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TYPICALLY DEVELOPING SIBLING INCLUSION IN OCCUPATIONAL THERAPY TREATMENT

A Thesis

Presented to

The Faculty of the Occupational Therapy Department

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

by

Celise Marie Carroll

December 2000

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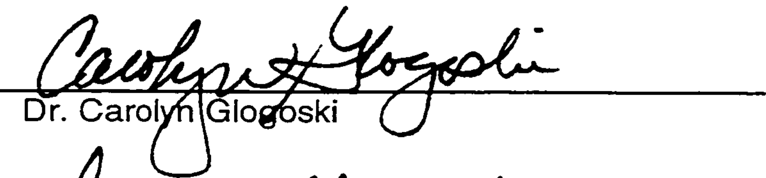

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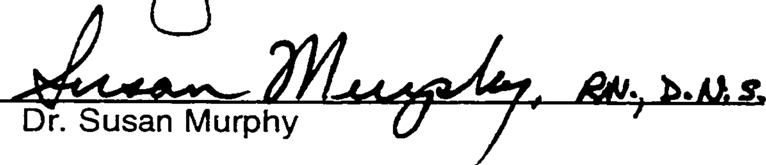

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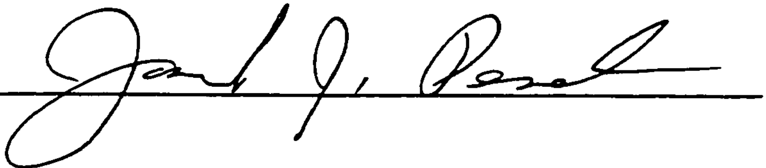

ABSTRACT

TYPICALLY DEVELOPING SIBLING INCLUSION IN OCCUPATIONAL THERAPY TREATMENT

by Celise Carroll

This study was conducted to evaluate the effects of including typically developing siblings in the occupational therapy treatment setting with their sibling with a disability. Effects were explored by comparing the perceptions of siblings and parents before and after the typically developing sibling was included in the therapy setting using qualitative methodology. Data was collected by individual in-depth interviews and participant observations. Three families and one occupational therapist participated in the study.

Results indicated that typically developing siblings demonstrated a need and a desire for basic information. The study created an opportunity for the parents to reflect on their children's relationship and recognize their growth independently and also together. The occupational therapist gained valuable insight for future sibling inclusion and all participants felt that this was a positive experience. This study begins to address the necessity of family education and modeling as an area occupational therapists can and should address.

ACKNOWLEDGEMENTS

One cannot consent to creep when one feels an impulse to soar. -Helen Keller

I would like to thank everyone who has inspired me throughout my life to soar. I would like to especially thank God for:

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CHAPTER 1

Introduction

Purpose

The purpose of this study was to evaluate the effects of including typically developing siblings in the occupational therapy treatment setting with their sibling with a disability. The effects were explored by comparing the perceptions of the siblings and parents before and after the typically developing sibling is included in the therapy setting. The results of this study have the capability to increase awareness of the sibling relationship in the family and in the occupational therapy setting. This study may also provide support and inspiration for other occupational therapists to provide similar opportunities for the children and families with whom they work.

Statement of the Problem

A child with a disability is one member of the family. Parents and siblings make up other members. The family systems model highlights the importance of the family influence on individual behavior (Sue, Sue, & Sue, 1997). Each member in the family is interconnected and interdependent with the other members. Of interest to this author are the sibling relationships that develop in the family systems of children with disabilities. Most often, during occupational therapy sessions, the sibling/s of a child with a disability are asked to stay outside in the waiting room or are not brought to the treatment session. These children are left out of the picture and do not understand what

goes on when their brother or sister is in treatment. This may create confusion for typically developing siblings as they are moving through their developmental stages and are left to question the nature of their sibling's disability and what it means for their own lives (Rothery, 1987). Miller (1996) suggests that it is easy for parents and other caregivers to forget the needs of the typically developing siblings.

There is a demonstrated need for basic information, empathy, and peer support for typically developing siblings of children who have a disability (Lobato, 1985; Menke, 1987; Rothery, 1987). When the siblings of the child with a disability are coping effectively with both their own developmental tasks and living with a sibling with a disability, they are able to be role models and play mates for their brother or sister (Rothery, 1987). This can have a positive effect on both the siblings' development and also contribute to the stability of the family as a whole (Rothery, 1987).

Miller (1996) proposes that a continuum, with "very positive" at one end and "very negative" at the other end, can be used to describe the effect of living with a sibling with a disability. There are various factors in the family structure that move the sibling along this continuum. It is often impossible to explain a child's behaviors without looking at the family as a whole. Miller concludes therefore, that one cannot be certain that there is one type of sibling who will fare better than another sibling even when given a similar situation. However, there is potential to improve the experiences of many siblings. The

experiences typically developing siblings have, compared to their peers, may be experiences that provide unusual opportunities. Typically developing siblings can acquire, from being in a family with a child with a disability, an increased acceptance of the range of human differences, an understanding of how to effectively communicate with family members and community professionals, increased family unity, and social competence (Rothery, 1987). They may also develop more nurturing behaviors, increased empathy, and increased self-esteem from having the opportunity of taking on different family roles such as caregiver, tutor, and teacher (Dallas, Stevenson, & McGurk, 1993; Faux, 1991; McHale & Gamble, 1989). This study provides an opportunity to address these benefits and make them recognizable for siblings and parents. This study hopes to increase awareness by involving siblings of a child with a disability in treatment sessions, providing them with information regarding their brother or sister's disability, and creating interactions that can facilitate the development of play skills in order to facilitate both childrens' development as members of a family, a community, and a school.

Research Questions

This study was designed to answer the following questions:

1. How do typically developing siblings' perceptions about their relationships with their siblings with a disability differ before and after being included in occupational therapy sessions?

2. How do perceptions of siblings with a disability about their relationships with their typically developing siblings, differ before and after the typically developing sibling is included in therapy?

3. How do the parents' perceptions about their children's relationship differ before and after the children are included in occupational therapy sessions together?

4. How does the occupational therapist perceive the effects of typically developing sibling inclusion on the sibling relationship and in the occupational therapy treatment setting?

5. Are there any perceived changes in the sibling relationship since the siblings have participated in therapy together?

Significance of the Study

Unruh (1992) explains that the needs of typically developing siblings should be of particular importance to occupational therapists for three reasons. The first reason relates to how the typically developing sibling affects the behavior of the sibling with a disability. The typically developing sibling can have a positive effect on encouraging behaviors and modeling for the sibling with a disability. The more positive the sibling relationship is the more valuable the interactions can be. Also, typically developing siblings may not be aware of how much help they should provide their sibling with a disability. The second reason concerns the typically developing sibling's emotional adjustment towards their sibling. The typically developing siblings may be experiencing

many of the same emotions and feelings as their parents only the siblings may not have as many resources to process these feelings. They may not have the opportunity to discuss their feelings or to gather information. This can have an effect on the typically developing siblings' daily activities such as school, play, and home life. Thirdly, occupational therapists are concerned with the integrity of the family system and assisting the family in maintaining their daily activities and life roles.

Unruh (1992) suggests that occupational therapists can influence the sibling relationship in many ways, including inviting typically developing siblings into the occupational therapy treatment setting. Occupational therapists are qualified to create a therapy session that can provide education and support, facilitate positive interactions between the siblings, model how to interact with the sibling with the disability, provide activities that demonstrate the abilities of a sibling with a disability, and examine the individual needs of each family. Occupational therapists can better serve children with disabilities and their typically developing siblings by creating optimal functioning in their daily activities and life roles through sibling inclusion in therapy.

This study will be significant to occupational therapy because it will contribute to knowledge and awareness about the effects of typically developing sibling inclusion. It can also demonstrate how occupational therapists can have an impact not only on the child with a disability but the family as a whole. This study may provide support and inspiration for other

occupational therapists to provide similar opportunities for the children and families with whom they work.

CHAPTER 2

Literature Review

The Importance of the Sibling Relationship

The importance of the relationship between children with a disability and their brothers and sisters has been examined extensively. The literature suggests that typically developing siblings are affected by their sibling with a disability in a variety of ways (Humphrey & Case-Smith, 1996). Some of the earliest lessons where children learn about sharing, rivalry, competition, and compromise come through the sibling relationship (Miller, 1996). Miller explains that sibling relationships are so important for development and growth, that it is essential to consider how the presence of a child with a disability affects the sibling relationship.

Studies examining the impact a sibling with a disability has on the typically developing sibling have produced inconsistent results. Miller (1996) states that there appear to be two directly opposing views. One view states that those siblings who relate well with the child with a disability gain positive benefits from the relationship, while another view points to a negative relationship between these children that continues to bear negative effects into adult life. Early research done in Britain and America assumed a negative relationship between the children (Gath, 1974). These studies focused mainly on mothers' reports and what the mothers perceived about the children's relationships with each other (Gath, 1974). The parents of a child with a

disability may not be aware of the true nature and extent of the typically developing sibling's feelings, behaviors, and concerns (Derouin & Jessee, 1996). More recent studies however, have focused on gathering data from children themselves and have been successful in finding positive effects on siblings (Derouin & Jessee, 1996; Faux, 1991; Lobato, 1985; McHale & Gamble, 1989; McHale, Sloan, & Simeonsson, 1986; Menke, 1987; Miller, 1996). Both types of research procedures continue to be used, sometimes with a combination of child-directed questions as well as parent responses.

The Positive Effects of Having a Sibling with a Disability

Faux (1991) underlines the importance of talking directly to the children, stating that there are few studies describing specific sibling relationships and interactions between children with a disability and their typically developing siblings. Studies have instead examined behavioral or psychological outcomes. Studies that look at the interaction from the child's perspective have been successful in finding positive aspects of living with a child with a disability (McHale & Gamble, 1989). Positive aspects that have been identified are: increased empathy, increased coping skills, high incidence of altruism, tolerance, and humanistic concerns in adults who have grown up with a sibling with a disability (Brett, 1988; Dunn, 1988; Dyson, 1996).

The Negative Effects of Having a Sibling With a Disability

A study done by Dyson (1996) found that in the presence of a child with a learning disability, the family may experience increased parental stress

leading to an alteration in family routines ultimately affecting sibling interactions. For example, the sibling with a disability may take away the attention of the parent from the typically developing sibling. Marcenko and Smith (1992) examined the impact of a family-centered case management approach for families of children with both a developmental disability and a chronic health condition. They found that difficulties typically developing siblings experienced included problems sleeping, anger, fear, resentment, and jealousy. These studies suggest that programs need to be developed to address these issues.

Typically Developing Sibling Programs

Programs that provide structured opportunities for typically developing siblings who have a sibling with a disability have produced positive results. In these programs, issues such as socialization, peer support, reciprocal interactions, and education were addressed (Chinitz, 1981; James & Egel, 1986; Lobato, 1985; Rothery, 1987; Schreibman, O'Neill, & Koegel, 1983). Researchers found that programs educating typically developing siblings resulted in positive changes in the content of their statements about themselves and their family members including their sibling with a disability (Lobato, 1985). Furthermore, reciprocal interactions between siblings increased with training given to the typically developing sibling (James & Egel, 1986).

James and Egel (1986) found that typically developing siblings are an underutilized population, especially when it comes to helping children with disabilities develop social skills. Knott, Lewis, and Williams (1995) suggest that much opportunity for interaction arises naturally within the sibling relationship. Siblings are more accustomed to interacting. They often share bedrooms and toys, bath time, dinner time, and other family activities.

Sibling interactions play an important part in the social life of not only a child with a disability but also for the typically developing child (Knott et al., 1995). Ambromovitch, Pepler, and Corter (1982) found that the style of social exchange siblings experience is the foundation for the social exchange they use with their peers.

Knott et al. (1995) looked at children with autism and their relationships with their siblings. The researchers asked the question, "Why do children with autism appear to play with their siblings when peer play causes them such difficulty?" Their results indicate that siblings are highly familiar with one another and they share similar experiences and backgrounds that not even the closest of friends could match. Siblings interact in a number of roles and in a variety of ways leading to skill development. Harding (1996) indicates that sibling relationships can be the most enduring and rich experiences for children and adults. She indicates that their relationship is important in developing each other's personality and self-identity.

The Typically Developing Sibling as Caregiver

At times typically developing siblings may be called upon to take on caregiver responsibilities (Miller, 1996). Miller explains that sometimes the responsibilities children take on may be inappropriate for their age. This may lead to embarrassing future situations. An example of this may be a female sibling who toilets and dresses her older brother with a disability (Miller, 1996).

In the study by Schreibman et al. (1983), the authors implemented behavioral training for siblings of autistic children. The results found that the siblings were able to control and evoke appropriate behavior from the child with autism. However, the authors realized that such increased control by the siblings could possibly be misused or exploit the sibling who is autistic. They suggested that siblings may be useful adjuncts to trained parents in being able to teach and maintain behaviors in siblings who are autistic. On the other hand, the consequences.of giving siblings too much responsibility suggest that siblings without a disability who are taken out of their "normal" developmental role and given extra responsibility such as a caregiver role have an increased chance of developing maladaptive behaviors (Faux, 1993). This in turn can affect the family system as any change in one part of the system affects all parts of the system.

However, Miller (1996) suggests that increased caregiver responsibilities do not always lead to maladaptive behaviors. If a typically developing sibling is afforded the opportunity to take on an appropriate

caregiver role, while at the same time encouraged to develop a healthy, age-appropriate relationship with the child with a disability, both children can facilitate each other's growth and development as well as influence the stability of the family.

These studies provide valuable insight into understanding and facilitating the sibling relationship. However, this population has received little attention in the occupational therapy literature (Unruh, 1992). Much of the information found has been from pediatric nurses and psychologists. Occupational therapy recognizes the importance of addressing an individual holistically to promote improved functioning and independence. Including the typically developing sibling in treatment is one step directed at addressing the child holistically.

Theoretical Framework

Family Systems Model. The family systems model reinforces the idea of occupational therapists treating a child holistically (Sue et al., 1997). Minuchin (1985) describes the family systems theory using six principles: 1. The family is a unit. The behavior of one member of the family cannot be understood without examining how that individual is connected with the whole family. 2. One member does not simply influence the behavior of another member, but instead the relationship is reinforced by actions towards one another, in a circular manner. 3. Families create balance for themselves. The family will attempt to always maintain equilibrium by adjusting their behaviors

accordingly. 4. Change happens as each member of the family grows and experiences different developmental tasks. The family adapts to change. 5. Each member in the family fulfills multiple roles. The young boy in a family may be a brother, a son, a God child, a grandson, a nephew. 6. Each role an individual fulfills comes with rules and boundaries. There are rules and boundaries within one role and between other roles. Over time, change affects what rules and boundaries are followed.

Wellness. Occupational therapy emphasizes balance within systems and an interaction between the environment and the individual that is congruent with the idea of wellness (Johnson, 1986). Wellness is a lifestyle designed to achieve one's highest potential for well being (Ryan & Travis, 1983). To facilitate a child's ability to find balance in his environment it is important to address his relationship to the environment.

Occupational Performance. When using the occupational performance frame of reference, the occupational therapist is concerned with the child's physical, cultural, and social environment as well as the child's performance areas, components, and contexts. The performance areas within which children function include self-care, school, and play. The performance components or underlying skills necessary for function in these areas are sensorimotor, neuromuscular, motor, cognitive, and psychosocial (American Occupational Therapy Association [AOTA], 1994). Performance contexts can be temporal or environmental. Temporal contexts consist of the child's age,

developmental stage, and the child's life stage such as pre-schooler, toddler, or first grader. There are three kinds of environmental contexts: physical, cultural, and social. The child's physical environment includes home, outdoors, and other objects. The cultural environment consists of beliefs, values, customs, and behavior standards of the child. Social groups, friends, and family make up the social environment (AOTA, 1994). Depending on the child's needs, these areas, components, and contexts (environment) are examined and adapted to facilitate a child's independence. Occupational performance looks at the child holistically, looking at each individual child's occupation and roles.

Ecology of Human Performance. Dunn, Brown, and McGuigan (1994) further defend the importance of context, the physical environment, social, cultural, and temporal factors that influence behavior, in their framework, the Ecology of Human Performance. Each individual's contextual experience is unique. The study of ecology is concerned with organisms and their interrelationships with their environments. The interrelationship of humans and their contexts and the effects these relationships have on performance is a concern of occupational therapists. Fundamental to this framework is the idea that the context and the individual are interactional. Dunn and colleagues assume that persons are both affected by and have an affect on their context. It is impossible to see the individual without first seeing the context (Dunn et al., 1994). Therapeutic intervention within this framework, employs a partnership

between the individual, the family, and the occupational therapist. Dunn and her colleagues developed five interventions: Establish and restore, alter, adapt, prevent, and create.

The fourth therapeutic intervention is defined to prevent the occurrence or development of maladaptive performance in context. This approach foresees possible or likely problems and attempts to increase positive outcomes by redirecting or changing the course of activities. Occupational therapists can change the course of events by the interventions they create. The fifth intervention creates circumstances to promote increased adaptation or complex performance in context. When using this intervention, therapists do not assume a disability is present or that a disability has the ability to interfere with performance. This intervention provides enriched task and contextual experiences that will facilitate performance (Dunn et al., 1994).

Play. Play as a modality is well recognized in the occupational therapy field and is a basic component in therapy sessions (Morrison, Metzger, & Pratt, 1996). Play has an organizing effect on human behavior and creates a foundation for adult competence (Reilly, 1974). Play is energized by a child's curiosity. The child explores the environment through play to learn how people, objects, and events work. It is through this exploration that the child builds knowledge about rules, learns how toys work, and becomes familiar with the appropriate use of objects in his environment. The child becomes more

competent as his understanding of how the world works increases with opportunities of play (Morrison et al., 1996).

Summary

The sibling relationship is important for it is an enduring relationship that can help children better cope with stressors in their lives (Nelms, 1990). Knott et al. (1995) suggest that much opportunity for interaction arises naturally within the sibling relationship. The majority of research suggests that living with a sibling with a disability can have both negative and positive effects on the typically developing sibling.

Negative effects appear to be present due to the typically developing sibling's decreased understanding of their sibling with a disability and decreased emotional support for their own development. This may create confusion as the typically developing siblings, while moving through their developmental stages, are left to question the nature of their sibling's disability and what it means for their own lives (Rothery, 1987). When the typically developing siblings are given an opportunity to cope effectively with both their own developmental tasks and living with a sibling with a disability, they are able to be role models and playmates for their brother or sister (Rothery, 1987).

Positive effects that have been identified, looking at the interaction from the child's perspective, include increased acceptance of the range of human differences, an understanding of how to effectively communicate with family

members and community professionals, increased family unity, and social competence (Brett, 1988; Dunn, 1988; Rothery, 1987).

Programs for typically developing siblings have been developed and supported by disciplines such as nursing and social work. These programs have focused on providing support and education for the typically developing sibling. Occupational therapy is underrepresented in the literature as a discipline that can facilitate the sibling interaction by including both siblings together in therapy. Occupational therapists can better serve children with disabilities and their typically developing siblings by creating optimal functioning in their daily activities and life roles through sibling inclusion in therapy (Unruh, 1992).

CHAPTER 3

Design and Methodology

The purpose of this study was to evaluate the effects of including typically developing siblings in the occupational therapy treatment setting with their sibling with a disability. The effects were explored by comparing the perceptions of the siblings and parents before and after the typically developing sibling was included in the therapy setting. This study was designed using qualitative methodology to collect pre-intervention and post-intervention data. Data was collected by individual in-depth interviews, participant observations, and notebook journaling by the families.

Sample

The researcher chose to do this study with a maximum of five families and a minimum of three. The three families participating in this study were the only families that met the following criteria. Selection criteria of the families for this study included: (a) single or married parents who had at least one child with a disability and at least one typically developing sibling living in the same home; (b) siblings at least 3 years old and at most 16 years old; (c) siblings with the ability to participate in interviews with the researcher; and (d) the families continuing therapy at The Northern California Children's Therapy Center (CTC) through the month of May, 2000. The differences in age between siblings could range from 9 months to 13 years.

Families were selected using purposive sampling. The researcher received permission from CTC to conduct her research study at their facility (see Appendix A). Permission was then received from the Human Subjects-Institutional Review Board to begin the study (see Appendix B). The researcher informed the occupational therapist at CTC about the purpose of the study, the steps involved in fulfilling the purpose, and her role in the research study. The therapist introduced the study to the families and children with whom she worked and received phone numbers from those families expressing interest. The researcher then arranged an initial home visit to explain the study in further detail and to obtain written consent (see Appendix C).

Family number one lived in Davis, California. The family was made up of Tom, Mike, and their mother and father. The family was Korean and Korean was the primary language spoken at home. Tom was six years old and Mike, his older brother, was eight years old. Tom received services at CTC due to concerns with both his gross motor and fine motor skill development.

In this family, Mike appeared to take on a caregiver role for Tom. Their mother described how Mike helped Tom buckle his seat belt and go to the bathroom. Mike's responsibilities included taking care of his brother when his parents could not. During the initial interview, Mike hid himself behind his mother as she described the ways he helped Tom.

Mike was very quick to answer and respond for Tom. Tom often repeated what Mike said. During a Chutes and Ladders™ board game, Mike reacted quickly when Tom would move the wrong piece or direction. Mike would often take the piece from Tom and move the correct one and/or move the piece in the right direction. When Mike was not looking, Tom was able to self-correct his mistakes. The boys laughed together when one of them had to go down the chutes and/or ladders.

Their mother reported that the children often played independently of each other. Mike enjoyed playing basketball outside while Tom liked to listen to music inside. Their father didn't think that they could play together. The boys' mother supported this, saying, "Sometimes Tom didn't know how to play a lot of the games. Mike knew all of the things, he knew all the sports men but Tom didn't know that." They did enjoy playing Pokemon™ and computer games together. Mike initiated the play by asking Tom to join him in what he was doing.

Family number two consisted of Chris, Leah and their mother and father. Their parents were divorced; their father lived in Davis and their mother lived in Winters. The children lived with both parents, switching off during the week. The family was Caucasian. English and American Sign Language were the primary languages spoken at home. Chris was nine years old and Leah, his older sister, was ten years old. Chris had moderate to severe bilateral hearing

loss and wore hearing aids in both ears. He received services at CTC due to concerns regarding global delays in several areas of development.

Leah and Chris were close in age and appeared to share a cooperative relationship. "Leah," her father said, "being the older sibling liked to direct the play and Chris would do most anything she asked him to." Chris was very cooperative when Leah was in a playful mood. Leah had been known to tie a leash around Chris's neck and lead him around as if he were her pet, dress him up, and play make believe games with him. The children played store or school together. When they did so, Leah was usually the teacher or the cashier and Chris was either the student or the customer. When Chris and his father played school, Chris was usually the teacher and his father was the student.

The interactions were initiated equally between the children. Leah often acted like a teacher for Chris, modeling and challenging his abilities. Leah liked to do flash cards with Chris. She was very helpful and self-volunteered often to help him. She was very skilled at encouraging him.

Family number three consisted of Keith, Ben and their mother and father. The family lived in West Sacramento. They were Caucasian and English was their primary language. Keith was the older brother and he was 6 years old. Ben was four years old. Keith received services at CTC due to concerns regarding fine motor, visual-perceptual, and gross motor skill delays.

Keith and Ben seemed to complement each other. The children were eager to show off their toys when the researcher came to their house. Keith tended to describe one toy or activity in the time it took Ben to explain ten things. Often, Keith would be describing something and Ben would interrupt him and try to describe three different things while Keith was still sharing one thing.

The children were both very good at being silly by themselves but especially so when they were together. One could easily set off the other child laughing, singing, and/or dancing. They not only feed off of each other they also gave each other ideas. Their mother said, "The children play well together. They build and have imaginary play together." Ben tended to be the leader, not necessarily the initiator. Both children initiated interactions equally. One would get an idea and the other would join in.

There were two occupational therapists at CTC, however, all three families participating in this study were seen by only one of the therapists, Brooke. Brooke had been working at CTC for two years when this study was conducted. She had been the sole occupational therapist working with these three families during those two years.

Setting

The two settings utilized in this study were CTC and the participants' homes. CTC was a non-profit organization founded by parents of differently abled children who had a need for therapy from pediatric specialists. CTC

strived to improve the quality of life for differently abled children through an integrated program of speech, occupational, and physical therapy, community education, and family support services. CTC was located in Woodland, California.

As a part of this study the occupational therapist at CTC in Woodland included typically developing siblings into her treatment sessions. The researcher conducted interviews with all family members in the natural setting, at their home. The participants' homes were located in Yolo County.

Instrumentation

An interview outline was developed (see Appendix D) and semi-structured interviews were conducted with the participants. The participants were asked age appropriate, non-threatening, open-ended questions. Reflective comments, prompts, and active listening were utilized by the researcher to get the most out of the interviews. An audiotape was used during the interviews to insure that the participants' responses were not missed by the researcher. Before the study interviews were conducted with the participants, the researcher conducted a pilot interview with one family who was not participating in the study. This trial interview assisted the researcher in testing the usefulness and appropriateness of questions asked.

The researcher took field notes during the occupational therapy treatment sessions. The researcher took field notes in order to: (a) record events, observations, and occurrences from the home visits and therapy

sessions, and (b) record personal impressions, feelings, and expectations (Depoy & Gitlin, 1998). The researcher videotaped the last therapy session. The videotape was then reviewed by the researcher in order to make note of interactions between the children. The researcher had an expert in the pediatric occupational therapy field review the tape as an independent rater. Interactions between the children that were significant were selected for inclusion in the study. Portions of the tape were then shared with the respective family during their post-interview as a prompt. The tapes were also used as a prompt when interviewing the participant therapist after the last sibling inclusion session was completed.

Procedures

The first step before beginning the interviews with the families included a home visit to obtain signed consent and to observe the home environment for each family. The researcher also gathered information about the family demographics. The study was explained in detail to the family. Each family received a blank notebook to use to share events or express feelings in-between interviews or treatment sessions. An explanation of the book was provided and the family was encouraged to use it throughout the study.

The researcher set up 2 hour appointments with each family for the initial interviews. These interviews took place in February and March of 2000. The researcher interviewed the typically developing sibling first, the sibling with a disability second, and then the parents together when applicable. The

occupational therapist then invited the typically developing sibling into therapy after all the pre-interviews were conducted. The sibling pairs shared therapy time for three sessions over a period of three weeks. The parent(s) were welcomed and encouraged to attend all three sessions but were required to be present for the last two sessions. The parents of family number one were unable to attend any of the therapy sessions. During the last interview they were shown clips from the video taped session. For family number two, the childrens' mother attended the second session and their father observed the third session. The mother of family number three attended the last two sessions. During the sessions the occupational therapist engaged the siblings in age appropriate activities, promoting play and facilitating sibling relationships. The therapist was provided with a protocol (see Appendix E) developed by the researcher explaining the purpose, suggested activities, and the object of the sessions. The researcher reviewed the protocol with the therapist to make sure it fit in with the child's treatment. The researcher observed the therapy sessions and took field notes that described the flow of activities and the children's interactions. The sibling therapy sessions began in the last week of February, 2000 and were all completed by March, 2000.

In April, 2000, after each sibling pair had participated in three sibling therapy sessions together, the researcher returned to the homes to conduct post-interviews. The typically developing siblings were interviewed first, followed by the sibling with a disability, and finally the parents. The participant

occupational therapist was interviewed after the sessions were completed with all the families (see Appendix D). The blank book presented to the family in the beginning of the study was collected at the time of the post-interview.

The families' names were kept confidential throughout the study. The families were identified by their number and/or a pseudonym. The interviews were, however, taped and the children's first names were used when interviewing the parents. The parents at times needed to refer to the children's first names when answering the questions. Also, the researcher asked some questions by filling in a child's name in the blank (see Appendix D). After the analysis was complete, the tapes were destroyed and the families were identified by their number. The video from the taped therapy session was given to the parents after the post-interview. When the collected data was sorted, family names were not identifiable. The number and corresponding family names were kept separately from the data by the researcher.

Data Analysis

Data analysis began after the first interview in February, 2000 and continued through April, 2000. As the data were being collected, the process of analysis of the data was also begun. Content analysis of the qualitative data was utilized, based on the research questions posed at the beginning. Depoy and Gitlin (1998) explain that a researcher's observations give rise to an initial understanding of the phenomenon being studied. It is this initial understanding that shapes the next data collection decision.

The researcher systematically examined the field notes and the transcribed interview responses to begin establishing the foundation for descriptive, narrative portrayals for each of the families' perspectives. The notebooks provided for each family to record feelings and events were examined and left with the families. They were used by the typically developing siblings in two of the families to draw pictures unrelated to the objectives of this study. Although, such a strategy has been found useful in longitudinal research (Murphy, 1992), the short term nature of this study did not allow sufficient time for the book to be used by the families in a way relevant to the research.

CHAPTER 4

Data and Results

The following information represents the findings based on data collected from the children's, mothers', and fathers' pre- and post-interviews, the occupational therapist's interview, and the researcher's participant observation field notes. The typically developing siblings' information is shared first, followed by the information from the siblings who have a disability, the parents', and the occupational therapist's. Field note observations are shared throughout this section as they relate to and strengthen participant responses.

Typically Developing Siblings

When the typically developing siblings shared their answers to the question of why their brother goes to CTC, all three children became timid and spoke softly. All children expressed an awareness that their sibling went to therapy because they needed extra help to learn. They were able to describe activities their sibling participated in at therapy.

When the children were asked to describe what was their favorite thing to do with their brother, the children demonstrated some difficulty finding answers. One of the children took a while to answer and another one wasn't able to give any specifics other than respond, "Play." When the question was asked a different way by asking the children what they get to do with their sibling all of them were able to provide answers without hesitation and with

more details. Two of the three children were able to describe things that they talked to their brother about. The children all expressed nice comments about their brother when asked to describe him. Besides the nice comments, two other comments were made such as "he is loud" and "sometimes he is mean."

When the children were first asked during the initial interview how they felt about going to CTC with their brother, two out of three children replied positively and expressed excitement. During the post-interview, all the children shared that it felt good and/or great to go to CTC with their brother. The children also described that they thought their brother felt happy and liked having them in therapy with them and that they would like to go again.

Siblings with a Disability

The children with a disability all expressed excitement when describing what was their favorite thing to do with their sibling. They did not demonstrate any difficulty finding answers to this question. All three children did however, have a hard time describing their sibling as well as sharing things they talked about.

The children responded positively when asked about how they would feel if their sibling came to therapy with them. After the sessions were complete the children continued to express positive feelings about their sibling attending therapy with them. The children also shared that they felt their sibling felt good and liked coming to CTC with them. Each of the children whole-heartedly felt that they would want their sibling to come to therapy with them again.

Parents' Descriptions

Sibling Relationship Defined. The parents all described their children's relationship as normal. Mike and Tom's father described that Mike is the older brother so he is supposed to take care of his younger brother. Chris and Leah's mother said, "I would say their relationship is fairly normal as far as just brother sister stuff." Their father said, "A love-hate relationship." Keith and Ben's father described his sons' relationship by saying, "They're brothers....I would say most of the time they play really nice together but there's a lot of times where they fight." Their mother shared, "They have very normal sibling behavior."

Parents' Perceptions Regarding What Their Children Say About One Another. The parents in all three families shared what they have heard their children say about one another as well as what they thought their children would say about their sibling. The parents also all expressed that there is a real love shared between their children.

> Mike sometimes complain [sic] to Tom because he always help [sic] him. He can't, Tom can't do this of everything, so sometimes Mike blame Tom. But sometimes Mike think Tom is a good, nice boy because when Mike gets sneezy, he, Tom, bring a tissue and wipe his nose but not really, runny nose, but he just a heard the sneezing noise but he just, he got the Kleenex tissue and wipe there and sometimes Mike say Tom is a little bit nice boy.
> Mother, family #1
>
> I think Tom think Mike's a good, good brother. I think a because Mike helped him, always helped Tom because Tom went to the bathroom and I'm very busy, so Mike you help Tom, so Tom asked the Mike, "Mike help me, help me." Tom always helped to Mike.

> He want to have Mike. So I think Tom liked to Mike sometimes. Sometime Tom want to play with Mike. Mike knows a lot of things Tom doesn't know. Mother, family #1

> Leah says that Chris is a brat. She's not complimentary even if you ask and that she wishes that she didn't have a brother, you know some of the typical things I hear from siblings so I'm not worried because I know she loves him and you can see that but the typical responses of you know it would be nice to be an only child, he's a pain in the butt but then she will also admit that it's pretty neat having a brother that's deaf because everybody knows you at school and the other kids will come to her--how do you sign this--so she kind of feels this, you know, elitism that you know that she's done resident signings for the school.
> Father, family #2

> Ben would say that Keith is my big brother, he's my close friend. He would say he's the person I like to be with who makes me feel secure and happy and actually that would go both ways. I think they offer each other a lot of security and safety and I think he's that he would say he's the person he wants to be with most often besides mom and dad. Mother, family #3

Parents' Descriptions of Their Childrens' Interactions. The parents' descriptions of how their children interacted and who was the initiator differed greatly between families. Mike and Tom's parents felt their children did not play together much at all. Chris and Leah played well together sometimes, while other times not so well. Ben and Keith's parents felt their children played really well together. The typically developing siblings often initiated the play or at least held their brother's attention to the activity. The parents described the typically developing sibling as the initiator because they were older (except for Ben). Ben and Keith equally initiated play.

Responsibilities and Being Helpful. The parents expressed that their children did not have too many responsibilities. Responsibilities such as homework, listen to their parents, take care of pets, clean their room, get dressed in the morning, put pajamas on at night, brush their teeth, take out the trash, and set the table were shared by the families.

The parents had more to share about how their children helped one another out. The typically developing sibling in each family tended to help out more than their sibling with the disability.

> When I get in our car, Tom can't buckle up and buckle down. He can't do it. Mike always help him so sometimes he blamed him so, "Why did you do, didn't do that." "I always help him, why?" "You are not young, you can do it, you try, you try, you try," but Tom says, "I don't know, I can't do that." I just said that you have to. When Tom go to the bathroom, he can't do the wipe, Mike helps him. Mike helps him pull his pants up and sometime he read the English book to Tom. Many things Tom can't do, his shoes unbuckle, Mike helped him saying, "Push push." He just help, always he help him. Mike helps Tom.
> Mother, family #1 .

> She [Leah] likes doing flash cards with him, the math flash cards. I really try not to make her responsible and I would do this even if he didn't have a disability but especially because of that she's a lot of her life has been centered around him going to the doctors and therapy with him. So I really try to let it be whatever she initiates. He gets kind of wild on the computer so sometimes I will ask her would you mind sitting with him while I go finish supper and if she says no, then I will accept that because I asked, I didn't say for her to do it because I don't want her to feel like she's got to be his parent. Father, family #2

> Ben helps Keith out by initiating a lot of social interactions. Both boys are role models for one another, look out for one another, cheerlead for one another, provide security for one another, and

> boost each other's self esteem. They are helpful by telling one another, "Wow, that's great." Mother, family #3

Parents' Perceptions of Sibling Inclusion

Benefits to Therapy. The parents discussed during the initial interview how they perceived sibling inclusion would be beneficial for their children. During the post-interview these benefits were brought up again. Common benefits expressed were an opportunity for role modeling for the sibling with the disability, an opportunity to facilitate increased understanding of the sibling with the disability and of others, increased performance, added interest and/or excitement, and security.

Mike and Tom's mother explained how Tom imitated Mike. Chris and Leah's father also felt that Chris followed Leah. Chris and Leah's mother saw that the value of sibling inclusion, for Leah, was that the more she knew about what happened with Chris and things he could and could not do, the more she would be able to understand him and others.

Ben and Keith's mother saw that sibling inclusion could be successful because of the modeling and the added interest and excitement that Ben would show towards some of the therapy tasks. She felt that Ben would be able to help Keith feel secure in trying new activities.

Challenges to Therapy. Although the parents felt there were many benefits of sibling inclusion they also felt that there may be some challenges as well. During the initial interview, the parents expressed concerns that including

the typically developing sibling would create feelings of failure for the sibling with the disability, bring in too much familiarity, introduce competition, and that it would be distracting.

It was shared that the typically developing sibling may be able to do the activities faster and with more detail, therefore creating disappointment for the child with the disability if he understood this was happening. Sometimes it was also thought that because the typically developing sibling and the parents were in the session, the child with the disability took advantage and acted up or became silly. Finally, it was thought that by introducing the typically developing sibling into treatment, the therapy routine would be altered, potentially creating a distraction for the child with the disability.

Things Discovered/Learned. The sibling inclusion therapy sessions provided the parents with an opportunity to learn something new. This had an effect on their previous perceptions, possibly changing them and introducing new ones. The parents shared that they learned (a) how much influence the children had on one another, (b) that the children had so much fun together at therapy, (c) that the children did not only play together but that they could play well together, (d) how little the typically developing sibling listened, (e) that play together in therapy was a good idea, (f) that it was okay for the children to explore and get dirty and wet, (g) that in therapy, the sibling with the disability was in charge, and (h) that the typically developing sibling benefited from therapy as well.

After watching the video of his children in therapy, Mike and Tom's father was surprised to see that his children had a lot of fun. He had not realized that Mike could play well with Tom. Their mother shared that last summer she had bought a small swimming pool for the two boys and she saw them interacting as they had on the video. Mike and Tom's mother recognized that play together in therapy was a good idea. It was a better idea than what she had previously perceived. She also realized the value of letting the children explore and get dirty.

> I didn't like their clothes dirty so I just say you have to stay clean, everything clean but Brooke, the occupational therapist play with foam soap. The children like to play together and get dirty. I think this kind of action is a better idea. But they're clothes is wet so I don't like that. Ooh it's wet. I just changed their clothes but they didn't care so I learned about this. Mother, family #1

Chris and Leah's mother realized that Chris liked being in charge in the therapy setting. She felt he liked having Leah there because he felt like he was the boss.

> That's like his territory and he knows that they are there for him and that Leah is an aide or a you know it's not where she belongs, it's where he belongs and I think he just he feels in control of being there and he knows that he will be supported by everyone that's there you know, that if Leah wants to do it one way it doesn't matter they're going to do what's best for Chris or whatever. Mother, family #2

Chris and Leah's father described that when Leah participated with Chris and she was doing the same activities he was, she was also working on

strengthening her coordination and developmental skills. He felt Leah was able to benefit from the therapy sessions as well.

Ben and Keith's mom discovered from observing the therapy sessions how little Ben listened. She also recognized how much influence the two had on each other.

> Seeing that if Keith wasn't listening very well, Ben wasn't listening very well and if Ben started to get distracted I thought Keith got more distracted as well. And um, but then seeing the positive when Ben got into the picture or something and Keith seemed to get into it and vice versa. Mother, family #3

Feelings About the Children Attending Therapy Together. The parents all expressed positive feelings about the children attending therapy together. Sibling inclusion was a positive experience, however, not one that they would do every session. Feelings the parents expressed were (a) it had worked for us because it fit their personalities, (b) sibling inclusion was a good thing and it was very positive, (c) it was nice to know that the children had lots of fun, (d) sibling inclusion may create more work for the therapist, (e) it would be good to include siblings every once in a while, and (f) it was beneficial for both children.

Reflections. The parents all said this experience gave them an opportunity to reflect on their children's relationship. They were able to appreciate both their children's growth together and independently, they were able to recognize how normal their children's sibling relationship was, and one family was able to re-live from watching the video-taped session where their family had come from and where it was now at the time of this study.

> While I was watching them, I thought man both of them have come so far from when Chris first started therapy. Because Leah would sometimes be in those therapy sessions, also. But you can tell that they're just both older and more cooperative and not both of them seeking attention but there for a reason as opposed to not really understanding maybe why either of them are there. While I was looking at the tape I thought, my goodness, you know they've just grown, in fact they've grown up in that building in a lot of respects, so I was just kind of re-living where we've all come from to see them doing that that day so that's pretty cool.
> Mother, family #2

Ben and Keith's mother was able to appreciate how much growth had gone on since her children were both little and she was able to see how normal their relationship was because their sibling relationship had always grown very normally despite the developmental delays. She said, "So it has been really nice." Chris and Leah's father was able to give his children's relationship a little more thought so that he could appreciate the neat relationship his children shared. He stated, "There is definitely a love relationship there."

Recommendations. Keith and Ben's mother said, "I could see sibling inclusion being beneficial if you guys were able to keep it up and have a schedule where it's like one out of every three sessions or something." Other parents responses supported this suggestion appreciating the benefits of including the typically developing sibling but also recognizing that individual therapy time for the sibling with the disability was also needed. Chris and Leah's father explained that in his family's case, sibling inclusion had worked out, but he suggested that each child would have to be looked at individually to

see how sibling inclusion fits in with each child's personality and each sibling pair's dynamics.

Occupational Therapist Perceptions

Brooke shared that in general, including siblings into the occupational therapy treatment setting depended on each individual child, the age of their sibling, and the sibling pairs' relationship with each other.

Concerns. Brooke shared that she had always felt sibling inclusion was good but sometimes she thought before even trying it, she would have a hard time for fear of compromising the child's therapy. She also did not want the parents to feel "oh we just come to play" and that she was really not doing anything or not concentrating on the child with the disability.

Prior Training/Education. Brooke felt that all of the baby-sitting she did in the years past had begun to prepare her to work with siblings. She also felt that even through occupational therapy school, her pediatric classes helped her learn how to work with children, not necessarily siblings specifically but learning how to help children learn.

Effects on the Sibling Relationship. Inclusion of siblings in therapy sessions provided an opportunity for the children to see each other's strengths and facilitated understanding for the typically developing sibling. The occupational therapist, however, perceived that sibling inclusion could weaken confidence levels of the sibling with the disability. Brooke felt that sibling

inclusion could have taken away from the child's confidence if the sibling with the disability recognized that their sibling was doing things more easily.

Effects in the Treatment Setting. The dynamics of each sibling pair helped organize the therapist's description of how sibling inclusion affected the treatment setting into three categories: helpful and good, helpful at times but challenging, and therapy was compromised and very hard. The sibling inclusion sessions with Chris and Leah were helpful and had good effects in the treatment setting. Leah was able to help Chris in a learning way; she didn't enable him but she helped him. She was able to challenge him without frustrating him. Chris was accepting of Leah helping him as long as she verbally did so versus taking the object away from Chris and doing it for him. Brooke did not have to initiate or provide support to maintain the children's interactions. Brooke felt that she could hand them an activity and they were always "raring" to go. They were able to figure things out even if they did not have enough instruction or structure. They were able to make their own structure depending on how much they needed.

The dynamics of Mike and Tom's interactions produced effects in the treatment setting that were helpful at times but challenging. Mike made it more challenging because he often wanted to direct and Tom had a "this is mine" attitude any time Mike came close to what he was doing. Tom was able to let Mike do things with him when the activity or game involved turn taking as long as Mike did not get involved in Tom's turn. Brooke felt she needed to provide

minimum to moderate facilitation in order to initiate an interaction and to maintain it. Brooke felt that Tom really needed the structure, whereas Mike did not. Brooke felt she had to try and find the happy medium so that Mike would cooperate without feeling like there was too much structure and so that Tom would have enough structure to be able to follow what was going on.

Brooke felt that in the sessions with Keith and Ben, therapy was compromised and it was very difficult to have a productive session. Ben was younger, more active, and not used to being in therapy. When in therapy alone, Keith would have silly, unfocused days, but with Ben in the room it was always one of those days. Brooke explained that some of Keith's skills were a lot higher than Ben's even though Keith's skills were not necessarily at his age level. She felt that by challenging Keith, Ben was also being challenged so much. She said it was therefore difficult to keep them both involved. They needed a lot of structure to be able to sit down and actually concentrate on the task at hand. Brooke provided maximum facilitation and structure in order to create interactions and to sustain them.

Constraints and Challenges. One challenge Brooke experienced was trying to facilitate the interaction while trying to stick with the therapy goals at the same time.

> I think it was hard because of the different skill levels that at times that was a big challenge for me. I mean I could always make up we did this because of this but to really feel that that's why we were doing it was hard and trying to keep the interaction without separating them you know so that that was really challenging and

> of course having their parents in there. I mean it's always nice to have the parents observe but it changes everything.

Brooke felt that at times for certain children, when their parents were in the room their behavior changed and the parents presented a distraction for the children.

A Learning Experience. Brooke shared that by the end of this study her perceptions had changed regarding sibling inclusion. She felt that she would like to experiment a little bit more and try sibling inclusion with other children in the future. Brooke also recognized the need to include sibling education in the treatment session. Leah showed interest when Brooke was explaining to Leah's father why she did certain activities with Chris.

> I learned a little bit more about talking to her about it because a lot of times you know, you think confidentiality and all that kind of stuff and I'm used to having his interpreter and Leah in there and a lot of times I don't talk about why I do it. I do with the parents when I see them but I don't see them very often so yeah that was kind of interesting. I did kind of notice that she was really really listening to that so it was kind of nice. Like oh, that's why she does that with him. Yeah, that was kind of neat.

Brooke was also able to discover that some of the behaviors the sibling with the disability exhibited were also seen in the typically developing sibling. She recognized that the hyperactivity seen in one sibling was also seen in his typically developing sibling. She was able to observe family characteristics through the typically developing sibling to get a more rounded picture of the sibling with the disability.

Future Training and Education. Brooke felt that it would be nice to have observation time at a facility that had an observation lab where there were

siblings present. She suggested somewhere where sibling interactions can be observed. Brooke said, "Somewhere you can see the interactions just in general to kind of learn how siblings react when one's better than the other in a lot of different things." Also, going to daycares or preschools and volunteering to do different projects would be advantageous.

Recommendations. Brooke felt that to be able to run sibling inclusion sessions in the future, it would be important to know how to work with children. She felt that a person's attitude and their ability to communicate with children were also important. She said, "I think it's really important to learn how to talk to children so that you're not demeaning one while you are helping the other one or making one feel wonderful and the other one feels very low."

Themes Identified

The themes identified through qualitative analysis of the data were the need for basic information, special attention, the typical sibling relationship, typically developing sibling roles, revelations, and common concerns.

The Need for Basic Information. When the children were asked why their sibling went to CTC, all the three children appeared to become shy, looked down at their hands or the ground, and quietly gave an answer. They appeared to be unsure of what was okay to say and would not expand on their answers when prompted. Mike said because Tom was not regular; Leah said because Chris had trouble with talking; and Ben answered, because Keith had to learn things. These answers reflected that the children had some understanding that

there was a reason their sibling was attending therapy. However, the lack of depth in their responses and their uncertainty with how they responded reflects their need for more information.

Special Attention. All of the parents reflected that occupational therapy for the child with the disability was a special time. It was a time where the child was the center of attention, did not have to compete with others, and where the child could be himself. From the interview responses, the parents also shared that the child with the disability received extra attention at home as well. Tom's mother worked with Tom after school on many things. She said she was always helping him learn something. Leah complained that her mother always helped Chris with his homework but not her.

All of the children with disabilities in this study had been receiving services at CTC since they were babies and toddlers. All of the parents commented on how therapy was just part of life for the typically developing siblings. Leah's dad even commented that Leah probably doesn't know if there is anything apart from therapy.

Much of the typically developing siblings' day seemed to revolve around what their sibling with the disability was doing. Chris had therapy four times a week and Keith not only went to therapy but he also participated in horseback riding. Up until this study, the focus of therapy had always been on the child with the disability. When Ben's' mother was asked what she thought Ben thought about Keith's therapy, she said, "I think it's something fun that he

doesn't get to go in and do; some extra attention from people outside the family that he doesn't get." Mike's mother also commented that Mike has said, regarding Tom's therapy, "Tom just plays, it's not therapy....Why do I go there?"

The Typical Sibling Relationship. Every parent commented positively about their siblings' relationship. Mike and Tom's parents said, "There is a normal brother relationship between them....I think it's normal." Chris and Leah's mother said, "I would say their relationship is normal as far as brother sister stuff." Their father defined "typical sibling relationship" as, "It is that we love each other, we're family, but sometimes we can get in each other's hair because we are around each other too much." Keith and Ben's father said, "They're brothers." Their mother shared that they had very normal sibling behavior and that they always have. The parents all seemed to have no concerns regarding their children's relationship with each other.

Typically Developing Sibling Roles. There were two roles that were observed and described that two of the siblings held other than their typical sibling role. Mike's parents shared how Mike takes care of Tom when they can't because he was the older brother. Their mother shared how Mike had always been an influence in Tom's life and had helped him since they were both little. Their mother described that Mike often helped Tom put his seat belt on, put his shoes on, wipe him when he went to the restroom, and helped him pull his pants up. During the initial interview when Mike's mother was explaining how Mike helps Tom, Mike hid behind her as if he were embarrassed.

During the occupational therapy sessions, it was also described by the occupational therapist as well as observed during field note observations that Mike wanted to direct the sessions. He appeared to have a hard time letting Tom do his own thing and letting Brooke direct the activities. He continuously wanted to change the activities or he would add something he had made up to the activity.

Brooke described the sessions as challenging because of Mike's need to direct. When Mike tried to direct, Tom was easily agitated and would become very upset. He would whine at Mike and push him away. Mike would say, "He doesn't want me to touch him....He doesn't want me to see." While the children played a game at home, it was also noticed that Mike was quick to jump in and help Tom even though Tom did not ask for it or need it. When Mike did not jump in and help Tom, Tom was able to self-correct on his own.

The other role that was described and observed was that of teacher with Leah and Chris. Leah was described by her parents as well as the therapist as being helpful when she needed to and wanted to. Leah's parents were especially encouraging for both their children to have the chance to be kids. They did not have too many responsibilities and the ways in which Leah helped Chris were initiated on her own for the most part and involved Leah being the leader and/or teacher.

Leah's dad explained that when Leah and Chris played school or store, Leah was always the teacher or the cashier. However, when Chris and his

father played, Chris was always the teacher or cashier. Leah's parents also described that Leah enjoyed doing flashcards with Chris. When Leah was asked what her and Chris talk about, she replied, "School, homework from school."

Both the therapist and Leah's parents shared that Leah was always invited to do things. If Leah's father asked her to watch over Chris while he fixed dinner, and she said no, he would have to accept that because he asked her, he didn't tell her.

> I understand from talking with the therapists that she's really good at encouraging him but it's always "do you want to come in" you know and they've been really good about that too, of just inviting her and usually she'll say yes. She likes to help. She's very helpful but it's usually self-volunteered. Father, family #2

Revelations. Each of the parents, the therapist, and one of the children revealed that they learned something through this experience. Leah learned that her brother took a while to do things. The parents and therapist both realized that sibling inclusion could increase the typically developing sibling's understanding of their sibling as well as of others. The parents and the therapist also agreed that sibling inclusion was a positive thing, not something that should occur every session but maybe every third session. The therapist thought that it was a positive enough experience that she was confident about experimenting and trying this with other children.

The parents learned also about their child who was typically developing. One mother discovered how little the typically developing sibling listened. She

also learned, however, as well as other parents, how much influence the children had on each other. The parents were able to see that not only could their children play together but that they could play well together. It was noted that through this experience, the sibling with the disability had benefited as had the typically developing sibling.

Common Concerns. Although the parents felt and saw the benefits before and after the siblings were included, they did have some reservations in the beginning. The parents felt that by including the typically developing sibling, the sibling with the disability could experience feelings of failure. The therapist also thought that sibling inclusion could decrease confidence levels of the sibling with the disability. Both the therapist and the parents were concerned that the typically developing sibling might come into the session and take over. The parents shared that their typically developing child was able to do things faster and with more detail than their child with the disability. Although questions regarding these challenges were not directly asked during the post interview, the parent's responses to other questions did not reflect that these concerns were still present.

CHAPTER 5

Discussion with Implications for the Profession

Themes and the Literature

The literature has suggested that there is a demonstrated need for basic information, empathy, and peer support (Lobato, 1985; Menke, 1987; Rothery, 1987). The typically developing siblings in this study demonstrated that they had a definite need for basic information. Two of the three typically developing siblings were unable to share one of their sibling's favorite things to do. The typically developing children also expressed this need when answering the questions about why their sibling goes to CTC. The children did not appear confident in the answers they gave. Rothery (1987) suggested that when the typically developing sibling is coping with both their own development as well as an understanding of their siblings, they are able to be role models and playmates for their sibling.

The occupational therapist noticed and the field notes reflected that the interest in learning more about their sibling with the disability was there for the typically developing sibling. During the sessions with Chris and Leah, Leah was able to learn more about Chris when her father asked questions. The therapist was able to see Leah's interest and was given an opportunity to foster her understanding of her brother and possibly of others. She was very attentive when Brooke began discussing why she was doing certain activities

for Chris. The more the occupational therapist explained the more Leah listened.

It was interesting that although the typically developing siblings had been going to CTC since their sibling was a baby, they were still not aware of everything their sibling did at therapy. While the three typically developing siblings had been involved in therapy sessions before, the focus had never been on facilitating the sibling interaction in the manner this study describes. Many of the parents described that therapy was a part of life, but a part of life that the typically developing sibling may not quite understand. Consider the possibilities if the typically developing sibling was afforded the opportunity to learn about their sibling over the course of therapy in order to really understand what it is they do and why it is so important for them to be there. Since therapy is already a part of life, by including the typically developing sibling in the process and allowing them to be invested, occupational therapists can create opportunities for the sibling pair so that what happens in therapy can be integrated into what happens at home. The attention does not have to focus on the child with the disability but on the family and how therapy affects the whole family.

The parents were proud to share that their children all had normal sibling relationships. These parents reflected more positive statements about their children's relationships than what the literature has suggested mothers tended to report. Unique to this study was the input given from the fathers as

well as the mothers. Studies that were reviewed for this study looked mostly at mothers' perceptions. The fathers in this study were instrumental in adding richness and depth to this study. The parents all recognized the value the sibling pairs had in their relationships.

This study reflected what Miller (1996) suggested, that typically developing children have unique experiences compared to their peers that may provide unusual opportunities. Dallas and colleagues (1993), Faux (1991), McHale and Gamble (1989) suggested that typically developing siblings may acquire, from being in a family with a child with a disability, an increased acceptance of the range of human differences. They may develop more nurturing behaviors, increased empathy, and increased self-esteem from having the opportunity of taking on different family roles such as caregiver and teacher.

Two family roles taken on besides the sibling role, included teacher (Leah) and caregiver (Mike). Leah appeared to be more nurturing than the other two typically developing children in this study perhaps because she was the only female participant. Her parents reflected how important it was for Leah to want to help Chris. During the occupational therapy sessions, Leah often became a teacher for Chris, challenging him and letting him make mistakes so that he could learn. She appeared to know how he learned and when he really needed help or when he was just being silly. Leah's self-esteem was boosted at school when she was able to teach her classmates sign language.

Leah demonstrated the ability to integrate being a teacher and a sister into her life.

Miller (1996) suggested that when a typically developing sibling is afforded the opportunity to develop an age appropriate caregiver or other family role and is encouraged to develop a healthy, age appropriate relationship with their sibling, both children can facilitate each other's growth and development. However, Miller also suggested that sometimes children may be called upon to take on caregiver responsibilities that are not age appropriate and that can lead to future embarrassing situations. When Mike's mother was describing ways in which Mike helped Tom out, Mike timidly hid behind his mother. He seemed embarrassed that she was sharing this information. However, what he was doing was not anything he needed to be embarrassed about. His parents had commented that he was told he was doing these things because he was the older brother. However, as he was getting older and realizing Tom was getting older he started understanding that there was more to it as reflected in his response that Tom was "not regular". His mother was beginning to share with him that Tom did have some delays in development and that he just needed some extra help.

Their mother had also commented that as Tom was growing up and he was learning how do more things on his own, Mike was having a hard time knowing when not to provide assistance. Mike had always helped Tom. It appeared as if he did not know what else to do. This was demonstrated in their

play. During a board game, the focus of the interaction was more on Mike helping Tom than playing and enjoying the game. In therapy, the occupational therapist was able to highlight and demonstrate some of Tom's abilities and create activities that incorporated turn taking. With moderate support she was able to facilitate a play interaction. This interaction was reflected in the video provided for the family.

This interaction seen on the video represented a revelation for the family. Their father had not realized that the children could play that well together because it had not been reflected at home. Other revelations the parents discovered reinforced the positive perceptions these parents had about their childrens' sibling relationship. The parents were able to recognize the value that sibling inclusion had on their children's relationship. The occupational therapist also recognized the value and she was inspired to experiment with other families. Chinitz (1981), James and Egel (1986), Lobato (1985), Rothery (1987), and Schreibman and colleagues (1983) found that programs that provided structured opportunities for typically developing siblings produced positive results. This was true for this study and program as well, even though the parents had originally expressed some concerns regarding sibling inclusion.

Themes and Theoretical Framework

Occupational Performance. Occupational therapists have the resources and the skilled ability to look at a child from multiple perspectives.

The occupational performance model addresses a child's physical, cultural, and social environment as well that child's developmental stage. Each child's performance areas are examined so that the occupational therapist has an understanding about how each child needs to perform in order to function as independently as possible in their life. The skills that make it possible for a child to function in all his areas are also examined so that those factors creating the most difficulty may be alleviated (AOTA, 1994). Play and school are two areas that occupational therapists address when working with children. Some of the skills necessary for a child to successfully perform in these areas have been found to come from the sibling relationship. Miller suggests that some of the earliest lessons where children learn about sharing, rivalry, competition, and compromise come through the sibling relationship. Including a typically developing sibling into the treatment setting and facilitating interactions can provide an opportunity for both children to gain necessary life skills. Modeling and creating opportunities for the children to practice in therapy can increase the children's ability to do so at home. Knott et al. (1995) indicated that siblings were highly familiar with one another and that they shared similar experiences and backgrounds that even the closest of friends could not match. They suggested that there are many opportunities for siblings to naturally interact because they share bedrooms and toys, bath time, dinner time, and other family activities. Occupational therapists can create a template which the children and family can apply at home.

The Ecology of Human Performance. It is also important to know how a child affects his environment as well as how he is affected by it so success can be achieved. The Ecology of Human Performance framework addresses the importance of context, the physical environment, social, cultural, and temporal factors that influence behavior (Dunn et al., 1994). It is impossible to see the individual without first seeing the context. Although, much of the focus of this study has been on the typically developing sibling, in the end it is both siblings who benefit.

The Family Systems Model. Miller (1996) proposed that it is often impossible to explain a child's behaviors without looking at the family as a whole. The Family Systems Model describes that the family is interconnected and interdependent with each member (Minuchin, 1985). The family influences individual behavior and individual behavior influences the family. Including the typically developing sibling into therapy not only introduces the typically developing sibling to the treatment setting but it also introduces the family to the occupational therapist. Sibling inclusion was one way the occupational therapist could learn more about the child's environment at home. It was also a way to give the family an opportunity to examine its process and adapt and reestablish equilibrium.

Changes in Perceptions

All of the participants involved felt that this was a positive experience. They were all able to express positive feelings regarding the impact of sibling

inclusion on the sibling relationship as well as the effects on the occupational therapy treatment setting. This experience also allowed the participants to learn and discover new things. The parents and the occupational therapist recognized that sibling inclusion was beneficial as well as challenging.

The sibling pairs were able to share their perceptions about one another through the interview sessions. Due to the short study period and the difficulty in developing questions that reflected what the child was feeling about his/her sibling there were no marked changes in how the children perceived their relationship. However, the children's positive perceptions regarding sibling inclusion was consistent throughout the study. The childrens' responses reflected that typically developing sibling inclusion had a positive effect on their relationship.

The parents and the therapist all shared many things that they learned and discovered throughout the sibling inclusion experience. Their responses indicated that the experience not only taught them things about the children but also changed their perceptions. Prior to the sibling inclusion sessions all expressed some concerns regarding sibling inclusion disrupting the "safe place" that the therapy session created for the child with the disability. The parents expressed that while in the therapy session, the child with the disability did not have to compete or be compared with somebody else. Their responses reflected that the therapy setting was a place where the children could just be

themselves and where the normal challenges of sibling and peer interactions were suspended.

The parents' and therapist's responses, on the other hand, during the post-interview were not consistent with these views. Their responses highlighted the positive effects without reference as they had earlier to concerns about the sessions creating a sense of failure for their child or decreasing their confidence level.

Although the parents and the therapist made the two valid points regarding challenges to therapy it is important to recognize that these are just that. They are feelings that should not structure choices about a child's life or therapy. Rather, they should be considered as perceptions to be aware of, to plan for, to monitor, and to see past, so as not to hinder a child's opportunity for success. Both the occupational therapist and the parents felt there were many benefits of sibling inclusion. One benefit shared by all was that sibling inclusion increased the typically developing sibling's understanding of their sibling with a disability.

Occupational therapists can influence the sibling relationship in many ways. Occupational therapists are skilled to see the extrinsic as well intrinsic value of an activity. Occupational therapists may choose an activity because it increases a child's performance for one of their goals. However, that same activity may also support and facilitate a sibling interaction. Occupational therapists are qualified to create a therapy session that can provide education

and support, facilitate positive interactions between the siblings, model how to interact with the sibling with disability, provide activities that demonstrate the abilities of a sibling with a disability, and examine the individual needs of each family (Unruh, 1992). Occupational therapists can serve children with disabilities and their typically developing siblings in order to foster optimal functioning in their daily activities and life roles.

Implications for the Profession

This study begins to demonstrate the necessity of family education and modeling as an area occupational therapists can and should address. The children, parents, and therapist in this study expressed and shared important benefits of sibling inclusion. The potential challenges perceived by the parents and therapist were never observed during the occupational therapy sessions. These are concerns that should be recognized and discussed. However, this researcher believes that they should not be viewed or used as barriers to providing a family-focused intervention environment. Incorporating these ideas into the occupational therapy education and training academia can increase awareness of the benefits sibling inclusion has, not only on the sibling relationship, but on each child's individual development, and on the interaction of the family.

Limitations

For this study, the researcher was interested in the richness and quality of the participants' perceptions. The following limitations may affect the direct

applicability of this study. The researcher included children of different ages and disabilities. This could be an asset as well as a limitation depending on how applicable this study may be to a particular reader. For example, an occupational therapist who works at a facility that serves families who have children with autism may not find this study directly applicable. The occupational therapist may, however, gain insight into this phenomenon to discover how these findings might be applicable to the population she serves. The same is true for using children of different ages. One sibling pair was six and eight years old. The second pair was nine and ten and the last pair was four and six. A variety of ages and disabilities were utilized so as to enrich the study and provide a broader range of family experiences and viewpoints. However, the size of the sample prevents any conclusions related to the ages or spacing of the siblings.

Another limitation affecting this study's direct applicability includes the fact that this study was conducted in one geographic area, at one facility, with only three families. The focus of this study was not to obtain information from an exhaustive sample but instead to share in-depth themes and relationships that would provide a direction for further study. The greatest limitation to this study was trying to develop questions that could reflect how the siblings felt about one another. This limitation, along with the short study period (three months), made it difficult to see how and in what ways each child's perceptions changed.

Future Research

For future research, the researcher would like to conduct a longitudinal study using the same focus with an expanded population. Ideas also include using occupational therapists as participants who structure their treatment around the family, incorporating family system ideals. There were also three new interests this study inspired. The first one is to examine how the sibling relationship changes over time when the typically developing sibling is the younger child. Another idea includes identifying underlying assumptions and perceptions occupational therapists have about children with disabilities and how this might affect the structure of therapy programs. Finally a study that investigates what children with disabilities think and perceive about their occupational therapy treatment would provide the perspective of the recipients of therapy services.

References

Ambromovitch, R., Pepler, D., & Corter, C. (1982). Patterns of sibling interaction among preschool-age children. In M. E. Lamb & B. Sutton-Smith (Eds.), Sibling relationships across the life span: Their nature and significance (pp. 61-86). Hillsdale, NJ: Erlbaum.

American Occupational Therapy Association. (1994). Uniform terminology for occupational therapy (3rd ed.). American Journal of Occupational Therapy, 48, 12.

Brett, K. M. (1988). Sibling response to chronic childhood disorders: Research perspectives and practice implications. Issues in Comprehensive Pediatric Nursing, 11, 43-57.

Chinitz, S. P. (1981). A sibling group for brothers and sisters of handicapped children. Children Today, 10(6), 21-23.

Dallas, E., Stevenson, J., & McGurk, H. (1993). Cerebral-palsied children's interactions with siblings II. Interactional structure. Journal of Child Psychology and Psychiatry, 34, 649-671.

Depoy, E., & Gitlin, L. (1998). Introduction to research: Understanding and applying multiple strategies (2nd ed.). London: Mosby.

Derouin, D., & Jessee, P. O. (1996). Impact of a chronic illness in childhood: Siblings' perceptions. Issues in Comprehensive Pediatric Nursing, 19, 135-147.

Dunn, J. (1988). Annotation: Sibling influences on childhood development. Journal of Child Psychiatry and Psychology, 29, 119-127.

Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. American Journal of Occupational Therapy, 48, 595-607.

Dyson, L. L. (1996). The experience of families of children with learning disabilities: Parental stress, family functioning, and sibling self-concept. Journal of Learning Disabilities, 29, 280-286.

Faux, S. A. (1991). Sibling relationships in families with congenitally impaired children. Journal of Pediatric Nursing, 6, 175-184.

Faux, S. A. (1993). Siblings of children with chronic physical and cognitive disabilities. Journal of Pediatric Nursing, 8, 305-317.

Gath, A. (1974). Sibling reactions to mental handicaps: A comparison of the brothers and sisters of mongol children. Journal of Child Psychology and Psychiatry, 15, 187-198.

Harding, R. (1996). Children with cancer: The needs of siblings. Professional Nurse, 11, 588-590.

Humphrey, R., & Case-Smith, J. (1996). Working with families. In J. Case-Smith, A. S. Allen, & P.N. Pratt (Eds.), Occupational therapy for children (3rd ed., pp. 67-98). New York: Mosby.

James, S. D., & Egel, A. L. (1986). A direct prompting strategy for increasing reciprocal interactions between handicapped and non-handicapped siblings. Applied Behavior Analysis, 19, 173-186.

Johnson, J. A. (1986). Wellness: A context for living. Thorofare, NJ: Slack.

Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and Down syndrome. Journal of Child Psychology and Psychiatry, 36, 965-976.

Lobato, D. J. (1985). Brief report: Preschool siblings of handicapped children--Impact of peer support and training. Journal of Autism and Developmental Disorders, 15, 345-350.

Marcenko, M. O., & Smith, L. K. (1992). The impact of a family-centered case management approach. Social Work in Health Care, 17, 87-100.

McHale, S., & Gamble, W. C. (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. Developmental Psychology, 25, 421-429.

McHale, S., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. Journal of Autism and developmental Disorders, 16, 399-413.

Menke, E. M. (1987). The impact of a child's chronic illness on school-aged siblings. Children's Health Care, 15, 132-140.

Miller, S. (1996). Living with a disabled sibling: A review. Paediatric Nursing, 8(8), 21-24.

Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. Child Development, 56, 289-302.

Morrison, C. D., Metzger, P., & Pratt, P. N. (1996). Play. In J. Case-Smith, A. S. Allen, & P. N. Pratt (Eds.), Occupational therapy for children (3rd ed., pp. 504-523). New York: Mosby.

Murphy, S. O. (1992). Using multiple forms of family data: Identifying pattern and meaning in sibling-infant relationships. In J. F. Gilgun, K. Daly, & G. Handel (Eds.), Qualitative methods in family research (pp. 146-171). London: Sage.

Nelms, B. C. (1990). Sibling relationships: More important now than ever. Journal of Pediatric Health Care, 4(2), 57-58.

Reilly, M. (Ed.). (1974). Play as exploratory learning. Beverly Hills, CA: Sage.

Rothery, S. A. (1987). Understanding and supporting special siblings. Journal of Pediatric Health Care, 1, 21-25.

Ryan, R., & Travis, J. (1983). Wellness workbook. Berkeley, CA: Ten Speed Press.

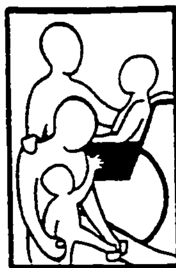
Schreibman, L., O'Neill, R. E., & Koegel, R. L. (1983). Behavioral training for siblings of autistic children. Journal of Applied Behavior Analysis, 16, 129-138.

Sue, D., Sue, D., & Sue, S. (1997). Models of abnormal behavior. In Understanding abnormal behavior (5th ed., pp. 32-69). New York: Houghton Mifflin.

Unruh, A. M. (1992). Siblings of children with special needs. Canadian Journal of Occupational Therapy, 59, 151-158.

APPENDIX A

NORTHERN CALIFORNIA CHILDREN'S THERAPY CENTER APPROVAL LETTER



NORTHERN CALIFORNIA
CHILDREN'S THERAPY CENTER
125 Court St., Woodland, CA 95695 (530) 668-1010

January 11, 2000

RE: Celise Carroll

To Whom It May Concern:

Celise Carroll has permission to conduct her research on The Impact of Well-sibling Inclusion During Occupational Therapy Treatment at our facility effective immediately.

Thank you,

Donna Jackson
Office Manager

APPENDIX B

HUMAN SUBJECTS-INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

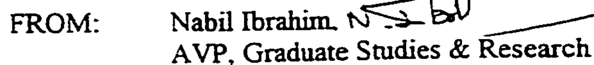
San José State
UNIVERSITY

Office of the Academic Vice President

Associate Vice President Graduate Studies and Research

One Washington Square
San Jose, CA 95192-0025
Voice: 408-924-2480
Fax: 408-924-2477
E-mail: gstudies@wahoo.sjsu.edu
http://www.sjsu.edu

TO: Celise Carroll
5811 El Zuparko Dr., #4
San Jose, CA 95123

FROM: Nabil Ibrahim, 
AVP, Graduate Studies & Research

DATE: January 24, 2000

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"The Impact of Well-Sibling Inclusion during Occupational Therapy Treatment"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Nabil Ibrahim, Ph.D., immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that all subjects need to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills, Fresno, Fullerton, Hayward, Humboldt, Long Beach, Los Angeles, Maritime Academy, Monterey Bay, Northridge, Pomona, Sacramento, San Bernardino, San Diego, San Francisco, San Jose, San Luis Obispo, San Marcos, Sonoma, Stanislaus

APPENDIX C

CONSENT FORMS

San José State
UNIVERSITY

Occupational Therapy Department

One Washington Square
San Jose, CA 95192-0059
Voice: 408-924-3070
Fax: 408-924-3088

Fieldwork Office
408-924-3078

Agreement to Participate in Research at San Jose State University

Title: Typically Developing Sibling Inclusion In Occupational Therapy Treatment

Responsible Investigator: Celise Carroll

Our family has been asked to participate in a research study that is investigating the relationship between my child with a disability and his/her typically developing sibling/s. We are eligible for this study because we have more than one child living in the home and at least one of those children has a disability. Also we have children who are between the ages of 3 and 16. The purpose of this study is to evaluate the impact of including typically developing siblings into the occupational therapy treatment setting with their sibling who has a disability. The results of this study could potentially benefit families in the future by helping occupational therapists as well as other health professional see the child holistically and understand the important benefits of including the whole family when treating a child.

We understand that:

The study begins in February and will continue through March. The occupational therapy graduate student will come to our house three times. Twice in February, once to gather preliminary research information, and another time to conduct interviews before our children are engaged in therapy together. She will come again in March to conduct interviews after our children have participated in therapy together.

During her visits to our home, she will ask to interview each member of the family participating in the study. The purpose of these interviews is to try to gain information into the sibling relationship from the perspective of the typically developing sibling, the sibling with a disability, and the parents. The interviews will be approximately 30 minutes long. They are not meant to be threatening and the questions asked will be appropriate to the interviewees understanding.

I have read and understand the above statements.

____
Parent or Guardian Initials

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San Jose, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

San José State
UNIVERSITY

Occupational Therapy Department

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Voice: 408-924-3070
Fax: 408-924-3088

Fieldwork Office
408-924-3078

In between the interviews, our typically developing child will be asked to participate in therapy with their brother or sister. The researcher will be sitting in the sessions observing as the child's occupational therapist incorporates the child's sibling into the session. This will happen during three sessions. I am welcome to attend all three sessions as well. I am required, however, to attend the last two sessions to observe. I will be reminded by telephone when this is to happen.

We will also have the opportunity to use the blank book provided to write notes pertaining to the sibling relationship or anything else we see notable. This book is also provided so that our children can express their thoughts and feelings by drawing or writing notes as well.

There may be a potential risk to my family of embarrassment or discomfort with being interviewed. Participation in this study is voluntary. Any member in my family has the option to refuse to answer any questions or participate in any part of this study. We also have the option to withdraw at any time, without any repercussions from San Jose State or The Children's Therapy Center.

There is also a potential risk of loss of privacy. All efforts will be made to protect confidentiality, according to law. Our names will not be revealed, either in storing the data or in writing up the results. A number will be assigned to my family as our identifier. Also, I understand that during the interviews, a tape recorder will be used. However, I also understand that the tapes will be erased after the information has been analyzed. The researcher will also be video taping the last therapy session and will be showing it to us during the last interview. We understand the video tape will be provided for us to keep after the interview.

This study is not intended to benefit my family directly. We may however, benefit from the positive feeling we may experience for participating in this study and feel good about ourselves for helping others better understand the importance of including siblings into treatment.

I have read and understand the above statements.

____
Parent or Guardian Initials

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
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Sacramento, San Bernardino, San Diego,
San Francisco, San Jose, San Luis Obispo,
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Occupational Therapy Department

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Fax: 408-924-3088

Fieldwork Office
408-924-3078

Questions about our family's participation in this research study can be answered by Celise Carroll, at (408) 360-8954. Comments or complaints about this research study may be shared with Gordon Burton, Occupational Therapy Department Chair at (408) 924-3074. Questions about research, subjects' rights, or research-related inquiry may be presented to Nabil Ibrahim, Ph.D. (Acting Associate Vice President for Graduate Studies and Research) at (408) 924-2480.

Our family has received a signed and dated copy of the consent form.

WE UNDERSTAND, THAT BY SIGNING THIS DOCUMENT, OUR FAMILY, INCLUDING OUR CHILDREN HAVE MADE THE DECISION TO PARTICIPATE IN THIS RESEARCH STUDY.

____________________________ ________
Parent or Guardian's Signature Date

____________________________ ________
Parent or Guardian's Signature Date

____________________________ ________
Name of Child or Ward Date

____________________________ ________
Relation to Child or Ward Date

____________________________ ________
Name of Child or Ward Date

____________________________ ________
Relation to Child or Ward Date

____________________________ ________
Name of Child or Ward Date

____________________________ ________
Relation to Child or Ward Date

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
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One Washington Square
San Jose, CA 95192-0059
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Fax: 408-924-3088

Fieldwork Office
408-924-3078

Full Mailing Address

____

__________________________ ________
Celise Carroll, OTS, Researcher Date

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
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408-924-3076

Agreement to Participate in Research at San Jose State University

Title: Typically Developing Sibling Inclusion In Occupational Therapy Treatment
Responsible Investigator: Celise Carroll

I have been asked to participate in a research study that is investigating the relationship between children with disabilities and their typically developing sibling/s. The purpose of this study is to evaluate the impact of including typically developing siblings into the occupational therapy treatment setting with their sibling who has a disability. The results of this study could potentially benefit families in the future by helping occupational therapists as well as other health professional see the child holistically and understand the important benefits of including the whole family when treating a child.

I understand that:

The study begins in February and will continue through March. The researcher will be interviewing families before and after the children are included in occupational therapy treatment sessions with me. I will also be interviewed after all the treatment sessions are complete. The purpose of being interviewed is to gain an occupational therapy perspective into the inclusion of typically developing siblings in the occupational therapy treatment session.

There may be a potential risk to myself of discomfort from being interviewed and/ or videotaped. Participation in this study is voluntary. I have the option to refuse to answer any questions or participate in any part of this study. I also have the option to withdraw at any time, without any repercussions from San Jose State or The Children's Therapy Center.

There is also a potential risk of loss of privacy. All efforts will be made to protect confidentiality, according to law. My name will not be revealed, either in storing the data or in writing up the results. A number will be assigned to me as an identifier. Also, I understand

I have read and understand the above statements.

____
Therapist's Initials

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
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UNIVERSITY

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that during the interview, a tape recorder will be used. However, I also understand that the tape will be erased after the information has been analyzed. The researcher will also be video taping the last therapy session of each child and will be showing it to myself during my interview and the respective families during their last interviews. I understand the video tape will be provided for the family to keep after their interview.

This study is not intended to benefit me directly. I may, however, benefit form the positive feeling I may experience for participating in this study and feel good about myself for helping others better understand the importance of including siblings into treatment.

Questions about my participation in this research study can be answered by Celise Carroll, at (408) 360-8954. Comments or complaints about this research study may be shared with Gordon Burton, Occupational Therapy Department Chair at (408) 924-3074. Questions about research, subjects' rights, or research-related inquiry may be presented to Nabil Ibrahim, Ph.D. (Acting Associate Vice President for Graduate Studies and Research) at (408) 924-2480.

I have received a signed and dated copy of the consent form.

I UNDERSTAND, THAT BY SIGNING THIS DOCUMENT, I HAVE MADE THE DECISION TO PARTICIPATE IN THIS RESEARCH STUDY.

____
Therapist's Signature Date

____
Celise Carroll, OTS, Researcher Date

The California State University:
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APPENDIX D

INTERVIEW QUESTIONS

Pre-interview questions for the typically developing sibling:

1. What is your favorite thing to do?

2. What is _________ (Sibling's name) favorite thing to do?

3 What is your favorite thing to do with __________?

4 Is there something you wish you could do better? If you could do something better, what would it be?

5 Is there something you wish ___________ could do better?

6. What do you get to do with ___________?

7. Can you describe ___________? Can you tell me about your brother/sister? What do you think of him/her?

8 What do you and __________ talk about?

9. How many times have you gone to therapy with ___________?

10. What did you do when you went to therapy with ___________?

11. What do you think your brother/sister does at therapy?

12. How do you feel/ What do you think about going to therapy with __________?

If the child has not gone to therapy with their sibling before, he/ she will be asked:

13. Why haven't you gone to therapy with _________ before?

14. What do you think happens when __________ goes to therapy?

15. What do you think would happen if you went to therapy with __________?

16. How will _________ feel if you go to therapy with him/her?

17. How would you feel about going to therapy with __________?

Post-interview questions for the typically developing sibling:

1. What did you think/ How did you feel about going to therapy with __________?

2. What did you do when you went to therapy with __________?

3. How do you think/ What do you think __________ felt/ thought about you coming to therapy?

4. What was your favorite thing you did at therapy?

5. What was your favorite thing you did at therapy with __________?

6. Would you go to therapy again with your brother? If so, why?

7. Can you tell me one thing that you learned about your brother from therapy? Can you tell me about your brother/sister? What do you think of him/her?

8. How come your brother goes to therapy?

9. What is your favorite thing to do with __________?

10. Do you guys do anything at home that you did at therapy?

11. Are there any new games/activities you play/do?
    Please describe how you play/do these activities.

Pre-interview questions for the sibling with a disability:

1. What is your favorite thing to do?

2. What is __________ favorite thing to do?

3. What is your favorite thing to do with __________?

4. Is there something you wish you could do better? If you could do something better, what would it be?

5. Is there something you wish __________ could do better?

6. What do you get to do with __________?

7. Can you describe ___________? Can you tell me about your brother/sister? What do you think of him/her?

8. What do you and ___________ talk about?

9. How many times has ____________ gone to therapy with you?

10. What did you guys do when ___________ came to therapy with you?

11. What things did you show ___________ when he/she came to therapy?

12. What activities/games did you do/play together?

13. What does ___________ do when you are at therapy?

14. How do you feel, what do you think about __________ coming to therapy with you?

    If the well-sibling did not attend therapy, he/ she will be asked:

15. Why hasn't __________ come to therapy with you before?

16. What do you think __________ does while you are at therapy?

17. What do you think would happen if __________ came to therapy with you?

18. How will/ What will __________ feel/ think if he/she comes to therapy with you?

19. How would you feel about ___________ coming to therapy with you?

20. What would you show ___________ when he/she came to therapy?

21. What activities/games would you do/play together?

Post-interview questions for the sibling with a disability:

1. What did you think/ How did you feel about ____________ coming to therapy with you?

2. What happened at therapy with ____________?

3. How do you think/ What do you think __________ felt/ thought about coming to therapy with you?

4. What was your favorite thing you did at therapy?

5. What was your favorite thing you did at therapy with _________?

6. Would you want ____________ to come to therapy with you again? Why?

7. Can you tell me one thing that you learned about ________ from therapy? Can you tell me about your brother/sister? What do you think of him/her?

8. How come ___________ came to therapy with you?

9. What is your favorite thing to do with __________?

10. Have you guys done things at home that you did in therapy together?

11. Have you played any new games/activities at home? Please describe these games/activities.

Pre-interview questions for the parents:

1. Can you please describe a typical day for your family.

2. Can you please describe a social/ play time between your children?

3. What do ___________ and ___________ like to do together?

4. When and where do the children play together?

5. How often would you say the children play together?

6. What are __________ responsibilities?

7. What are __________ responsibilities?

8. How does _________ help __________ out?

9. How does __________ help ___________ out?

10. What does __________ say about ___________?

11. What does _________ say about ___________?

12. What is __________ favorite activity?

13. What is __________ favorite activity?

14. How is the interaction between _________ and __________ initiated?

15. How would you describe the relationship between ___________ and ___________?

16. How may times has ___________ been to therapy with ___________?

17. Out of those times, how many times has __________ participated in therapy?

18. What happened during that/ those session/s?
    if the well-sibling has not been to therapy, the parents will be asked

19. How come the well-sibling has not been to therapy or has not participated in therapy before?

20. What do you think __________ thinks about his brother's/ sister's therapy?

21. What do you think would happen if _________ went to therapy with __________?

22. How would you feel about ___________ going to therapy with ___________?

Post-interview questions for the parents:

1. Has the family schedule changed at all in the last month?

2. Has the experience of going to therapy together influenced the child's play at home?
   interactions initiated?
   duration of play?
   children's talk to each other, to you about each other?

cooperation?

Show video tape here with edited highlights:

3. What happened during that/ those session/s?

4. What do you see is happening here?

5. Have your children played like this before?

6. Throughout the sessions, what are some things if any, that stuck out to you?

7. How do you think _________ felt about going to therapy with __________?

8. How do you think _________ felt about having ___________ come to therapy with him/her?

9. How did you feel/ What did you think about the children attending therapy together?

10. What is one activity the children play together frequently or most often?

11. Does the interaction between the children differ from how the children interacted before the therapy sessions?

12. Is this an activity that the children played together before the therapy session?

    If yes, ask: How does the interaction differ?
    If no, ask: Can you describe for me how your children interact during this activity?

13. Are there any new activities or games you see the children playing, please explain their interactions?

14. Has this experience given you an opportunity to reflect on the children's relationship?

15. What are your feelings or thoughts about this?

16. Have you noticed anything you hadn't seen or recognized before? If so, what?

Interview questions for the occupational therapist:

1. What are your feelings on including siblings into the therapy setting?
   positives?
   negatives?

2. What training/education have you had that you feel has prepared you for this experience?

3. What kind of education/training do you feel is needed or would be helpful?

4. What do you think/feel would be important to know to be able to do this in the future?

5. How do you feel the sessions went?

6. How did you feel about including the typically developing siblings into your therapy sessions?

7. How did including the typically developing siblings affect the treatment session?

8. Was therapy compromised? Were you able to reach goals? How difficult/easy was it to run the session with the siblings?

9. Has this experience changed your perception about sibling inclusion in the therapy session? Is so, how?

10. What would you do differently in the future?

11. What is one thing that stuck out for you during the session between ____________ and _____________?

12. What, if any differences did you see from the first session to the last session?

13. How natural was it for the sibling pairs to interact and play together?

14. Were there any missed opportunities that you felt the siblings might have had more interaction?

    What constrained you from facilitating sibling interaction?
    What challenges, if any did you come upon?

Utilizing the video tape:

15. Can you tell me what was going on here? (look at edited parts of video of each child)

16. How much facilitating did this pair need?

APPENDIX E

OCCUPATIONAL THERAPY TYPICALLY DEVELOPING SIBLING INCLUSION PROTOCOL

Where: The Northern California Children's Therapy Center
Times per week: once a week/sibling pair
Length of session: 45 to 60 minutes

Purpose: The purpose of these sessions are to facilitate appropriate sibling interactions, to showcase the abilities of the child with a disability that the typically developing sibling may not be aware of, to educate the children on why certain activities are chosen for therapy while at the same time educating the typically developing sibling about his/her sibling's disability, and to demonstrate the skills and knowledge occupational therapists possess in working with families, especially siblings.

Session to include (when appropriate--therapist discretion):

Activities that create an interaction between the children
(i.e. if an activity is coloring in a coloring book have the children look through the book together to find a certain page that they can both color, have them share the crayons or markers or if you are using playdough have them make something together like a cake or a pizza with both children together deciding how to make it, instead of each one having their own piece of playdough making their own cake or pizza.

Games that require two or more players (i.e. board games, catch, obstacle course relay)

Activities that require fantasy or imaginative play (i.e. playing house, school, dress-up, gas station, building forts, etc.) Try to create an opportunity for the children to take turns being leader, the teacher, the mommy.

Activities where the sibling with the disability can showoff what he can do (i.e. skills that you have been working on that the child can demonstrate for his sibling, activities that are unique to the child with the disability that he can explain and demonstrate for his sibling)

In the example of the coloring book, this activity itself may not create an interaction since the children can just color their own part so this is where it may be necessary to provide more structure and facilitation on the therapists part in order to promote the interaction (i.e. Johnny can you tell your brother what you are coloring and what color you are using or if it is a certain picture the therapist might be able to ask can you tell your brother what dragons do)

Depending on the activity, the children may need more direction from the therapist. If the children are able on their own to maintain an interaction, the

therapist may back away to her discretion in order to allow the children to develop their interaction skills.

There may be times when the therapist may need to be actively involved in the interaction. The therapist may need to continuously encourage it, support it, or redirect it.

The object of whatever activity is going on is for the children to recognize each other's presence and to connect with each other. Also, to provide an opportunity for the child with the disability to play out different roles (i.e. being the teacher and the typically developing sibling being the student or being the mommy and the typically developing sibling being the baby). This may require more assistance on the part of the therapist since both children may not be used to the "new role". The therapist may need to provide more structure and facilitation.

Completed by Celise Carroll for her research study looking at the effect of typically developing sibling inclusion in the occupational therapy treatment setting (February 2000).