all" (Soha).

The third category to emerge from responses to this topic focused on going to school, which consisted of responses from two participants, both of whom had siblings with Down

syndrome. For example, Suhana said about her sister, Kamala, “Yes. I want her to go to a good school. She does not go to a school like us.” The last category was other, and included comments from two participants, who either had no worries (Bhanu) or worried that the sibling would not make any improvements (Sohan).

When asked about their dreams their siblings with disabilities seven participants reported that they wanted their siblings to be normal or get cured, which revealed that they did not have accurate knowledge about their siblings’ disabilities (see Table E.5 in Appendix E). For example, Suhana stated “I want to see her get well,” and 12 year old Farzana and 13 year old, Akshar who had siblings with an intellectual disability and ADHD respectively, mentioned “Doing good, being active and able to walk and talk” and “I want to see her get cured. She should be normal.” On the other hand, six participants’ responses were categorized as focusing on education and a career. For instance Soha stated “Higher studies. He has a keen interest in dancing. If he watches any dance, he can copy that fast. He likes dancing... That’s what he wants to be also.” And, Shehnaz revealed, “She should become a Public Service Officer. She should serve people.”

The third category that emerged from the theme of dreams was staying with or helping the sibling, which was communicated by four participants. Nine year old, Jahnavi replied, “I want her to stay with me.” The fourth category related to the topic of dreams focused on being able to play together, which was described by three participants. For example 16 year old Soma reported about her sister with developmental delays, “I would like to play together with her, talk to her and share things with each other.” The last category focused on respect, which was described by Shehnaz in the following way: “Never teased by anyone. Now also they don’t tease but they should not say why is she slow, why is she like this or that.”

### **Sibling relationships**

The second research question focused on the impact of a disability on sibling relationships. When participants were asked to identify some things they liked about their siblings and activities they participated in together, the results revealed that all 12 participants liked something about their brother or sister with a disability such as their sibling's smiles, painting, and playing. These data suggest that interviewees perceived their younger siblings with disabilities in a favorable light, for they were able to identify at least one positive attribute.

Participants' replies about specific things they liked about their siblings were divided into five categories: skills, activities, emotions, character or nature, and general. Six of the 12 participants reported that their siblings had skills that they liked including: playing with balls, dancing, reading, and being intelligent. In these responses, participants focused on strengths that their siblings with disabilities possessed. For example, Akshar stated "She can catch the ball well and throw it to me," and Sohan reported, "He plays well." Three female and two male participants highlighted activities that they liked to do with or observed their siblings doing, such as eating, sleeping, singing songs, playing, and painting. For instance, Suhana said that she liked "when she [her sister with a disability] eats [a] banana," while Arbaz responded that he liked his brother's "Painting and some nice activities. Sometimes he is good."

The third category that emerged from the participants' replies included a focus on expressions. Three female participants reported that they liked their siblings' smiles, laughter, and cries. Nine-year old Jahnavi said about her sister with Down syndrome, "Like when she cries, laughs and [is] being mischievous," and Farzana said, "His smile or laugh." The fourth category involved the siblings' nature or character, and included topics such as a sibling with a disability doing things for the participant (Soma), and a sibling showing love, engaging with others and doing no wrong (Shehnaz). The final category was general, and only included Jahnavi's reply of

“Everything.” These data focusing on things that participants liked about their siblings with disabilities reveal that siblings of children with Down syndrome shared more positive things about their brother or sister than the siblings of children with autism. These five categories of participant responses are presented in Table E.6, Appendix E.

To understand the relationship between the typically developing siblings and their brothers or sisters with disabilities, the researcher asked the participants what they like to do together. All 12 participants shared examples of things that they enjoyed doing together, and their replies were coded into five categories: playing, caretaking, watching TV, reading and coloring, and going out together (see Table E.7 in Appendix E).

Eleven of the 12 participants reported that they specifically liked to play with their younger siblings with disabilities. These participants stated that they liked to play with balls and dolls, jump and cycle together, and play cricket and basketball. For example, Soma said, “I like to play ball, also with dolls [with my younger sibling].” Jahnavi stated, “Jumping and playing around with her.” Only Soha, who had a brother with an intellectual disability, did not mention playing together. Three sub-categories emerged from the larger category of play: sports/gross motor activities ( $n = 6$  participants), general play ( $n = 5$ ), and playing with dolls ( $n = 1$ ).

The second category that emerged from the theme about things that participants liked to do with their siblings with disabilities was caretaking. Three participants reported that they liked to take care of their siblings or share their feelings with each other. For example, Suhana noted about her sister with Down syndrome that she liked “Loving, taking care of her,” while 13-year old Shehnaz stated about her sister with Down syndrome “I want to share my feelings with her.” Interestingly, all three of these participants were females who had sisters with disabilities.

The third category that emerged regarding things the participants liked to do together focused on watching television ( $n = 3$  participants). For instance, Akshar said, “Watch television... cartoons, movies, songs,” and similarly Bhanu noted “Watching TV, cartoons like Rangers. My brother loves to watch Rangers.” Three participants reported that they liked to read and color. Rukmini described this activity as “I read poems and do actions. She follows me and does a little bit,” and Arbaz revealed that they “Do ‘Rangeela colors’ [a form of coloring and painting in India, also called Rangoli].” Among these three participants, two of them had siblings with autism. Only one participant reported that he liked to go out with his sibling, as is evident in the following quote by Fardeen, whose brother had Down syndrome: “Yes, he likes to go outside very much. I like to take him to shops.”

### **Other people’s attitudes about disabilities**

The final research question focused on children’s feelings about the way their siblings with disabilities were perceived by peers and in the community. Specifically, participants were asked to consider peers and community members’ reactions when they took their siblings outside. The results showed that many of the children with disabilities did not have opportunities to play with children from the neighborhood. Also, data revealed that children often teased the participants about their siblings with disabilities. The participants reported that neighborhood children scared the children with disabilities, called them names, and did not play with them. While five of the 12 participants said that adult neighbors responded positively to their siblings with disabilities, three participants reported the opposite. Additionally two participants stated that their relatives were their neighbors and therefore were accepting of the siblings with disabilities.

Data revealed that some neighborhood children played and interacted with the children with disabilities, which was reported by six participants (see Table E.8 in Appendix E). For instance, Suhana stated in regard to her sister with Down syndrome, “Children play hide and seek, toy top spinning,” while Sohan stated, “Neighbor children play cricket with him. No one teases.”

Five participants reported that neighborhood children teased their siblings or did not play with them. Among these five participants, four of them were females. This category included responses such as “If by any chance he goes alone, other children will scare him or beat him. And he does not reply back to them or beat them. He sometimes cries or just silently comes back home” (Soha), and “Other children do not play with her” (Rukmini, who had a sister with autism). Five participants also noted how adult neighbors’ help, offer suggestions and give positive responses, to their siblings. Among these five participants, three of them had siblings with Down syndrome, which might lead one to conclude that Indian society has more positive attitude towards children with Down syndrome than children with autism. For example, Akshar reported, “They say good things always. They do things for my sister. They sweep our place, or bring things for her,” and Fardeen, brother of Zaib, who had Down syndrome said, “They say good things. Like he is improving. They look at him and say that he is now getting better.”

Three participants shared examples of adult neighbors’ negative responses to their siblings with disabilities. For instance, Arbaz reported “They ask why is he like this? When will he be nice, and is not hyperactive or screams? See your brother, what he is doing; destroying things and throwing things away in my home, he hits small children. They will take his cap.” Likewise Suhana said, “They tease her. They say that she does not have any intelligence. They sometimes beat her too.”

In addition to community members' responses to the children with disabilities, participants shared their feelings about how their peers interacted with their siblings, and peers' interest and knowledge about disabilities (see Table E.9 in Appendix E. Seven participants spoke of their peers' knowledge and interest in their sibling's disability. For example Soha said, "They know about his disability," while Shehnaz stated, "They just know that she is a Down syndrome baby, and she is very slow in everything. Once there was a program in our school and she came there and all my friends saw her and asked why she is like that and why can't she talk. My teacher and I talked to them."

Three participants described their peers played and interacted with their younger siblings. These comments included: "They talk to him" (Soha) and "Friends play with her when they are in a good mood. Playing ball, hide and seek, running bees, gardener gardener" (Jahnavi). Two of these three participants had siblings with Down syndrome.

Negative responses from peers were a topic discussed by three participants. For example, Akshar commented about his sister with ADHD: "She goes to others' home and brings things from others' places. My friends do not play with her because [her] behavior is not good. That's why." Similarly Bhanu said about his brother who had developmental delays, "He beats my friends as well. They also beat him." The data revealed that children who had behavioral problems faced more negative responses from neighborhood children.

When asked whether they took their siblings outside, five participants shared negative responses while three participants shared positive responses, and for two participants, it was atypical to go outside alone (see Table E.10 in Appendix E). Responses were not available from Soma and Fardeen since the parents of these two participants replied before the children had a chance to share their ideas. The main reason that participants gave for not taking their brother or

sister outside was either behavioral problems or physical problems. Four participants reported that they did not go outside with their siblings because they behaved badly, pulled hair, and beat others. Two of these four participants had siblings with autism. For example Rukmini reported, “Because she behaves badly. Sometimes she sits on the road and hits her head.” Similarly Arbaz stated, “He misbehaves on the road.” Likewise Suhana and Soha stated that it was uncomfortable for them to go outside alone with their siblings with disabilities.

Three participants reported that physical problems prevented them from taking their siblings with disabilities outside. For example Jahnvi reported, “She can’t walk well and doesn’t have balance,” while Farzana stated, “He can’t walk well.” Meanwhile, participants who took their siblings outside described these experiences. For instance, Shehnaz reported, “This summer holiday when I used to go to neighbors’ house, she also came,” while Bhanu said, “Yes. He comes.” Two participants (Suhana and Soha) reported that it was atypical to go outside alone, therefore it was not unusual that their siblings likewise spent the majority of time in the house.

### **Debriefing**

As noted earlier, 18 consent forms were distributed to potential participants by teachers and 13 forms were received, with individuals expressing an interest in the study. This shows the eagerness of parents to be engaged in this kind of research, to share their children and their experiences, and to learn more about this topic. Following the interviews the parents were asked debriefing questions to give them an opportunity to add and clarify anything their children said or that concerned them. Jahnvi’s mother mentioned, “She said something that she gets angry but I didn’t know about it. I saw when Arati goes to them [peers] they say hi, hello to her and they try to engage her. But yes, they directly go to Jahnvi first” in regard to her daughter’s comment about being teased by peers. All of the participants’ parents agreed in general with their

children's comments and opinions. Additionally, during the debriefing four parents described in more detail their children's disability. Farzana's mother mentioned that "They say why is he like this and say oh, they have a son like this. We get too much advice from others." While Soma, Akshar, and Arbaz's mothers described their children's behavioral problems.

## **Summary**

The first research question investigated in this study focused on the perceptions of typically developing children toward their siblings with disabilities. The results revealed that all 12 participants could easily name something that they liked about their brother or sister with a disability. All participants reported that their siblings had strengths, highlighting the positive perceptions that these children had about their younger siblings with disabilities.

The second research question focused on the impact of disabilities on the sibling relationship. Data revealed that sibling relationships in general were positive although some variability was noted based on the type of disability with the two siblings of brothers or sisters with autism having less positive perceptions about their siblings than the other participants.

The third research questions addressed how children felt about the way their siblings with disabilities were perceived in school and in the community. Results suggested that many of the children with disabilities did not have opportunities to play with neighborhood children. Also, data revealed that children often teased the siblings of children with disabilities. While five of the 12 participants said that adult neighbors responded positively to their siblings with disabilities, three participants reported the opposite reaction.

## CHAPTER 5

### DISCUSSION

The purpose of this study was to examine the knowledge and attitudes that children of Indian families have regarding disability, particularly their perceptions of having a younger sibling with a disability. Additionally, typically developing siblings' understanding of the impact of disability on the family structure and relationships, including perceptions of disability in the context of their schools and society was investigated. Results that emerged from the 12 interviews revealed that the relationships between the siblings seemed positive, and that they spend time with each other. Interestingly, the siblings did not have accurate knowledge about their young brother's or sister's disabilities. Also, it can be assumed that the siblings gained understanding about their brother or sister with disabilities from their everyday experiences. Issues that emerged from the results that are worthy of further discussion are: first, typically developing Indian siblings have limited knowledge about their younger siblings with disabilities; second, children with disabilities are not welcome in Indian society; and third, elder siblings worry a great deal about the future of their younger siblings with disabilities. A discussion of these issues, followed by the limitations of the study, ideas for future research and implications for practice are described next.

#### **Siblings' limited knowledge about disabilities**

The results of this study revealed that the 12 typically developing Indian siblings who were interviewed could explain their younger siblings' conditions somewhat, but overall but they did not have accurate knowledge about the siblings' disabilities. For example, they were not able to name the disability, but most of them were able to describe their siblings' struggles or limitations. Lobato et al. (2005) found that Latino siblings had relatively less accurate knowledge

about disabilities compared to non-Latino participants in the USA. The Indian siblings in the current study displayed a similar degree of knowledge about disabilities as the Latino siblings in this aforementioned study. Some of the Indian participants described their siblings' behavioral problems, with one even stating that his brother did not have any talents. Data from the current study highlight how siblings' perceptions can be negatively affected by their lack of knowledge about disabilities.

This lack of knowledge may be attributed to a communication gap between the parents, medical personnel, teachers and other professionals, and the siblings. The critical role of parents in informing typically developing siblings about their brother's or sister's disabilities and how this awareness could improve sibling relationships was suggested by Sage and Jegatheesan (2010). These researchers recommended that since parents are the first and most important teachers in their children's lives, they play a significant role in nurturing sibling relationships. It can be assumed that in Indian societies where it is common for siblings to stay together even after marriage, if the typically developing siblings do not have accurate knowledge it will be hard for them to adequately take care of their brothers or sisters with disabilities. In this small exploratory study, it did not appear that the participants' age influenced their knowledge about disabilities. Thus, it is possible that a family's openness, willingness, and comfort in sharing information about special education plays an important role in siblings' perceptions and knowledge about disabilities.

On the other hand, elder siblings' lack of knowledge did not appear to impact the time that the siblings' spent with each other, such as playing or watching television. All 12 siblings described what they liked to do together with their younger brothers or sisters with disabilities, with activities ranging from playing and eating to watching movies, and reading poems. These

data show that the specific disabilities themselves might have had little effect on the sibling relationships, but rather finding enjoyable shared experiences might be key to engaging in positive interactions. Raghuraman (2008) reported that positive and negative feelings within sibling relationships were not affected by the disability. Though in the current study, the data show that sibling relationships in general were positive, some variability was noted depending on the type of disability. In the current study, the two siblings of brothers or sisters with autism described less positive perceptions about their siblings than the other participants. This is similar to the findings described by Orsmond and Seltzer (2007). In their study, they concluded that the siblings of individuals with ASD had less positive relationships compared to siblings of individuals with Down syndrome. The perceptions of Indian siblings of children with autism could be attributed to their younger siblings' behavioral and communication skills, and inaccurate knowledge of why their siblings with autism act the way that they do.

### **Children with disabilities have limited access to play in Indian society**

Another issue that emerged from the results of the current study was related to the fact that children with disabilities are not always welcome in Indian society. In fact, according to the typically developing siblings, their brothers or sisters with disabilities have limited access to play with other children in their neighborhood. Several siblings described how their brother or sister was often teased or bullied by other children, which resembles data from previous studies. In a literature review by Rose, Monda-Amaya, and Espelage (2011), data showed the students with disabilities are the victims of bullying more frequently than students without disabilities. The authors also explained that students with severe cognitive and physical disabilities are more victimized than students with high incidence disabilities.

In the current study, the children with disabilities did not appear to have many opportunities to play with other children. Some of the elder siblings reported that in addition to the negative way neighborhood children treated their siblings, adult neighbors also teased their younger siblings. Past studies have shown the importance and benefits of play for the children with disabilities. For example Lifter, Sulzer-Azaroff, Anderson, and Cowdery (1993) and Ginsberg (2007) described play as important for children's creativity, cognitive, emotional, and physical development. Data from the current study reveal that young Indian children with disabilities do not get many opportunities to play and engage in peer interaction. There are no studies that explore the perceptions of typically developing Indian children toward children with disabilities within the context of play. The current study can bring the attention to how children with disabilities are often excluded from engaging in positive peer interactions during play.

The elder siblings in the current study also reported that their adult neighbors often provided suggestions or asked questions about the child with disabilities, in what appeared to be an attempt to offer assistance. These characteristics of neighbors and society are similar to what was described by Dhar (2009), who reported that in Indian society, children with disabilities are either treated with sympathy or they are ignored.

From the above discussion it appears that there is still a large gap between inclusion and the reality that children with disabilities face within Indian society. If teachers take the initiative to talk about disabilities and include more children with disabilities in regular education classrooms, then the attitudes of typically developing children may change towards the children with disabilities. Dorsey, Mouzourou, Park, Ostrosky, and Favazza (2016) described how reading books about disabilities in early childhood classrooms and having healthy discussions can influence the acceptance of children with disabilities by their typically developing peers.

## **Worries about future**

From the interviews, it seems that the typically developing siblings are worried about their brother's or sister's future including: What will they become? Will they have a fulfilling career? and Will they be respected by members of society? Some of these Indian siblings also described how they want their siblings to go to regular schools, yet all of the participants' siblings attended special or segregated schools for children with disabilities. Whereas in the USA, according to National Center for Education Statistics, the number of students attends regular schools is 6,464,000 during 2013-14 school year. According to 38<sup>th</sup> Annual Report to Congress on the Implementation of the Individuals with Disability Education Act, 2016, 65.8 percent children between 3 and 5 years old were served under IDEA, Part B in regular early childhood program for some amount of their school time in 2014.

Moreover, most of the siblings shared their dreams of wanting their siblings to be cured and become normal. This finding reveals that these Indian siblings did not realize that their brother or sister would not be completely cured in the future. It is safe to assume that the parents, teachers, or medical personnel never fully discussed the younger children's disabilities with the elder siblings, which could lead to inaccurate information and false or unrealistic ideas about the future. Burke, Taylor, Urbano, and Hodapp (2012) described how typically developing siblings in their study anticipated taking care of their siblings with disabilities in their future. Since after parents, siblings usually take care of their brother or sister with disabilities, a study by Arnold, Heller, and Kramer (2012) showed that typically developing siblings needed more information related to disabilities and support for their future caregiving role. Hence it can be assumed that the typically developing Indian siblings of children with disabilities need more information and support for taking care of their siblings in the future. Otherwise, these unrealistic dreams could

impact negatively on siblings' relationships and children's perceptions in the future when they begin assuming larger caretaking roles for their younger siblings with special needs.

### **Limitations**

One limitation is that the presence of parents during the child interviews occasionally resulted in their interfering with the responses shared by their typically developing children. At times parents would prompt the child, or immediately add to the child's comments. This resulted in a lack of clarity regarding what the child really thought or if he/she was simply responding in what he/she perceived as an "appropriate" response. Another limitation of this exploratory study is that the number of participants is relatively small. Since India is a very diverse and highly populated country, perceptions of 12 participants do not capture the culture and the immense complexities of this society. One final limitation of this study is that the researcher did not conduct any observations to investigate communication and social interactions between siblings with and without disabilities to assess their relationships; in the current study only participants' perceptions were gathered. Another limitation of this study is that the researcher was unsuccessful in checking the data for accuracy as the participants between 13 and 16 years old were either busy or could not be contacted to provide feedback on the themes.

### **Future research**

There is a need for future research on this topic as there is not enough of a focus around Indian children with disabilities and their siblings, and society's attitudes towards them in the context of this large and diverse country. It would be interesting to conduct observational studies to more closely investigate sibling relationships, to interview parents about sibling relationships, to study cultural views (i.e., neighbors' or teachers' perceptions) of children with disabilities, and

to compare different regions of India and different socio-economic backgrounds with regard to disabilities.

### **Implications for Practice**

Several implications for practice with regard to disabilities in the context of India emerged from the findings in this study. First, doctors and teachers should provide accurate information about disabilities to parents and encourage them to share that knowledge with their typically developing children and other family members. Parents must try to understand how typically developing siblings feel about their brother or sister with disabilities. This will help the parents to engage in discussions with their typically developing children and work on the sibling relationships. Parents must provide support and communicate when typically developing siblings face uncomfortable situations for their siblings with disabilities. In India, the joint family system is still very common. In this model, other family members share the responsibilities with parents to support the typically developing siblings when they need it. Family members need to educate the siblings about their brother or sister with disabilities, so that siblings can rationalize their thoughts and answer their friends and neighbors when they pose questions and make comments. It is important to help typically developing children have clear perceptions about their brother's or sister's conditions. This will lead typically developing siblings to have clearer expectations for their younger siblings with disabilities, which in turn could strengthen the sibling relationships in future.

Second, teachers need professional development so that regular schools can accept more children with disabilities and create positive and welcoming environments for children with disabilities. Teachers need to include and invite the families and siblings of students with disabilities to talk about disabilities and its impact on the individuals with disabilities and on the

family members. Teachers also need to implement strategies to make classrooms more inclusive. Therefore, teacher educators need to train future teachers with a strong understanding about disabilities so that future professionals become better prepared to accommodate children with disabilities in their classrooms and make the students aware about individuals with disabilities. Moreover, teacher educators should provide feedback on how teachers' perceptions and knowledge reflect on students' attitudes towards disabilities. Third, non-governmental organizations and public welfare program should have support groups for the siblings of children with disabilities, and make and distribute brochures about various disabilities and the rights of children with disabilities. These organizations also need to understand the impact on siblings of children with disabilities and work towards building relationships among siblings and with neighbors and society. Through such efforts of awareness and the creation of accepting classrooms and communities, children with and without disabilities will find a common platform to begin to develop relationships and friendships with each other. The more typically developing children get opportunities to interact with children with disabilities, then the more it will support the inclusion of all children in the all aspect of life.

## **Conclusion**

From this exploratory study, it can be concluded that Indian siblings have limited knowledge about disabilities and are worried about their younger siblings' future and career. If parents, medical personnel, and teachers can help typically developing children gain accurate information about disabilities, it might result in the creation of positive and sustainable relationships with their younger brothers or sisters. Moreover, the inclusion of children with disabilities is very important in schools and neighborhoods so that society at large can embrace more positive perceptions towards individuals with disabilities.

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APPENDIX A

MATRIX OF ARTICLES

Citation	Purpose	Participants	Procedures	Results
Angell, Meadan, and Stoner (2012)	To examine the experiences of siblings of individuals with autism spectrum disorders (ASD)	Twelve siblings of children with ASD participated in this study. The participants were between the ages of 7 and 15 and their siblings with ASD were between 6 and 15 years old	The researchers did a qualitative study by interviewing the typically developing siblings	The researchers indicated that the typically developing siblings played roles of helper, entertainer, and caregiver in the lives of their brother or sister with ASD
Bat-Chava and Martin (2002)	To examine the characteristics that influence the sibling relationships between children with hearing implants and their hearing brothers or sisters	Parents of 29 children with hearing aids participated in this study. The children who were hard of hearing were between the ages of 5 and 11 and had one or more siblings with hearing. Some families had more than one children with hearing aids	The researchers did a qualitative study by interviewing parents using in-depth questions about their children's social life and social functioning before and after receiving hearing aids	The researchers indicated that sibling relationships did not vary based on using hearing aids. But when siblings experienced negative comparisons, the sibling relationships were also negative
Bellin and Rice (2009)	To examine the quality of sibling relationships in families who have youth with Spina Bifida	224 families participated in this study. The siblings of youths with Spina	The siblings completed 140 items on a survey and the parents completed a one- page	Family functioning was linked to stronger and warmer sibling relationships

	in the context of individuals, family and peers	Bifida were between 11 to 18 years old and lived in the same house with their siblings	survey (which were mailed to the families' address)	than were peer factors
Cox et al. (2003)	To learn how siblings of children with disabilities adjust, their attitudes in daily life and its relevance to the overall health of the family	46 children including 25 brothers and 21 sisters of children with disabilities participated in this study; aged between 6 and 18 years while the average age of children with disabilities was 5 years	Interviewed with 18 open-ended questions	65% responses were Proactive, which meant the siblings responded to a stressful situation with problem-solving reasoning or physical actions; 19% responses were Interactive, whereby siblings responded to a stressful situation by seeking for social support; 13% responses were Internally Reactive, where the siblings expressed emotions and engaged in cognitive responses to a stressful situations, and 3% were Nonactive Responses, where the siblings did not show any physical or emotional response or they denied responding to stressful situations

Lobato et al. (2005)	To examine Latino siblings' knowledge about children with disabilities and their adjustment towards this issue, and to compare the knowledge about siblings' disability between Latino and non- Latino siblings	20 Latino and 20 non-Latino typically developing siblings	Interviews and questionnaires were part of the study; participants were free to speak in English or Spanish	Latino siblings had relatively less accurate knowledge about disabilities compared to non-Latino siblings, but siblings from both groups shared similar understandings about the cause of their siblings' disabilities
Neece et al. (2010)	To examine the impact on siblings of children with an intellectual disability	114 families were recruited for this longitudinal study; target children were classified into two groups, developmental disabilities and typically developing	The researchers scored the Stanford- Binet IQ when the target child was 5 years old (at a center visit) and parents were interviewed about child behavior problems and sibling impact at home when the child was 5, 6, 7, and 8 years old	The parents of children with an intellectual disability reported that the siblings were negatively impacted compared to the parents of typically developing siblings. Another finding was that if the typically developing sibling needed to help his/her sibling with a disability due to their problem behaviors or got embarrassed by their

				<p>behavior then those incidents impacted negatively on their relationship and spending time together was not enjoyable</p>
<p>Orsmond and Seltzer (2007)</p>	<p>To examine whether the sibling relationships were effected based on the type of disability, specifically Down syndrome and Autism Spectrum Disorder, and to examine the positive and negative aspects of having a sibling with DS or ASD</p>	<p>The participants were divided into two groups of siblings of individuals with Down syndrome and siblings of individuals with Autism Spectrum Disorder. Each group had 77 participants</p>	<p>The participants were part of a longitudinal study. The siblings of individuals with DS and ASD answered questionnaires</p>	<p>Siblings of individuals had less close relationships and spent less time with their brothers or sisters with ASD compared to siblings of individuals with DS. Also the first group was less positive about the future of their siblings with ASD</p>
<p>Raghuraman (2008)</p>	<p>To examine the emotional health of the elder siblings of children who were deaf or hard of hearing compared with the elder siblings' emotional well- being of children with typical hearing</p>	<p>There were two groups and each consisted of 35 children of elder siblings. One group, who had brothers or sisters with disabilities, aged between 6 and 12 years old, and the other group of children of typically developing siblings, aged between</p>	<p>Family members were interviewed using; "Demographic questionnaire," "Psychological variables and parental partiality," "Sibling Perception Questionnaire," "Sibling Relationship Questionnaire,"</p>	<p>The elder siblings of children with hearing loss were not much different than the elder siblings of children without hearing loss in terms of love, warmth, conflicts, and depression</p>

		2 and 7 years old	“Temperament questionnaire,” and the “Home routines assessment”	
Sage and Jegatheesan (2010)	To examine typically developing children’s perceptions of their siblings with autism and the relationship between two siblings from different cultural backgrounds	1 European American and 1 Asian American family, each of the families had an elder typically developing son and a younger son with autism	Interviews with parents and elder siblings, observations of family conversations, and video recordings of the sibling interactions while they played	The elder sibling from the European American family had a clear understanding of his younger brother’s autism. Their interactions showed that both shared a good relationship with warmth and care towards each other. On the other hand, the elder sibling of the Asian American family showed little understanding about his younger brother’s autism, and had problems communicating with him
Skotko et al. (2011)	To examine the perceptions of siblings of individuals with Down syndrome	822 siblings of individuals with Down syndrome participated in this study	Participants answered of three-page questionnaire survey	Most of the siblings loved their brother or sister with Down syndrome. The

Smith et al. (2013)	To recreate the study done by Trent et al. (2005) on teaching social interaction strategies to typically developing elder siblings for the younger siblings with Down syndrome in play sessions. The other purpose was to evaluate the sibling initiated intervention of responsive interaction on the purposeful communicative behavior of younger siblings with Down syndrome. The study investigated both the nonverbal and verbal communication of children with Down syndrome	Participants were three typically developing elder siblings between 6 to 12 years old and three younger siblings with Down syndrome, between 5 to 11 years old	The observations and training for the elder siblings were done in the siblings' house. The research was divided into 4 stages; "baseline," "nonverbal mirroring training," "verbal responsive training," and "follow-up" (Trent- Stainbrook et al, 2007). The intervention sessions occurred twice in a week, and each session lasted 30 to 60 minutes	results also showed that the participants' love and pride for their siblings was not impacted by the severity of the brother's or sister's disability  Communication status did not have any impact on the warmth, closeness, conflict, and rivalry of sibling relationships when one sibling had disability. But typically developing siblings were engaged more in helping, teaching and managing behaviors than the siblings with disabilities
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APPENDIX B  
IRB APPROVAL

UNIVERSITY OF ILLINOIS  
AT URBANA-CHAMPAIGN

Office of the Vice Chancellor for Research

Office for the Protection of Research Subjects  
528 East Green Street  
Suite 203  
Champaign, IL 61820



June 13, 2016

Michaelene Ostrosky  
Special Education  
Education Bldg  
1310 S Sixth St

RE: *The perceptions of typically developing siblings of young children with disabilities in India*  
IRB Protocol Number: 16853

Dear Dr. Ostrosky and Ms. Bhattachali:

Your response to stipulations for the project entitled *The perceptions of typically developing siblings of young children with disabilities in India* has satisfactorily addressed the concerns of the University of Illinois at Urbana-Champaign Institutional Review Board (IRB) and you are now free to proceed with the human subjects protocol. The IRB approved, by expedited review, the protocol as described in your IRB application with stipulated changes. The expiration date for this protocol, IRB number 16853, is 06/08/2017. The risk designation applied to your project is *no more than minimal risk*.

Copies of the attached date-stamped consent form(s) must be used in obtaining informed consent. If there is a need to revise or alter the consent form(s), please submit the revised form(s) for IRB review, approval, and date-stamping prior to use.

Under applicable regulations, no changes to procedures involving human subjects may be made without prior IRB review and approval. The regulations also require that you promptly notify the IRB of any problems involving human subjects, including unanticipated side effects, adverse reactions, and any injuries or complications that arise during the project.

If you have any questions about the IRB process, or if you need assistance at any time, please feel free to contact me at the OPRS office, or visit our website at <https://www.oprs.research.illinois.edu>.

Sincerely,

A handwritten signature in black ink that reads "Ronald A. Banks".

Ronald Banks, MS, CIP  
Human Subjects Research Coordinator, Office for the Protection of Research Subjects

Attachment(s): consent and assent letters

APPENDIX C  
INSTRUMENTS

SECTION I: PARENT INTERVIEW QUESTIONS

1. How many children do you have? What are their ages? Tell me a little but about each one, such as their grade in school, what they like to do, etc..
2. Tell me about your child's disability.
3. What does your typically developing child know about his/her sibling's disability?
4. Is it alright if I talk about your one child's disability with your typically developing child during the interview? Here are the questions I planned on asking (show the parent the questions); is there anything I should avoid saying or asking?
5. Is there anything else you would like to share with me?

SECTION II: SIBLING INTERVIEW QUESTIONS

The sibling relationship

1. What kinds of things do you like to do with your brother or sister?
2. What kinds of things is your brother or sister good at?
3. What do you like most about your brother or sister?

Knowledge and understanding about the sibling's disability

1. Tell me about the disability that your brother or sister has. If the participant does not say much, then the following probe questions would be asked:

A. How did your brother or sister come to have this disability?

B. When a person has this type of disability, what does it mean for the child? For the child's way of talking? Way of walking?

2. If the parents inform the interviewer that they talk about the sibling's disability with their typically developing child, then the following question will be asked: What special things does your brother or sister require because of his/ her disability?

How their friends and society perceive disability and its impact on them

1. Do you have opportunities to do a lot of things with your friends? What do your friends know about your brother's or sister's disability?

2. What happens when you bring your friends to your home?

3. How do they interact with your brother or sister?

4. Tell me about a time when you took your brother or sister (with disability) with you to spend time with your friends.

5. What do your neighbors say about your brother or sister?

6. Describe how the children in your neighborhood play with your brother or sister. What do they like to play with him or her? (Prompt: If the response resembles no, then ask: Why do you think they do not play with your brother/ sister?)

7. Have you ever been teased about having a brother or sister with disabilities? Tell me about it.

8. Have you ever noticed other people teasing your brother or sister about his/ her disability?

What did they say or do?

9. What worries or concerns do you have about your brother or sister?

10. Finish these sentences for me ---

- a) In 5 years I think my brother or sister will....
- b) One dream I have for my brother or sister is ...
- c) One dream I have for myself is ...

11. Is there anything else you would like to share with me?

### SECTION III: DEBRIEFING QUESTIONS FOR PARENTS

- 1. Did anything surprise you about what your child said?
- 2. Is there anything you want to clarify?
- 3. Is there anything you want to tell me that your child forgot to say?
- 4. Is there anything else you want to add?

## APPENDIX D

### CONSENT LETTER

#### CONSENT LETTER FOR INTERVIEW

University of Illinois at Urbana-Champaign

Dear Parent:

Date: June, 2016

My name is Ankita Bhattashali, and I am a master's student in the Special Education Department at the University of Illinois, Urbana-Champaign. My advisor is Dr. Ostrosky who is the Project Investigator of the research study described here. This letter is an invitation to participate in the study we are conducting to understand the perceptions of typically developing siblings of young children with disabilities in India. The information we obtain from this study will help family members understand how disabilities shape relationships between children. It will also provide policy makers and program directors with information that might help them stipulate better support to families. Additionally, this study might help teachers understand the impact of a child with a disability on his or her siblings.

Participation in this study is voluntary. If you agree to participate, you will be involved in the following procedures:

(a) *A brief face-to-face interview with you about your family:* You will be interviewed in-person about your family, and your child with disability. The interview should take less than 30 minutes. You can choose to be interviewed at your residence or at the school. The interview will be audio recorded for accurate data collection and transcription.

(b) *A face-to-face interview with your child:* Your typically developing child will be interviewed for approximately half hour in a mutually agreed upon location and time. The interview will be audio recorded for an accurate data collection and transcription. The questions will focus on the sibling relationship, knowledge and understanding about disabilities, and how friends and society perceive disability and its impact on your typically developing child.

You and your child may decline to answer any of the interview questions if you so wish. You are free to withdraw from this study at any time for any reason.

(c) *Debriefing with you after the interview with your child:* After the face-to-face interview with your child, you will be requested to debrief the interview. The questions will focus on whether you want to clarify anything your child mentioned, you want to add something, which your child forgot to mention, and if you would like to share anything else. This debriefing should take less than 20 minutes

(d) *Checking the accuracy of the data:* We will send you the transcription of your child's interview if your child is between 13 to 16 years old, to make sure they are free of error. We will also send your child the themes we found from the interview to insure that they are an accurate reflection of what your child said. We will ask you to send feedback to us.

All information you and your child provide will be confidential. Notes and transcriptions collected during this study will be retained for three years in a secure location and then destroyed. The audio recordings will be destroyed after the transcription of the data. You and your children's names or any other personal identifying information (e.g., name of the school or the teacher, residential address etc.) will not appear in the study report. Only the researchers who are involved in this study will have access to the original data. You and your child are not likely to experience any risk from participating in this study, beyond those risks of daily living. If you or your child become emotionally upset by any question, the interview will be stopped. If you or your child get emotionally upset, you may contact the School Principal or the school teachers to solicit their suggestions.

Please consider participating in this study if you meet ALL of the following criteria:

- (a) You are a parent who has at least one child with disability, and one typically developing child.
- (b) The child with disabilities is between 3 and 8 years old, and the typically developing child is between the ages of 8 and 16 years.

If you are willing to participate in the study, please sign this consent form and return it to your child's teacher, or to Ankita Bhattashali when she meets you to explain the research. Attached is a copy of this consent form. Please keep it for your records.

If you have any questions or concerns about this study, please contact Ankita Bhattashali (+917207884582; [bhattas2@illinois.edu](mailto:bhattas2@illinois.edu)) or Micki Ostrosky (+1217-333-0260; [ostrosky@illinois.edu](mailto:ostrosky@illinois.edu)). You may also contact Ms. Ayesha Rubina (+919246263876), if you have any questions about this study. You may call collect. We will be happy to answer any of your questions. If you feel that you or your child have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at +1[217-333-2670](tel:217-333-2670) or e-mail OPRS at [irb@illinois.edu](mailto:irb@illinois.edu). You may call this number collect if you identify yourself as a research participant.

When this research is discussed or published, no one will know that you and your child were in the study. However, laws and university rules might require us to disclose information about you. For example, if required by laws or University Policy, study information which identifies you and the consent form signed by you may be seen or copied by the following people or groups: a) The university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for Protection of Research Subjects; and b) University and state auditors, and Departments of the university responsible for oversight of research.

Thank you for your considering participating in this important study.

Sincerely,

Ankita Bhattashali, MSW.  
Micki Ostrosky, Ph.D.  
Department of Special Education  
College of Education  
University of Illinois at Urbana-Champaign

I am 18 years of age or older and I have read and understand the above consent form and voluntarily agree to participate in this study and give permission to be audio recorded for my interview \_\_\_ YES \_\_\_ NO.

I give permission for my child's interview to be audio recorded \_\_\_YES \_\_\_NO.

Name (please print) : \_\_\_\_\_

Signature: \_\_\_\_\_

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

APPENDIX E

DATA TABLES

Table E.1

Knowledge about sibling's disability or things s/he struggles to do

Communication	Motor	Cognitive	Behavior	Medical	Adaptive
Suhana. "She does not talk properly."	Jahnavi. "Can not and jump well, does not have good balance."	Suhan. "Has less intelligence; her brain needs to be cured by prayers."	Rukmini. "Like normal children do not make that noise/sound she screams and hits her head on the ground."	5. "And she gets fits." 9. "She gets convulsions."	Jahnavi. "Cannot eat." Shehnaz. "She cannot eat though sometimes she eats little bit."
Soha. "Only thing he does not talk clearly. It takes time for him to utter words"	Farzana. "He cannot walk well."	Jahnavi. "Slow mentally, understands things slowly."	Arbaz. "Whatever he wants, we have to give him. He throws everything and his behavior is not normal."		
Rukmini. "Does not talk, makes noise."	Fardeen. "He can walk but very little bit."	Arbaz. "Can not follow the game rules."			
Soma. "She mainly has speech problem. Other things are okay. She understands everything but can not tell anything"	Shehnaz. "She tries to jump but she falls and sometime s she cannot jump. She can't balance as well. She cannot walk, she	Sohan. "He doesn't have talent. He can't write."			
Fardeen. "And not able to talk."			Bhanu. "That he beats me. He beats my friends as well."		
Arbaz. "Not able to talk, he					

uses only few words.”	walks but she cannot run, jump or walk fast.”					
	Aksar. “She can talk but sometime s falls down while she walks.”					
	Sohan. “He is not active.”					
7	6	4	3	2	2	

Table E.2

Perceptions about sibling’s skill level

Motor Skills, and playing	Daily living Skill	Social-emotional Skills	Cognitive Skills
Suhana. “Even she plays too.”	Suhana. “She eats well.”	Soha. “Talks well, replies promptly.”	Farzana. “Good at reading Quran, praying to Allah.”
Jahnavi. “My sister is good at throwing the ball, I mean throwing the ball correctly. Nowadays she is doing this but before she could not do so. I can’t remember the other thing now.”	Rukmini. “Eating, sleeping.”  Fardeen. “Loves to eat.”	Fardeen. “He laughs a lot.”  Shehnaz. “She never hurts or scolds me. If I say her something, she will understand that and I also understand her. She helps me while I do my homework. She helps everyone. If I am writing, and I	Soma. “If we say something, she understands or catches that quickly. She does things before us. She can hold the pencil.”  Fardeen. “Like if we say fold your hands, he does that or tell him to sit quietly and he
Soha. “Playing ball.”	Aksar. “She works at home, she sweeps the floor, and sometimes brings food when we sit to eat.”  Arbaz. “Handling phone.”		

Farzana. "Playing games."	Bhanu. "He is good at everything. Watching TV."	forget something, she will bring it to me."	follows that."
Rukmini. "Playing ball and finger claps."			
Arbaz. "Painting."			
Sohan. "Playing cricket."			
7	6	3	3

Table E.3

Provisions required by the sibling with a disability

Intervention	Support	Nothing
Jahnvi. "Goes to OT, PT and behavioral class."	Suhana. "Brain needs to be cured by prayers."	Bhanu. "Nothing."
Rukmini. "Medicines, training."	Jahnvi. "Needs support from all of us."	
Soma. "Training for speech."	Soha. "He likes dancing, so I want to help him to be a dancer. And for that I need parents' supports as well. That's what he wants to be also."	
Fardeen. "Physiotherapy."		
Shehnaz. "She should be like us. She should run, jump and walk. She should do everything like us. She should practice."	Farzana. "Needs to play with the children." Arbaz. "Needs to play more, talk to others."	
Aksar. "She has problem while walking. It is good she comes to this school. Its good for her. She disturbs others a lot. She screams a lot and laughs out loudly."		
Arbaz. "Needs a good		

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doctor.”

Sohan. “He should be put in sports.”

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Table E.4

Worries about their siblings with disabilities

Being normal	Being independent and having a good future	Going to school	Other
Soma. “Like she should get back her speech. That’s the main worry.”	Jahnavi. “Yes. Like what will she become, what will happen to her, all these.”	Suhana. “Yes. I want her to go to a good school. She does not go to a school like us.”	Bhanu. “No.” Sohan. “No improvement.”
Fardeen. “Soon, after a short time, he should be normal. He should be like us, he should talk like us.”	Soha. “But only thing if he understands his life, then his future will be secured. He should have a good career, that’s all.”	Fardeen. “Go to school.”	
Shehnaz. “She should do everything like us. And be a respectable person in society like us. She should never do any mistake and be normal person.”	Rukmini. “Yes, like she should fulfill her basic needs by herself and should not depend on others.”		
Aksar. “She should be normal. She should talk well so that I can play with her.”			
Arbaz. “If he becomes better then we can teach him game rules and he can remember the			

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rules and play with us.”			
4	3	2	2

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Table E.5

Dreams for the siblings with disabilities

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Get cured/ become normal	Education and a career	Staying with or helping the siblings	Able to play together	Respect
Suhana. “I want to see her get well.”	Suhana. “I want her to go to a good school.”	Jahnavi. “I want her to stay with me well.”	Jahnavi. “Like she will play with me and talk to me.”	Shehnaz. “Never teased by anyone.
Farzana. “Doing good, being active and able to walk and talk.”	Soha. “Higher studies. He has a keen interest in dancing. If he watches any dance, he can copy that fast. He likes dancing...	Soha. “So I want to help him to be a dancer. And for that I need parents’ supports as well.”	Soma. “I would like to play together with her, talk to her and share things with each other.”	Now also they don’t tease but they should not say why she is slow, why she is like this or that.”
Soma. “I want her to play and talk like normal children.”	That’s what he wants to be also.”	Farzana. “I want to take him with me.”	Fardeen. “Want to play with him.”	
Shehnaz. “She should be like us... She should be normal like us and do things like us.”	Rukmini. “She should go to normal school. Job.”	Sohan. “Here only [with us].”		
Aksar. “I want to see her get cured. She should be normal.”	Shehnaz. “She should become a Public Service Officer. She should serve people.”			
Arbaz. “He should be normal... He should be good. He should get cured.”	Bhanu. “In television...police.” Sohan. “He will be a cricket player.”			

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Table E.6

Things they like about their siblings with disabilities

Skills	Activities	Expressions	Character/ nature	General
Farzana. "He is very good, he cannot walk but he is intelligent. If I tell him to bring something, he does."	Suhana. "When she eats [a] banana."  Jahnavi. "Sing songs, and imitates mom."  Rukmini. "Playing, eating, sleeping. She plays with me so much."	Jahnavi. "Like when she cries, laughs and being mischievous."  Soha. "When he cries, sometimes if I talk loud to him, he cries."  Farzana. "His smile or laugh."	Soma. "She does things before us."  Shehnaz. "She loves us and she never cries if we say something to her. She never does anything wrong. When people come, she says hello."  Arbaz. "Sometimes he is good."	Jahnavi. "Everything."
Shehnaz. "She dances with us and listens to songs. She dances very well."	Fardeen. "I like to play with him and lie down with him on the bed."			
Aksar. "She can catch the ball well and throws it to me."	Arbaz. "Painting and some nice activities."			
Bhanu. "He reads little bit."				
Sohan. "He plays well."				
6	5	3	3	1

Table E.7

## Things siblings like to do together

Playing	Caretaking	Watching TV	Reading and coloring	Going out together
Suhana. "To play."	Suhana. "Loving, taking care of her."	Shehnaz. "Watching movies."	Soha. "Reading poems."	Fardeen. "Yes, he likes to go outside very much. I like to take him to shops."
Jahnvi. "Jumping, playing around with her."	Rukmini. "Eating with her."	Aksar. "Watch television.. cartoons, movies, songs."	Rukmini. "I read poems and do actions. She follows me and does a little bit."	
Farzana. "Playing red hands."	Shehnaz. "I want to share my feelings with her."	Bhanu. "Watching tv, cartoons like Rangers. My brother loves to watch Rangers."	Arbaz. "Do Rangeela colors."	
Rukmini. "Playing with her."				
Soma. "I like to play. Ball, also with doll."				
Fardeen. "I like to play. Play with bat and ball. Today in the morning he took the ball out of the cabinet and told me to play with him."				
Shehnaz. "I like to play with her. We play cricket"				

and cycling.”

Aksar. “I like to play together, bat, ball, cycling.”

Arbaz. “I like to play with him... football, basket ball, cricket.”

Bhanu. “Playing everything.”

Sohan. “Playing cricket.”

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11	3	3	3	1
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Table E.8

Reactions from community members

Neighborhood children play and interact with the child	Neighborhood children tease the child or don't play with him or her	Adult neighbors help, offer suggestions and respond positively	Other	Adult neighbors' negative responses
Suhana. Children play hide and seek, toy top spinning.”	Jahnavi. “ If I get teased I get very angry. But when she goes to play my friends say that get the bat from your sister and I get angry. I feel why they say such things or just because she has down syndrome that's why.”	Jahnavi. “Neighbors say good things, “like, she is improving and getting clever.”	Farzana. “And cousins play with him.”	Suhana. “They tease her. They say that she does not have any intelligence . They sometimes beat her too.”
Jahnavi. “Children play ball, they say hi, hello etc.”		Soha. “Some people give suggestions.	Rukmini. “Cousins talk to her, just they call her and they	
Farzana.				

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<p>“Neighbor children interact well with him.”</p>	<p>Soha. “If by any chance he goes alone, other children will scare him or beat him. And he does not reply back to them or beat them. He sometimes cries or just silently comes back home.”</p>	<p>Like they say if he spends time with other children then he will pick up things fast.”</p>	<p>come to her, talk to her do some actions and that makes her happy.”</p>	<p>Farzana. “They tease him.”</p>
<p>Soma. “Children in the neighborhood play ball with her.”</p>	<p></p>	<p>Fardeen. “They say good things. Like he is improving. They look at him and say that he is now getting better.”</p>	<p>Fardeen. “No one has time to play.”</p>	<p>Arbaz. “They ask why is he like this? When will he be nice, and is not hyperactive or screams? See your brother, what he is doing; destroying things and throwing things away in my home, he hits small children. They will take his cap.”</p>
<p>Shehnaz. “They play very nice, they never say anything to her. They play with her also.”</p>	<p>Rukmini. “Other children do not play with her.”</p> <p>Soma. “They call her mad (mad words prompted by mom) and they tease her. They don’t</p>	<p>Shehnaz. “They say that your sister is very good. She is Down syndrome baby but she does everything. She is somewhat good and better than the last time. Sometimes she tries to run. They say that she is doing everything properly and good at everything.”</p>	<p>Bhanu. “No one teases.”</p>	<p></p>
<p>Sohan. “Neighbor children play cricket with him. No one teases.”</p>	<p>They don’t understand that she has only speech problem. They hit and run away.”</p> <p>Aksar. “No, they don’t play. She laughs too much. She doesn’t sit quietly. She talks a lot.”</p>	<p></p>	<p></p>	<p></p>
		<p>Aksar. “They say good things always.”</p>		

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		They do things for my sister. They sweep our place, or bring things for her.”		
6	5	5	4	3

Table E.9

Reactions from peers

Peers knowledge and interest in the disability	Peers play and interact with the sibling with a disability	Negative peers reactions	Other
Suhana. “They know that she does not have brain /intelligence.”	Jahnavi. “Friends play with her when they are in a good mood.” Playing ball, hide and seek, running bees, gardener gardener.”	Farzana. “They get scared of him, when he makes sound like ‘aaaa’.”	Fardeen. “No one comes to home. School’s friends stay at school, I don’t bring them home.”
Soha. “They know about his disability.”	Soha. “They talk to him.”	Aksar. “She goes to others’ home and brings things from others’ place. My friends do not play with her. Because [her] behavior is not good. That’s why.”	Sohan. “I don’t like to do friendship.” (dad said he doesn’t have any friends).
Farzana. “They know about his disability.”	Shehnaz. “I was very happy when I saw my friends were talking to her. This summer holiday when I used to go to neighbors’ house, she also came. She played with them, she threw ball and used to say 6, 4 and she tried to run”	Bhanu. “He beats my friends as well. They also beat him.”	
Rukmini. “Friends do not know that she has autism, but they do know that she has some problem, ask questions like why she is doing like this. They call her but she doesn’t come. She sits near them.”			
Soma. “They know about her disability. They interact and			

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play with her, they ask how did it happen.”

Shehnaz. “They just know that she is Down syndrome baby, and she is very slow in everything. Once there was a program in our school she came there and all my friends saw her and asked why she is like that and why can’t she talk. My teacher and I talked to them.”

Aksar. “They know that she has problem. She says hi and calls them by their names.”

Arbaz. “They know that he has some mental issues.”

Bhanu. “They know that he beats me.”

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Table E.10

Reasons related to taking siblings outside

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Behavioral Problems	Physical Problems	Siblings do take them outside	Atypical to go outside alone
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Jahnavi. “She pulls my hair. She throws stuffs here and there. That’s why I don’t take her.”	Jahnavi. “She cant walk well and doesn’t have balance”	Shehnaz. “This summer holiday when I used to go to neighbors’ house, she also came.”	Suhana. Sibling doesn’t go alone outside
Rukmini. “Because she behaves badly. Sometimes she sits on the road and hits her head.”	Farzana. “He can’t walk well.”	Bhanu. “Yes. He comes.”	Soha. The typically developing sibling doesn’t go out alone
Aksar. “The thing is she sometimes laughs loudly.”	Aksar. “And falls down on the road.”	Sohan. “Sometimes.”	
Arbaz. “He misbehaves on the road.”			
4	3	3	2