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Involvement of Family Communication Partners in Using an iPad to Enhance the Communication Skills and Appropriate Behavior of Youth with Severe/Multiple Disabilities in Saudi Arabia

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INVOLVEMENT OF FAMILY COMMUNICATION PARTNERS IN USING AN IPAD TO ENHANCE THE COMMUNICATION SKILLS AND APPROPRIATE BEHAVIOR OF YOUTH WITH SEVERE/MULTIPLE DISABILITIES IN SAUDI ARABIA

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

Effat Shugdar

College of Education and Behavioral Sciences
School of Special Education

August 2017

This Dissertation by: Effat Shugdar

Entitled: *Involvement of Family Communication Partners in Using an iPad to Enhance the Communication Skills and Appropriate Behavior of Youth with Severe/Multiple Disabilities in Saudi Arabia*

has been approved as meeting the requirement for the Degree of Doctor of Philosophy in College of Education and Behavioral Sciences in the School of Special Education

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ABSTRACT

Shugdar, Effat. *Involvement of Family Communication Partners in Using an iPad to Enhance the Communication Skills and Appropriate Behavior of Youth with Severe/Multiple Disabilities in Saudi Arabia*. Published Doctor of Philosophy dissertation, University of Northern Colorado, 2017.

The purpose of this study was to determine how a family communication partner (usually the mother IS primarily responsible for communication with a youth with a communication disability) could be trained to use an iPad and communication software for increasing appropriate communication and decreasing inappropriate behavior of youth with severe/multiple disabilities. The research design was a qualitative case study consisting of pre- and post-interviews along with the intervention. Three mothers were given special training in using the MyTalkTools® app on the iPad as an AAC tool and using these tools in working with their youths. Data were also collected on youth behavior changes during the training. The data analysis included within-case analysis through the life story and a cross-case analysis to find similarities and differences between three cases. The results showed significant improvements in the communication behavior and reduction of inappropriate behaviors for the three youths with their family partners as effective trainers in different settings at home. Future research is recommended to expand and apply this study with larger sample sizes and more areas in Middle East countries.

Key words: youth with severe/multiple disabilities, AAC, iPad, communication, behavior, family communication partner, FCT.

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Completion of a Ph. D. program and its ensuing dissertation component is at the very least an arduous and time-consuming process. These activities also must share everyday life with family members and the demands of parenting in my case. I am thankful Allah helped me achieve my dream. A special thanks to my parents who have been ever constant in their support, love, and help.

First of all, I would like to acknowledge and recognize Allah as an inspiration and guide, giving me strength and holding forth before me the benefits and rewards upon completion of this process and reminding me of the importance and commitment to education. Also, I appreciate my family's support and encouragement, which enabled me to continue on my chosen path, and emphasized the need for better educational services for students with severe and multiple disabilities in Saudi Arabia.

A continuing source of encouragement and motivation has been my daughter, Wafaa. It was the thought of so many children in Saudi Arabia who desperately need improved educational services that prompted me to continue. She has also been a source of joy and love in spite of the challenges of raising a child in a different country.

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CHAPTER I

INTRODUCTION

Students with severe/multiple disabilities (S/MD) have a wide range of ability levels depending on the severity and type of disabilities. These students frequently experience challenges in five specific areas of development: communication skills, cognitive functioning, sensory functioning, motor skills, and adaptive skills (Project IDEAL, 2008; Turnbull, Turnbull, & Wehmeyer, 2007). Students have difficulty generalizing knowledge and skills across environments, forgetting skills used infrequently, and needing significant support to participate in activities in educational, community, and vocational settings (Giangreco, 2006; Turnbull et al., 2007). Those students with some speech often use very basic language and elementary communication functions such as requesting, rejecting, and engaging in age-inappropriate social interactions (Beukelman & Mirenda, 2013; Seigel & Cress, 2002; Snell, Chen, & Hoover, 2006; Stephenson & Dowrick, 2000).

Chen (2008) stated students with S/MD have deficits in communication, which reduces their ability to interact with people. Students with S/MD encounter difficulty understanding other people’s communication and likewise in having others understand and correctly interpret their S/MD idiosyncratic communication forms. For example, students with S/MD might exhibit behaviors or responses for expressions such as breathing fast to indicate no and breathing regularly to say yes, which might not be clearly and easily understood by others (Downing, 2005).

Individuals with S/MD have the ability to live, work, engage in recreation, and access other community activities and services just as do individuals without S/MD (Brown et al., 1979). Brown et al. (1979) suggested students with S/MD need to learn essential skills to function within different environments inside and outside the school setting and need to be able to communicate with their non-disabled peers who form the population from which future teachers, counselors, colleagues, neighbors, employers, and community members are drawn. Therefore, many students with S/MD have educational programs that focus on helping them improve their communication skills such as using augmentative and alternative communication tools (Downing, 2002; Ganz & Simpson, 2004; Turnbull et al., 2007).

However, some students with S/MD who have communication disabilities use behavior to communicate. Some students use vocalizations and body language to indicate their needs while others engage in socially inappropriate behaviors including aggression toward their communication partners and disruption (Chen, 2008; Lancioni et al., 2007; Volkert, Lerman, Call, & Trosclair-Lasserre, 2009). Concomitant with learning and improving communication skills is the need to reduce challenging behaviors such as aggression, tantrums, self-injury, and loud vocal utterances, which interfere with and impede the acquisition of more advanced and socially desirable communication skills that are also easier to understand (Holden & Gitlesen, 2006; Lancioni et al., 2007; Neitzel, 2010; Prizant & Wetherby, 2005; Sigafoos, 2000). Students who do not receive communicative instruction as part of their education are at significant risk of establishing and maintaining challenging behavior (Frea, Arnold, & Vittimberga, 2001; Radstaake et al., 2013).

Definition and Description of Individuals with Severe/Multiple Disabilities

The category of severe/multiple disabilities (SMD) refers to those students with severe and/or co-existing impairments who often require significant support across multiple skill areas such as communication, mobility, and life skills (Project IDEAL, 2008). The Individuals with Disabilities Education Act (IDEA; 2004) defined students with multiple disabilities (MD) as follows:

> Multiple disabilities means concomitant impairments (such as mental retardation-blindness or mental retardation-orthopedic impairment), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. Multiple disabilities do not include deaf-blindness. (Section 300.8, #7)

Another definition and description of this population came from a national advocacy, support, and research organization named TASH (not an acronym, but a created name), which stipulated persons with severe disabilities are “those individuals who require extensive ongoing support on more than one major life activity in order to participate in integrated community settings and to enjoy a quality of life that is available to citizens with fewer or no disabilities” (Meyer, Peck, & Brown, 1991, p. 19).

In the professional literature, this population was often referred to as having a variety of labels including students with severe disabilities, students with profound disabilities, students with multiple disabilities that resulted in severe impairment in one or more areas of functioning, or students with significant or profound communication deficits (this could include students with autism, Down syndrome, genetic disorders, or difficulties associated with birth such as oxygen deprivation). Sometimes the term *developmental disabilities* is used and a less frequently used term is *significant support needs* (see Colorado Department of Education, 2009; Downing, 2005; Snell & Brown, 2010).

For the purpose of this study, I used the term *severe and/or multiple disabilities* (S/MD) to discuss the population upon which I focused. This term of S/MD refers to students with severe cognitive and intellectual disabilities who might also have other sensory and complex communication needs and includes both those with severe disabilities and those with multiple disabilities with concomitant severe deficits in functioning (Chen, 2008). The following criteria were also used in the selection of studies to support this research study:

1. Studies conducted in the last 12 years.
2. Studies that included students with S/MD who had a complex communication disorder and challenging behavior.
3. Studies that focused on both the reduction of challenging behavior and an increase in communication skills.
4. Studies that incorporated augmentative and alternative communication techniques to enhance communication.

Description of the Problem

Students with S/MD often demonstrate an absence of or an impairment in communication functions such as speaking, gestures, eye contact, facial expressions, and/or written communication that interferes with their ability to communicate effectively (Beukelman & Mirenda, 2013; Chen, 2008; Downing, 2005; Seigel & Cress, 2002; Snell et al., 2006). Language limitations of students with S/MD are reflected in their reduced abilities and skills in understanding and responding to communications of others or in requesting their own needs and wants (Chen, 2008; Snell et al., 2006).

Students with S/MD at times exhibit unconventional or socially inappropriate communication behaviors such as acting aggressively toward themselves and others or are disruptive by making noises since they lack the ability to speak intelligibly (Beukelman & Mirenda, 2013; Seigel & Cress, 2002). These behaviors pose difficulty in communicating for students with S/MD and reflect a problem in communication for these students in two important ways. First, these inappropriate behaviors, which could include aggression, self-injury, and destruction, have replaced typical ways children learn to communicate but these behaviors do accomplish something for the individual. This means people who work with the student need to understand how these inappropriate behaviors function for him or her. Second, these inappropriate behaviors are learned so it takes more effort to override a learned inappropriate behavior than to learn a new, more appropriate behavior. Without appropriate communication skills, individuals with S/MD are at a great disadvantage in interacting with the world and the people in the world around them. This is particularly true in developing countries where (a) education of students with S/MD is limited, (b) no technology or special services are available, and (c) professionals have little background or experience in working with these students. My home country of Saudi Arabia is one of those countries.

Saudi Arabia has strived for improvement in special education services for students with disabilities. However, some students with severe/multiple disabilities do not receive services, especially after they finish elementary school. My professional experience included teaching elementary school-aged students with severe/multiple disabilities for five years at a private school for students with disabilities. I found the majority of families were unable find a place that would accept or provide services to these students after they graduated from elementary school. Most of these students made only unintelligible utterances, perhaps a few basic words like yes and no, utilized baby-talk or babble, and frequently engaged in inappropriate behavior in lieu of appropriate communication.

In addition, in Saudi Arabia, parents are not generally involved in their child's education and often have little insight or understanding about what their children are learning in school. Families with a child with S/MD often employ a domestic maid who is directly involved in childcare and the tasks of daily living. This maid usually comes from another country and also is not involved in the education of the child but instead provides daily care for the child in the home.

Families in Saudi Arabia are also very close and extended families often live together in one family home. In contrast to the United States, getting together with friends and neighbors is much less common in Saudi Arabia; whereas family gatherings are much more frequent. The extended family is most often involved in any kind of communication with the child with S/MD, particularly after the completion of elementary school when public education for these children ceases. Therefore, in examining settings and other significant persons for interaction with students with S/MD, in Saudi Arabia, it is more appropriate to look at home settings with family members rather than friends and settings outside the home.

Purpose of the Study

The purpose of this study was to determine how a family communication partner (a designated family member primarily responsible for communication with the student with a communication disability) could be utilized as a resource for increasing appropriate communication and decreasing inappropriate behavior of children with S/MD while employing an iPad and communication software as an assistive augmentative communication (AAC) form. A two-phase qualitative research design was used to explore the experiences of the participants before and after implementing a communication intervention. After the first set of interviews, participants took part in functional communication training. They learned to use an assistive technology communication app on a tablet and then introduced the device to their youth with S/MD at home. After the intervention had been implemented, a second set of interviews captured the changes in their experiences around communicating with their youth with S/MD. In addition to capturing the experiences of the participants, observation data provided insight into whether the introduction of the communication device resulted in changes in the communication behaviors of the youth with S/MD.

Rationale

Communication is a natural skill all children need to develop and learn for their daily activities (Turnbull et al., 2007). Communicating with others requires understanding how people send and receive messages in creating meaning within and across different situations, cultures, media, and channels, which is a critical foundation in contemporary society (Korn, Morreale, & Boileau, 2000). Communication plays a role in shaping the social and interactive aspects of life, which helps in eliminating the cultural boundaries and continuing positive improvement in society. Communication skills permit individuals to interact with different groups of people in diverse situations including their peers, parents, and professionals (Reed, McLeod, & McAllister, 1999). Communication skills help individuals be responsible and participate in community activities (Morreale & Pearson, 2008). Good communication ability not only adds to an individual's understanding of people, it also adds to the understanding of the complexity of different cultural aspects and permits participation in multiple environments with a variety of people (Berry & Modiano, 2005; Scudder, 2004).

In Saudi Arabia today, students with S/MD often leave elementary school at age 12 and spend their days at home with their family. Once they leave school, these students no longer receive related services such as physiotherapy, occupational therapy, speech language therapy, or other services and their families often have limited knowledge about how to help them become as independent as possible. Few resources are available for youth with communication challenges.

A large body of research has documented the positive impact of using augmentative alternative communication systems with individuals with multiple disabilities and communication challenges. However, access to this kind of technology remains limited in many places in the world. The findings of this study documented the impact an easily accessible and simple-to-learn assistive technology could have on the communication within families of youth with S/MD. Additionally, the findings of this study might be used to improve the services for individuals with S/MD so they might receive access to individualized communication systems. I believe when individuals with S/MD are better able to communicate their thoughts and needs directly using a communication device, this allows them to communicate with a wider range of communication partners and improve the quality of their life. Therefore, the greatest consequence of my study might be found in the changing attitudes of family members of youth with S/MD as they experience clear, direct communication from their youth for the first time.

Definitions of Terms

In the following section, I have provided a definition of key words and terminology to provide clarity and eliminate ambiguity.

Augmentative and alternative communication. A system of communication services for individuals who have impaired or non-existent speech for the majority of their communication interaction and need to compensate for this loss by using other ways to communicate (Downing, 2005).

Challenging behaviors. Unconventional or socially inappropriate communication responses such as acting aggressively toward themselves and/or others or are disruptive by making sounds or body movements (Beukelman & Mirenda, 2013).

Communication matrix. An assessment tool developed by Rowland (2011) to pinpoint exactly how an individual with S/MD communicates and offers guidelines for ascertaining logical communication goals (Rowland & Fried-Oken, 2010).

Family communication partner. The designated or primary family member who serves as the major communication link between the student with S/MD, other family members, and significant others. Often this is a sibling when both parents work or have low educational levels, or aunts, grandmothers, or other close relations.

Functional communication training. Focuses on teaching those communication responses that fulfill the same purpose as a child's challenging behavior (Carr & Durand, 1985).

Mand. A beginning form of verbal behavior where humans acquire the ability to request their wants as a first attempt to meet their needs (Skinner, 1957).

Picture exchange communication system. Focuses on teaching a child to exchange an image or symbol for the preferred item (Ali, 2009).

Severe and multiple disabilities. An umbrella term that includes very significant deficits found in many disorders including autism, moderate to severe intellectual impairment, Down syndrome, and/or two or more disabilities present in individuals that severely impair language development. Thus, S/MD does not refer to a particular class of disabilities but rather to the severity of the disabilities regardless of diagnosis or label (severe or multiple disabilities), which have led to significant deficits or delays in development and skill acquisition.

CHAPTER II

LITERATURE REVIEW

Research in the past few decades has established several successful interventions, techniques, procedures, and materials to use when helping children and youth with S/MD learn appropriate communication skills (Pinto, Simpson, & Bakken, 2009). One of the most beneficial interventions in improving communication skills is the use of augmentative and alternative communication (AAC; Beukelman & Mirenda, 2013; Downing, 2005). Augmentative and alternative communication is a systematic process to enhance and expand various communication forms except oral speech. This system includes two systems of communication: unaided and aided. An unaided communication system depends on body expression such as gestures, body language, or sign language. An aided communication system requires external tools or equipment besides body expression and comprises two categories: low tech and high tech. Low tech involves exposure to objects of reference, photographs or pictures, graphic symbols and/or text, which does not require external sources for power such as batteries. On the other hand, high tech systems involve tools or devices that require external sources for power to operate the device such as a switch control, platform equipment, electronic aid to speech, or pointer for a board. High tech tools and devices are of recent origin, correspond to rapid advances in computer technology, and along with their applications are evolving constantly (Beukelman & Mirenda, 2013; Downing, 2005).

Many studies have applied particular interventions using AAC techniques to develop communication skills and reduce challenging behaviors for students with S/MD, starting with low tech interventions. A recent meta-analysis by Walker and Snell (2013) measured the effectiveness of four low tech approaches to teach augmentative and alternative communication: (a) functional communication training (FCT), (b) picture exchange communication system (PECS), (c) milieu training, and (d) choice making for students with SMD who exhibited challenging behavior. The results of their meta-analysis indicated the two most effective and frequently used AAC interventions with students with S/MD were FCT and PECS. Functional communication training was most frequently provided to participants (84%) and had the highest significant effect with AAC. The PECS was less frequently used (8%) and did not have as high a treatment effect.

Consequently, the literature reviewed research into the two most frequently used AAC interventions to improve communication skills and reduce challenging behavior in the last 12 years--particularly the more frequently used FCT and PECS.

Functional Communication Training and Challenging Behavior

Recent representative studies were reviewed examining current practice and knowledge of FCT on challenging behavior and are presented in this section. Each study is summarized, analyzed, and critically discussed regarding the use of FCT on increasing communication and reducing challenging behavior.

Functional communication training is a set of procedures that utilize the principle of differential reinforcement (DR) where an alternative, more appropriate response is selected and then reinforced to replace the specific problem behavior used for obtaining a desired reinforcer (Tiger, Hanley, & Bruzek, 2008). The alternative response needs to be in the same class or type as the problem behavior and this alternative response is then differentially reinforced (rather than the problem behavior). Functional communication training was originally described by Carr and Durand in 1985; since that time, it has become the most widely employed method of intervention to reduce problem behavior. The first step in FCT-- a functional analysis--is conducted before the treatment is initiated to determine what environmental events currently functioned to reinforce problem behaviors and what conditions elicited problem behavior, which Michael (1982) described as those pertinent procedures that established and increased the power of the specific reinforcer. The second step is where an alternative response to replace the problem behavior is selected to be a socially-acceptable communicative response, which is shaped and trained by using the reinforcer(s) that maintained the problem behavior (as identified in the functional analysis) to build and strengthen the alternative response. The third step in FCT is to extend the use of the newly taught alternative response to other settings and teachers/caregivers (Tiger et al., 2008).

Implementing FCT involves the inclusion of various phases related to the intervention technique, four of which are necessary--beginning with a functional analysis, selection of and teaching a new, more appropriate response to be taught (such as a mand or tact); differential reinforcement of new and problem behavior; and determination of a schedule of reinforcement to increase the communication responses and replace the challenging behavior (Donovan, 2003). An optional fifth phase, generalization, is often added at the conclusion of the intervention to ascertain the degree to which the new communication response appeared in different settings and with different people.

Functional Analysis

This first step is necessary because FCT and challenging behavior are inextricably linked together. Challenging behavior serves as a way of communicating, albeit inappropriately, to obtain access to reinforcers, whether they be social, physical, or emotional. Before FCT can be carried out, it is necessary to study the circumstances surrounding the challenging behavior. One of the difficult factors related to reducing challenging behavior is in many instances, these challenging behaviors are used by the individual as a form of communication (Casey & Merical, 2006). This is particularly true for individuals with S/MD for whom challenging behavior is their only form of communication. What these individuals have learned is engaging in challenging behaviors results in major and immediate changes in their environments such as attention, receiving food, or obtaining preferred toys or activities. Therefore, to understand challenging behavior, it is important to understand the purpose or the function of the problematic behavior. A functional assessment provides important information about the function of problematic behaviors for each individual in order to address planning of interventions to replace these behaviors with more appropriate ones.

In addition to understanding the function of challenging behavior, it is also important to analyze both the type of reinforcer and the type of response (Bailey, McComas, Benavides & Lovascz, 2002). The alternative response needs to produce the same reinforcer as the challenging behavior and the response needs to take the same amount of effort or less than the challenging behavior. A limited amount of research supported the success of these factors; settings in which this success was demonstrated were limited to more controlled settings. Bailey et al. (2002) investigated the effectiveness of using a functional analysis including response effort in reducing severe aggressive behaviors in a 24-year-old man with significant developmental disabilities in a residential setting. Two communicative replacement responses were selected to replace aggression in obtaining attention: pointing to a drawing of two people talking or spelling the word "talk" on his communication board. Two types of attention were investigated: social interaction with staff, physical contact from staff such as hugs or pats on the back, or both. Results of the functional analysis performed prior to the initiation of interventions revealed the aggressive behavior was lower when both kinds of attention were provided. At this point, the intervention was begun, consisting of five-minute sessions given between two and four sessions per day for six weeks. Results indicated a much higher reduction in aggressive behavior when pointing was the alternative behavior than when spelling was used. In addition, an independent pointing response was achieved but at no point was there an independent spelling response. This study demonstrated the effectiveness of using a reinforcer and response analysis in designing a FCT to teach alternative, more appropriate responses that replaced challenging behavior.

Selection of Mands/Preferences

Following the functional analysis around challenging behavior is the selection of a specific mand or requesting behavior to be taught as a more appropriate communication response to replace the challenging behavior. A successful intervention documented by empirical research focused on the teaching of individualized language that met functional needs of children with severe communication deficits such as requesting specific items or expressing needs and desires (Davis et al., 2009). These researchers conducted a single subject-study that took place in a therapy room at a private school to implement FCT with a 4-year-old student diagnosed with pervasive developmental disorder-not otherwise specified (PDD-NOS) and who demonstrated challenging behavior when favored toys were withdrawn. Thus, there were two foci of the study: (a) to increase appropriate communication skills and (b) to decrease inappropriate behavior. Baseline and FCT sessions were five minutes in length and were conducted one to two times per day. During baseline, the student exhibited a high rate of challenging behavior with no independent communication (defined as unprompted communicative behavior) when he did not have access to his favorite toys. After the baseline phase, there was an alternating treatments design--one that involved 15 minutes of access to toys and the other, which did not provide this access.

When the child was given pre-session access for 15 minutes to the toys, the student reduced his challenging behavior and increased independent (unprompted) communication during the FCT session (Davis et al., 2009). For example, the student used verbal protests such as “no” (challenging behavior) or more appropriate communication such as saying “more toy.” In this study, the independent variable was the use of a constant time delay procedure in which the favored toy was presented for 10 seconds, the toy was then removed, and the therapist modeled the desired response “more toy” two seconds later. When the student responded with a prompted or unprompted utterance of “more toy,” he was rewarded with an additional 10 seconds access to the toy. Results of the study indicated that when the child was given access to a preferred toy for 15 minutes prior to the FCT training session, there was a marked decrease in challenging behavior during the session as well as an increased appropriate communication behavior during that session.

In an evaluation of procedures for selecting mands, Winborn, Wacker, Richman, Asmus and Geier (2002) compared the use of existing mands to novel mands during FCT to decrease problem behavior. Winborn et al. worked with two children with developmental delays and seizures; one of them was two years and six months old (Ike), and the other child (Julie) was two years and five months old. The researchers employed a multiple-baseline design to carry out the FCT for existing mands and novel mands in the therapist room at an inpatient hospital unit. The functional analysis was Phase 1; Phase 2 consisted of existing training and a new mand in distinct stimulus conditions using a counter-balanced order. Phase 3 (choice analysis) was identical to mand training with one exception–-the child was able to choose whether to use an existing mand or a newly taught mand to obtain reinforcers.

During the functional analysis, problem behavior was sustained through negative reinforcement. In the mand training of Phase 2, Ike’s problem behavior was variable throughout existing mand training. Within seven sessions of training independent manding with Ike, the problem behavior decreased and novel manding increased. Similarly for Julie, the existing mand improved during the first three sessions and the problem behavior was reduced soon after beginning the introduction of FCT, indicating both existing and novel mands were effective in replacing problem behavior. Throughout Phase 2 when existing mands were used, there were higher rates than when new mands were taught, which resulted in lower rates of problem behavior. The authors noted had the study concluded at this point, the conclusion drawn would support using new mands for FCT. However, at this point, Phase 3, the choice phase, was initiated. Both children chose to use existing mands more frequently than novel mands with much reduction in problem behavior. The authors proposed explanations for choosing existing mands might be past experience with these mands in obtaining reinforcement or perhaps increased effort might have been needed for novel mands. They concluded that in designing FCT training of mands, careful consideration of past experience with existing mands be evaluated.

Winborn et al. (2002) discussed two limitations of their study: one was the absence of a reversal or extinction phase during Phase 2. The other limitation was time limit for number of sessions without conclusive results. In addition, the written description of this study was missing detailed descriptions of the procedures, the procedures for participant selection, and an explanation of the time and length of sessions. In addition, no attempts at any generalization were undertaken. Nonetheless, this study brought up the issue of past experience with existing mands.

One problem in FCT is the form of the appropriate communicative response for requesting (mand; Harding et al., 2009). Frequently, a verbal response is the desired form of manding behavior but when children display language delays and limited vocalizations, alternative forms of manding are included such as the use of augmentative communication responses like word/picture cards and devices. Harding et al. (2009) noted little information is known related to the effects on treatment effectiveness due to preference of mands so they designed a research project to provide more information on this phenomenon. The stated purpose was to examine the emergence of preference for one of three different topographies of manding: vocalizing, manual signing, or touching a communication device during FCT when reinforcement of each was the same.

Three boys, ranging in age from 1 year 10 months to 3-years-old participated in the research of Harding et al. (2009). For all three boys, problem behavior included aggression and property destruction with one boy also exhibiting self-injurious behavior. The youngest boy had not yet been officially given a diagnosis, a second one was diagnosed with developmental delays and disruptive behavior disorder, and the oldest was diagnosed with expressive and receptive language delays. In all three boys, vocalizations were only single words or occasional two-word phrases. The study had two components--a functional analysis that identified the controlling conditions of problem behavior and a treatment component where FCT probes occurred during weekly or monthly home visits during which preference for a specific topography of manding was ascertained, which also monitored problem behavior. The researchers used a non-concurrent, multiple-baseline design across the three participants; at the conclusion of the research, parents' satisfaction with treatment was ascertained by a questionnaire. A six-second partial-interval recording system collected data relating to each child's behavior; independent, trained data collectors assessed the occurrence of the child's behavior. Inter-observer agreement calculated for 30% of all sessions produced an average of 96-97% for problem behaviors and independent manding, and an inter-observer agreement of 95% for the three different topographies of manding. Treatment sessions lasted five minutes during which each child was allowed to select his preferred toys for reinforcement. All three forms of manding were presented and taught: first directly, then with probes, and then independent appearance of manding to request a desired toy. Any problem behavior was ignored with the exception of destructive behavior, which was blocked neutrally and toys were removed until the cessation of problem behavior.

Results of this study by Harding et al. (2009) showed all three boys exhibited a higher rate of problem behavior during the three baseline sessions in their homes, varying from 20% to 70% of the five-minute sessions but fell to zero for all three boys. The oldest boy reached this zero rate and maintained it through all remaining treatment sessions; the youngest boy reached this zero rate after 16 sessions, and the third boy reached zero rate after five sessions. All three boys exhibited a preference for vocalization by the end of the treatment with less preference indicated for the use of a device. All three boys exhibited a near zero preference for signing throughout the treatment sessions. Parent rating indicated a score of seven out of seven where one represented not at all acceptable and seven represented very acceptable.

Harding et al. (2009) concluded one significant outcome was the availability of signing and using a device as alternatives to vocalizations did not impede the development of vocalizations as many parents feared when these options were presented. Also, the provision of alternative forms of manding might have assisted the initial development of manding behavior and provided visual cues as well as vocal cues. As a result of this study, no evidence of any correlation was found between problem behavior and any forms of manding; manding gradually replaced problem behavior.

One aspect missing from this study by Harding et al. (2009) was a follow-up probe to assess the maintenance of manding over time. Also, very limited information was presented about the training of the parents for implementing FCT nor was there any follow-up or evaluation of the effectiveness of parental training. There was mention of a videotape of parents conducting some sessions but no further description about using this videotape as a teaching tool. But in general, the description of this research was well written, understandable, and conclusions were supported by the results.

In a study by Kahng, Hendrickson, and Vu (2000), comparisons were made between single and multiple functional communication training responses to replace problem behavior. Single FCT responses consisting of requesting a category rather than a specific item ("I want treats" versus multiple FCT responses, "I want Nintendo," and "I want chips"). The participant of this study was a 7-year-old boy who had been diagnosed with severe mental retardation and autism. An alternative mand used line drawings as part of a PCS procedure. The boy was taught how to form a complete sentence by pairing the FCT response of "I want" with the PCS response of choosing a picture of a specific item and naming that item. Training sessions took place in a living unit equipped with a table, two chairs, and other necessary materials (e.g., work materials and toys); a single subject reversal design was used where baseline alternated with treatment three times. At the end of the third treatment period, problem behavior dropped to near zero from the initial baseline of approximately eight per minute and manding increased from zero to one or two times per minute. Also, the use of multiple FCT responses was more effective than a single FCT response. The authors noted the use of a reversal design countered potential sequential effects.

Although this study was limited and no attempt at generalization was made, the reversal design was well thought out and the procedures in general were completely described--with one exception. Nowhere did Kahng et al. (2000) mention the length of each session nor was there any indication on whether sessions occurred one or more times a day, or on alternative days.

Functional Communication Training With and Without Extinction of Challenging Behavior

Next, decisions regarding differential reinforcement need to be made as alternative ways to address FCT and challenging behavior simultaneously. There are differences of opinion and research studies that investigate the use of extinction, other techniques for responding to challenging behavior, or focusing only upon FCT.

Casey and Merical (2006) observed most of the research on FCT actually has two components--in addition to the FCT, a component like extinction or punishment is paired with FCT. To ascertain FCT effects without an additional component, these authors studied only FCT with an 11-year-old boy diagnosed with autism; although functioning at a near-normal intelligence level, he exhibited severe challenging behaviors. In spite of these maladaptive behaviors, mainly self-injury and aggression, this boy was mainstreamed for most of the day and all assessments and interventions took place in the boy’s regular classroom. After a brief functional analysis was conducted during which the boy indicated a preference for a gestural response over a verbal response, a multiple-baseline design was selected to take place in one classroom initially (seventh period, lasting about 50 minutes) and then would extend into the boy’s other classroom periods when the effectiveness of an FCT intervention was positively demonstrated. During this intervention, the boy was instructed to point to a sticky note that said “I would like a break, please” with the break meaning a break from instructional demands. No escape or avoidance from instructional demands was made if either self-injury or aggression occurred. After three days, the boy did not need instruction as he independently pointed to the note to request a break. Self-injury behaviors dropped from a high of 20 per period and an average of seven per period to zero per period. These results demonstrated FTC could be effective even without the use of extinction or punishment in inclusive settings.

In an effort to examine the effectiveness of FCT without extinction and relying solely on continuous and intermittent reinforcement to reduce problem behavior, Worsdell, Iwata, Hanley, Thompson and Kahng (2000) designed a study to test whether extinction actually was a necessary component of FCT. The researchers noted the use of extinction introduced negative side effects that sometimes became so disruptive the FCT training was stopped and replaced by procedures instituted for reducing the severe disruptive behavior. Further, the authors pointed out design flaws in previous research that did not use extinction but produced little effectiveness in FCT. Additionally, most real-life settings were unable to implement consistent treatment schedules (intermittent or continuous) due to errors, interruptions, or other events occurring in the natural environment. Therefore, Worsdell et al. sought to examine the effects of intermittent, inconsistent implementation of FCT in two procedures: maintaining a constant schedule for functional behavior on a FR1 (fixed ratio of reinforcement for every one response) and simultaneously varying the schedule used for reinforcing problem behavior.

Worsdell et al. (2000) concluded the unsuccessful results from the procedure of eliminating extinction was not solely due to the use of extinction but was also a function of the schedule of reinforcement employed. Their results supported the premise that in an FCT, extinction could be replaced by an alternative procedure (variable schedule of reinforcement) more likely to occur in natural environments.

In an analysis of competing reinforcement schedules and their effect on the acquisition of functional communication, Kelley, Lerman, and Van Camp (2002) examined FCT during three procedures for addressing problem behaviors: extinction, response blocking, or both. Three students from 9- to 10 years-old, who all demonstrated severe mental retardation and significant behavior problems, were taught functional communication using a reversal and multiple baseline across subjects design while experimental responses to problem behavior were either extinction, response blocking, or a combination of these two procedures. Results in general indicated teaching functional communication was less effective when problem behaviors were intermittently reinforced and was more effective when extinction of problem behavior was used. However, significant differences were found in each of the three participants; these variations were explained by the possible presence of other factors such as attention and topography of the communication response. Overall, this study's results were not especially reliable because of idiosyncratic responses of each participant and the probability of other factors likely influencing the efficacy of communication training such as prompting procedures, magnitude and delay in reinforcement schedules, and communication response topography. However, the one consistent finding of the effectiveness of extinction did support findings from other studies.

Schedules of Reinforcement

Another decision in implementing an FCT intervention was the selection of a particular schedule of reinforcement, which involved decisions around how frequently to reinforce the chosen mand being taught, what kind of schedule of reinforcement to use, and how gradually to extend the time period between the presentation of reinforcers (called schedule thinning).

An interesting study by Falcomata, White, Muething, and Fragale (2012) employing FCT combined with a chained schedule of reinforcement to reduce challenging behavior that had multiple functions provided more insight into this problem. Using a single-subject design with alternating baseline and treatment conditions with an eight-year old student diagnosed with autism accompanied by challenging behaviors, the authors first determined through a functional analysis the different functions the challenging behavior served. During training sessions conducted in a small, self-contained room, a bracelet was worn by either the therapist or the student to signal which schedule of reinforcement was in place (fixed interval or fixed ratio). When FCT began, which focused on increasing requesting responses (mand), a chained schedule of reinforcement was used under two different conditions. When the student wore the bracelet, a fixed ratio of one response (occurrence of a mand or request) was used to reinforce the student by allowing access to a preferred activity. When the therapist wore the bracelet, this signaled a fixed interval of 30 seconds as the schedule of reinforcement to gain access to a preferred activity.

Results showed a significant increase in mand (requesting) behavior, a significant decrease in challenging behavior during the treatment sessions, and a slightly higher rate of mand behavior under the fixed ratio schedule than under the fixed interval schedule (Falcomata et al., 2012). However, there were no significant differences in the low rate of challenging behavior under the two schedules. The results indicated pairing FCT with chained schedules of reinforcement was effective in increasing communication and decreasing challenging behavior. Suggestions the authors made for future studies included the extension of this procedure to teach more advanced mands and to extend generalization to other settings.

One confusing aspect of Falcomata et al.'s (2012) study was the overuse of acronyms. Also, the authors did not explicitly describe the design--it had to be inferred by the reader. The article was not clearly written, particularly in describing the interventions and the use of the bracelet, which resulted in confusion and rereading. Finally, the FCT in the literature review was not discussed, merely named, resulting in confusion as to whether this term referred to a general intervention or a single treatment procedure.

One problem that appeared throughout the literature on FCT along with treatments to reduce problem behavior was related to the rate at which the reinforcer was provided for alternative competing behavior instead of problem behavior (Hagopian, Kuhn, Long, & Rush, 2005). When that reinforcer was provided frequently (every few seconds), alternative behavior tended to increase and problem behavior decreased. However, when attempts were made to lengthen the time between preferred behavior and reinforcement, there was an increase in problem behavior and a decrease in preferred behavior. This problem of schedule thinning was examined by Hagopian et al. (2005) along with a comparison of two treatment conditions: FCT with extinction and FCT with extinction and access to a competing stimulus. The purpose of their research was to determine which treatment condition produced the best results in decreasing problem behavior while extending the delay from preferred behavior until delivery of reinforcer. Initially, this delay was only a few seconds and the goal was to reach a delay more sustainable and practical such as 20 minutes.

Hagopian et al. (2005) observed previous research on FCT used a functional analysis strategy to ascertain what reinforcers were maintaining problem behavior for each student and that specific procedures for this determination had been in place for over 15 years (Iwata, Dorsey, Slifer, Bauman, & Richman, 1994). Treatment interventions were then based on teaching more appropriate communication responses to receive these same reinforcers. A problem arose when the initial schedule for reinforcement, which was extremely short (a few seconds), was thinned out to a more feasible time period such as a delay of 10 minutes before reinforcement was delivered. During this thinning period, problem behaviors frequently increased and attempts to reduce these problem behaviors during thinning resulted in the use of several techniques. One technique was to return back to a shorter delay in reinforcement delivery while other techniques included punishment for problem behavior and incorporated alternative activity during thinning such as access to tangible items, i.e., competing stimuli. The authors also observed no study to date had described specific procedures to determine which competing stimuli could be identified to best enhance FCT. As a result, Hagopian et al. also described a unique procedure that would make this identification for each student. Thus, their study contained three components. The first component (Phase One) was a functional analysis procedure to identify specific reinforcer maintaining problem behaviors for individual students. The second component (Phase Two) was a competing stimuli assessment procedure to identify the most powerful one that would compete successfully with the reinforcer maintaining problem behaviors. The third component (Phase Three) compared two treatment conditions to determine which was more effective in reducing problem behavior and increasing communication while thinning the schedule of reinforcement from a few seconds up to 20 minutes.

Three participants were identified--all had been admitted to an inpatient unit because of their severe behavior problems. All were male: one was 13-years-old (Stephen) and diagnosed with pervasive developmental disorder, attention deficit hyperactivity disorder, and mild mental retardation. A second male was 12-years-old (James) who was diagnosed with autism and mild mental retardation. The third male was a 7-year-old (Matt) who was diagnosed with autism, attention deficit hyperactivity disorder, and moderate mental retardation. All three boys engaged in destructive, aggressive, and self-injurious behaviors severe enough to place them in an inpatient unit.

The results of Phase One (functional analysis) indicated problem behaviors were being maintained for each boy as follows: for Stephen, social attention; for James, access to a preferred item, and for Matt, physical attention and a tangible item (Hagopian et al., 2005). The results of Phase Two (competing stimuli assessment) indicated the most effective competing stimuli for each boy: for Stephen--Game Boy, puzzles, and Dr. Seuss books; for James--whirly lights, Elmo books, remotely operated car, and bubbles; and for Matt--whirly lights, music, and Game Boy.

The experimental design (Phase Three) followed an ABAB (BC) design, where A represented baseline, B represented FCT with extinction, and BC represented FCT with extinction and competing stimuli. The results for Phase Three for each boy were as follows: Stephen’s problem behaviors were highest (8-16 per minute) during baseline but dropped quickly to an average of three per minute during the first occurrence of B where a brief delay from desired response to reinforce was present. At the second occurrence of

B, the rate of problem behaviors dropped to zero and the schedule of reinforcement was thinned to 15 seconds. At the occurrence of BC during the B treatment, problem behavior still occurred two to three times per minute and the schedule was thinned only to 20 seconds. However, during the C treatment, problem behavior dropped to zero even when the schedule of reinforcement was thinned to 240 seconds (four minutes). James's problem behaviors averaged between one and two times per minute during both baseline periods, dropped to an average of one time per minute during the B treatment, and the schedule thinned to 20 seconds. However, during the C treatment, problem behavior dropped to zero even when the schedule was thinned to 20 minutes. Matt's problem behavior averaged three times per minute during baseline periods, dropped to an average of two during the B treatment, and the schedule of reinforcement thinned to two minutes. However, during the C treatment, problem behavior dropped to zero times per minute and the schedule of reinforcement was thinned to nine minutes.

Although Hagopian et al.'s (2005) study provided detailed information both on a rigorous procedure for identifying competing stimuli and when comparing FTC with extinction versus FTC with extinction and competing stimuli, several major weaknesses appeared in this report. First, the written description of this study was very confusing. For example, although competing stimuli were thoroughly described, actual reinforcement procedures incorporating these competing stimuli were not as clearly described. Some terms used were not defined or described, e.g., automatic reinforcement, predetermined schedule, and schedule thinning. The graphs were particularly confusing inasmuch as important components were not identified; in the case of Figures 3 and 5, the graphs were so complex they were extremely difficult to understand. In addition, Figure 4 purported to show the rate of communication responses during treatment conditions. According to this graph, rates of communication responses actually dropped to zero or near zero per minute. There was no explanation of this; in fact, the authors reported that treatment goals were attained. Similarly, there was no explanation of how treatment B and treatment C were presented. Sometimes, it appeared to be sequential, but at other times, no clear plan can be determined for the occurrence of treatments A and B. Throughout the article a lot of acronyms were used, which added to the difficulty in reading the report of this research. Nevertheless, Hagopian et al's research does demonstrate a clear reduction of problem behaviors when the presentation of competing stimuli and resultant reinforcement with these stimuli is added to FCT.

The last phase was generalization--the appearance of the mand taught in a treatment setting was generalized to other settings. The long-term goal of FCT is not just to teach specific mands to replace challenging behavior but to extend the use of these mands throughout other settings in the child's life. One problem that appeared when functional communication skills were taught was the high rates of requesting that occurred sometimes when requested reinforcers were not available or not feasible (Volkert et al., 2009). In addition, difficulties arose when attempting to generalize the functional communication response to natural settings.

To address these problems, Kuhn, Chirighin, and Zelenka (2010) designed a study to teach two students--an 8-year-old girl and a 9-year-old boy with developmental disabilities who had been admitted to an inpatient unit because of severe problem behaviors--to recognize possible discriminative stimuli that occur in naturalistic settings. The discrimination taught was to indicate the person who would deliver the reinforcement was either busy and unable to deliver a reinforcer (cooking, answering the telephone, etc.) or was not busy and available to deliver a reinforcer. Both students were provided FCT in an individual therapy room on the inpatient unit, which included a one-way window from which observers could record behavioral responses of the students using event recording. Sessions were 10 minutes in duration and 6 to 10 sessions per day were conducted. Events were recorded in 10-second periods throughout all sessions. A functional analysis was conducted for each student to determine what specific reinforcers maintained each of the problem behaviors and at which point FCT sessions were introduced. The specific functional communication response was individually determined ("excuse me" for one student and "talk to me" for the second).

After the functional analysis determined which kinds of stimuli were maintaining problem behaviors, discriminated functional communication training (DFCT) was initiated in which the students were exposed to two conditions of the therapist exhibiting "busy" behavior and two conditions of the therapist exhibiting "non-busy" behavior (doing nothing, watching television, etc.). The therapist alternated between busy and non-busy activities every three minutes and provided the appropriate reinforcer (as determined by the functional analysis) when verbal requests from students were made while the therapist was not busy (Kuhn et al., 2010). When verbal requests from the students were made while the therapist was busy, students were ignored. In addition, one of the students was taught to ask "are you busy?" to verify observations of busy versus not busy behavior. The second student was unable to acquire this additional requesting behavior.

By the end of the study, both students were able to discriminate by direct observation whether the therapist was busy or not and to emit requesting behavior only when the therapist was not busy (Kuhn et al., 2010). Problem behavior dropped to near zero and was maintained throughout the sessions. When the therapist was busy, the students engaged in several alternative behaviors such as looking at the therapist, playing with an available toy, or walking around the session room. It was concluded by the researchers that the students paid attention to the behavior of the therapist as schedule-correlated stimuli (when reinforcement was possible and when not). Furthermore, generalization to non-trained busy versus not busy activities was quickly achieved by both students. The significance of this study was the possibility to teach students how to determine if persons in their environment were available to provide reinforcers or not, to engage in appropriate behaviors while the person was not available, and the application of this discrimination in typically normal environments. It was suggested one reason for continuation of problem behavior was the lack of discrimination between when reinforcement was or was not available.

Kuhn et al. (2010) described several limitations of their research: only verbal behavior was examined as a communication response, generalization to real world settings was not attempted, and the examples of busy versus not busy behaviors were clearly distinguishable. One limitation not addressed by the researchers was the very short time (three minutes) of alternating between busy and not busy behaviors. This interesting and well-designed study offers potential for further research in the role of discrimination to determine if reinforcement is available as a factor in problem behavior.

Several studies have examined aspects of generalization in FCT. O'Neill and Sweetland-Baker (2001) examined generalization of trained responses by FCT to different trainers and settings, duration of this generalization, and an investigation into the role of contingencies for both appropriate and problem behaviors. Two participants, one 6-years-old and the other 15-years-old, were identified by a local school district as having autism and severe mental retardation, had no functional vocal behavior, and needed substantial prompting to carry out basic self-care and classroom activities; they also demonstrated severe disruptive behavior (hitting, kicking, scratching) and destructive behavior (damaging materials, throwing objects around the classroom). A single-subject, alternating treatments FCT intervention was carried out through a series of 10-minute sessions conducted in each student's classroom. The functional analysis occurred under the four conditions of social play, escape from demand task, attention, and tangible reinforcement. Baseline and FCT were then initiated followed by a generalization probe across untrained tasks.

Results of O'Neill and Sweetland-Baker's (2001) research indicated significant increases in unprompted requests along with a near zero rate of disruptive behavior for both boys after FCT. Generalization probes yielded more mixed results but showed the same general pattern of increases in unprompted requests and lower levels of disruptive behavior. The authors concluded generalization might occur but was not as significant as in FCT and not to the extent desired by educators and clinicians. They also noted a few limitations such as the wide disparity in ages and settings of the two boys and the lack of identifying the mechanisms that led to generalization. The authors further suggested that future research into generalization examine the effects of FCT in various dimensions.

The report of this single-subject study was generally complete with the exception of details regarding “various locations” in students’ classrooms. Procedures were clearly described and the results were presented in a concise and understandable manner.

Schindler and Horner (2005) selected three students from a preschool early intervention program for children with autism based on teacher identification of students with high levels of problem behavior, formal diagnosis of autism from a certified psychologist, a one-to-two-word vocabulary, and observed levels of problem behavior in multiple school settings and at home. One participant was a 5-year-old male, the second was a 4-year-old female, and the third was a 4-year old male. All three participants were observed in three preschool settings: one-on-one intensive training, snack time, and explore time in free play with sensory-based activities. In addition, observations were made in one home setting--the living room/family room area. Functional analysis for each participant identified specific problem behaviors and controlling variables. Problem behavior was selected as the primary dependent variable with functional communication skills the secondary dependent variable; both were measured as percentage of observation intervals. A concurrent multiple baseline across-settings design allowed the documentation of interaction effects due to FCT by presenting a low-effort intervention phase immediately after baseline where parents and teachers used interventions that required minimal time to set up or implement, where there was very little change in procedures carried out by these parents and teachers, and utilized pre-existing skills such as prompting and rewarding of acceptable communication skills.

At this point in the study (Schindler & Horner, 2005), FCT was carried out in three to five 10-minute sessions in a one-on-one isolated cubicle in one classroom where communication was rewarded both socially by praise and attention as well as brief access to a preferred activity identified in the functional analysis. Once the criterion of the use of a functional communication skill, at least five times per session without a direct prompt for at least two consecutive sessions, was met, a second low-level intervention phase was introduced, identical to the first low-level intervention phase, in the same three secondary settings.

Results of Schlinder and Horner’s (2005) research indicated for all three participants, communication responses were rarely if ever used in baseline and in the first low-level intervention phase; whereas problem behavior was high and variable in baseline and first low-level intervention phase. During the FCT phase, problem behavior was significantly reduced from percentage rates between 20% and 40% to levels of 5% to 14% in the one-on-one setting--not in the three secondary settings. Appropriate communication responses rose from 0% to 6% per 10-minute session in the FCT setting only. During the second low-level intervention phase, problem behavior remained low and the use of appropriate communication responses remained higher across all three secondary settings, indicating the changes in both problem behavior and communication responses were attributed to the FCT. The authors concluded the results did not really document traditional generalization but rather the documentation of the interaction effect of FCT in one-on-one settings with secondary settings. This well-described and well-designed research extended the understanding of generalization to a variety of other settings.

To summarize the findings of research on FCT, functional refers to the teaching of more appropriate communication to use rather than problem behavior (in contrast to teaching academic communication to reflect learning or communication behavior for other purposes). The intent of this more appropriate communication behavior is to replace problem behavior to express needs and desires. Initial functional analysis determines the specific reinforcers maintaining problem behavior for each individual; selection of more appropriate behaviors requires the consideration of abilities, skills, and preferred topographies to maximize success in replacing problem behavior. Decisions need to be made regarding how to respond to problem behavior when it appears and whether to use extinction or other differential procedures. During the teaching of more appropriate communication behaviors, selection of a schedule of reinforcement for that behavior and thinning of the schedule is made. Finally, generalization probes provide information on the extent of the newly taught response when the child is in different settings from the training setting and with people other than the researcher. One critical factor in FCT and problem behavior reduction is the long-term effects over several years (Kern, Gallagher, Starosta, Hickman, & George, 2006). Most research in generalization is conducted within a few months of the study and very little extended, long-lasting behavior change is documented. In addition, without this longitudinal data, very little information is available to identify barriers and enablers for this change in behavior after FCT.

Picture Exchange Communication System

Picture exchange communication system (PECS) is a specific low tech augmentative alternative communication system (AAC; Ali, 2009; Cannella-Malone, Fant, & Tullis, 2010; Hart & Banda, 2010) in which the method of requesting a response to be taught as a replacement for problem behaviors involves the use of cards--each with a unique picture indicating the request (Hart & Banda, 2010). Rather than using verbal communication to teach and imitate a new verbal response, a nonverbal motor method is employed where the teacher initially prompts the desired behavior by putting his/her own hand over the child's hand and places it on a specific picture to indicate a specific request (e.g., picture of a truck as a way of gaining access to play with the truck). Gradually the hand-over-hand prompt is used until the child independently makes the desired response. Most often, this response takes the form of pointing to the specific picture; however, other responses can replace pointing when this is physically impossible, e.g., eye movements tracked by technological devices (Hart & Banda, 2010; Lancioni et al., 2007). Because PECS is used significantly less than FCT, fewer studies are available so fewer studies were reviewed.

Hart and Banda (2010) described six distinct training phases in PECS--beginning with the first step of teaching the child to physically exchanging a picture for a desired reinforcer where the trainer sits across a table from the child. The second phase expands the distance between trainer and child by having the child seek out the trainer to carry out the exchange. In the third phase, discrimination among several pictures is taught, building on the first and second phase to expand the "vocabulary" of the child. Next, beginning sentences are taught such as the verbal response "I want" with the motor response of indicating the picture representing the desired reinforcer. The fifth phase involves teaching the child to answer the question "What do you want?" and adding more descriptors to the desired reinforcer ("I want red truck"). At the final phase, the child is prompted and encouraged to make comments as well as make requests ("I see red truck").

The PECS is a relatively new set of procedures (since 1993) that has not been the focus of detailed study (Hart & Banda, 2010). These researchers conducted a meta-analysis of single-subject design studies focusing particularly on students with developmental disabilities who had poor communication skills and exhibited problem behaviors. They further restricted their meta-analysis to studies that included generalization and sought to assess the extent to which PECS was a socially valid intervention and the extent to which these PECS studies followed rigorous methodology.

A total of 36 participants across 13 studies were analyzed using two researchers and calculating inter-rater agreement (Hart & Banda, 2010). Most of the studies conducted a prior description of current communication levels, finding ranges from no speech to an extremely limited repertoire of single words. Most of the settings were in various school locations--such as isolated treatment rooms, segregated classrooms, and regular classrooms--but four were conducted in homes or group homes. In 1l of these 13 studies, the participants had access to the desired items and pictures of them. Training sessions were quite varied in terms of length and intensity; in some studies, the descriptions of the training sessions were insufficient to make comparisons between studies. Only two of the studies actually carried out all six phases of the PECS with most of the studies concentrating on the first three phases. A success rate of 94% in mastering the presented phases of PECS was reported for all of the 13 studies with several studies describing modifications to usual PECS procedures (such as starting with syllables before words, tapping the table while saying the syllable, and using phrases after words but before sentences). Results on decreasing problem behaviors were mixed--three studies showed a significant reduction, two studies showed a moderate reduction in problem behavior, and two studies indicated a decrease or elimination of aggressive behaviors. In seven of the studies, generalization to other persons and settings was reported and an additional study provided anecdotal evidence of generalization. Only two studies indicated social validation of the PECS from teachers and parents and six employed a multiple baseline or multiple probe designs. Most frequently, alternating treatment and ABAB designs were used.

Hart and Banda (2010) concluded PECS appeared to be highly or moderately effective as a technique to increase more appropriate ways of communicating for students with developmental delays or disabilities. They suggested PECS might also be effective for students with autism because of the use of concrete visuals and preferred reinforcers. However, it was not possible to determine the extent to which PECS significantly increased speech because most of the studies stopped at Phase 3. Hart and Banda suggested further studies that included all six phases, used sound methodological procedures to establish rigor, and included generalization and social validity to advance knowledge about the effectiveness of PECS. Limitations reported by the authors were the use of single-subject designs only and the short duration of treatments and generalization probes.

An experimental study conducted on the effects of PECS on the behavior of a young student with autism was carried out by Hines and Simonsen (2008). They examined the effects of using FCT techniques in which the use of picture cards was selected as the method of teaching more appropriate responses to replace problem behaviors. These researchers sought to determine if the intervention actually increased the use of picture cards for requesting and if there was a functional relationship between the presence or absence of the cards and behavior during baseline, intervention, and maintenance.

Results of Hines and Simonsen's (2008) study indicated that during baseline, the student did not use the picture cards at all but began using them during the training sessions and continued to use them during the maintenance phase. The increased use of picture cards was accompanied by a reduction in problem behavior--from an initial 95% of intervals to less than 10% at the end of the maintenance phase. This decrease in problem behavior extended into both Condition A and Condition B during the maintenance phase and was accompanied by increases of appropriately enabled behavior. There was a slight difference in rates depending on whether or not picture cards were present but it was not a significant difference.

This extremely well-written report (Hines & Simonsen, 2008) was clear and thorough--from the beginning statement of the topic and the problem, relevant and logically presented review of the literature, through the methods, results, and discussion sections. The methodology was complete including thorough descriptions of picture cards, methods of measuring behavior, and the presentation of results both graphically and narratively. The authors noted several limitations including the use of only one young participant, only a descriptive AB design, and a low percentage of observations (12%) used in calculating inter-observer reliability. Only one weakness was apparent in this article: at no point did the authors define "appropriately engaged behavior" as an alternative response when picture cards were absent (Condition B) during maintenance.

One of the concerns with PECS is the amount of effort needed for an individual to carry out the taught alternative communication behavior (Buckley & Newchok, 2005).

When it takes more effort to use the alternative behavior response than to continue the inappropriate problem behavior, it might be more difficult to acquire this response. Buckley and Newchok (2005) reviewed previous research on less effortful responses in FCT, which included a few that used PECS. However, they noted an absence of research regarding the impact of effort within one communication system where a response chain required a series of responses combined to constitute one mand (for example, finding a specific picture from many possibilities, picking up the picture, and handing the picture to the teacher versus a single response such as pointing to a picture). The development of a response chain is often the next step after teaching a single response to meet communication requirements in natural settings where simply pointing to a picture is not always feasible.

In an attempt to extend the research on PECS and carry out a well-controlled empirical study, Charlop-Christy, Carpenter, Le, LeBlanc, and Kellet (2002) conducted a multiple baseline, single-subject design to assess the effectiveness of PECS with three boys with autism. The first participant was 12-years-old, the second one was three years and eight months old, and the third one was five years and nine months of age. All three participants displayed limited verbal skills, no spontaneous speech, and were in need of interventions to increase speech skills. Also, two of the boys exhibited several problem behaviors before and during the intervention, and the first one exhibited problem behavior during treatment. Intervention initially took place in the clinic's small, self-contained treatment room equipped with a table, two chairs, and a one-way mirror. The second setting was an empty university classroom adjacent to the clinic and additional settings included the child's classroom and home. In addition to training sessions, free-play sessions were arranged once a week prior to, during, and following the training sessions in the clinic's treatment room. Academic sessions were also presented once a week prior to, during, and following the treatment sessions; no PECS materials were available but similar materials were present and an academic task was given to access possible ancillary gains. The PECS materials consisted of cards with sentence strips ("I want," and "I see") and black-and-white pictures of the desired item to complete the sentences. All cards had Velcro strips on the back that were to be placed in the students' PECS book containing the attaching Velcro strips. The authors used a multiple-baseline design across subjects to ascertain collateral effects (unexpected positive or negative effects on behaviors that had not intentionally been targeted by the intervention) that could be attributed to the PECS training on multiple-dependent measures in speech, social-communicative behaviors, and problem behavior in all settings. Training sessions were conducted in each setting twice a week for 15 minutes and the particular order of settings was randomly determined.

Baseline procedures for every session in all settings remained the same throughout--where the therapist provided five opportunities each for spontaneous speech and verbal imitation--and were presented at the beginning of each minute of the session (Charlop-Christy et al., 200). The spontaneous speech opportunities consisted of the therapist holding up a picture of the desired object and waiting 10 seconds for a vocal response. If the child made an appropriate vocal response, the desired object was given to him for the remainder of the minute. The verbal imitation opportunities were identical with the exception of the therapist modeling a word or short phrase related to the object. During the free-play sessions, the therapist played and spoke with the child using the desired toys but the child was free to play with other toys, move about the room, and assume any posture. Prior to training, a preference assessment determined the three to five most preferred toys for each child. All sessions were videotaped and inter-observer reliability was calculated, yielding an average of 96% agreement.

During the training sessions following baseline sessions, each child was taught PECS using differential reinforcement and prompting where the main dependent variable consisted of number of trials and elapsed time for the child to reach the required criterion of 80% of trials with correct unprompted responding. Other dependent variables consisted of spontaneous and imitative speech responses, other social-communication responses in free play (such as cooperative play, joint attention, requesting), and problem behavior. Six phases of training consisted of physical picture exchange, expansion of spontaneity, picture discrimination, sentence structure, “What do you want,” and commenting. The first five phases involved mand training and included strategies to promote generalization, which was followed in phase six by tact training (where the student was taught to describe an object). After training sessions were complete, an initial follow-up assessment was conducted for several weeks in which the PECS book was always available. One child who was still available was also followed up 10 months after training had ceased for three consecutive weeks.

Results of Charlop-Christy et al.’s study (2002) showed all students met the 80% criterion for all PECS phases in an average of 170 minutes, an average of 246 trials, each phase taking from 8 to 45 minutes, and 12 to 70 trials. The researchers noted progress was more rapid during the third and fifth phases whereas the second and fourth phases generally took an increased number of trials and more time. In measuring spontaneous speech, all three children showed a significant increase from a baseline of 0% to 10% to the post-training rate of 90% to 100%. Imitative speech also increased from a baseline of 0% to 20% to the post-training rate of 60%-90%. Problem behavior decreased from a baseline rate of over 50% to a post-training rate of near 0%. The researchers concluded the use of PECS was a feasible and effective procedure to teach children with extensive language deficits to acquire significant language skills, particularly in mand behavior. In addition, collateral improvements were noted during free-play with increased cooperative play and the use of verbal skills learned in training sessions with a decrease in problem behaviors. Limitations noted by the researchers included the small sample size and the lack of replication with other students. In addition, although this study was well-designed and implemented with most procedures described completely, the difference in duration of the free-play versus training sessions was not explained. However, the various graphs were extremely informative in displaying the results.

Problem behavior usually refers to maladaptive behavior as a way of communicating for a purpose, to obtain a desired object or activity, or to escape unwanted activities. However, a second class of problem behavior that manifest in individuals with S/MD are behaviors not goal-oriented but restricted repetitive stereotyped behaviors such as flapping of hands or repeated head turning (Shahzadi Malhotra, Bhatia, & Singh, 2010). The PECS was used as an adjunct to several traditional interventions to reduce these repetitive stereotypical behaviors including contingency management, differential reinforcement of alternative behavior (DRA), task direction, and reprimand by these authors with a 7-year-old boy diagnosed with childhood autism. Baseline assessments consisted of the administration of several rating scales (i.e., Childhood Autism Rating scale, Vineland Social Maturity scale, and Visual Analogue scale), which identified the behaviors to be targeted (hand flapping, head turning, and training in self-help and communication skills). Because the administration of these scales ascertained most of the stereotypical behaviors were unrelated to social consequences, the authors selected the use of DRA, contingency management, task direction, and reprimand in addition to the six phases of PECS.

Intervention sessions took place over a period of three months in 32 sessions; at the conclusion, it was determined the child demonstrated a 60% improvement in self-help and communication skills along with a reduction of stereotypical behavior to near zero as determined by re-administration of the same scales and parental reports (Shahzadi Malhotra et al., 2010). Shahzadi Malhotra et al. (2010) concluded the combination of PECS with other traditional intervention techniques could significantly increase adaptive behavior and decrease stereotypical behaviors since the focus was on reinforcing the adaptive behavior rather than focusing on the stereotypical behaviors. However, several major flaws in the study and in the published article appeared including no clear design description, no presentation of data over sessions or related to phases of PECS, no indication of when different interventions were employed, nor how a specific intervention might be related to a specific outcome. In addition, the single statement indicating gains were maintained at the three-month follow-up illustrated the ambiguity of findings, absence of data, and the lack of specific procedures used in the follow-up. These deficiencies obscured the significance of the study and its results but did show an interesting line of research using PECS for reduction of stereotypical behaviors in combination with other traditional techniques.

In summary, PECS has been used as a specific application of low tech AAC where pictures are used initially to begin development of more functional communication skills to replace maladaptive behavior. Although in the formal model of PECS where six phases start with exchanging a picture for a desired item or activity and end with the use of simple words and phrases to indicate preferences, in many cases, only the first two or three phases were accomplished in part due to limitations for vocal speech production or initiation in individuals and where PECS materials were used as the sole communication technique. The PECS often targeted developing improved communication skills, sometimes also targeting the reduction of problem behavior, but also sometimes just monitoring problem behavior to gauge collateral effects of PECS (Cannella-Malone et al., 2010). The majority of studies were carried out with younger children and only a few studies with older youth and adults. The PECS is also a cumbersome system, involving pictures and cards that need to be organized in some manner, and can become bulky over time as the child's vocabulary increases. In addition, success of PECS could be affected by the physical effort needed to manipulate pictures and objects. Overall, PECS is not widely used as an intervention when compared to the frequency of FCT.

Many of the disadvantages of PECS were tempered or eliminated by high tech AAC interventions. One such high tech device is a speech-generating device (SGD) used to replace or augment speech communication and often as an alternative to PECS. When Boesch, Wendt, Subramanian and Hsu (2013) compared PECS to SGD interventions to increase social-communication skills and speech development, they found little difference in effect for elementary students with severe autism and extremely limited functional communication skills. Similar studies by other researchers have also yielded contradictory result according to Boesch et al., although one study was cited that found greater gains in augmented versus non-augmented language interventions, leading to a recommendation for more research to provide more clarity on these comparisons.

A series of comparative studies of the use of manual signs and PECS by van der Meer, Didden et al. (2012), van der Meer, Kagohara et al. (2012), and van der Meer, Sutherland, O'Reilly, Lancioni, and Sigafoos (2012) using single subject designs found individuals expressed preferences for one modality over others in learning requesting skills, particularly SGDs. These devices mimic speech by emitting speech digitally and/or by synthesized speech (e.g., as used by Steven Hawkings) and can be found with many different configurations to adapt to the specific needs of individuals who have little to no functional speech. Although most research with SGD aimed at increasing requesting behavior, a few studies assessed speech production (Dyches, 1998; Olive et al., 2007; Parsons & La Sorte, 1993; Schlosser et al., 2007). Although SGD was found to be relatively effective for increased speech production, very few studies examined the effectiveness of SGD on increased social-communicative interactions and skills (Schepis, Reid, Behrmann, & Sutton, 1998; Sigafoos et al., 2009).

An informative study was found in the meta-analysis of single case research on AAC with individuals with autism spectrum disorders (Ganz et al., 2012). Ganz et al. (2012) investigated overall impacts of various aided AAC interventions including PECS, SGD, other picture-based systems, as well as individual behavioral outcomes and comparisons with young children with autism and severe communication delays. Included in their meta-analysis was a determination of the effects of interventions on challenging behavior and social skills as well as communication skills. They found significantly higher effects with PECS and SGD over other picture exchange systems, the highest effect was on communication, but were also effective in reducing challenging behavior and increasing social skills. The authors hypothesized there was a high relationship between good communication skills and social skills and also good communication skills were more efficient and effective than challenging behavior.

In their recommendations for future research, Ganz et al. (2012) cited the need for more research on the relationship between communication and social skills, on differential effects of different types of AAC interventions, and on better and more specific determination of reasons for reduction of challenging behavior. Ganz et al. also pointed out the lack of research of AAC with older youth and adults and the need to substantiate AAC with these populations. Finally, the authors noted the need to investigate specific features of AAC such as symbol iconicity, display layouts and organization, and selection techniques to provide clearer explanations for effects obtained.

High Tech Assistive Augmentative Communication Intervention

In the past few years, advances in computer technology and in mobile devices have led to the investigation of these devices for educational purposes as well as entertainment and social networking (McNaughton & Light, 2013). In the area of AAC for students with little or no speech or appropriate communication skills, the iPad (and similar devices) offers several benefits over traditional teaching materials. First, the increased general use and social acceptance of mobile devices no longer set apart users as visible indicators for need of assistive technologies but rather are now seen as participating in mainstream life activities. Secondly, these devices are linked to the

Internet, exponentially increasing access to vocabulary and visual/auditory support for this vocabulary. Also, practitioners and educators extol the ease of use, the reduction in preparation time, and the efficiency of storage acquired in using these devices over traditional picture/symbol cards and notebooks. Other advantages noted by these researchers are greater empowerment of consumers and more independence for them, increased functionality and interconnectivity, and increasing quality research on the use of iPads as AAC devices. However, authors also point out the need for more effective collaboration among key users, practitioners, and researchers, and for continued improvements in technological features and displays especially related to special motor skill needs by individuals with significant communication impairments.

Because the iPad is a relatively new technology and its use in teaching communication skills to students with severe communication delays is even more recent (only since 2010), not a large body of research surrounds its use in this way. A systematic review of the use of iPods and iPads in teaching students with developmental disabilities yielded 15 studies meeting their criteria and covering five domains, one of which was communication (Kagohara et al., 2013). Eight studies within the last four years showed an increase in communication behaviors was obtained for both younger and older participants with the majority being teenagers; all were in educational programs for individuals with various developmental disabilities and severe communication problems. One recommendation from this review was to expand research to include individuals with more severe and multiple disabilities since research with this group was extremely limited. Kagohara et al. (2013) also noted devices such as iPads are gaining increasing acceptance; today’s young people customarily use these devices, reducing the stigma that used to be attached to assistive technology and might in fact enhance a feeling of belongingness to the general population.

Flores et al. (2012) compared the use of PECS and the iPad as AAC systems and as viability tools to improve communication for five students with autism spectrum and developmental disabilities in elementary school. The researchers found in addition to most students increasing their communication behaviors, students preferred using the iPad to the PECS technique. One of the students actually threw the picture cards in the trashcan when he arrived for the session at the snack table as an indication of his preference. Another student grabbed the iPad to communicate rather than using the picture cards on the snack table. This study reported several advantages of using iPads as an AAC. First, the students preferred to use the iPad rather than PECS. Second, the iPad was easier and faster for the students to communicate. Third, there was increased speech for some students by the end of the study. Additionally, school staff indicated a preference for using the iPad, stating the iPad was much easier in preparation, less awkward, required less physical manipulation, and required fewer materials to use for them and for the students. The only concern expressed by the authors was using the iPad provided less opportunity for eye contact; however, this was only suggested as a possible drawback and not a result of observation.

In a comparison of traditional computers versus the iPad, Saylor and Rodriguez-Gil (2012) noted the iPad offered several benefits over the traditional computer. Simply eliminating the mouse and keyboard in favor of touch screens reduced many of the navigation problems and understanding about how to use the device. Other advantages included an interface learners engaged with directly, better ability to customize for specific needs and interests of individuals, portability and ease of use, interactive screens, and the availability of selections that appealed to and encouraged engagement with the teaching materials. One feature was noted as both a possible benefit and as a possible barrier--the light touch. Having a light touch is more effective for those individuals with less strength but can be a barrier for those with little control over the strength in touching the screen as a too hard or a too lengthy touch could lead to deactivation of the speech-producing mode of the device. However, this latter possible problem could be tempered with AssistiveTouch, which helps in control of motor movements. Other possible problems that need consideration include glare and brightness of the screen, the necessity to learn how to activate and navigate through the device's applications, and visual characteristics such as figure/ground, size of font and symbols, support for the device, and busyness of the screen. The authors concluded practitioners need to carefully consider both the advantages and possible challenges but that, overall, iPads open up new doors for more effective and efficient communication training for students with special needs.

One particular advantage of iPads and other speech-generating devices was explored by Bradshaw (2013) who found spoken language was more generally accepted and preferred as a way of communicating versus pointing to a picture/symbol card. It was also perceived as more socially normative and led to less stigmatization and negative stereotyping. Bradshaw also found portable devices were easier to use and resulted in a more positive communicative relationship with others. She did note factors that needed more investigation included reliability, service, and availability of technical support but there seemed to be increasing improvement over quality of speech production from a mechanical robot sound to more natural speech.

Requesting and High Tech

Lorah, Crouser, Gilroy, Tincani, and Hantula (2014) examined the use of an iPad in conjunction with a speech-generating device application called Proloqu2Go to teach preschool children with autism to progressively discriminate more complex picture/symbols in a display on the iPad screen. The researchers conducted a five-phased training program involving within stimulus prompting and prompt fading to teach manding for preferred items (one out of four presented). This training technique successfully taught all students in the study to discriminate increasingly complex picture/symbols to support the limited existing research on manding using a handheld speech-generating device with pre-school children with autism. This study also provided detailed descriptions of the five-phase discrimination training to assist other practitioners in using this strategy and supported the initial use of stimulus prompts with subsequent fading of these prompts, allowing the device itself to become the instructor. Finally, this study demonstrated the rapidity at which participants progressed through the five phases and the continued retention of mastery beyond training.

At present, several choices are available for different iPad displays and AAC applications to teach communication skills for students with severe communication delays. Gevarter et al. (2014) investigated three different displays using two applications of a multi-element design to compare mand acquisition in three preschool boys with autism. Their findings showed display differences could influence rate of acquisition--the Scene and Heard photographical hotspot configuration led to marginally better performance than the GoTalk Widget symbol button configuration for two of the three students. Also, differences in organizational structure in displays seemed to have an impact but the reasons for this difference need more study. The authors recommended selection of display and AAC application be carefully matched to characteristics of individual students. A further recommendation was to conduct more detailed studies of aspects of display such as highlighting, figure/ground, symbols versus pictures, placement of navigation buttons, and differences in mode of responding such as multiple tapping, clicking, and dragging.

Almost all of the studies on utilization of iPads as AAC tools to increase communication skills with persons with substantial speech impairments or delays involved training in institutional settings, schools especially, but also included rehabilitation or specialized centers such as day programs. In contrast, Helps and Herzberg (2013) carried out a case study with a 17-year-old girl with multiple disabilities in her home and whose mother was always present during the training sessions in the hopes of reinforcing the girl’s use of the iPad. Although the focus was upon training the girl to select and engage in leisure activities via the iPad, the intervention also required the teaching of accessing and using the iPad as a device including such steps as turning on the device and using navigation controls that could also be applied in communication training. Results indicated the girl was successfully able to turn on her device and select several types of activities such as watching a movie or playing games independently after seven weeks of intervention, thus decreasing the number of mands from others. She also indicated her preference for the iPad over other devices such as a television as she could work independently without relying on others. In a follow up three months later, all the skills taught were still demonstrated and she easily switched between her choices of activities. One persistent problem was the girl's inability to double-tap a selection, which limited her ability to access preferred songs. However, she retained a sense not only of empowerment but also of ownership, clearly demonstrating her sense that the iPad was hers and she could use it on her own. It would have been interesting and beneficial if the authors had made informal observations of the effects of the mother's presence during the training sessions as no mention of this was made (Helps & Herzberg, 2013).

Parental Involvement in the Development of Communication Skills

Most of the studies of parental interventions to teach language acquisition to children with language impairments involved young children. Roberts and Kaiser (2011) conducted a meta-analysis of parent-implemented language interventions not utilizing any AAC device with this population because parents play such a pivotal role in their children's language development. These authors particularly examined studies that focused on importance and impact of parental involvement including amount of parent-child interaction, responsiveness to child communication, amount and quality of linguistic input, and the use of language learning support strategies. This meta-analysis is discussed because it showed the effectiveness of involving parents in language acquisition training and documented comparisons of parental and therapist interventions as well as differential effects between children with and without intellectual disabilities. They also examined how the type of language acquired affected the magnitude of effects and how parent-implemented interventions positively affected parent-child interactions, which was largely overlooked in the few studies of parental use of AAC interventions. In fact, of the seven aspects of language examined, only receptive language and expressive syntax were significantly improved by therapist intervention over parental interventions; acquisition of skills in the other five (overall language, expressive vocabulary, expressive language, receptive vocabulary, and rate of acquisition) was significantly better for parental intervention over therapist intervention, given the intervention method was the same and the only difference was who implemented the intervention.

Given the evidence of the effectiveness of using parents as interventionists, it is surprising few studies involving parents in language acquisition used high tech AAC in comparison with those studies using teachers or therapists in artificial settings, especially for students with severe and multiple disabilities where family members were the ones with the most familiarity of communication characteristics for their family member with severe communication deficits (Jansen, 2013). One reason posited for this lag in studies using parents was there could be challenges in implementing AAC interventions for those with severe or multiple disabilities (Johnston, Reichle, & Evans, 2004). Many of these challenges such as unfamiliarity with AAC devices and applications, lack of awareness of importance of reinforcing appropriate behavior, and frequent but unintentional reinforcement of alternative but socially or contextually inappropriate behavior could be overcome by educating parents, including them in interventions, and supporting them as communication partners.

A study by Romski et al. (2010) supported the effectiveness of using parents as interventionists in their comparison of the effectiveness of augmented and nonaugmented language interventions with young children with developmental delays. These authors measured performance on augmented and spoken word size and use, vocabulary size and communication interaction with both augmented input, augmented output, or unaugmented spoken communication interventions. Parents received coaching prior to and during interventions held in a laboratory session but also in home settings to increase generalization of acquired language by participant children. Results documented significant increases in communication skills for children in both augmented interventions over those in nonaugmented interventions; the smallest difference was found in acquisition of target spoken vocabulary but greater differences were found in non-spoken language acquisition skills. Of the two augmented interventions, output interventions (e.g., production of speech as expressive language skills) were more effective than input interventions (e.g., understanding and comprehensive as receptive language skills).

Additional support for utilizing parents as interventionists was substantiated by Kent-Walsh, Binger, and Hasham (2010) in their study of the effects of parent instruction on emergent literacy skills through storybook reading using AAC. This study included both European American and African American families whose children experienced severe communication deficits. The authors examined both the effect of their four-session instructional program on parents' implementation and generalization of the intervention and the effect of the parents' use of least to most prompting strategies on children using AAC. Measures of parental use of strategies and of children's acquisition of literacy skills were gathered. Results indicated highly positive results for all of the mothers and children participating in the study including a rapid rate of a high level of competency by mothers and increases not only in literary skills but of parent-child communication interactions. Kent-Walsh et al. pointed out these mothers quickly and easily mastered the skills necessary to use the AAC devices and applications as well as strategies to improve the quantity and quality of their children's communicative responses.

Although the majority of research in high tech AAC interventions, including those involving or utilizing parents as interventionists, has been quantitative, O'Keefe, Kozak, and Schuller (2007) conducted a qualitative study using focus groups comprised of adults with physical disabilities affecting their communication and requiring the use of AAC throughout their lives. These adults were also professionals in child language development, developmental psychology or speech and communications, and reflected upon their lifelong experience with AAC and their communication with others. The adult participants specifically described their preference for measuring success in more qualitative terms such as the ability to communicate successfully with others in specific situations, the willingness of others to communicate with them, and the attainment of respect achieved through their ability to communicate. O'Keefe et al. noted many researchers who focused on quantitative analysis might not be gaining a complete picture of communication needs and perceptions of success from the perspectives of those people who actually use and depend upon AAC for their language and communication skills and interactions.

This point of view was reinforced in a qualitative study involving focus groups comprised of parents of individuals using AAC as they described the benefits and challenges of learning to use AAC technologies (McNaughton et al., 2008). Although only parents of children with cerebral palsy were interviewed, their perspectives provided valuable insights into parental experiences in learning how to use AAC to communicate with their children. The authors described six emergent themes: (a) issues surrounding selection of specific AAC technology, (b) knowledge and skills necessary to use AAC technology, (c) barriers experienced during the learning process, (d) issues in individualizing interventions, (e) importance of educating society, and (f) understanding and respecting recommendations from others.

Cultural Factors Related to Communication and Interaction

As rapid advances in computer technology, devices, and applications relating to developing communication skills are made and as widespread access to the Internet and use of computers expands throughout the world, a need has arisen to determine if and how documented success with high tech AAC in Western countries and most frequently in English could be replicated in other parts of the world and with other languages. Along with these concerns has been research into cultural factors that relate to communication and communicative interaction. Parette and Brotherson (2004) discussed the importance of developing a family-centered and culturally responsive approach for decision-making when utilizing AAC with young children with communication deficits from diverse cultural and linguistic backgrounds. Noting that IDEA (2004) mandates family-centered practices and strategies, these authors highlighted several concepts in implementing these practices and developing culturally sensitive interventions. They emphasized the importance of involving family members as early as possible, of building and maintaining understanding and respect for culturally and linguistically diverse families, inclusion of these family members in all decision making, and appropriate selection of high tech devices and applications in developing interventions. Parette and Brotherson also noted the importance of providing various kinds of support for family members including emotional and psychological as well as educational and technical support. Additional considerations included understanding the role of natural environments, self-determination, and specific family issues. Finally, the authors described the value of cultural reciprocity for meaningful information gathering during decision-making processes.

Several studies in AAC with children from other cultural backgrounds have informed our understanding of the importance of cultural sensitivity in developing communication skills for students with disabilities. Parette, Huer, and Wyatt (2002) investigated AAC issues for young African American children with disabilities, noting (a) introducing AAC in other cultural milieus often increased stress in these families, (b) cultural mistrust issues could surreptitiously undermine intervention efforts, (c) language use patterns and communication styles could differ widely from Anglo-Saxon English styles, and (d) family and community social values formed an important context shaping how and when communication interaction took place.

In research with Latino parents supporting language acquisition with AAC, Binger, Kent-Walsh, Berens, Del Campo, and Rivera (2008) used a mixed method including focus groups to enhance cultural sensitivity and to insure that interventions and decisions about interventions were based on Latino perspectives. The authors also developed a training program for parents in using AAC to support the development of communication skills and interactions with their children. Binger et al. utilized Latino reading material reflecting Latino cultural values. They found all parents and caregivers successfully learned to use instructional strategies incorporating AAC and all children increased their language acquisition skills.

The demographics in the United States has changed so much in the last few decades that a new concept has emerged: cultural pluralism depicting the transformation of American society from a “melting pot” metaphor to a salad bowl metaphor (Bridges, 2004). As a communication specialist, Bridges (2004) reflected on this paradigm shift as it impacted research in AAC and reaffirmed the need for more research in this area to expand the current knowledge base relying primarily on English language studies with participants mainly from European American Anglo-Saxon cultures. She proposed that researchers concentrate on several specific areas: (a) the generation of theory-driven studies to provide rationales; (b) development of collaborative research studies involving multiple disciplines; (c) inclusion of more qualitative studies gathering perspectives, experiences, autobiographies and especially from international and multi-cultural sources; (d) longer term studies with more information on generalization; and (e) a three-tiered approach to data analysis including individual, group, and societal levels. Although cultural sensitivity is important for all aspects of teaching and learning, it is especially critical in communication training where differences in language and speech go beyond vocabulary and production of sounds to include differences in cultural communication styles and nonverbal language. She also emphasized the need for manufacturers to develop communication systems with a variety of language and graphic options. Finally, Bridges pointed to the importance of case studies as providing a foundation for knowledge and understanding culturally and linguistically diverse AAC users. She described a few seminal studies from ethnographic, focus group, case study, and ecological studies that have added important understandings and insights to the vast quantitative body of research and how these qualitative studies not only illuminated new understandings and increased our knowledge but also highlighted the use of various research methods and models in a more holistic rather than mechanistic manner.

To extend the investigation of high tech AAC interventions with other cultural groups using qualitative methodologies, this research study sought to understand the effects of early involvement of Saudi Arabian parents in increasing communication skills using AAC for their children with multiple and severe disabilities. A case study approach was utilized to probe communication partner participation (who might not always be the parent in Saudi culture) in researcher-based training of youth with multiple and severe disabilities with concomitant significant communication deficits to increase requesting behavior, initiate new conversations, and decrease challenging behavior. This study investigated perceptions and communication patterns of families as they attempted to communicate with their family member with communication deficits and to provide insights into ways these communication behaviors and interactions were influenced by the involvement of these family communication partners in training youth with severe communication deficits to utilize high tech AAC to increase communication skills.

CHAPTER III

METHODOLOGY

A qualitative case study design using cross-case analysis and quantitative support was used to explore the impact of using an assistive augmentative communication (AAC) device on family communication and interactions among three young adults with severe and multiple disabilities, including speech and language disabilities, and their families. None of the participants or their families had experience with alternative communication devices despite the fact the youth who participated in the study were identified with speech and language disorders and had little to no existing understandable language communication skills. The young adults all used idiosyncratic communication methods such as vocal sounds and gestures, pointing, and facial expressions. In addition, they also displayed inappropriate and challenging behaviors as ways to communicate such as yelling, screaming, and throwing objects.

The purpose of this study was twofold: (a) to ascertain how the family communication partner could be utilized as a resource for increasing appropriate communication of Arabic children with S/MD employing an iPad and communication software as an assistive augmentative communication tool and (b) to substantiate the use of the iPad as an AAC to improve communication and behavior of these children.

Research Questions

The study was designed in two phases to answer the following research questions:

Q1 In Phase One, how do family members or primary caregivers of youth with S/MD communicate with their youth with S/MD?

Q2 In Phase Two, what is the perceived impact on behavior and communication of youth with S/MD when a female family member or caregiver has been provided with training in functional communication training using iPad with MyTalkTools?

Theoretical Perspective: Constructivism

In this study, the theoretical perspective used was constructivism. According to Creswell (2012), people's experiences help them develop their understanding of the world around them. They develop subjective meanings based on their lived experiences and on their interactions with the objects they encounter in their life. "Constructivism describes the individual human subject engaging with objects in the world and making sense of them" (Crotty, 1998, p. 79).

Seen through the perspective of constructivism, reality is always subjective and experiential; it results in multiple perspectives of truth rather than a single universal version of truth. One of the researcher's tasks is to interpret the multiple realities that exist and construct a version of reality that includes multiple shared perspectives that are all equally valid. Thus, qualitative research is by nature subjective as research findings are inevitably co-created from the perspectives of both participants and researchers (Merriam, 2009).

Research Design

Qualitative research uses methods that help the researcher understand the unique lived experiences of the participants including the use of interviews, observations, and the gathering of artifacts. While the goal of qualitative research is to develop useful inferences based on individual perspectives, no universally generalizable applications are based on the findings of the study in most cases. The quality of these findings rest on the skills of the researcher. According to Creswell (2007), a skilled qualitative researcher cannot only capture the complexity of the participant's experience through interviews and observations but is also able to identify the categories and themes that emerge from the data. Furthermore, a skilled researcher then provides rich and textural descriptions that accurately reflect the experience of the participants. Thus, individual lived experiences can be transformed into a way of explaining a shared social reality through the reflection of human experience.

This qualitative study with quantitative support was conducted in two phases--one before the implementation of a communication intervention and one after the intervention. Pre-post intervention data collection was designed to capture any changes in the communication and behavior of a youth with S/MD and the impact of these changes within her family. Qualitative case studies often focus on exploring a phenomenon already present through the lived experience of participants. In this study, changes in parental perception of the phenomenon before and after an intervention were studied as well as behavior changes in the daughters after the intervention.

Case study design is a specific form of qualitative research that seeks to gain a broad and rich description of the phenomenon under study including investigations into perceptions and perspectives from the participants involved in the study and embedded in the phenomenon (Merriam, 2009). This research design was appropriate for several reasons. First, this design was suitable for a contemporary experience rather than an historical study (Yin, 2014). Second, this topic was influenced by many factors beyond the control of the researcher. Third, the main focus of the research questions was "how" in order to gain a fuller, in-depth understanding of the case of communication interactions within families with youth with S/MD and the impact of introducing an assistive technology communication tool--an iPad with the MyTalkTools app. Fourth, each case centered on a home context where the youth with S/MD resided rather than a school context, which was no longer available. Fifth, the case of communication interactions was a complex social phenomenon in a holistic context. Finally, the intervention to improve the appropriate communication skills of family members with youth with S/MD was conducted in the family home of these youth involving a family member who served as a communication partner to add to the understanding of the phenomenon under study.

The Cases

The case studies of this study consisted of three families, primarily the mother-daughter dyad of the family living in a large city in Saudi Arabia, in which one of the offspring has S/MD. Each family formed one case. Boundaries for these cases included (a) the time frame of the study--although data collection for the study was conducted in the fall of 2016, the cases themselves encompassed the lifetime of the youth with S/MD; (b) the cases were limited to families with youth who had S/MD and who had not yet been introduced to assistive augmentative device; (c) the youth had little or no existing understandable or age-appropriate communication skills; (d) the youth with S/MD had finished elementary school (the last level of schooling available to these youth) and were living at home and not attending school at the time of the study; and (f) families were within the lower to middle class based on financial and educational status. Families with a low to middle class socio-economic status were chosen as a focus of study because families at a high socio-economic level often had the ability and means to travel outside the country to obtain specialized communication training and to purchase advanced technological communication devices not available to the general population.

Description of Study Phases

This study was conducted in two phases--pre-intervention and post-intervention. In both phases, open-ended interviews and informal observations with mothers of the youth with S/MD took place. Data from phase one were used to answer the first research questions while data from phase two included post-intervention interviews with the mothers along with quantitative observational data of the youth as support to answer the second research question.

In each of the three cases, the mothers participated in qualitative interviews in the pre- and post-intervention phases as well as in the observations. Their participation was direct and active throughout both phases of the study. In the following chapters, the mother-participants are referred to as “the participants.” Although their daughters also participated in the intervention and in observations, their participation was limited to observations in both the pre- and post-intervention phases of the study. In the following chapters, the youths are referred to as “daughter-participants.”

Phase One

During the first phase in addition to interviews and observations, an examination of available school documents and artifacts was also conducted. The pre-intervention interview in the first phase of the study was designed to inquire into current communication skills and behaviors of each youth with S/MD. The focus of these interviews was to understand the perspectives of female family members regarding communication issues for the youth with S/MD and how these family members perceived their role or function in the youths' communication. Observations using a video recorder were used to capture additional descriptive data regarding the kind and quality of family communicative interactions with their youth with S/MD. After the first phase of observations, interviews, and document inspections had been completed, the participants attended a functional communication training (FCT) workshop where they learned about functional communication and augmentative communication devices and strategies.

The goal of this workshop was to introduce participants to the MyTalkTools app and learn how to customize this for their child's communication needs. The three participants were invited to attend this workshop together so they could share information provided during the workshop and learn from each other's comments, questions, and feedback. The workshop was held at the Association of Children with Disabilities Center in a large city in Saudi Arabia. This center was selected because it was convenient for each of the participants. Their children had all attended primary school at the Center so they were familiar with the facility. The director at the center was very interested in the study and provided a classroom complete with a white board, audio-visual equipment including a projector, internet access for the five-day workshop, as well as daily coffee, tea, and snacks.

The workshop took place during a week when school was not in session so there were few other activities and a minimum of distractions. Each participant received a personal iPad with a protective case and a wheelchair mount. The wheelchair mount consisted of a clamp that mounted onto the armrest of a wheelchair with a 24-inch long adjustable metal goose neck tube leading to the tablet holder. This allowed users to adjust the height and angle of the iPad according to their personal preferences. Participants then downloaded the MyTalkTools app and learned to customize this for the specific needs of their child. Table 1 provides an outline of the training steps.

At the conclusion of the initial interviews, participants were asked to write down their daughter-participants' communication needs in their notebook including names of family members and other communication partners, daily routines including meals and prayers, as well as interests and activities. The workshop included information on using the MyTalkTools app to teach requesting ("I want to eat") and initiating ("hello", "how is your day?"). This information was used to create the initial folders in their MyTalkTools app.

During the workshop, the participants learned how to customize the app and use it to communicate. Participants practiced using their MyTalkTools apps with each other, made changes, and refined their folders until they were satisfied it would meet the needs of their youth with S/MD (see Appendix A). Once they finished customizing the app, the participants were taught how to carry out the intervention at home and continue to support the communication efforts of their child with S/MD. It was then the participants' responsibility to implement this intervention at home with their daughter and to instruct other family members how to support the communication between the youth with S/MD and the rest of the family.

Table 1

Outline of the Communication Partners Training Workshop

Days	Objectives	Materials
First Day**:** Introduction to Functional Communication Training (FCT)	• Presentation introduced parents to common functional communication strategies used by children and young adults with expressive speech and language disabilities, • Including the use of inappropriate behaviors to convey needs, desires, and frustrations. • Providing parents with written materials in Arabic.	• Paper folder • Copy of FCT PowerPoint • Worksheets regarding the communication strategies of their youth with S/MD • References to books, websites, and specific online videos regarding FCT
Second Day: Introduction to Augmentative and Alternative Communication (AAC)	• Presentation included overview of AAC devices, introduction to using the *MyTalkTools* app on the iPad. • Providing parents with an iPad, and then showing additional materials to be used during the intervention.	• iPad • iPad screen protector • Wheelchair mounting device • Materials to make keyguards • Several stylus types
Third Day: Demonstration of MyTalkTools app	Showing parents how the MyTalkTools app worked on an iPad: • How to navigate folders • How individual subject cells function when tapped. • How to download app from website • How to use the edit mode to customize app for their specific needs by creating: ○ Folders ○ Sub-folders ○ Tailor individual cells by adding photos, printed word, and audio recordings. • Giving parents written step-by-step instructions for how to download, set up, and manage the MyTalkTools app in Arabic. • Working with parents on each of these tasks on their iPad. •	• iPad • MyTalkTools app • Small notebook • Pen • MyTalkTools guideline book
Fourth Day: Customizing the app for the youths	• Completing with parents each of the previous tasks on their iPad. • Reviewing the small notebook to determine the needs and wants for each youth. • Customizing MyTalkTools to their youth's needs.	• iPad • MyTalkTools app • Small notebook • Pen • MyTalkTools guideline book

Table 1 Continued

Days	Objectives	Materials
Fifth Day: Modeling the use of MyTalkTools app	• Modeling the use of the MyTalkTools app through role-playing. • Showing a video of a student with S/MD who used vocalizations and behavior, including crying and kicking, to communicate to her teacher. • Playing a second video showed the same student using MyTalkTools to communicate by touching a sequence of subject cells on her iPad and requesting a piece of chocolate. • Finishing view the videos, parents participated in several role-playing scenarios using their personal MyTalkTools app to communicate.	• iPad • MyTalkTools app • Video clip

Phase Two

The second phase took place after the participants implemented the intervention using a communication device to increase communicative interactions in the family. The primary communication partner in the family was provided with FCT training sessions to instruct them in using an iPad with a MyTalkTools application. After training, the communication partner independently implemented using the iPad to facilitate communication with the youth with S/MD.

During this phase, some modifications were necessary for each youth depending on each youth's individual needs. These modifications were made by me and the communication partner together, insuring the communication partner understood the reasons for these modifications (see Appendix B for equipment materials). Specific processes in these modifications are described in detail in Chapter IV.

The overall aim of the intervention was to increase the quality and quantity of family/youth communicative interactions in two ways: (a) to increase the youth's appropriate expressive communication skills and (b) to decrease the youth's inappropriate behaviors used in lieu of appropriate communication skills. Data collection during this phase consisted of participant interviews as well as observations of the communication among family members with the youth with S/MD to gauge the effect of the training program upon family communication and to document ways in which the FCT training impacted communication interactions among other family members.

Method

Participants

The sample used in this study was a purposeful sample based on specific inclusion criteria. The rationale for using purposeful sampling was to select cases that provided the most information-rich data; this allowed me to gain insights and understandings of the phenomenon in question (Merriam, 2009). Participant dyads of mothers and their daughters were recruited from the Association of Children with Disabilities (ACD) Center in a large city in Saudi Arabia where their daughters had attended primary school. I contacted the Director of the ACD Center and scheduled a face-to-face meeting so I could describe the purpose of my study and request participants. At the meeting, I provided the Director with a written summary of my study in Arabic and showed him the informed consent form I would use in the study (also written in Arabic). The Director was eager to support my research study and offered to help recruit alumni of the school who met the criteria of my study as well as to provide space for me to hold training sessions with parents. I was provided with four names and phone numbers of potential participant dyads who met the criteria set forth in this study. I contacted each of the potential participant dyads and met with them to discuss participating in the study. Although all four of the potential participant dyads were interested in participating, one family was moving to another city during the time of the study and could therefore not be included. However, the other three participant dyads agreed to take part in the research study.

The three participants of this study consisted of family members of youth with S/MD living in Saudi Arabia. Each participant served as the primary communication partner for the youth with S/MD within their family. Selection criteria for family member participants included:

1. Families who had a young family member with severe or multiple disabilities including communication disorders,
2. Families whose main communication partner was a female family member (in concert with how Saudi society is structured), and
3. Families with youth with S/MD who did not have experience using an augmentative communication device prior to the study.

The three participants recruited for this study were Maha, Noora, and Sara. Each of these participants had daughters with S/MD, resulting in a profound communication deficit; these daughters served as the daughter-participants. Their daughters were all between 18 and 22 years of age, had finished their formal education at around age 12, and were currently living at home. Each participant dyad is described below.

Maha/Reem. Maha is a 46-year-old homemaker who lives with her husband and four children still living at home. Her oldest three children, two sons and a daughter, are married, live with their own families, and yet visit almost daily with their own children. Maha’s children range in age from 17 to 30. Her daughter Reem, who has S/MD, was 22 at the time of the study. Maha visits her own mother every weekend when her family is at home and can take care of Reem.

Noora/Alaa. Noora is a 45-year-old middle school geography teacher. She lives at home with her husband and five of her six children. Her eldest son is married and lives with his own family. Her daughter Alaa has S/MD and was 18 at the time of the study. Noora is the sole provider in her family. She has a number of female friends outside of her family with whom she often socializes by going out for tea and meals. She also enjoys traveling and has traveled extensively with her sisters, going to Turkey, Dubai, and even to Malaysia on vacation. On her next trip, she wanted to go to France.

Sara/Rosa. Sara is a 38-year-old divorced single parent of six children who all live at home. They range in age from 14 to 22. Her oldest children were twin daughters, one of whom was Roaa, who has S/MD. Sara is a homemaker. Her mother lives with her. Sara's main social outing is going to the mosque when she can get away. Most of the time, Sara is content to stay at home and care for her family.

Setting

All interviews and observations took place in the participant dyads' homes in a large city in Saudi Arabia. Participants also attended a workshop in functional communication training (FCT) and the use of a specific augmentative training device (the *MyTalkTools* app). This workshop took place in a center for children with disabilities that all participants were familiar with as their participant-daughters had previously attended school there.

Data Collection

Prior to starting the study, approval to conduct the study was obtained from the Institutional Review Board (IRB) at the University of Northern Colorado (see Appendix C). Once I received IRB approval, I began the data collection process. In this study, data were gathered in two phases using semi-structured interviews with participants, observations, and document review to fully capture the essence of the phenomenon being explored.

In qualitative research, it is important to collect data that capture the essence of the phenomenon being studied (Merriam, 2009). In this study, this was primarily done through interviews with participants whose lived experiences contributed to developing understanding and insights into the phenomenon being explored. Collecting multiple sources of data by using several data collection methods increased the trustworthiness of this qualitative research study. Both qualitative and quantitative support data were gathered to answer the research questions. According to Yin (2014), it is not the differential use of qualitative and quantitative data that distinguishes different methodologies but the use of those data in analysis, reporting, and discussion.

During the first phase of the study, qualitative data were collected through semi-structured interviews with participants, observations of mother-daughter dyads in their homes, and through a review of documents. In the second phase of the study, qualitative data were captured using follow-up interviews of participants and observations of mother-daughter dyads in the home. Quantitative data consisted of discrete counts of behaviors of participant-daughters using partial-interval recordings gathered during the observations using data sheets in both phases of the study. Observations were videotaped to allow me to review and confirm both qualitative and quantitative findings.

Throughout the data collection process, I kept a fieldwork journal. I used this journal to write down my thoughts, ideas, and reflections throughout the research process. Merriam (2009) suggested that using the researcher's impressions and experiences noted during the data collection process could provide additional richness to the study description. Additionally, my fieldwork journal served as an audit trail documenting my decision-making processes as I conducted the research.

Interviews. The primary source of data for this study consisted of interviews with family members of young adults with S/MD. Interviews are a frequently used approach to capturing the experience of participants in qualitative research. This approach offers an opportunity to explore factors that cannot be acquired in other ways such as through reviewing documents and artifacts or through observation (Merriam, 2009). The use of interviews, in particular the use of semi-structured and open-ended questions, provided participants with the opportunity to openly discuss topics they might not have talked about previously. The individual interviews allowed me to explore the personal experiences of the participants while also including their emotional, social, and cultural perspectives.

For the first phase of the study, I developed a set of semi-structured questions based in part on previous interviews taken from the literature and in part from items on a communication matrix (Rowland, (2011). These questions were designed to capture each participants' experiences of parenting a child with S/MD and communication challenges and to establish a sense of what life was like for these families. An initial list of questions was submitted to a fellow researcher, a professor of Special Education working in Saudi Arabia, to check the questions for accuracy of wording and appropriateness of the interview questions as they related to the research questions. Feedback from this person was incorporated into the final list of questions. I then translated these interview questions into Arabic and sent them to a doctoral student in Special Education who was originally from Saudi Arabia to review the translation for accuracy and understandability. Her feedback was then incorporated into a final interview guide of 22 semi-structured questions.

I then developed an interview protocol that was followed during each interview session. After contacting participants by telephone, I met with each participant individually in her home at mutually agreeable times. Before starting the interviews, participants were asked to sign an informed consent form (see Appendix D for English and Arabic versions). In addition to a brief explanation of the purpose of the study, the informed consent forms contained a permission statement for using an audio recorder for the interview. I read the interview questions aloud to each participant and their responses were then audio recorded. During the interviews, participants were often asked follow-up or probing questions to clarify their responses or to elicit additional information. I also took notes in my field note journal during the interviews, highlighting things of particular interest that emerged from the interview and jotting down follow-up questions. Each interview lasted approximately 90 minutes.

The post-intervention interview questions used during the second phase of the study were designed to capture the changes that occurred after the participants received training in functional communication and had started using an AAC device at home to assist their youth with S/MD to communicate better. The 21 semi-structured interview questions were also developed based in part on existing research that included interviews found in the literature and from a communication matrix (Rowland, (2011). These interview questions were also reviewed by the same colleague as were the first questions before being translated to Arabic and reviewed for accuracy (see Appendix E).

Observations. Observations are often used in qualitative research to capture quantitative examples in support of the phenomenon being studied in a natural environment. This data collection method is used to note daily activities, nuances of behavior, details in the physical environment, as well as verbal and non-verbal communication between participants. Therefore, observations can provide a wealth of detail that might otherwise be missed and add to the thick description of the study (Creswell, 2012). According to Merriam (2009), observations can also be used as a method for verifying and triangulating the findings from interviews and artifact reviews. In this study, observations were used to substantiate the interview findings and assist in collecting quantitative data. The observations were used to record the communication interactions between the participants and the daughter-participants with S/MD during daily activities as well as any other communication partners present.

At the start of the study, I described the purpose of using observation to the participants and explained I would be a non-participant during the observation. A non-participant role requires the researcher not engage with the participants during the observation but instead watch the interaction without comments and take field notes from a distance (Creswell, 2012). I requested the consent of each participant to video record the daughter-participant. This was included in the informed consent form each participant signed (see Appendix D). Each observation was recorded using a video camera and lasted approximately 10 minutes.

To make sure the communication and physical behaviors I observed were representative, I observed the daughter-participant with S/MD in several different settings both before and after the intervention. Each youth was observed in three different settings: during a meal experience, a free-time experience, and a play experience. During the observations, I wrote notes in my field journal about the communicative interactions that took place between participants and their daughter-participants, focusing on the context of the communication.

Document review. Participants were asked to provide documents related to their daughter-participants with S/MD. They provided medical documents that offered information about their children's condition: age of onset, medical diagnosis, and general health. They also provided educational documents that detailed their children's academic records; level of academic proficiency in reading, writing, math, and religious studies; as well as documents written by related service providers. These documents included detailed assessments of their special needs as well as educational goals and offered insights into strategies that had been used to support the children's communication and physical development until they left school at 12 years of age. A thorough review of the documents was conducted. This third source of data was used to add thick description to each case, to support the findings from the interviews, and to triangulate the data.

Quantitative data. The quantitative data consisted of discrete counts of occurrences of behaviors of the daughter-participants with S/M in three observations of 10 minutes each using a partial interval schedule. Quantitative data were collected through observations of daughter-participants at home in the course of daily routines during both phases of the study using data sheets (see Appendix F). The data sheets allowed me to determine baseline levels of each young adult's physical and communication behaviors prior to the intervention in the first phase of the study and record changes in the same behaviors in the second phase of the study following the intervention. Examples of the physical behaviors observed included the young adult body posture, especially whether they bowed their head down or held it up to look at their communication partner; facial expressions including frowning, smiling, and laughing; and aggressive physical behaviors including pushing things aside, kicking, or hitting other people. Examples of the communication behaviors observed included initiating and responding to communication with others; using words, sounds, and gestures when communicating; and screaming or yelling as a form of communication with others.

Because it was very challenging to accurately record behaviors, some of which could happen at the same time, video recordings of the observations were used to assist in collecting these data. In this way, I was able to review the video and record the presence and frequency of each behavior in a 40 second time period during each of the three specific situations: meal time, play time, and free-time. This allowed me to collect accurate data of the daughter-participants with S/MD both before and after the intervention and to be able to analyze the data with the confidence that I was in fact comparing the same behavior in the same setting before and after the intervention.

Data Analysis

The goal for analyzing the data collected during this study was to gain an in-depth understanding of the experiences of families of youth with S/MD with significant communication challenges using their own words. In qualitative research, data are analyzed by organizing and reducing the data into smaller, coherent segments and then clarifying the themes that emerged from the often multiple sources of data used in the study. From this analysis, interpretations are drawn and conclusions are reached (Creswell, 2012). The data used in this study consisted of participant interviews, observations, and a review of relevant document.

The data analysis process consisted of several steps including organizing, coding, and comparing data from several sources (Merriam, 2009). In this study, data were analyzed in two phases. In the first phase, data from each case were analyzed to gain insight into each case. In the second phase, a cross-case analysis was conducted to determine similarities and difference across the cases.

Interviews. After the data were gathered, I prepared them for analysis. The interviews, which were conducted in Arabic, were transcribed into written Arabic. I decided to do this myself because the Arabic dialect of the participants could be difficult for others to understand and I wanted to ensure the nuances within the interviews were captured by a native speaker. Once I had transcribed the interviews, I asked each of the three participants to read through her interview transcript and make any clarifications. None of the participants wanted to make any changes. Therefore, I translated the interviews into English myself. I asked a Saudi colleague, who had studied in the United States and who was fluent in English, to review my translation to ensure it was accurately translated. Once the interviews were transcribed, translated and reviewed, they were stored in individual folders for each case on my laptop. I also transcribed my observation notes and field notes, scanned the documents used in the document review, and added these to the correct folder.

The methodological framework used to analyze the data was the constant comparison method--where similar segments of data are identified and isolated before being compared with one another in order to determine similarities and differences (Merriam, 2009). This required a systematic approach of searching for patterns among words, phrases, and concepts before coding these patterns into categories. The criteria for identifying these patterns and assigning codes to them followed the recommendations described by Lincoln and Guba (1985). Segments revealed information relevant to the research questions; these segments represented the smallest possible piece of information that could stand by itself and still be understood without any other information. Examples of such segments could be single words such as “hit” or “bite” or phrases such as “inappropriate behavior.” After a number of these segments were identified, they were grouped into basic categories. The basic categories were then grouped into larger categories or patterns that were then arranged according to their relationship with other patterns to identify core categories; each core category shared common conceptual elements. These categories needed to relate to the purpose of the study, were exhaustive in that all relevant elements were accounted for, and were mutually exclusive--the relevant elements clearly related to one and only one category. Categories also needed to be sensitive to the meaning within the data and to reflect substantially the same conceptual level; Merriam (2009) termed this conceptually congruent. Then within each core category, themes and subthemes were identified by separating out distinguishing characteristics within the core category.

The analysis process required multiple readings of all the data for me to become fully immersed with the data. As long as I found something new or gained more understanding, I continued the process of rereading through the data. To track my insights, discoveries, and new considerations upon each reading, I used different colored pencils every time I went through the data and used tables to help me visualize the connections as well as the differences between the cases. My criterion for adequate engagement with the data was when I reached a point at which additional re-readings of the data no longer yielded new ideas or information.

Observations. Several video-recorded observations were made of the daughter-participants in several different settings with the youth with S/MD. Observations lasted 10-15 minutes in each situation; situations included meal time, free time, and play time with each youth. During the observations, I took notes of the communication interactions in my field journal. After the observations, I viewed the videos and made notes on the data sheets. To confirm the data captured provided an accurate picture of the communication interactions between the participant and her daughter with S/MD, five minute segments of the video observations were used for each situation before and after the interventions. The video was played for 30 seconds before being paused. Then I noted the physical and communication behaviors I had seen before returning to view the next 30 second segment. Using the observation data sheets, I examined the physical and communication behaviors including types of communication (initiation, response, request) and noted the frequency of each communication behavior, the duration, and whether the behavior of each daughter-participant was appropriate or challenging.

Observation field notes, which focused mainly on the environment and context of communication between the participants and their daughter-participants, were transcribed into an electronic document and these data were used to support participants' statements regarding the communication that occurred in the home as well as to assist me in making suggestions to each participant regarding the customization of their iPad and MyTalkTools app. After I finished viewing the observation videos, I transcribed the information into electronic data sheets for analysis. Data gathered from the observations allowed me to make direct comparisons between the youth's physical and communication behavior before and after the intervention and to evaluate the impact of the FCT training on family communication interactions involving the youth with S/MD.

Document review. I conducted a thorough document review of all materials provided to me by the participants including reports that offered information about the medical diagnosis of the youth with S/MD, educational reports from the youth's school years, and annual specialist related service reports, including physical therapist, occupational therapist, and speech-language therapist reports. The rationale for including the document review was to triangulate findings from other data sources. In my study, the data collected through document review supported participants' statements about their child's medical diagnosis as well as services they received while they attended school. This third source of data was used to add thick descriptions to each case, to support the findings from the interviews, and to triangulate the data.

Field notes. My field notes consisted of observations and notes taken during interviews, observations, and the document review. They also included comments written during the FCT training. These were summarized in terms of evaluating the participants' acquisition of specific skills, challenges they encountered during acquisition, questions asked, and successes experienced by the participants. The field notes were used to triangulate the findings.

Qualitative Research Rigor

Because qualitative research often relies on seemingly subjective interpretations of data rather than on a quantitative analysis of numerical data, it was critical that procedures to ensure the integrity of the research were followed. To ensure my findings were reliable and valid, I used the following validation strategies to establish trustworthiness: credibility, transferability, and dependability.

According to Merriam (2009), credibility, which is also known as internal validity, is established when researchers capture the participants' experiences, viewpoints, and reality with a high degree of accuracy. Qualitative research is credible when others who share similar experiences recognize the researcher's interpretation of the findings as his/her own. I used triangulation of multiple sources of data along with thick descriptions and member checks of the findings to ensure the credibility of the study.

Transferability is the extent that research findings can be applied to other individuals, settings, and situations (Merriam, 2009). While generalizability is not considered a goal of qualitative research, providing sufficient description of the phenomenon being studied increases the possibility future readers would identify aspects that could be generalized to their situations. In this study, I used two strategies to address the transferability of the study: the use of thick description and purposeful sampling. Using thick description, I presented a highly detailed and descriptive reporting of the settings, participants, and findings of the study. For purposeful sampling, I applied the process of selecting a sample based on pre-determined criteria to recruit participants who experienced the unique phenomenon being studied.

In qualitative research, dependability refers to the degree the research findings could be replicated if future studies were conducted in similar situations (Merriam, 2009). Because qualitative research often addresses phenomena experienced by a sub-set of people in a population and because the settings for qualitative studies can be highly individual, ensuring dependability can be challenging. Creswell (2012) suggested several strategies to increase both the validity and reliability of qualitative research: the use of triangulation, thick description, member check, and an external audit. In addition, clarifying researcher bias could increase the dependability of the study as well as carefully documenting the procedures used to generate and interpret the data (Merriam, 2009).

Triangulation. One of the most powerful approaches in ensuring the trustworthiness of qualitative findings is the use of triangulation. According to Merriam (2009), cross-checking and confirming findings by using multiple sources of data can enhance the internal validity and, therefore, the transferability of the findings. Triangulation can also reduce researcher bias since several sources of data are used to support the findings. In this study, I used multiple and different sources of data including interviewing family members of youth with S/MD, observations of participant-daughters in both phases of the study to provide quantitative support data, and artifacts such as medical and school reports to achieve triangulation. This approach helped in corroborating the evidence from various sources to inform perspectives or themes (Creswell, 2012).

Thick description. A high quality qualitative study yields a wealth of data about the phenomenon being studied. By providing rich narrative description about the individuals who participated in this study and the context of the study, I hoped to provide readers with a sense of the reality in which they lived. Similarly, by describing themes that emerged from the data using direct quotes taken from participant interviews, I sought to support the external validity of the study. To increase the credibility of the findings in the study, I cross-checked participants' statements with the findings from observations and artifacts and described the findings using thick description.

Member checks. The use of member checks is a strategic process of double-checking the emerging findings with the source from whom those data were obtained by verifying the findings with the participants to rule out misunderstandings and misinterpretations (Creswell, 2012; Merriam, 2009). To document this verification, I recorded participants' reactions to the researcher's findings, noting agreement or writing down alternative suggestions from participants. In addition, I asked participants to review a transcript of their interview and provide comments and feedback as to the accuracy of the information.

External audit. I asked a peer from Saudi Arabia to read and comment on the interview questions in both languages, Arabic and English, to scrutinize the congruent meaning in both languages, and to read the findings that could provide an additional check on the effect of the researcher's stance. Additionally, an English-only speaking peer was asked to verify the themes that emerged from the interviews and to help clarify my descriptions of the context of the study.

Audit trail. A strategy I used to establish consistency included taking field notes and keeping a reflective journal. This provided an audit trail of the deductive and inductive reasoning I used to aid me in understanding and decision-making. Additionally, the audit trail assisted others to perceive how I developed and organized ideas and generated explanations.

Researcher bias. Controlling for researcher bias is an attempt to reduce as much as possible the influence of bias throughout the study as a result of personal beliefs and expectations and is accomplished through processes of reflectivity (Merriam, 2009). Reflectivity can be defined as the acknowledgement of researchers' personal stance and their awareness of their own biases, beliefs, and perspectives in order to be alert to their intrusion into the search for participants' perspectives and meanings. Among others, Creswell (2012) recognized that researchers necessarily have their own personal stance and their processes of research from beginning formulations of possible questions to a final report detailing the findings reflected this personal stance.

My cultural background as a Saudi Arabian national and a devout Muslim coupled with my professional background as a special education teacher working with students with S/MD have shaped my experiences of the phenomenon I studied. These experiences have shaped my conviction that many students with S/MD are more capable than their disabilities suggest; providing them with opportunities to display their abilities could have positive and wide-reaching effects, both for them and for their surroundings. Additionally, families who have children with disabilities often need unique supports and are in need of the kind of positive, empowering interventions demonstrated in my research study. Being a devout Muslim, I take the advice written in the Quran about children seriously. According to the Quran, all children are entitled to an education as well as spiritual guidance and religious learning. The physical, emotional, and spiritual wellbeing of children is the responsibility of all who care for them.

To address the possible influence of my personal beliefs and experiences during the research process, I took several steps to ensure the objectivity of the study. I was in close contact with my research advisor during all phases of the study, discussing the research methodology, design, and procedures to limit any potential biases. I have used both English-speaking and Arabic-speaking peers to review materials and provide constructive feedback, which have been incorporated into my documents as well as the written narrative in this dissertation. I also kept a reflective journal to record my personal beliefs, perspectives, and positions as they emerged throughout the study. I used this journal during interviews to add my thoughts and notes as well as during the data analysis process where I bracketed my personal values and ideas.

Table 2

Summary of Strategies to Ensure Trustworthiness

Criteria	Strategy
Credibility	Triangulation Clarifying Researcher Bias Member Check Thick Description
Transferability	Purposeful Sampling Thick Description
Dependability	Triangulation Thick Description Member Check Audit Trail

Ethical Considerations

Before starting my study, I obtained permission to conduct this research study from the Institutional Review Board (IRB) at the University of Northern Colorado (see Appendix C). I developed an informed consent form that detailed the purpose of the study, the rights of the participants, and the risks and benefits of participating (see Appendix D). I read this document with the participants and made sure they understood their right to withdraw from the study at any time before requesting they sign it. I also described the actions I would take to ensure the participants' confidentiality and how I would handle the data from this study. By explicitly addressing these ethical considerations, ethical rigor was upheld from the start of the study.

Confidentiality Measures

Although it was not possible to guarantee the anonymity of the participants, every effort was made to ensure their confidentiality. No data were collected until IRB approval had been received and participants' consent forms were obtained. To protect the identity of the participants, pseudonyms were used in all written reports.

Data Handling Procedures

All interviews including the audio-recordings, written transcripts, and field notes were stored on a password-protected computer in a locked cabinet in my home. The researcher and the researcher advisor were the only persons able to access this data. The signed informed consent forms were kept in a locked cabinet in my advisor's office. Data connected to this study will be kept for a period of no longer than three years starting from the first day of the study. After three years, all data connected to this study will be deleted.

CHAPTER IV

RESULTS

This chapter provides an ethnographic description of three cases of mother-daughter dyads: Maha and Reem, Noora and Alaa, and Sara and Roaa. Each of these cases is written as a narrative story with details taken from interviews, observations, and review of documents. I used the interviews to gather demographic information and gain insight into the lived experiences of each of the participants as parents of daughters with S/MD. Additionally, interview data were used to become acquainted with the communication opportunities and practices for those youth with their family members and the ways they interacted together in the home setting. In this chapter, each case story is presented individually to discuss the three phases--before and during the FCT workshop on using the communication app on the iPad as well as after the intervention was implemented by each of the participants.

Following the case stories, details of the cases are compared and contrasted to form a cross analysis of the themes that emerged from the interviews as well as changes that occurred as a result of the intervention. Similarities and differences in each case are then examined. This cross-case analysis was based on interview as well as observation data and illustrates the impact this intervention had on the participants and their youth with S/MD.

Life Stories of Participant-Dyads

Maha and Reem's Story

Biography. Reem is a 21-year-old young woman who lives with her family in a large city in the Kingdom of Saudi Arabia. She is the fifth of seven siblings with three brothers and three sisters and she is the only sibling with a disability in her family. Reem's mother Maha is a full-time housewife and the primary caretaker of her daughter.

Diagnosis. When she was 1-year-old, Reem was diagnosed with cerebral atrophy. Maha was told this condition was due to a pre-term delivery during which there was diminished oxygen to the child's brain. As a result of her condition, Reem has an intellectual disability, a physical disability, and a speech and language disability. Until she was 12-years-old, Reem attended elementary school in an exclusive setting for students with special needs. School records revealed along with basic classroom instruction, Reem received several related services including physical therapy, occupational therapy, and speech therapy. A number of assessments in the school records included a cognitive assessment by a school psychologist who identified her intellectual disability with an intelligence quotient (IQ) of 61.

Education. Reem's academic development was slow and much delayed. At school, she learned basic academic skills and was able to identify the alphabet, individual letters and letters at the beginning of a word, numbers up to 50, shapes and colors, addition with zero up to 10, and gave the name of a number of animals and expressed their sounds. Currently, Reem knows the five prayers in the day and can identify the word God (Allah). While she recognizes money and understands how much basic supplies cost, e.g., candy or juice, Reem does not seem to understand the cost of expensive items such as a handbag or jewelry. Due to her physical disability, Reem is unable to hold a pencil or write her name.

Services. Reem is currently in her early 20s. Maha reported her daughter's verbal communication is like that of a 5-year-old, which seems to correspond with her academic abilities. Although she made some academic progress at the school she attended, her mother felt the primary benefit of elementary school was social. At school, Reem received speech therapy; her mother believed this helped her to improve her speech and increase her conversation skills. Attending the school for students with special needs gave Reem a chance to interact with other students and to spend time outside the home. However, for the past 10 years since she left elementary school, Reem has remained at home, receiving no specialized services and interacting only with her extended family. Prior to the intervention, Reem spent her days watching television or YouTube, playing on an iPad, using her mother's cellphone to call her relatives, or occasionally playing games or coloring.

Setting. Reem and her family live in a large expensive house enclosed by a gated courtyard owned by her family in a new and upscale neighborhood in their city. This area is quiet and the people who live there are considered to be upper class and well to do. The two-story house has a special entrance for Reem's wheelchair that was built when the family moved in. Since Reem's aunts live on the first floor and Reem and her family live on the second floor, the house has an elevator. The living room is spacious and airy, furnished with a black and light gray corner sofa that wraps all around the three walls of the living room. Several coffee tables face the sofa with a special semi-circular wheelchair accessible table for Reem on one side. A large-screen television faces the sofa. Reem’s family uses this comfortable room for family activities, watching television, eating meals, teatime, and play space for children who are visiting. In Reem’s family, the women pray in their rooms while the men go to the mosque to pray.

Communication. Due to her physical disability, Reem’s speech is often unintelligible to anyone who does not spend time with her. Although talking is the primary mode of communication at home, Reem’s communication is limited to single words and very short sentences. Although Reem can request specific things, saying, “I want this, I want that,” much of her communication is limited to answering yes or no questions. Based on the report by her speech therapist in 2005, Reem was able to pronounce several one-syllable words. She could speak short two- or three-word sentences that were intelligible about 40% of the time; however, this percentage might be increased if Reem’s communication partner was familiar with her and the topic at hand. There are several differences between the pronunciation of Arabic and English sounds; some Arabic sounds have to be made from the middle of the throat and some from the front of the tongue with closed teeth. Of the six sounds from the throat, Reem was able to pronounce only one sound at 30% of intelligibility and only one sound from the front of the tongue at 40% intelligibility. Reem’s speech therapy goals also included increasing the motor control of the muscles in her mouth and throat. Her speech therapist noted Reem was able to blow bubbles into water using a straw. She also made progress in chewing food by moving her tongue and controlling her bottom lower jaw, which decreased saliva production. In the final report from school in 2007, the speech therapist reported Reem was able to say some words consisting of two syllables and sentences with two to three words at 50% intelligibility as well as say some one-syllable verbs.

Because her mother and the maid are her primary caregivers and spend most of the time with her, they are the ones who understand Reem’s speech most clearly. Although Reem talks to every member of her household, misunderstandings arise due to her garbled speech. Maha is usually present to help clarify what she says and to explain to others. When her family asks Reem a question, she usually directs her answer to her mother who then translates her replies to her family. Because of this, other family members tend to limit their communication to simple request interactions. In addition to her mother, the maid, and her youngest sister, Reem’s main communication partner is her aunt who lives downstairs. When they are together, her aunt speaks to her at length and asks Reem to share what is happening in her life.

Daily routine. Reem spends her day watching children’s programming on television. She received a short training class on a drawing and coloring computer program and has played educational games on the computer. Her experience with these activities on the computer helped her learn to play games and to use the coloring and drawing app on her iPad. Reem also enjoys watching YouTube.

Reem’s morning routine is similar to the rest of her family; she gets up, gets dressed, and completes her morning care routine--brushing her hair, her teeth, and washing her face with assistance from her mother--before eating breakfast. She spends most of her day in the living room, sitting or lying on the floor, or sitting in her wheelchair at her table. Because she needs to keep her legs straight, Reem prefers to sit on the floor, resting against the sofa when she watches television. She eats her meals with her parents and plays with her younger sisters and her nieces and nephews. Occasionally, Reem goes with her family to a local mall for shopping. Once a week

Reem goes downstairs to spend time with her aunts, whom she adores; this is the only real time she spends out of her family's rooms. When her uncle comes to visit, he likes to joke with her and tease her to Reem's delight. At night, Reem sleeps in a bedroom she shares with her parents.

In the evening, Reem participates with her family for the evening meal and spends time with her siblings, niece, and nephew until approximately 9:00 p.m. Her bedtime routine mirrors her morning routine; her mother or the maid help her brush her hair, clean her teeth, and put on her pajamas. Then she goes to her parents' bedroom to sleep.

Behavior. Reem is generally an easy-going person. However, Maha reported Reem often becomes frustrated when she is not understood. If she is trying to convey something to a family member, she often has to repeat herself many times to be understood. Sometimes even her mother does not understand what Reem wants. Then Reem becomes very upset and so angry she screams. Reem also likes to get her way when it comes to deciding what to watch on the TV, what activity the family does together, even who gets to talk on the phone. If she does not get what she wants, she gets angry and will scream, kick, drop onto the floor, and yell very loudly. Reem's father is very gentle and lenient with her and does not give her the same consequences for her behavior he insists on for her siblings. So Reem is used to getting her way when he is at home. Maha, on the other hand, describes Reem's behavior as stubborn and insistent and tries to discipline her when she misbehaves. According to Maha, Reem behaves more appropriately when she is alone with her mother and the maid than when the whole family is present. This might be in part due to the fact that they understand Reem better than the rest of the family and they do not challenge her desires as much.

Medical history. A summary review of medical records indicated Reem's disability was the result of oxygen deprivation during her pre-term birth. She does not have epilepsy and, therefore, does not use anti-epileptic drugs. She underwent soft tissue tightness release surgery in 2005. In terms of motor skills, she is able to roll over, sit, and pull herself across the floor but she cannot crawl, stand, or walk. She has a convergent squint and wears glasses to correct this; her hearing is within the normal range. Reem has poor fine motor coordination and control; although she can hold a pencil, she only holds it with two fingers and can scribble. She does not have the motor control to write letters or numbers but she enjoys drawing on paper with colored pencils and markers. Reem has moderate to severe spasticity in both lower and upper extremities but almost full passive movements of the joints in her upper and lower limbs. Since she was a baby, she has suffered from ongoing constipation, which is relieved by biweekly enemas.

Independence. In terms of her self-help skills, Reem needs assistance from others for many tasks of daily living. Her speech therapist estimated Reem was only independent in 30% of her daily living activities. She can feed herself using her fingers, a spoon, and can also drink from a cup without spilling. She can undress herself but needs assistance in dressing, brushing her teeth, and toileting.

Interests. Reem's interests are limited to watching children's shows on the television, using drawing apps on the iPad, and attempting conversation with a few family members. She has a passion for collecting handbags and her siblings occasionally take her to the local mall to go shopping for a new handbag. When asked what she wants for a present, she always says "new handbag!" In Saudi Arabia, there are few opportunities for individuals with disabilities to participate in the community. Public areas such as parks, restaurants, libraries, gyms, and pools are not usually accessible for individuals in wheelchairs; culturally, it is uncommon for families to take their disabled family member with them when they go out. Adapted toys, games, and equipment for individuals with disabilities are not readily available. Additionally, traditional cultural parenting in Saudi Arabia consists of taking care of their children's needs rather than playing with them or interacting with them.

Mother's goal(s). When asked about her goals and wishes regarding communication between family members and Reem, Maha wished "that Reem would speak on her own without having to be asked." Her mother hoped to improve Reem's verbal communication skills so she could engage in conversations with her family members and speak fluently with everyone and not only with her mother. Also, Maha wished for Reem to be able to sit on a regular chair by herself and control her emotions better:

> I want her to improve her manners; how to respect her parents and treat them and how to treat her siblings, and to learn to pray. Her behavior is more important. I want her to respect everyone and not be stubborn. …But I want her to learn this from someone outside the house, not from me, because she will accept teaching from other people, and with me she acts stubborn and does not accept teaching because I am with her all the time.

Noora and Alaa's Story

Biography. Alaa is 16-years-old and lives with her mother Nora and her family in a small traditional house consisting of nine rooms, two living rooms, a kitchen, a guest room (not used), and three bedrooms and two bathrooms; it is located in a mountainous area in an old province neighborhood in a large city in the Kingdom of Saudi Arabia. Alaa is the sixth child of seven; she has a twin sister, two brothers, and two other sisters. One older brother is married and does not live in the house. One sister is also married with two young boys, all of whom live in the family home. The married sister and her two boys, along with the sister's brother, occupy one bedroom, the parents use the second bedroom, and the remaining three sisters, including Alaa share the third bedroom. An older sister who is attending medical school uses the second living room as a combined bedroom, study, and social area.

Diagnosis. Alaa is the only child in the family with a disability; she has cerebral atrophy and tetraplegia cerebral palsy. Nora noticed Alaa did not move or sit like her twin sister and took her to the doctor for an examination when Alaa was seven months old. The doctor took X-rays and found Alaa had cerebral atrophy and tetraplegia cerebral palsy. While he was able to provide a diagnosis, no early childhood services were referred to her for treatment. So Nora began to read about her daughter's disability when she was 2-years-old and followed up with doctors and hospitals. When she enrolled Alaa in the DCA, she learned more from the lectures given by the therapists there (physiotherapist, occupational, and speech).

Alaa's early development was different from her twin sister. Her sister met conventional milestones for crawling, standing, and walking as well as communication and playing. Alaa was not as independent as her sister and her medical report confirmed delayed milestones and slow physical development. This report also noted the presence of hyperaflexia, spasticity, and hypertension with a recommendation for physical therapy and rehabilitation.

Education. Based on a notebook Alaa received at school, she studied math, science, literacy, and Islamic education. In literacy, she learned the alphabet and the shape of the letters at the beginning, middle, and end of a word (in Arabic, the shape of letters changes depending on their position in a word), vowel sounds, and the correct order of words in sentences. She could recognize her first name independently. In science, Alaa learned basic physical concepts such as cold and hot, fast and slow, soft and hard. She explored the movement of things in the environment, learned about the 12 months of the year, as well as about animals and their characteristics. She was also introduced to community studies such as public safety, parks and recreation opportunities and street maintenance, ironically including cleaning roads. In Islamic education, she learned about the five prayers during the day, how to clean herself when going to the bathroom, and how to honor her parents. For math, no information was available about what Alaa had learned in the school. Towards the end of her schooling, Alaa received a three-day training in using drawing and painting programs on the computer and some educational games. This short training session helped her to use her cellphone and her tablet for fun during her day.

Services. When Alaa enrolled in the DCA, she received related services including physical and occupational therapy as well as classroom instruction. Her movements became more controlled and purposeful and her walking improved once she received therapy. When she was at school, Alaa used a walker to move between classroom activities. Alaa finished elementary school at age 12 and has not received any further services in the subsequent four years, remaining at the home with her mother, her adult siblings, and her nieces and nephews. Alaa now spends most of her day sleeping in the shared family living room and watching the television in that room during the night.

Setting. To get to Alaa’s house, I parked my car two miles away and had to walk through the trash-filled, unclean, stinky, and crowded streets, jostling other people as well as colonies of feral cats. This province neighborhood is noisy and crowded. Many people throw their trash straight onto the street, resulting in frequent bad smells. It is an old neighborhood with unimproved alleys and narrow streets that allow only one car at a time. There are no sidewalks in this neighborhood and not enough parking for the residents who live there. I had to climb several stairs just to reach the house entrance. Although the house is essentially one level, nearly every room has one or two high steps, going either up or down, making it impossible for an individual in a wheelchair to navigate independently.

Communication. Alaa has a significant speech disability and communicates only with her mother, her twin sister, and the housekeeper, who understand her. Although Alaa is usually a quiet and easygoing person, she occasionally becomes very angry and upset when she feels frustrated. She sometimes explodes into physical aggression such as biting, pinching, or kicking her mother or the maid when they are assisting her. These episodes are also accompanied with screaming and crying, which can last for half a day before she can be soothed. Nora does not know why Alaa does this as Alaa is not able to communicate her frustration to her family. But Nora believes Alaa's frustration is due to the lack of independent physical mobility.

Daily routine. Alaa now spends most of her day sleeping in the shared family living room and watching the television in that room during the night. This does not interfere with other members of the family who watch the television in that room during the day. Under this schedule, she usually gets her breakfast and goes to sleep about 9:00 a.m. Alaa likes to watch the daily talk shows, especially when her father is not watching television. Alaa uses a wheelchair to get around. She can stand when transferring from her wheelchair to the floor or to the toilet but needs full physical assistance when she is out of her wheelchair. She does not have a walker to use at home, and no longer walks at all. Sometimes Alaa eats lunch, which usually occurs after 4 p.m. in Saudi Arabia, with her family in the living room. However, she usually prefers to eat with the maid who feeds her. Usually the family has time together for lunch, teatime, or Arabic coffee with snacks in the evening in the living room, but Alaa does not like to engage with them. She prefers to stay in the room that the three sisters share as a bedroom watching the television in that room or playing with her cellphone.

Behavior. Alaa is depressed and angry about her disabilities because it leads to isolating her in the house. She used to have goals and be eager for all the things she would do when she grew up but, unfortunately, she hardly interacts with others anymore and she is stubborn. Particularly when her verbal communication does not work, Alaa gets angry quickly. She screams, uses bad language (curses), and hits the maid or her mother. Alaa seems to have a nice vocabulary of “trigger words”--words she can use to gain control over her family such as curse words and demands (for money, for “her bank card”, for the bathroom). When she uses these words, she gets what she wants, especially attention from her family and the maid.

Medical history. Based on DCA school records from 2009, Alaa’s IQ measured by the Stanford Binet was 73. An assessment by the physical therapist indicated her physical mobility was acceptable when she used her walker. At school, Alaa was able to crawl on her hands and knees and could sit independently in a classroom chair with arms. It was noted her right side was stronger than her left side. Alaa’s fine motor skills were somewhat affected by her cerebral palsy; although she was able to use both hands, her left hand was weaker than her right. Although she could hold a pen and write, her writing was never clear or legible.

Independence. Alaa's speech was estimated to be 60% intelligible by the speech therapist at DCA. She could say short sentences with lack of clarity of some sounds. For self-care at that time, Alaa was independent in eating and drinking, she could dress and undress herself with minimal assistance, and she could also go to the bathroom with limited assistance. However, in the intervening years since Alaa stopped attending school, her daily living skills have regressed and she now needs considerable help in tasks of daily living. The maid who has been with the family for many years knows Alaa very well; together with Nora, they are the primary caregivers who assist Alaa in these tasks of daily living.

Interests. Alaa loves traveling and eating out. She has traveled abroad twice so far in her life. Her first trip was three years ago when she, her mother, her sister, and her brother went to Malaysia for a three-week vacation. Alaa's second trip was a vacation to Turkey last year. Nora reported Alaa was happy and obedient during those trips. At home, Alaa needs assistance when she goes to the bathroom and uses the toilet. The maid generally provides this assistance. However, taking Alaa to the bathroom is physically challenging for her mother so during their vacation when they left the hotel, Alaa used a diaper to avoid accidents. Nora asked that Alaa not use it for excrement when she was outside the hotel. During these trips, Alaa listened to her mother's request.

When she is at home, Alaa prefers to be fed by her mother Nora or her maid. However, Alaa enjoys eating in restaurants and when the family eats out, she will feed herself with minimal help from her mother. McDonald's and an Indonesian restaurant are Alaa’s favorite places to go, especially the Indonesian restaurant, because it has an accessible ramp and elevator to accommodate her wheelchair, which makes it easy for her family to take her there. Also, Alaa has her own smart phone. She does not use the phone to call anyone; rather she uses apps on the phone. She follows people on the Snapchat app. She likes to follow tourism and watch monster clips or pictures on Snapchat. Alaa also has a few games on her phone she plays every day.

Mother’s goal(s). In terms of wishes for the future, Nora wants her daughter to become more engaged socially: “I want her to come sit with us and have fun with her siblings and joke with them, to initiate and participate in family conversations, be able to be more flexible in accepting suggestions or comments from her family.” For this to occur, Alaa would need to improve her communication skills and tolerance for feedback from her family. Nora stated, “It bothers me that she is so withdrawn, and angers easily… and does not talk to them or play.” Nora also desires that Alaa become more self-sufficient in tasks of daily living, eating by herself, and strengthening her arms and legs so she is more independent in transfers such as in toileting. Alaa’s mother would also like Alaa to learn the English alphabet to extend her learning, create more outlets for expanding her horizons, and enable Alaa to be able to communicate with others when the family travels, often to places where English is commonly spoken as well as the country’s native language: “I wish also she learn English alphabet and some words for she could use them when we will travel.” Finally, Nora hopes Alaa could learn to accept the limitations of her disabilities and reduce the frequently recurring aggressive behaviors in which Alaa engages.

Sara and Roaa's Story

Biography. Roaa is 22-years-old and lives in a big apartment in a nice area of a large city in Saudi Arabia that has both residential and business services. She lives with her mother Sara, her grandmother, four siblings, and two maids; one works for her grandmother and the other works for Roaa's family. Roaa has a twin sister and they are the oldest children in the family. Roaa is the only sibling with a disability in the family. Sara is a full-time housewife and the primary caretaker with the maid and the youngest sister for Roaa.

Diagnosis . Roaa has had tetraplegia and cerebral atrophy since birth but her disability was not discovered until she was 1-year-old. Sara had taken her to the hospital because she had phlegm and they were performing a cleaning for her. A doctor who was present noticed something about Roaa and had an X-ray taken. After he saw the X-ray, he came to Sara and said, "I am sorry sister, but your daughter has cerebral atrophy and will be disabled." At that time, Sara was only 16-years-old when she gave birth to the twins. Also, the twins were born early (at six-months gestation) and stayed in incubators for two months. When Roaa was discharged and came to the house, Sara noticed when she bottle-fed Roaa, her face began to turn blue and her breathing stopped. She thought it was normal and would simply wait until she began to breathe again. This continued for a long time until Sara took her to the hospital and they discovered her disability. A medical report when Roaa was 10 indicated a very low birth weight and a low IQ score. She had surgery to release tightness of hip abductors, iliopsoas, and hamstrings bilaterally to prevent further hip joint dislocation. This surgery helped improve her ability to stand in a walker for longer periods of time and maintain a sitting position with good balance.

Roaa continued to complain of knee pain so it was recommended that physical therapy be continued at home as reported in her medical documents. Sara began to read and understand what this disability was, how to manage it, and also enrolled Roaa at the DCA.

Education. Roaa received her primary education from the DCA. She studied math, literacy, science, religion, and art. Roaa could count and recognize subjects of numbers from 1 through 100. She had skills in addition and subtraction to 10. Also, she read the clock time when it was half past, quarter past, and quarter till. For literacy, she could recognize some letters of the alphabet and sync them with words but she could not distinguish the letters in different places in the words. Roaa is not able to spell or read a word except her first name. She knows the colors, shapes, change of state (solid-liquid), classification (people, plants, animals), and the name of the weekdays. In religion, Roaa knows and prays each of the five times a day, reads some surra in the Quran, and knows the five pillars of Islam.

Services. For the past 10 years, Roaa has been at home after she finished her elementary education at the DCA. Sara could not find a professional place to serve her daughter. Roaa's mother would prefer to put her daughter in a place that could help her daughter to improve her mental and physical skills.

Setting. Roaa and her family live in a large apartment in a building that has a wide and accessible entrance and elevator. The apartment consists of three bedrooms, a living room, two hosting rooms, three bathrooms, and kitchen. This apartment is bright and broad. Roaa usually likes to move between the living room and one of the hosting rooms in which her grandmother stays. She uses her bedroom with her youngest sister for sleeping time only. When she spends time in the living room, she prefers to lie down on the floor, crawl around the room, and play with her two kittens.

Communication. Usually, Roaa prefers to communicate with her mother Sara physically and verbally with limited words. Sara reported she would "lie down on the couch with my arm stretched out, and she would be close to me, so she would stretch out her arm and try to feel my hand and kiss it, and I do the same for her, and then she said I love you Allah save you for me." Sara thinks this kind of communication helps Roaa to feel secure and safe. She can understand Roaa from her eyes and her face expressions even though the words alone are difficult to understand. When Sara and Roaa are at home, they can talk and chat and understand each other but if they are at a family party and someone talks to Roaa, everyone looks at her mother to figure out the meaning of what Roaa is saying. Sara can also understand Roaa's needs from her body movements and shaking, especially when she begins to move a lot; that means she needs to go to the bathroom. If Roaa is tired, angry, or something is bothering her, Sara sees tears in Roaa's eyes and as soon as her mother speaks to her, she cries.

Roaa also attempts to communicate with all her siblings, thanking them and praying for everyone who cares about her and assists her during the day, especially when she asks for help. Roaa has good communication with her sisters, particularly with the married sisters, but sometimes they do not understand her just from her eyes. Her sisters often brush her hair, put make-up on her, and joke with her. This leaves Roaa feeling happy and calm, which then facilitates her listening to her mother and following the rules all day. Roaa likes to be praised about her looks and communication when she is talking with her sisters or aunts. Roaa prefers to communicate with her aunts more than her sisters because the aunts understand her more easily and quickly by watching her facial expressions. Roaa's aunts spend time with her, sitting and talking to her, indulging her, joking with her, feeding her, playing with her, and giving her more attention than the other children in the family. Roaa feels there are people who interact with her and feel she exists. Similarly, her oldest brother carries her and takes care of her when the family goes out by moving her into and out of the car and into the house. He pushes her wheelchair and takes her for strolls so she always prays for him as her way of communicating and tells him, "May Allah never deny me your presence my brother..... May he keep you for me! I love you, thank you."

On the other hand, Roaa's younger brother provokes and angers her very much; although he does care for her and shares with her, he is very moody with her. Likewise, her baby sister only does what Roaa asks because she has to, but reluctantly; she is the only one with her at home. She sees her as a burden but Roaa handles her behavior normally as she treats and interacts with others by saying, "Thank you! May Allah grant you health!" Additionally, when Roaa has a doctor's visit, Sara is the one who responds to the doctor's questions. Sometimes the doctor talks and listens to Roaa and she talks back to him but usually he does not understand what she is saying as it is not clear to him. So Roaa turns to her mother as if to say "talk to him and explain." Mostly she moves her head down and Sara sees "sadness in Roaa's eyes!"

Daily routine. Roaa wakes up, washes herself, has breakfast, and then watches television. Then Roaa slides off by herself from the wheelchair and lays down on the floor so she can move. Sara prefers to keep her on the floor to benefit her body and muscles as she moves and rolls over right and left. Sometimes, Roaa likes to have paper and colors to scribble on and pass the time. After that, she returns to her wheelchair. This is mostly how she spends her morning. In the late afternoon, Roaa takes a nap for a couple of hours; then she wakes up and watches television or movies on YouTube such as cartoons or a series of shows and games on her tablet.

Behavior. Roaa's behavior becomes more problematic when Sara does not understand her, especially when Roaa says a long sentence. For instance, when she asks her mother to cook a particular recipe such as kufta using nice and polite words in a longer sentence that then becomes jumbled and her mother does not understand, Sara often becomes irritated and tells her, "I don't understand, what do you want? Yes, I understand kufta, but do you want me to buy some or make it at home?" Then Roaa clarifies, "Make me kufta." Sara frequently asks Roaa to say what she means more directly (by which she means using fewer words more clearly). But Roaa likes to try to say long sentences and wants to be courteous; she does not want to speak in orders (such as "make me kufta"). She knows it is tiring but she wants to ask nicely. Often, when Sara cannot understand Roaa's requests, she asks Roaa to repeat the request. At first, Roaa does repeat her request a couple of times but eventually her mother becomes irritated and asks Roaa to say it directly. Roaa's reaction is to be quiet and she appears to think about how she can convey what she wants to her mother and then says, "I don't want anything."

Many times, Roaa will soil herself with urine when she is with the maid as a way to gain attention from her mother or siblings. Also, Roaa can be stubborn and insistent. Sara thinks Roaa needs firmness to teach Roaa to act more appropriately with the maid. Her mother feels the maid overly indulges Roaa by doing extra things for her that other family members will not do. But when the maid becomes firm with her, Roaa straightens herself up. The problem is in soiling herself, which Sara perceives as challenging her and the maid. Sometimes, Roaa keeps her mouth open and drools onto her blouse and it begins to have an unpleasant odor. Sara feels Roaa does these things to herself because she wants to get more attention from her family members such as wanting her mother to carry her around and always stay busy with her. Sometimes the urinating and drooling happen when her siblings go out a lot and Roaa stays at home alone for a long time without going out. As a consequence of these behaviors, Sara ignores Roaa for a day by not talking to her or giving her any attention. This leads Roaa to apologize to her mother and to promise not to repeat these behaviors anymore. She appears to want her mother and her siblings to pay more attention to her. Also, Roaa acts badly toward the maid by biting and hitting her while the maid is carrying her, which often happens when Roaa stays at home, does not have a chance to visit, or when she is being neglected by her siblings in the home. She appears to want the maid to get so angry the maid will leave the house, thereby forcing her mother and siblings to communicate with and take care of her.

Sometimes, Sara needs to travel outside the country and she is not able to take Roaa with her, which makes Roaa sad and cry a lot. For example, Sara traveled with her mother for health care to Egypt and Roaa stayed home with her siblings and the maid for three weeks. Roaa was crying a lot, was sad, and even did not want to eat. Sara had explained to Roaa the purpose of the trip prior to leaving. Roaa seemed to understand and accept her mother traveling but after Sara left, Roaa’s behavior worsened.

When I asked Sara if she had gone on a trip before and left Roaa behind, she replied, "Yes, twice, and I left her with my mother." Then when I asked Sara how Roaa responded to her absence, Sara reported although Roaa was initially angry, this anger only lasted momentarily; in general, Roaa seemed content and happy as the grandmother cared for her, spent a lot of time with her, perhaps even more so than Roaa's own mother.

Medical history. Roaa was born prematurely at 28 weeks with a very low birth weight, resulting in a diagnosis of tetraplegia and cerebral palsy, which remained unidentified until Roaa was a year old. She had surgery to release the tightness of hip adductors, iliopsoas and hamstrings, which seemed to help for a while in physical movements. She still complains of knee pain.

Independence. Roaa is dependent on her mother and the maid for all her daily living needs. Mostly, Sara provides Roaa's personal care, cooks favorite foods, and enjoys their free time together. The maid helps Roaa go to the bathroom, cleans clothes, and moves her by lifting her up and down from the wheelchair. Sometimes, Roaa feeds herself by using her fingers to hold a piece of bread but not holding a spoon. She can hold a cup with a straw to drink for a short time.

Interests. When Sara gives Roaa a lot of attention from the beginning of the day, this seems to change Roaa's attitude for the remainder of the day. For example, when Sara wakes up in the morning and kisses and hugs Roaa, telling her, "I love you my heart" and asks Roaa what she would like, Roaa becomes happy and obedient. Also, when Sara announces a special day for Roaa such as going to a restaurant or having a short trip somewhere, telling everyone this activity is for Roaa, this helps Roaa be happy and communicate and interact with the family more.

Mother's goals. Sara's hopes for her daughter in the future are that her speech becomes clearer so people can understand what she is saying. Improved communication skills would enable Roaa to talk more and be able to express her thoughts and feelings with anyone, thereby widening her social circle instead of remaining dependent on the mother and her aunts. "I wish she would talk like her sisters," Sara expressed. She also wants Roaa's youngest sister, who is living with them, to treat Roaa better or play and joke with her more. Roaa's situation is difficult as not everyone can easily handle her. In addition, Sara wishes Roaa could say long sentences as her sisters do because Roaa seems to desire to be more like them. Through longer sentences, Roaa could then be more polite rather than seem demanding. She also hoped Roaa's siblings could give her extra time to listen and understand what Roaa was saying. Finally, Sara remains optimistic about ways for Roaa to improve her life.

Common Themes

Several common themes emerged from the stories: challenges related to communication, a lack of information about disability, a lack of resources and services, and social isolation. The three families shared similar experiences in each of these areas. Each of these themes is described in the following section.

Challenges Related to Communication

The participants shared how their daughter's disability resulted in multiple challenges connected with communication. While the participants generally used verbal language to communicate with their daughters, the youth used a blend of verbal language including individual words and simple phrases, sounds, body language, behaviors, and physical gestures such as pointing with hands, eyes, or head. Much of the communication by the youth with disabilities was idiosyncratic and the participants often felt they were the only ones who were able to understand their daughters. For instance, Sara was able to interpret Roaa's body language but did not believe other family members were aware of this form of communication. Although Reem had some intelligible speech and could make simple requests for food, water, and specific activities, family members often communicated with her by asking very simple yes/no questions. Only Maha and the family's maid, who spent a significant amount of time with Reem, seemed to use all of Reem's communication channels, words, gestures, and behavior to interpret what she was trying to tell them. Over time, Alaa became so frustrated with her family's lack of attempts to understand her non-verbal communication, she spent most of her time alone with the television when her mother was not at home. Although Noora wanted Alaa to be connected to the rest of her family, her lack of verbal communication skills had been a significant barrier to her being able to join in family activities.

The lack of expressive verbal communication among the three daughter-participants had led to their using other means to communicate with variable success. All three participants reported their daughters often used demanding and inappropriate behaviors to get what they wanted. This included screaming or laughing loudly; Reem used this when she wanted to decide which television program to watch during family time. Alaa used inappropriate behaviors when she felt criticized by her family. The participants also shared that their daughters often became extremely frustrated when they were not able to communicate their needs and desires; this frustration often erupted in behaviors such as yelling, hitting, pulling hair, kicking, and biting. The youth also soiled themselves when they were frustrated, knowing this caused their mothers some distress.

Lack of Resources and Services

The participants all mentioned the lack of meaningful day programs for individuals with disabilities in their city. Although Reem attended daily Quran classes, none of the daughter-participants attended a program designed for young adults over the age of 12. This lack of services meant the daughter-participants spent the majority of their days at home with their mothers or the family maid, the youths did not receive specialized instruction in skills, and families did not receive information about resources such as technology, equipment, or effective strategies for managing issues related to their daughter's disabilities. Noora shared the challenges she had experienced in accessing health care for her daughter Alaa. There was a lack of medical and dental treatment available to individuals with disabilities; even private hospitals had refused to see or treat Alaa due to her disabilities. The lack of services extended to a lack of someone outside of the family who could advocate for the needs of the youth with disabilities.

Social Isolation

The lack of outside services also resulted in social isolation for all three daughter-participants and their families. Although Reem was very connected to her family and was included in all family activities, she had few opportunities to communicate with or socialize with people outside of her family. Like the other daughter-participants, Reem did not spend time with friends--only with family. Without a day program or community meeting place, the daughter-participants literally had nowhere they could go to meet peers and connect with friends.

The social isolation of the families increased as their daughters became older. When they were very young, it was easy to take them along on social outings. However, when the girls became too heavy to carry easily, the physical environment outside the home became more inaccessible and it became more difficult to go out. Reem occasionally went shopping with her sisters and Noora took Alaa out to eat at restaurants but these outings were limited to times when someone was available to help carry them between the car and their wheelchair as well as past physical obstacles such as curbs and stairs. Not only were the daughter-participants isolated by their disabilities, their families felt the effects of this as well as their activities were limited by the needs of their daughters and by the lack of wheelchair access in society. Family outings were often planned in advance and a designated caregiver was nominated. For instance, Sara often volunteered to stay at home with Roaa in order for her other children to go out and enjoy themselves. This often put a strain on family members who wanted the whole family to go out together.

Intervention Outcomes

In this section, the processes of interventions and subsequent results of these processes are described in detail for each daughter-participant. As the training started and progressed, adaptations and modifications were made depending on the needs of each youth, the settings, and interactions occurring during these times. Initially, this resulted in a trial by error approach until a modification that was helpful and useful emerged.

Reem

Follow-up at home. When Maha was asked about her hopes for her daughter Reem's communication, she indicated she wanted her daughter to be more independent. She wanted Reem to be able to engage in conversations with her family, to initiate conversations, and to speak with other family members without her mother having to interpret her speech. She also wanted Reem to be less frustrated when she attempted to communicate and to display more respectful manners.

Reem's chief communication frustrations seemed to center around not being understood. Although she had a large and loving family, she had a limited number of communication partners due to the unintelligibility of her speech and the limitations of her conversational topics. Providing Reem with an iPad containing an AAC app was chosen as a way to increase her communication skills, improve her ability to be understood by multiple communication partners, and decrease her frustration.

Personalizing MyTalkTools for Reem. Based on information about Reem collected from the interview, observation, and documents, a communication board of the MyTalkTools on the iPad was created and programmed based on Reem's needs and wants. Reem's MyTalkTools opening screen was programmed with seven categorized folders: food, drinks, free time, clothes, family, going out, and greeting phrases (see Appendix G). Every image used in Reem's MyTalkTools app consisted of a picture of the person, item, or action it represented, the word of the picture written in Arabic, and an audio recording of her mother speaking the word. Each folder contained either communication boards containing six to nine subject cells or sub-files with more category choices. When Reem wanted to call her sister, she tapped on the Family folder. Her Family board opened and she could see all of her family members represented by nine individual cells, which included their pictures, names, and text speech. She then selected the family member she wanted to talk to by tapping his or her picture. Some folders consisted of more than nine choices; in this case, sub-files were used to help organize the contents. For instance, tapping on the Food folder open revealed four sub-files, one for each meal type: breakfast, lunch, dinner, and snacks. When a file was tapped, it opened to reveal a board including the most popular food choices for the family that were difficult for Reem to say verbally.

Introducing MyTalkTools to Reem. I showed Reem the MyTalkTools app on my iPad after the interview with her mother. Reem seemed to immediately grasp the usefulness of the app and started asking her mother when I was going to come back and show her how to use it. Every day when Maha returned from the parent education sessions, Reem asked if it was ready yet. On the final day of the education sessions, Reem's mother came home with her customized MyTalkTools app. She showed her daughter how this app worked and Reem got to try it for the first time. She was very excited about this but she ran into some difficulties with the fine motor skills required to tap on an image. However, because Reem was generally able to use her index finger accurately, Maha decided to let her daughter try to use the app using the stylus included with the iPad.

Maha was asked to document her experience in implementing the intervention with her daughter for a day at home. She was given a journal and was asked to write down how the first day went. Maha included information about her daughter's response to the iPad, which requests Reem made, and how the rest of the family responded to Reem's use of the iPad. I also gave her a data sheet to track Reem's behavior; however, Reem's frustrations around communication decreased immediately and her mother did not mark any behavior outbursts once Reem started using the iPad.

Using MyTalkTools. Maha wanted Reem to start using the iPad during her daily routine at home when she was alone in the house with her mother. The first time the iPad was used, Maha mounted the iPad on Reem's wheelchair and left her watching the television while she went to the kitchen to cook the lunch meal for the family. While she was in the kitchen, she heard Reem calling her by using the iPad a few times. However, at first Maha could not recognize what Reem was asking for. She heard many message sounds at one time so she joined Reem in the living room and asked her to focus on one subject on the iPad. She supported Reem's hand by holding her arm in place, asking Reem to use her index finger to tap on the right picture. With her arm supported, she was able to make several clear requests. First, Reem asked her mother to bring her some water. Then, Reem asked her mother to change the television channel and, finally, Reem called her mother to help her to lie down on the floor to rest. Maha was delighted to hear her daughter communicate with her independently: "It is the first time that I could leave Reem by herself in the living room and go to the kitchen to cook." In addition to saving time, Maha was delighted Reem was safe.

Adapting the iPad for independence. After this first day, I went to Reem's house to discuss her experience in using MyTalkTools with her mother. Maha reported Reem understood the idea of using the iPad to request her needs and wants. She was able to use her right hand with the index finger but she had trouble with the motor skills required to tap a single picture on the screen even when using the stylus pen. When Reem stretched her index finger toward the iPad, her whole hand became tense and she could not control it. To address this challenge, I developed an adapted temporary keyguard to improve Reem's physical response and control her hand motion. The keyguard was created using Duck Brand 1/3-inch wide Silicone Weatherstrip Seal. This material was chosen because it is soft to touch and creates a clear edge. It was mounted directly on the protective screen of the iPad following the pattern of a six-cell communication board. This created a tactile guideline that helped Reem control her hand motion and tap on the target picture.

This simple temporary keyguard solved Reem's motor control issues and she was able to use *MyTalkTools* on her iPad. Reem was able to communicate with her mother and her family members during daily routines such as meal times, teatime, free time, and during family time. Using the keyguard, Reem could independently request her preferred food and drinks for each meal. Since Reem so quickly comprehended how to use her MyTalkTools app, I increased the subject cells on the communication boards to nine and adapted the temporary keyguard at the same time.

Changes resulting from using MyTalkTools. In observing Reem communicating with her mother, they were both able to interact verbally via the iPad in most of Reem's daily activities. I noticed Reem's mother did not respond to Reem's question or call if Reem did not communicate with her using her iPad. Instead, Maha asked Reem to call her by using the iPad so she could reply to her immediately. Then, Reem laughed and clicked on the MyTalkTools . Before using the iPad, Maha needed to check on her every few minutes; once Reem started using her iPad, her mother reported she did not need to check on Reem so often: "With giving Reem the iPad, I could do the housework in a different room and that encouraged Reem to use the iPad and helped me to focus on my work as well." Also, Reem's mother noticed Reem's posture improved, in particular her head position. She sat up straighter and looked straight ahead instead of bending her head down as she used to do most of the time.

Reem’s family is quite large and all of her siblings were interested in interacting with her via the iPad. When Reem did not use the iPad to communicate with her siblings, they asked her to use it with them so she could get what she asked for. This also worked well with extended family members such as her aunts. When Reem went to visit her aunts, she communicated with her aunts using the iPad. This made it easy for her aunts to understand Reem and speeded up their conversation.

An interesting outcome occurred when Reem used MyTalkTools consistently: Reem’s verbal vocabulary started to improve. Prior to using MyTalkTools, Reem’s verbal vocabulary consisted of saying “yes or no” when responding to others along with a limited childish vocabulary consisting of “baby words.” She started repeating the words and phrases programmed into her MyTalkTools app. Using the iPad also increased Reem’s ability to initiate a simple conversation with her family members. For instance, when Reem went to the living room to enjoy family time, she could initiate a conversation by saying, “Hi, I came here.” This encouraged her family members in the living room to respond back to her, “Hi Reem, we are happy to have you with us.”

Lastly, Reem’s frustration and inappropriate behaviors decreased markedly after she started using the MyTalkTools app to communicate with her family. She stopped screaming and dropping to the floor on the first day she used the iPad. Maha stated, “Reem has been calm when she interacts with us via the iPad. Using the iPad saved time and effort to understand Reem’s needs and wants.” Being able to understand her daughter so quickly and easily and seeing the decrease in Reem’s frustration when communicating has made Maha feel more relaxed and much less stressed than before. She noticed Reem was happy and confidant about herself when she communicated with the family but perhaps especially with her mother who said, “Reem used to have her head down when she asked for something, but I have realized now it is different. Every time I see her communicating with us, she tries to keep her head up and click on the iPad with her happy face.”

Quantitative support data. Pre-intervention observations of Reem occurred in three different settings: mealtime with family members in the kitchen, free time in the living room with other family members present, and play time in the living room where Reem was playing with either her sister or her nephew. Two observations for 10 minutes in each setting were made and post-observations were also completed for these settings and similar times.

By comparing Reem’s communication in the three setting pre- and post-interventions, Reem’s physical communication and communication behavior improved by using MyTalkTools on the iPad. Her inappropriate behavior also decreased while an increase in appropriate behaviors was documented. For example, yelling and screaming were noted in pre-intervention observations to range from nearly 20% to nearly 30%; in post-intervention observations, these behaviors were not present at all. In being actively engaged with the communication partner, pre-intervention rates were 0% and increased to nearly 58% in one setting. The results are summarized in Table 3.

Table 3

Pre- and Post-Intervention Observations of Reem

	Meal Time		Play Time		Free Time	
	Pre	Post	Pre	Post	Pre	Post
Physical Behaviors						
Keeps Head Down	54.35%	17.05%	56.65%	6.75%	33.3%	13.3%
Sits Up Straight	00%	37.35%	00%	58%	00%	46.6%
Maintains Eye Contact with Communication Partner	00%	6.75%	00%	17.1%	00%	13.3%
Smiles/Laughs	00%	16.95%	00%	23.9%	00%	16.65%
Frowns	23.85%	00%	20%	00%	23.25%	00%
Aggression (Pushing Items/People Away, Hits, Kicks)	23.75%	00%	20%	00%	26.55%	00%
Drools	54.45%	23.7%	53.3%	23.75%	56.55%	19.95%
Cries	00%	00%	10%	00%	13.25%	00%
Communication Behaviors						
Initiates Communication (Gesture, Verbal/Word, Sound)	13.9%	13.6%	19.95%	16.85%	6.65%	13.3%
Responds to Communication (Gesture, Verbal/Word, Sound)	16.9%	13.6%	33.3%	17.1%	19.95%	13.3%
Uses Words (Correct Word/Name, Incorrect Word/Name)	17.4%	16.95%	23.3%	30.7%	19.9%	26.6%
Uses Sounds (Vocalization, Grunt, Singsong)	23.75%	00%	20%	00%	29.9%	00%
Uses Yelling/Screaming	23.85%	00%	29.95%	00%	19.95%	00%
Gestures with Hand to Request (Attention, Glass of Water, Remote Control, Phone)	00%	00%	20%	17.1%	9.95%	00%
Gestures with Hand to Respond (Yes, No, Indicate Needs)	00%	00%	20%	00%	00%	6.65%
Gesturing with Head to Request/Respond	34.2%	20.25%	23.3%	13.6%	26.55%	6.65%
Quiet/Withdrawn from Communication Partner	46.73%	00%	40%	00%	73.55%	00%
Active/Engages with Communication Partner	00%	37.2%	00%	57.85%	00%	53.25%

Alaa

Follow–up at home. Nora wanted her daughter to be more self-sufficient in daily living tasks at home. Her hope for this project was for Alaa to be socially engaged with her family, to initiate and participate in family conversations, and also to accept suggestions from her family. Alaa's family often travels to countries where English is commonly spoken along with the country's native language. Thus, Nora wanted Alaa to learn the English alphabet and some simple phrases to continue her learning and enable Alaa to communicate with others during family travels. One of her long-term hopes is Alaa can learn to accept the limitations of her disabilities and reduce the frequently recurring aggressive behaviors in which Alaa engages.

Personalizing MyTalkTools for Alaa. Nora had some background in using technology like a smartphone, tablet, and projector. This helped her to learn easily about MyTalkTools on the iPad. By collecting data about Alaa's wants and communication needs, she was able to personalize MyTalkTools relatively quickly. Alaa's initial MyTalkTools opening screen contained six folders including broth and soups, drinks, illness and feelings, hand and arms exercises, the English alphabet, and watching television (see Appendix H). Each of the folders was illustrated with an image of the action or item it represented and each image included the word written in Arabic. When Alaa tapped on the image, she heard an audio recording of her mother's voice saying the word. The folders contained communication boards with up to 12 subject cells or additional sub-files with more category choices. It increased to 12 subject cells because Alaa was able to use the six folders successfully from the first day of using the iPad.

The other six subjects were “I want…” to go to the bathroom, McDonalds, Asian restaurant, use cellphone, and sleep. Each categorized folder contained communication boards with 9-12 subject cells or sub-files each with more category choices.

Nora recommended creating a request cell on the opening screen. This cell consisted of an image of Alaa’s picture with the words “I want” in text and speech. This allowed Alaa to request specific items including ordering food at local restaurants. For example, Alaa loved to eat at McDonalds or a local Asian restaurant. Nora asked these two restaurants to provide her with a copy of their menus so she could add these to Alaa’s MyTalkTools. Each of these folders contained sub-files that helped organize the contents of the menus. When Alaa went to these restaurants, she was delighted to be able to use her iPad to communicate with family and order the meal of her choice. This was highly reinforcing for Alaa.

Introducing MyTalkTools to Alaa. I introduced the Ipad to Alaa and her mother the first time I met with them. I showed them the MyTalkTools app on my iPad and demonstrated how it worked. Alaa was very interested and wanted to start using it immediately. Like Reem, she kept asking her mother if the iPad was ready after each education session. Nora shared what she had learned during the education sessions each day with Alaa. Once she finished the five days of training and had customized the MyTalkTools app for Alaa, she returned home and Alaa immediately began using the iPad. Alaa had no difficulty using MyTalkTools; she simply tapped the image she wanted and selected the image using her index finger. Nora tried to persuade Alaa to use the stylus but she did not need it.

Nora was also asked to document her experience with using the iPad to enhance Alaa's communication. She received a journal and from the first day included information about how Alaa used the iPad, the requests she made using MyTalkTools, and how the family responded. She also received a data sheet for tracking Alaa's behavior. Alaa's frustrations with communication immediately decreased and her aggressive behaviors toward her mother and the maid also lessened.

Using MyTalkTools. Nora's main concerns were about helping Alaa engage in family time and calling for a bathroom trip. She asked Alaa to use the iPad and she could take her to her favorite restaurant also by using MyTalkTools on the iPad. Alaa listened to her mother and was able to use MyTalkTools during family time beginning with her first social engagement with them. On the first evening Alaa started using her iPad, she was in her bedroom watching television when she had heard her mother calling the family members to come for Arabic coffee and dessert. Alaa used her MyTalkTools app to call the maid and ask her to take her to the living room so she could have coffee and dessert as well. At first the maid asked Alaa if anything was wrong or if there was something bothering her. Alaa just laughed and told the maid she was fine--she just wanted to go and sit with her family and have coffee and dessert. When Alaa went to the living room, her mother hugged her, kissed her head, and thanked her for coming and enjoying their time together.

Another hope Nora had for her daughter was to use the iPad to call for assistance when she needed to use the bathroom. Prior to receiving the communication device, Alaa rarely gave her mother and the maid enough time to get her to the bathroom. However, once she started using the MyTalkTools app to call for assistance, she was far more patient with them when she needed to go to the bathroom. Nora noticed whenever Alaa used her MyTalkTools app, she noticed a smile on her daughter's face.

Nora reported Alaa independently used the MyTalkTools app on her new iPad from the first time. She had worried that this would be challenging for Alaa but found it was easy for the entire family. She also mentioned she felt safe and comfortable in letting Alaa sit in a different room because Alaa could call anyone by the iPad and they could hear and respond to her immediately.

Adapting the iPad for independence. Alaa was able to use MyTalkTools on the iPad independently using the index finger of her right hand. However, when I observed her using the iPad the first time, I noticed she kept her head down because her mother preferred to use the iPad case holder instead of mounting the iPad on the wheelchair due to the weight. I asked Alaa's mother if I could mount it on her wheelchair instead, explaining it would improve her posture, her ability to face the people she was talking to, and could help avoid posture-related problems in the future. Nora agreed to this so I set up the iPad mount holder on the right side of the wheelchair arm and then mounted the iPad. During this visit, I also increased the number of subject cells from 6 to 12 cells mixed with categorized folders and independent subjects.

Changes resulting from using MyTalkTools. Initially, Nora viewed the iPad with the MyTalkTools app simply as a communication device. She did not realize using the app would help Alaa in other areas. However, she quickly saw that in addition to providing a better means of communication between herself and her daughter, using the iPad improved Alaa's social interaction with other family members, allowed her to independently order a meal at a restaurant, and reduced her daily frustrations at home. She said, “I did not know that was a key for Alaa’s life.”

To make using the MyTalkTools app as motivating as possible for her daughter, Nora made a deal with her. If Alaa used her new iPad consistently, they would go and eat out once a week at one of Alaa’s favorite restaurant. Nora reported her daughter seemed much happier after she started using her communication device. Alaa smiled more often and was more relaxed and happy. She was able to engage socially with her family and enjoyed spending time with them. For the first time, Alaa was able to make herself understood quickly and clearly; she was able to capture her family’s attention and hold simple conversations, which had never happened previously. When she used her iPad, Alaa experienced her family was pleased to give her what she wanted.

Using her MyTalkTools app, Alaa was able to initiate a simple conversation with her mother when they were having coffee together. Alaa started joining her family for lunch as well as for coffee and dessert, which delighted her mother. Mealtimes had previously been a source of stress and frustration for both Alaa and her mother. The iPad helped them relax and both felt much happier as their communication improved. Nora said, “Everyone in the family has observed that Alaa’s behaviors have changed and that she has become calm and happy.”

Adding the “I want..” phrase as an independent cell on the opening communication board also changed Alaa’s oral language. Every time she tapped on the “I want…” image, she repeated the phrase verbally until her own words became clear and understandable. Going to the restaurant once a week proved to be a big motivating factor for Alaa to use her iPad frequently. This gave her an opportunity to communicate and interact with people outside of her family who were intrigued and interested in her new form of communication. When she went to the restaurant, she was able to order her food independently using the MyTalkTools app.

Nora noticed two additional effects she did not anticipate. The first was Alaa did not have as much mucus in her mouth as previously. Raising the iPad also raised Alaa's head up and when she was communicating with others, her upright position and eye contact made it easier for her to swallow more often. Additionally, she started to repeat the words and phrases added to her MyTalkTools app. Using her mouth to speak also encouraged her to swallow more often. The second benefit came from adding the hands and arms exercises cell. Alaa saw this image every time she looked at her screen and she started to do her exercises three times a week on her own. Nora was delighted she did not have to remind Alaa to do the sequence of exercises and Alaa was happy to do this by herself by following the pictures on this board.

Quantitative data. Alaa had been observed at three different times: meal times, play times, and free time in the living rooms. Each observation was done twice and lasted for 10 minutes in the pre- and post-interventions. In comparing Alaa's data in the pre- and post-interventions, I noticed Alaa had made significant changes in her physical and communication behaviors. For instance, Alaa was withdrawn from engaging in communication. In the three different settings: the meal times, free times, and the play times, Alaa's observation range was between 59.9% to 79.6%. By contrast, her post-observation withdrawn behaviors in these settings were 0%. Her physical behaviors and communication behaviors representing engagement in communication increased 68%

through 73.1%. Table 4 shows Alaa's data in both pre-intervention and post-intervention observations.

Table 4

Pre- and Post-Intervention Observations of Alaa

	Meal Time		Play Time		Free Time	
	Pre	Post	Pre	Post	Pre	Post
Physical Behaviors						
Keeps Head Down	69.85%	20.35%	73.15%	19.95%	00%	16.6%
Sits Up Straight	00%	54.4%	00%	56.6%	00%	59.8%
Maintains Eye Contact with Communication Partner	00%	20.25%	00%	19.95%	00%	16.6%
Smiles/Laughs	00%	33.65%	00%	29.9%	00%	33.2%
Frowns	00%	00%	23.25%	00%	00%	00%
Aggression (Pushing Items/People Away, Hits, Kicks)	00%	00%	29.95%	00%	00%	00%
Drools	59.85%	27.2%	63.2%	23.3%	66.5%	16.5%
Cries	00%	00%	33.25%	00%	00%	00%
Communication Behaviors						
Initiates Communication (Gesture, Verbal/Word, Sound)	00%	30.5%	00%	26.6%	00	29.9%
Responds to Communication (Gesture, Verbal/Word, Sound)	00%	23.85%	9.95%	26.6%	00%	29.85%
Uses Words (Correct Word/Name, Incorrect Word/Name)	00%	57.7%	9.95%	53.25%	00%	59.8%
Uses Sounds (Vocalization, Grunt, Singsong)	00%	00%	00%	00%	00%	00%
Uses Yelling/Screaming	00%	00%	33.25%	00%	00%	00%
Gestures with Hand to Request (Attention, Glass of Water, Remote Control, Phone)	00%	00%	23.25%	19.95%	00%	9.95%
Gestures with Hand to Respond (Yes, No, Indicate Needs)	00%	00%	00%	13.3%	00%	23.2%
Gesturing with Head to Request/Respond	00%	27%	29.9%	19.95%	00%	16.6%
Quiet/Withdrawn from Communication Partner	59.9%	00%	53.2%	00%	79.6%	00%
Active/Engages with Communication Partner	00%	68%	00%	66.6%	00%	73.1%

Roaa

Follow-up at home. Sara considered her 22-year-old daughter to be a young lady who should be independent in her talking, social communication, and interacting with others inside and outside the house. Therefore, her goals for Roaa were to improve her communication skills so she could have a clear talking voice that could be understood by everyone, not just her mother. She also wanted Roaa to be able to spend time with her sisters, expanding her social communication and enjoying "girl conversations" with them. Finally, Sara wanted Roaa's siblings to spend time with her and include her in their conversations.

Personalizing MyTalkTools for Roaa . Roaa's communication board was developed based on the information about Roaa that had been gathered during data collection. The initial opening screen of her MyTalkTools app was programed with only four folders including categories of food, drinks, mother, and clothes (see Appendix I). Each folder contained an image, the word of this image written in Arabic, and an audio recording of the word by her mother so Roaa could hear the word pronounced every time she touched the cell. Tapping a folder opened either a communication board with up to six subject cells or sub-files, each of which contained a communication board with four to six subject cells.

Roaa's MyTalkTools app was programmed with no more than six subject cells due to her lack of fine motor skills. She was not able to extend her fingers and use them independently to tap on the iPad screen; instead, she used her entire right fist. Sara and I determined it would be better to start with fewer choices on each board to increase her success using the app. However, after Roaa started using her MyTalkTools app, her mother decided to add two more folders to the opening screen--games and television.

Roaa’s main communication partner was her mother and Roaa enjoyed talking to her. She liked to thank her mother for everything she did throughout the day and often told her how appreciative she was of her mother’s work and effort. Roaa often used long and convoluted sentences with her mother that her mother struggled to understand. She often told her daughter to use shorter sentences. By including the My Mom folder, Roaa had many choices of phrases and sentences she wanted to use when she talked to her mother. When Roaa tapped on this folder, the communication board contained six cells of the most common phrases Roaa used with her mother: “Mom thank you for loving me. Mom I am sorry that I gave you a hard time. Mom could you please cook (this meal) for me. And mom I love you.”

Just as with some of the other folders, the drinks folder contained sub-files--water, cold drinks, hot drinks, milk, and yogurt. Each sub-file contained a communication board with subject cells listing her choices in that category. When Roaa tapped the selected file, she was able to state clearly the drink she wanted, many of which were difficult for her to pronounce verbally.

Introducing MyTalkTools to Roaa. The first time I met with Roaa and her mother, I showed them the MyTalkTools app on my iPad and allowed Roaa to practice and play with it. It was obvious she was ready to use MyTalkTools from the beginning. Roaa was very eager to start using the MyTalkTools app and asked her mother every day if it was ready. When Sara had finished the training sessions and personalized the MyTalkTools app for her daughter, all she had to do was give it to Roaa, who immediately started going through all the folders, communication boards, and subject cells to become familiar with how it worked.

Sara was asked to document her experiences with the MyTalkTools app once she presented it to Roaa. She included information about her daughter's response to the iPad, the requests Roaa made, and how the rest of the family reacted to Roaa's use of the iPad. She received a data sheet for tracking behavior outbursts; however, she did not use this as Roaa's outbursts ceased as soon as she received the iPad.

Using MyTalkTools. Sara wanted her daughter to communicate independently with her siblings and the maid instead of depending on her all the time. When she returned to her house from the education session, Sara handed the iPad to Roaa and then went to check on her mother who lived with them. While Sara was helping her own mother, she heard a voice saying, "Mom I love you." Roaa's mother looked around her but did not see any of her children nearby. She then went to the living room and saw Roaa smiling at her. Roaa tapped on her iPad and said the same phrase again to her mother. Sara laughed and responded back to Roaa, "I love you my daughter too, and please use the iPad with your siblings too for you could have fun with them." At that time, Roaa's siblings were in school and it was almost time for them to come home. The first one who arrived home was Roaa's youngest brother. When he walked to the living room, Roaa said, "Hello Ahmad, how are you?" Ahmed did not recognize the voice. Roaa was giggling and Ahmed turned his head toward her and asked her, "Is that you Roaa?" She said, "Yes." Ahmed ran to his mother and asked her, "Mom, what is that iPad with Roaa in her wheelchair?" Sara said, "This is Roaa's voice, she is going to communicate with us using her iPad."

Adapting the iPad for independence. Based on Roaa's specific needs, her iPad was mounted to her wheelchair so it rested on the right armrest just under her hand. When she was not using her iPad, she could still rest her arm on the armrest or just her elbow with her hand resting in her lap. Roaa had poor hand mobility and was not able to use her fingers independently to navigate the MyTalkTools app. However, using her right fist, she was able to tap on the screen of her iPad, which occasionally resulted in touching the wrong folder. Therefore, I recommended she use a stylus to improve her accuracy. Roaa tried using a hand-held stylus but was not able to maintain her grip on it. Because the muscles of her hand were so tight, holding the stylus hurt her fingers and she kept dropping it. I decided to replace the regular stylus with an adapted stylus called RJ's Cooper Tablet Handpointer, which consists of a T-shaped pointer where a plastic rod rests in the user's hand and the cylindrical pointer emerges from the rod and between the user's fingers. The handpointer is held in place by comfortable, stretchy Velcro and can be easily adjusted to an individual user's needs. Once the handpointer was adjusted to fit Roaa's unique needs, she was immediately able to use it on her iPad. The RJ's Cooper Tablet Handpointer was the perfect tool for Roaa as it allowed her to use her iPad accurately and comfortably without pain or fatigue in her hand. Roaa told her mother she was very happy with this new tool.

Changes resulting from using MyTalkTools. Before she started using the MyTalkTools app to communicate with her family, Roaa spent most of her time on the floor in the living room, sometimes drawing or playing, sometimes laying down and watching television. However, once she received her iPad, she preferred to be in her wheelchair and talking with her family. She asked the maid to take her around the house so she could find someone to talk to. In the mornings, Roaa liked to eat breakfast with her grandmother and talk to her. Roaa’s grandmother was impressed with how Roaa could use her iPad to communicate and how easily she was able to respond and interact with her granddaughter. Her grandmother said, “I wish you had this device earlier. It is much better for you to enjoy your day instead of just watching television.”

Roaa was also able to communicate with her siblings more succinctly using her MyTalkTools app. In addition to making her communication clearer to them, using the app also reduced the amount of time it took for them to communicate as they no longer needed to ask Roaa to repeat herself multiple times. This improved her social interaction with her siblings and with the girls around her same age in her extended family. An example Sara shared was one time when Roaa thanked her youngest sister for helping her and her sister said, “You are welcome.” Roaa then talked back to her nicely, pointing on “soft words that made her sister turned back to her with a laugh and kiss Roaa.” Using MyTalkTools was very empowering to Roaa; she told her mother it made her feel more like her twin sister.

The MyTalkTools app also helped Roaa communicate more clearly with her mother. Roaa was very close with her mother and always had a lot to tell her. Using MyTalkTools allowed her to express herself and share her feelings with her mother easier than before. Because it was easier for Roaa to communicate directly with the maid and her family without needing her mother to interpret her communication, Sara felt some of the responsibility lift away from her shoulders. She did not worry as much about Roaa and did not feel she needed to check on her daughter as frequently: “I am more relaxed now and happy, it has given me some time for myself.”

Sara liked the way her daughter visited with family members. Conversations between Roaa and her aunts became more enjoyable and she was able to use humor and joke around with them. Her aunt said, “I love Roaa visiting us, and I love to see her come to talk to me in my place.”

Roaa’s frustrations over miscommunication decreased significantly. She decreased her biting behavior toward the maid because she could communicate with her more easily. Also, unless she was sick or not feeling well, Roaa stopped soiling herself as much as she did before. Because Roaa spent more time in her wheelchair, she did not drool as much as she had when she spent most of her time on the floor. Her sitting posture improved since she now sat up straighter to face her communication partners. The MyTalkTools app gave her a voice and the attention of her family members. Roaa seemed happier and smiled more.

Quantitative data. Roaa was observed for pre- and post-intervention in three different settings: meal times in the living room, play time in the bed room and living room, and free time in her grandmother’s room. Each observation lasted for 10 minutes and was done twice. Roaa showed significant improvements in her physical and communication behaviors in the post-intervention. The majority of her post-intervention observations showed a dramatic decrease in non-appropriate behavior and an increase in communication skills. An example of aggressive behavior was kicking her legs when her partner did not understand her request or her communication. The range for aggressive behavior was 10% to 23% in pre-intervention observations but dropped to 0% in post-intervention observations in all settings. Likewise, using words in pre-intervention observations ranged from 0% to 6% but rose to 39% to53% in post-intervention observations (see Table 5).

Table 5

Pre- and Post-Intervention Observations of Roaa

	Meal time		Play time		Free time	
	Pre	Post	Pre	Post	Pre	Post
Physical Behaviors						
Keeps Head Down	56.55%	13.3%	56.35%	20.35%	53.45%	20%
Sits Up Straight	3.3%	59.9%	26.5%	57.75%	20.55%	60%
Maintains Eye Contact with Communication Partner	00%	13.3%	00%	17.05%	00%	16.65%
Smiles/Laughs	3.3%	19.9%	6.6%	23.7%	00%	19.95%
Frowns	19.9%	00%	26.5%	00%	30.55%	00%
Aggression (Pushing Items/People Away, Hits, Kicks)	23.25%	00%	23.2%	00%	10%	00%
Drools	53.2%	26.6%	59.75%	30.55%	64.85%	26.6%
Cries	00%	00%	00%	00%	00%	00%
Communication Behaviors						
Initiates communication (Gesture, Verbal/Word, S=sound)	00%	23.25%	00%	20.35%	00%	26.65%
Responds to Communication (Gesture, Verbal/Word, Sound)	6.6%	33.3%	23.2%	27.05%	33.55%	26.65%
Uses words (Correct Word/Name, Incorrect Word/Name)	6.6%	39.85%	00%	47.45%	6.65%	53.3%
Uses Sounds (Vocalization, Grunt, Singsong)	16.6%	00%	00%	00%	13.3%	00%
Uses Yelling/Screaming	13.25%	00%	9.95%	00%	10%	00%
Gestures with Hand to Request (Attention, Glass of Water, Remote Control, Phone)	00%	00%	00%	6.65%	00%	6.65%
Gestures with Hand to Respond (Yes, No, Indicate Needs)	00%	00%	00%	9.95%	00%	3.3%
Gesturing with Head to Request/Respond	19.95%	23.25%	33.15%	30.65%	13.3%	13.3%
Quiet/Withdrawn from Communication Partner	56.5%	00%	53.05%	00%	57.8%	00%
Active/Engages with Communication Partner	00%	53.2%	00%	57.75%	00%	63.3%

Cross-Case Analysis

Cross-case analysis is a qualitative research method used to increase our understanding of the phenomenon being studied. This analysis approach compares similarities and differences between the cases by examining factors and relationships that support the findings of each case. By comparing and contrasting participant statements as well as study outcomes across cases, researchers are able to describe commonalities and differences and explain how these related to the phenomenon (Khan & VanWynsberghe, 2008). In the following section, responses from the three participants as well as quantitative support data from the intervention are contrasted and compared to facilitate a greater understanding of the phenomenon being studied. Similarities between the cases are presented first and followed by differences found in all three cases. Data are presented in graphs and tables.

Prior to the intervention being implemented in the home, each of the mothers expressed her hopes for changes in the communication of their daughters. Maha wanted her daughter Reem to initiate conversations and improve her communication skills so she could independently engage in conversations with other family members. She also wished her daughter would improve her posture and display better manners. Nora wanted her daughter Alaa to be more socially engaged with her family and be able to initiate and sustain conversations with her parents and siblings. She also wished Alaa could communicate with people she met when the family went to restaurants. Nora was interested in having her daughter learn English so she could communicate with others during travels abroad. Sara wished her daughter Roaa could speak more clearly and be understood by all family members. Roaa longed to speak longer sentences and her mother hoped the intervention would provide her the means to build authentic communication between Roaa and her siblings. All of the mothers agreed in addition to improving communication, they hoped to see a reduction in negative behaviors such as yelling and hitting once their daughters' ability to communicate improved.

Data from the pre- and post-intervention observations of daughter-participants were used to compare and contrast the cases of this study as these data clearly revealed the changes in communication and physical behaviors that occurred during the course of the study. Two broad categories of behavioral responses were examined--physical and communication behaviors. In each of these two categories there were positive behaviors appropriate for the situation and behaviors that were negative and inappropriate. For example, positive physical behaviors consisted of maintaining good posture by sitting up straight and making eye contact with a communication partner while poor physical behaviors included slouching in the chair with the head kept down, drooling, and crying. Positive communication behaviors included initiating communication, responding to others' communication, and engaging with others while inappropriate communication behaviors consisted of withdrawing from interaction, yelling, and being aggressive.

Each of the three youths who participated in the intervention demonstrated both positive and negative behaviors in each category; however, while there was some overlap in their physical and communication behaviors, each youth faced unique challenges in communication that varied from youth to youth. Prior to the intervention, Reem's main communication challenge consisted of being very withdrawn from the communication process. She rarely initiated conversations and her responses were often limited to sounds or gestures that were difficult for her family to interpret correctly. Reem would often sit with her head down, face away from her communication partner, and drooled a lot. Alaa often displayed aggressive behaviors during interactions such as yelling, kicking people, and pushing things away. She was withdrawn not only from conversations in her family but also from family activities and preferred to spend her time in her room watching television. Roaa, who delighted in using long, unintelligible phrases to thank her family, was generally quiet and withdrawn until a family member engaged her in conversation. She demonstrated poor posture with her head hanging down, frequently frowned, lacked eye contact, and drooled. Roaa responded to communication by her family but they were often not able to understand her attempts at verbal communication. Her frustration at not being understood often resulted in her yelling, kicking at them, and even biting her mother and the maid. Thus, Reem exhibited withdrawal behaviors whereas both Alaa and Roaa resorted to aggressive behaviors.

In the initial pre-intervention observations, inappropriate behaviors in both physical and communication categories had a high occurrence. Appropriate behaviors such as eye contact, sitting up straight, initiating communication, and active engagement with communication partners occurred at a low rate or sometimes were not present. Each participant expressed her goal was to see a decrease in negative, inappropriate behaviors as well as to see an increase in the appropriate, positive behaviors by the end of the intervention (see Table 6).

Table 6

Summary of Pre- and Post-Intervention Behaviors for Reem, Alaa, and Roaa

	Average Data					
Target Behavior	Reem		Alaa		Roaa	
Physical Behaviors	Pre	Post	Pre	Post	Pre	Post
Keeps Head Down	48.10%	12.37%	47.67%	18.97%	55.45%	17.88%
Sits Up Straight	0%	47.32%	0%	56.93%	16.78%	59.22%
Maintains Eye Contact	0%	12.38%	0%	18.93%	0%	15.67%
Smiles/Laughs	0%	19.17%	0%	32.25%	3.30%	21.18%
Frowns	22.37%	0%	8%	0%	25.65%	0%
Aggression	23.43%	0%	10%	0%	18.82%	0%
Drools	54.77%	22.47%	63.18%	22.35%	59.27%	27.92%
Cries	8%	0%	11%	0%	0%	0%
Communication Behaviors						
Initiates Communication	13.50%	14.58%	0%	29.00%	0%	23.42%
Responds to Communication	23.38%	14.67%	3%	26.77%	21.12%	29.00%
Uses Words	20.20%	24.75%	3%	56.92%	4.42%	46.87%
Uses Sounds	24.55%	0%	0%	0%	9.97%	0%
\ Uses Yelling/Screaming	24.58%	0%	11%	0%	11.07%	0%
Hand to Request	10%	6%	8%	10%	0%	4%
Hand to Respond	7%	2%	0%	12%	0%	4%
Head to Request/Respond	28.02%	13.50%	10%	21%	22.13%	22.40%
Quiet/Withdrawn	53.43%	0%	64.23%	0%	55.78%	0%
Active/Engages	0%	49.43%	0%	69%	0%	58.08%

Similarities

Examination of the post-intervention data indicated a common overall increase in appropriate behaviors in all three cases. Each youth with S/MD spent more time sitting up straight and engaging in eye contact with their communication partner after the intervention. For example, prior to receiving the iPad, Reem spent almost half of the time she was observed keeping her head down. She did not maintain eye contact with her mother in any of the settings. After the intervention, Reem maintained eye contact on average 12% of the time she was observed with the most eye contact (17%) during play time. Alaa and Roaa had similar results; they did not maintain eye contact with their communication partner before receiving the iPad and did so 19% and 16%, respectively, after receiving the iPad. Before the intervention, each youth kept her head down, drooled, and frowned a lot. After the intervention, Reem, Alaa, and Roaa sat up straight in their chair (47%, 57%, and 59%, respectively) and smiled (19%, 32%, and 21%, respectively). Perhaps most striking was the change in engagement seen in each youth. Prior to the intervention, all of the youth were quiet and withdrawn most of the time they were observed (53%, 64%, and 56%, respectively) with 0% engagement. However, once they received their iPad and were able to communicate more easily, their engagement increased dramatically (49%, 69%, and 58%, respectively).

When it came to communication behaviors, Alaa and Roaa demonstrated the greatest changes in their positive communication behaviors. They both responded to their communication partners far more than before and began initiating communication. Before the intervention, Alaa only responded 3% of the time she was observed while Roaa responded 21%. After the intervention, Alaa responded 27% of the time while

Roaa responded 29% of the time. Similarly, Alaa, who did not initiate communication once during the pre-intervention observations, was seen initiating communication 29% of the time while Roaa increased her initiation from 0% to 23%. On the other hand, Reem showed only modest gains in initiating communication--from 13% pre-intervention to 15% post-intervention--while her responses declined from 23% to 15%. Because these youths all had difficulties with verbal speech, they often communicated using sounds, gestures, and body language.

When looking at inappropriate behaviors, again there was a common overall decrease in inappropriate behaviors, sometimes dropping to no occurrences at all during post-intervention observations. All three youths demonstrated episodes of aggression toward their communication partner before they received the iPad. On average, Reem displayed aggressive behavior 23% of the time, Alaa 10% of the time, and Roaa 19% of the time. These episodes dropped to 0% in all three settings once the youths could communicate more easily. Additionally, Reem and Alaa had fewer instances of crying behavior--down from 8% and 11%, respectively, to 0% after the intervention. Before the intervention, all of the youths communicated by yelling or screaming. Reem yelled 24% of the time she was observed on average while Alaa and Roaa yelled 11% of the time. However, this negative communication behavior dropped after the intervention to 0%.

Differences

A few differences were seen in the responses of all three youths. However, these differences were not as profound as the similarities. Reem was the youth who communicated the most with her communication partner prior to the intervention. She initiated and responded to communication more frequently than did the other two youths and she used more words prior to the intervention. An interesting finding was Reem started using more mature language after the intervention. The MyTalkTools app gave her the opportunity to use a wider vocabulary than she had done previously while also modeling more appropriate language. Her use of words only increased from 20% to 25% but her mother noted Reem’s spoken language became more intelligible to everyone in the family after the intervention.

The intervention also had a dramatic impact on Alaa and Roaa’s use of verbal speech. Prior to the intervention, Alaa and Roaa communicated primarily using sounds and body language. However, after the intervention, their use of words increased dramatically--from 3% to 57% in Alaa’s case and from 4% to 47% in Roaa’s case. According to her mother, Alaa previously spoke in single-word utterances whenever she wanted something (“water,” “bathroom,” “McDonald’s”). However, after she started using her iPad, her communication changed and she started using full sentences (“I want some water,” “I want to go to the bathroom”). The MyTalkTools app helped her expand her verbal vocabulary as well as improve her sentence structure. These changes made it easier for her mother to understand her even when she did not use her iPad. For Roaa, the intervention provided her with a way to use full, polite sentences. Prior to using her iPad, Roaa would try to speak like her sisters but her speech was not clear enough to be understood and it took her a long time to say what she wanted to say. Her attempts to talk often resulted in her family becoming irritated with her. However, after she started using her iPad, Roaa was able to speak the way she always wanted to and be understood by everyone. Also, when she used the iPad to communicate, Roaa would repeat the words, improving both her pronunciation and the speed of her speech. Using the iPad allowed Roaa to have the kind of conversations she longed for with family members.

It was interesting to observe that once they were able to communicate using their MyTalkTools app, their body language changed. Reem's use of sounds to communicate decreased from 25% to 0% and her use of hand and head gestures decreased from 17% to 8% (hand gestures) and 28% to 13% (head gestures). In Alaa and Roaa's cases, their use of hand gestures increased (8% to 22% for Alaa and 0% to 8% for Roaa) while Alaa increased her use of head gestures to respond to communication from 10% to 21%. Roaa's use of head gestures increased only minimally. Visual representations of visual and communication behaviors pre- and post-intervention are provided in Figure 1 for Reem, Figure 2 for Alaa, and Figure 3 for Roaa.

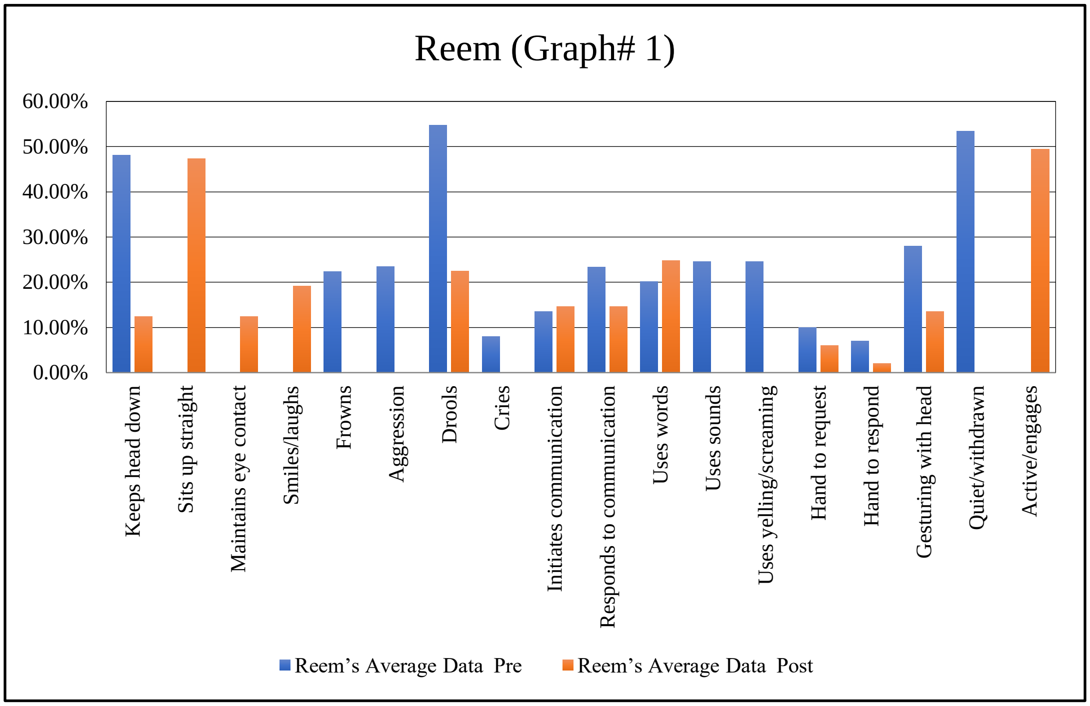

Figure 1. Reem's visual and communication behaviors pre- and post-intervention.

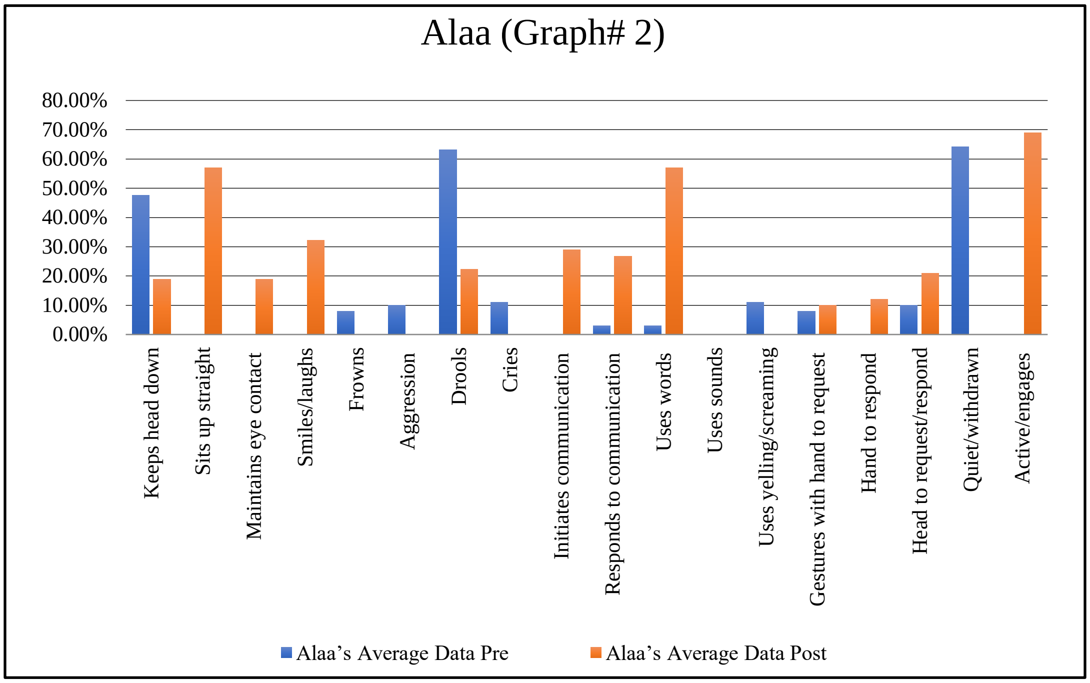

Figure 2. Alaa’s visual and communication behaviors pre- and post-intervention.

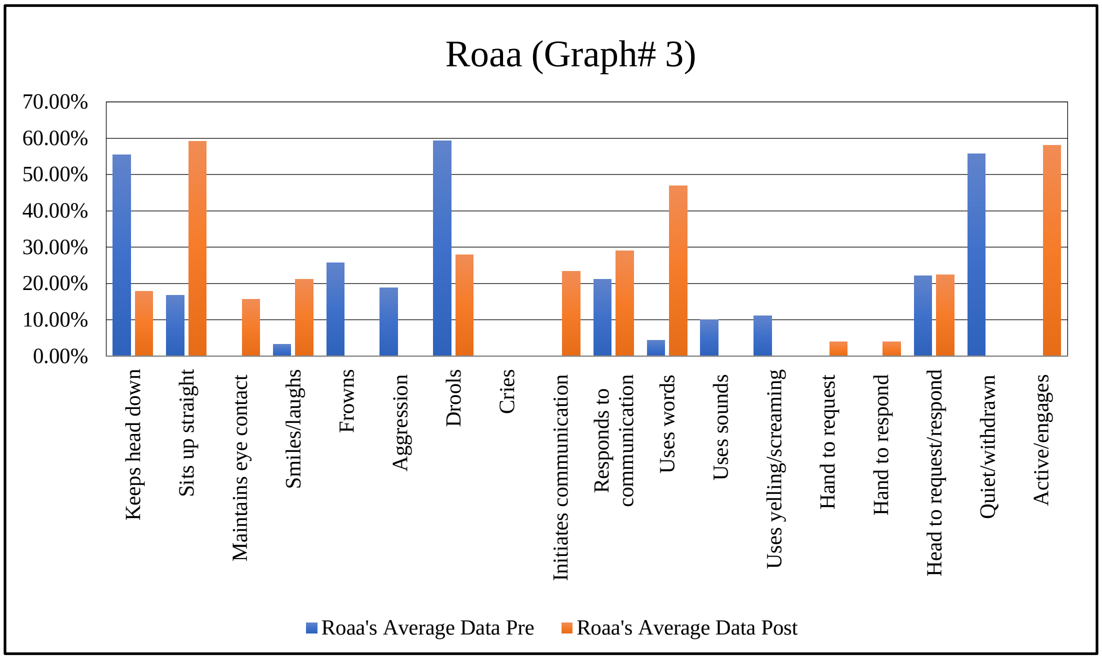

Figure 3. Roaa’s visual and communication behaviors pre- and post-intervention.

Summary

In this chapter, the findings from this study were presented. First, each individual case was presented through narrative stories of each case based on data collected through interviews, observations, and review of documents. Data illustrating changes in the physical and communication behaviors among the youth with S/MD before and after the intervention were also presented. Then the cross-case analysis revealed similarities and differences among the three cases.

Themes that emerged through the stories included the challenges related to communication and a lack of support from the medical and education system to improve the communication of the youth with S/MD. Additionally, each youth featured in the cases demonstrated idiosyncratic behaviors as they attempted to communicate. An intervention consisting of providing assistive technology for communication was implemented by the three mothers and changes following this intervention were reported. In general, for all three cases, inappropriate behaviors showed a dramatic decrease; whereas profound increases were demonstrated for appropriate behaviors. Although the data only referred to pre- and post-intervention observations, the increases in appropriate communication occurred early in the intervention, positively affecting not just the youth's behaviors and communications but also reflecting the benefit to the entire family as they were able to communicate easily and clearly with their youth with S/MD for the first time.

CHAPTER V

CONCLUSIONS

The purpose of this study was to establish how a family communication partner could assist her youth with S/MD to increase the youth's appropriate communication behavior while also decreasing inappropriate behaviors using an alternative augmentative communication (AAC) device as well as to demonstrate that assistive technology could have an impact on the communication and behavior of young adults with S/MD. A two-phase qualitative research design was used to capture the experiences of the participants (communication partners in this study were mothers) prior to and following the communication intervention. The mothers were interviewed before they engaged in a functional communication training (FCT) workshop to learn to use the AAC device. After the workshop, each mother was responsible for implementing the communication intervention at home with her daughter with S/MD.

This qualitative research study employed interviews with three mothers, observations of the mothers and their youth with S/MD, and documents reviews to support participant statements. The data analysis revealed several common themes described in the life stories: a lack of educational and vocational services once the participant's youth left elementary school when they were 12-years-old; resultant social, physical, and academic declines; social isolation of the family as well as the youth with S/MD; and communication challenges faced by the youth and their families.

The literature review revealed few studies that addressed using assistive technology to improve communication among young adults with S/MD. No studies were found describing the use of this technology in Saudi Arabia. Consequently, the findings from this study make a contribution to the literature addressing the unique communication needs of young adults with S/MD and their families.

Research Questions

The following research questions guided this study:

Q1 In Phase One, how do family members or primary caregivers of youth with S/MD communicate with their youth with S/MD?

Q2 In Phase Two, what is the perceived impact on behavior and communication of youth with S/MD when a female family member or caregiver has been provided with training in functional communication training using iPad with MyTalkTools?

Since this study consisted of two parts to investigate the communication interaction and the behaviors for the youth with S/MD by using iPad as AAC tool, there were two types of data--qualitative and quantitative. The three cases had similar results in recurring themes and qualitative data and some minor differences.

Summary of Findings

From the very first introduction of using the iPad, these youths understood the purpose of the iPad and were eager to use it. The results of the study showed these three youths with S/MD made significant gains in communication interaction with their family members accompanied by significant reductions in unacceptable behaviors. Using the iPad as an AAC device with these youths helped them communicate clearly with their family members for the first time. The participants, who were the primary communication partners for the youths, all noted an immediate decrease in inappropriate behaviors. Given the procedures employed, it was clear that providing an iPad as AAC tool and training the family communication partner to teach their youth were immediately successful and had a large impact upon the youths with S/MD and their family members.

Research Question One

The first research question guiding this study asked how family members or primary caregivers of youth with S/MD communicated with their youth with S/MD. Each youth with S/MD had speech and language impairments that hindered her ability to use verbal communication. Findings suggested the mothers primarily used verbal communication when speaking to their daughters and often used simplified language suitable for younger children when addressing their daughters who were all between 18- and 22-years-old. The youths, who were unable to speak clearly, used a range of communication approaches including simple words (in one case baby language), one-word sentences, sounds, facial expressions, and head and hand gestures. The three youths with S/MD also used inappropriate or aggressive behaviors to communicate, which was very challenging for their family members and the maids who worked with them. During the pre-intervention observations, the youths with S/MD did not initiate communication with their family members and they were passive when responding to communication from their mothers. They often kept their heads down and none maintained eye contact with their family communication partners. The mothers confirmed this was common behavior for each of their youths.

Research Question Two

The second research question guiding this study asked the perceived impact on behavior and communication of youth with S/MD when a female family member or caregiver was provided with training in functional communication training using iPad with MyTalkTools. Good communication is central to the well-being of a family. The findings of this study demonstrated the impact of good communication not only on the speaker but also on all family members. The three mothers learned to use an iPad with a personalized communication app and applied it with their youth with S/MD at home. They each reported this intervention improved the quality of life for their daughters and changed both their ability to communicate clearly with a range of communication partners but also positively impacted their behavior. The three youths immediately understood the concept and purpose of using the iPad and quickly and eagerly used it correctly. Two of the youth in this study required physical modifications so they could use their iPad independently. Implementing this intervention of using an iPad was relatively easy for the mothers despite their initial lack of knowledge or experience with technology. Prior to the FCT workshop, the mothers had only a basic knowledge in using cellphones and tablets.

In addition to providing the youth with S/MD with an independent means of communicating on a range of topics, the mothers also reported their youths displayed significantly less inappropriate behavior, were more eager to participate in family activities, and were less dependent on their mothers to help them communicate with other family members. Each mother reported she could leave the room and not worry about their daughter as she had done earlier because she knew her daughter now had the ability to let her know if she needed assistance.

Another finding was after the youth with S/MD started using their MyTalkTools app to communicate, their verbal communication improved. The iPad served as a model for more accurate communication. Reem’s vocabulary increased and she started using more mature language. Alaa began to use multiple word sentences instead of single-word utterances. Roaa was better able to capture her mother’s attention to say what she wanted to say.

Finally, the quantitative findings showed two main increases in the youths’ behaviors. Inappropriate physical behaviors such as looking down, frowning, and drooling were replaced by more appropriate physical behaviors including sitting up straight in her wheelchair, maintaining eye contact with the communication partner, and smiling more. Inappropriate communication behaviors such as yelling, kicking, hitting, and biting were considerably reduced while appropriate communication behaviors including initiating conversations, responding to the communication of others, and using the correct name or word for items increased significantly.

Discussion

Once an individual with S/MD leaves a formal education program at age 12 in Saudi Arabia, there is an almost complete lack of services available for the individual and the family. Few outreach programs provide educational or vocational services and no day programs are available where these youths can go to receive services, training, or social interaction with similar youth. In addition to the lack of programs, few places are accessible to individuals who require a wheelchair. Thus, most youths with S/MD spend their days at home with their family--most often a family member or a maid. In this situation, many youths with S/MD are no longer able to maintain the skills they learned at school. Without outreach services from a physical therapist, occupational therapist, or speech-language therapist, many families are unaware their youth with S/MD could be more independent given specific accommodations at home.

When the family communication partners were approached to participate in this study, they were eager to receive education and training about using the iPad as AAC with their daughters. They recognized the challenges their daughters faced and this motivated them to find a way to improve their daughters' lives. They were all eager to enhance the quality of their communication with their youths with S/MD. The three mothers attended the FCT workshop and actively took part, asking questions and discussing ideas. Including families in intervention required understanding a family's culture, background, and linguistic and other issues (Binger et al., 2008; Parette & Brotherson, 2004). Learning technical operation and strategies of using AAC is a challenge task for families who need to use AAC with their children (McNaughton et al., 2008). The mothers all had some experience using basic technology yet none had any experience with alternative augmentative communication or assistive technology devices. These variations of the mothers' background knowledge led me to introduce basic details on using the iPad and downloading the MyTalkTools communication app to get all mothers to the same technological level of knowledge and understanding. The process of connecting the device to the Internet Wi-Fi, downloading the MyTalkTools app, and customizing the app took time as the mothers needed to repeat and practice the process until they were confident they knew how.

The lack of services to individuals with S/MD in Saudi Arabia can also lead to social isolation. In this study, the social isolation faced by the youth with S/MD had a major impact on all three families who participated. This was a result of several factors.

First, public school ends at six grade in Saudi Arabia for these youths. The effect of this stopped any further academic progress as well as led to a regression in both behavior and communication skills the youths had previously achieved in school. As children with S/MD grow into young adults with S/MD, their physical needs often change but there are no outreach services to help families deal with these changing needs. Without outreach services, families often do not know about specialized equipment or interventions that could help their youths in daily life. Therefore, introducing the iPad as AAC tool to these mothers was an optimal idea with less cost and investment. Also, it was available and possible to have it along with the required Internet connection. Using the iPad was a great option for these mothers and their girls to enhance their daily life routines. Therefore, I believe the cultural environment such as the family culture could affect the intervention procedure, especially when there are limited services and professional resources (Geiger, 2010). These mothers' contributions supported the intervention to be successful and fully utilized with their girls and enabled them to have access to tools to improve communication in the absence of formal schooling with concomitant reductions in inappropriate behaviors. Given the eagerness of the youths, the commitment of the mothers, and the dramatic changes in communication behaviors, this study has shown the possibility of utilizing training for mothers to use iPads with their youths with S/MD as an effective intervention for these youths who are at present confined to their homes.

Furthermore, public facilities such as libraries, day programs, and agencies are not yet available for youths with S/MD in Saudi Arabia. Lack of services is frustrating for families with children or youths with intellectual and developmental disabilities (Friedman & Kalichman, 2014) and greatly restricts their children's options to participate in community life. The youths in this study did not have access to a day program nor did they spend time with friends. They spent their days at home with their family. This social isolation limited their opportunity to communicate with anyone outside their families. For example, Alaa was isolated at home without a day program to keep her busy and without connection to her friends from school. She did not go out in public often and she had a very limited social environment. Her only contacts seemed to be her family and the maid. Alaa's family contributed to the isolation at home because their movements were limited due to Alaa's physical needs, especially by the need for wheelchair access and by someone always having to stay home with her. Her mother Nora seemed to accept this but it appeared to be a burden on the rest of the family. In particular, her father wanted her to have a TV in her room but Nora understood this would cause further isolation within the family. Television was enormously isolating for Alaa as she preferred watching TV to interacting with her family and her whole day and night routine was flipped due to her TV schedule. Changes in isolation occurred as Alaa grew from a baby to a young adult. It was easy to take her places when she was very young because her family could carry her. However, after she turned 12, she grew too heavy to carry and needed her wheelchair. The environment became inaccessible to her as her mother could no longer carry her places so growing up also resulted in increased isolation.

In addition to the lack of services, a lack of universal design could also lead to social isolation in Saudi Arabia. Very few places are accessible for a person in a wheelchair; this in itself limits where families can go if they want to go out. Universal design is not a magic treatment but is a complementary rehab treatment for those with disabilities because it offers equal access for individuals with and without disabilities, a finding that supported the research of Lid (2014). Barrier-free designs that incorporate accessibility into physical environments are not yet common in Saudi Arabia so stairs remain a challenging barrier to independence for many. Similarly, a lack of accessible transportation can also result in increased isolation.

A final theme to emerge from the life stories of the youths with S/MD was the individual and unique communication challenges each of the families faced. During the first interviews, the mothers all shared how challenging it was to have a child with S/MD. The needs of the child with the disability had a significant impact on the lives of each family member; for some of the siblings in particular, this led to feeling burdened by the responsibility and limitations. The mothers discussed feeling depressed and discouraged, particularly when they saw how frustrated their daughters were in their lives. They often felt powerless to improve their lives. Thus, children and youth with complex needs are frequently checked and provided with nearly continual care depending on their development level (Friedman & Kalichman, 2014). Each of the families interviewed for this study had learned to accept the limitations of having a child with S/MD, keeping their daughter at home, and limiting their outside activities because of the difficulties involved with transportation, accessibility, and lack of communication. One of the most significant outcomes of this research was the increase in independence of the youths and the decreased pressure on the mothers to be constantly attending them.

Although the intervention was similar for all three youths, there were similarities and differences in the impact it made in their lives. The ability to communicate made it easier on communication partners but also increased the youths’ standing in the family.

Prior to the intervention, the three youths with S/MD were always dependent upon a caregiver to meet their needs and help them communicate. However, once they started using the iPad, they became far more independent in their communication. They were able to communicate with other family members without assistance and interpretation by their mother. They began to initiate more of the communication as well as respond more actively to their communication partner. Their communicative body language improved dramatically when they took charge of their own communication. As a result, these youths were more respected and included in family activities and communication, aiding the development of increased self-esteem.

However, in some daily activities, their communication was affected by the partner who most often interacted with them. For instance, since Reem was very young, she was surrounded by family who babied her. At 21 years of age, Reem was still using simple words and phrases she learned as a toddler so it was sometimes a challenge for her to initiate communication. However, the iPad provided her with the opportunity to use more mature language. Once Reem saw her family reacted positively to her new form of communication, she began using similar language when speaking.

Prior to the intervention, Alaa spent most of her waking hours alone in her room or in front of the television. However, after she began using her iPad, she wanted to join her family in daily activities. The iPad not only gave her the ability to communicate better with her family, it also gave them the opportunity to see how competent she really was--it changed her social standing in her home.

Before she received her iPad, Roaa wanted nothing more than to communicate easily like her sisters. Her disability prevented her from speaking clearly and easily, which often led to her family becoming irritated with her. Once she began using her iPad, she was able to speak the way she wanted to by using longer, complex sentences. Her family responded to her new communication approach with interest and Roaa's attempts at communication were now met with patience.

I believe educators need to trust in the abilities and motivation of individuals with S/MD and their families so they can live their lives appropriately. Presuming competence is one of the keys to implementing AAC effectively with individuals with S/MD and their families. Presuming competence guides the professional to catch all the differences of the individuals' needs and extract their intelligence to increase their success in their life (LoStracco, 2017). That was one of my key sources of effectiveness in conducting the study with these youths. I had already worked with some of them and noticed their progress and growth.

Using the iPad helped these youths with S/MD to improve their self-confidence in initiating communication, requesting needs or wants, and engaging in a communication interaction. Also, this allowed these girls to be independent in their communication without waiting for someone to interpret their messages, gave them a freedom to express their feelings, and reduced the dependency on the caregiver. Use of the iPad assisted the mothers and their daughters to be relaxed and led to less tension so they could stay independently in the room.

Conclusion

Using iPad as AAC tool in improving the communication interaction between youths and their partners and to reduce challenging behaviors was a new idea in one large city in Saudi Arabia. This idea could open the communication door for these youths and their families due to limited services for this population. The lack of services for youths with S/MD impacts their progress in different developmental areas. This lack leads these youths to remain at home and restricts their usage of all their abilities, skills, and movements. These girls had also been isolated from the community and even from their families. It seems they all gave up doing things or engaging in activities inside or outside the house. These girls were isolated at home without a school program or going somewhere outside since there were limited places and facilities where these girls could go. A lack of facilities with universal accessibility meant these girls had to be carried and this was not always possible. These girls spent their days without any programs to keep them busy, or connected them to a routine, and without services. They had limited or no interactions with friends or other peers. They spent their time watching television, playing with cellphones, or coloring on paper. This isolation also affected the mother because of her need to stay with her daughter at home. Limited services for these youths with S/MD contributed in creating their communication and behavior difficulties. These youths had previously exhibited frustrations, angers, aggression, and withdrawal, all of which were ameliorated when the intervention was carried out.

Limitations

This study had several limitations. First, the sample size was small and gender-specific. The sample was limited to three mothers who had a girl with S/MD. The gender category was restricted to females for both target participants, particularly when the fourth participant dropped from the study as this was a mother with a male youth with S/MD who wanted to share in the study. The present study showed evidence that the youths were able to use the iPad in three different settings at their homes but there was no chance to provide evidence of using the iPad outside of the homes.

Another limitation was the setting of the study. This study was limited to one large city in Saudi Arabia. This city was different than the others due to the availability, quality of services, and the socioeconomic classifications. In addition, the people who lived in this city were considered upper middle class. Perhaps people in a different city would be able to more easily offer devices and materials for their youths.

A final limitation was the researcher was a significant part of the study, both when working with and training the participant mothers and when assisting the mothers in the implementation. Perhaps if someone else had served in this role, the results might have been different.

Future Research

Future research could replicate this study in multiple areas, particularly in Saudi Arabia. Conducting a study with a variety of youth and including both genders who have other communication disorders would add to this body of research. Similar training to these mothers could be used to train other mothers or other communication partners to expand the knowledge of using iPad as AAC; it would an easy, affordable, and natural method to extend this intervention to more families. An added benefit to this approach would be the possibility of linking more families with S/MD youth together and perhaps building a base of support for families and advocacy.

Another avenue for further research would be to carry out longitudinal studies that would follow individuals with S/MD for several years to document how extensively these youths continued to use the iPad, to observe any further gains or possible regressions, and to identify salient factors in continuing the success of using the iPad as a communication device.

More research could investigate use of iPad not just within the home but also outside the home in various community activities. Families might need help in identifying possible settings such as restaurants and shopping areas and planning for these outings. As these youths and their families begin moving out into their communities, the general public will become more aware of individuals with disabilities, are able to observe how these individuals can become more of a part of the general public, and increase acceptance and inclusion of people with disabilities as a normal part of society.

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APPENDIX A

COMMUNICATION PARTNER TRAINING WORKSHOP

Disabled Children Association
MAKKAH CENTER

جمعيـــة الأطفـال المعوقين
مركز مكة المكرمة

كشف حضور وانصراف
ATTENDANCE SHEET

DEPT. .... القسم
DAY .... اليوم

DATE / 17 7 / 2016 ١٤هـ / / التاريخ

الرقم S.No.	Name الاسـم	IN حضـور		OUT انصـراف		ملاحـظات Remarks
		IN	Sign. التوقيـع	OUT	Sign. التوقيـع	

Attendance Sheet of the Parent Training Workshop

جمعية الأطفال المعوقين
Disabled Children's Association

MyTalk

UNIVERSITY of NORTHERN COLORADO

"مشاركة افراد اسر البالغات من ذوي الاعاقات الشديدة او المتعددة لتحسين مهارة
التواصل والسلوك المرغوب فيه با استخدام الايباد
في المملكة العربية السعودية"

مقدمته الدكتورة المرشحة: عفت محمود شقدار
اشراف الدكتور: جوون لكنر
جامعة شمال كلورادو
ربيع ٢٠١٦ م

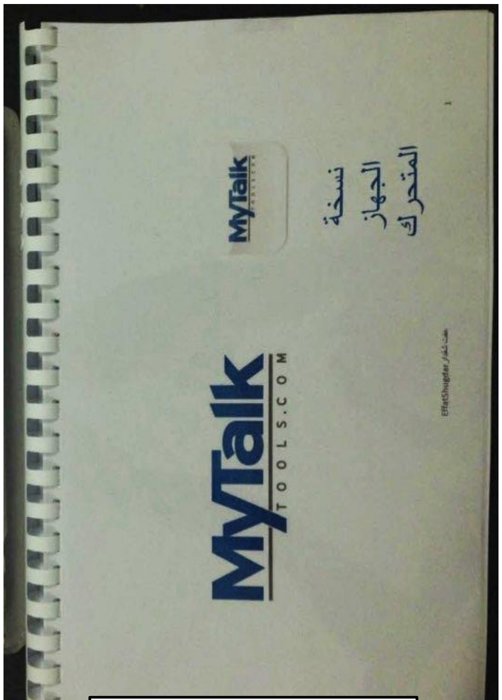
Involvement of Family Communication Partners
in Using an iPad
to Enhance the Communication Skills
and Appropriate Behavior of
Youth with Severe/Multiple Disabilities
in Saudi Arabia

University of Northern Colorado
Developer: Effat Shugdar
Advisor: Dr. John Luckner
Spring 2016

جمعية الأطفال المعوقين
Disabled Children's Association

الرقم المجاني : 8001241118
www.dca.org.sa

Paper Folder



MyTalkTools Guideline

Small Notebook & Pen

APPENDIX B

EQUIPMENT MATERIALS

iPad

MyTalk™ TOOLS.COM

Communication App

iPad Protective Screen

Tab Grabber eReader Holder for

RJ's Cooper Tablet Handpointer

Duck Brand 1/3-inch wide
Silicone Weatherstrip Seal

APPENDIX C

INSTITUTIONAL REVIEW BOARD APPROVAL

UNIVERSITY OF
NORTHERN COLORADO

Institutional Review Board

DATE:	June 7, 2016
TO:	EFFAT SHUGDAR, PH.D
FROM:	University of Northern Colorado (UNCO) IRB
PROJECT TITLE:	[755785-4] Involvement of Family Communication Partners in Using an iPad to Enhance the Communication Skills and Appropriate Behavior of Youth with Severe/Multiple Disabilities in Saudi Arabia
SUBMISSION TYPE:	Continuing Review/Progress Report
ACTION:	APPROVED
APPROVAL DATE:	June 6, 2016
EXPIRATION DATE:	June 6, 2017
REVIEW TYPE:	Expedited Review

Thank you for your submission of Continuing Review/Progress Report materials for this project. The University of Northern Colorado (UNCO) IRB has APPROVED your submission. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of June 6, 2017.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Sherry May at 970-351-1910 or Sherry.May@unco.edu. Please include your project title and reference number in all correspondence with this committee.

This continuation for your IRB is approved for another year. Best wishes with your continued work on this project.

Sincerely,

Dr. Megan Stellino, UNC IRB Co-Chair

APPENDIX D

CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH—ENGLISH AND ARABIC VERSIONS

CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH
UNIVERSITY OF NORTHERN COLORADO

Project Title: Involvement of Family Communication Partners in Using an iPad to Enhance
the Communication Skills and Appropriate Behavior of Youth with
Severe/Multiple Disabilities in Saudi Arabia

Researcher: Effat Shugdar, Ph.D. candidate,
School of Special Education
E-mail:shug4523@bears.unco.edu

Research Advisor: John Luckner
E-mail: john.luckner@unco.edu

<u>Purpose and Description:</u> The primary purpose of this research is to study how a family member communicates with the youth family member who has difficulty talking and also how this family member can help a young family member with severe talking problems improve her talking skills by using an iPad and special software to assist both the family member and the youth. I will conduct the interview twice for up to 90 minutes each time. The interviews will be before and after the training. Then, I will meet with you and your youth for 20-30 minutes a day for five days a week over a period of 4-6 weeks to talk with you about how you and your youth talk with each other now, to show you how to use the iPad to help improve your youth's talking, and to see how this training affects your youth's talking in family activities such as meal time, free time, and play time. Compensation in the form of an iPad and the $ 100 dollars will be given to each family.

I will carry out up to 30 training sessions with you and your youth family member. The purpose of these training sessions is to give you an iPad and show you how you can use it to help your youth talk better. Most of the time you will be the one who works with your youth, but sometimes I will work with your youth just to show you how to do something. I will video record the training sessions but the focus will be upon the work with the iPad rather than your faces. When we finish these training sessions, your family can keep the iPad to keep helping you to talk with each other. All the papers, audio recordings and video recordings will be kept in locked cabinets or on locked computer files, and your real names will not be used so no one can know who you are. All these papers and recordings will be destroyed once the research is completed.

I foresee there are minimal risks to your youth beyond those that are normally encountered in learning activities and talking with one another. "Talking about your youth's behavior and communication issues could make you feel sad or even angry. If you wish, you can stop the interview at any time." Participation in this research may help your youth to talk more and to talk better. I will audio and video record these training sessions but the focus will be upon how you and your youth use the iPad, not your faces. All records including the audio and video recordings will be kept private and locked. To further help maintain confidentiality, computer files of your youth's performance will be created and her name will be replaced by numerical identifiers. The names of you and your youth will not appear in any professional report of this research.

Please feel free to phone me if you have any questions or concerns about this research and please retain one copy of this letter for your records. Thank you for assisting me with my research.
Sincerely,

Participation is voluntary. You may decide not to allow your youth to participate in this study and if she begins participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact Sherry May, IRB Administrator, Office of Sponsored Programs, Kepner Hall, University of Northern Colorado, Greeley, CO 80639; 970-351-1910.

Youth's Full Name	Youth's Birth Date (month/day/year)
Parent/Guardian's Signature	Date
Researcher's Signature	Date

UNIVERSITY of
NORTHERN COLORADO

استمارة موافقة للمشاركة البشرية في بحث علمي
جامعة شمال كلورادو

عنوان البحث: مشاركة شريكات التواصل في العائلة لاستخدام جهاز الايباد لزيادة مهارات التواصل والسلوك المناسب للبالغات من ذوي الاعاقات الشديدة او/ و المتعددة في المملكة العربية السعودية

الباحثة: عفت شقدار، دكتوره مرشحة، قسم التربية الخاصة   مشرف البحث: د. جون لكنر
تلفون: ٩٧٠ ٣٠١ ٩٨٢٠ ايميل: shug4523@bears.unco.edu   ايميل: john.luckner@unco.edu

الهدف والوصف: الهدف الرئيسي من البحث هو لدراسة عن كيفية التواصل بين افراد العائلة وبين البالغات الاتي لديهن صعوبة في الكلام وعن كيفية اهتمام افراد العائلة لمساعدة البالغات ذوي المشاكل الكلامية الشديدة لتطوير مهارات الكلام لديها عن طريق استخدام جهاز الايباد وبرنامج خاص لمساعدة افراد العائلة والبالغات. انني ساعمل مقابلة شخصية مرتين قبل وبعد البرنامج التدريبي وكلا المقابلتين سوف تستغرق من الوقت 90 دقيقة. وبعد ذلك ساقوم بتطبيق البرنامج التدريبي معاك وبوجود الابنة البالغة لمدة 20 الي 30 دقيقة لمدة خمس ايام في الاسبوع لمدة 4 الي 6 اسابيع. وسوف اريكم كيف يمكن استخدام الايباد لمساعدة الابنة البالغة على الكلام ولدراسة مدى فعالية التدريب على كلام الابنة البالغة خلال الانشطة المختلفة كوقت تناول الطعام، والوقت الحر، وقت اللعب. وسيكون هنالك مكافئة مادية بملغ وقدرة 100 دولار مع الاحتفاظ بجهاز الايباد.

انا سوف اقوم بتنفيذ البرنامج التدريبي لمدة 30 جلسة معاك ومع الابنه البالغة. والهدف من هذا التدريب هو اعطائك جهاز الايباد وتدريبك على كيفية استخدام الايباد مع الابنه لمساعدتها على الكلام بشكل افضل. معظم الاوقات ستكوني مع الابنه لاستخدام الايباد وسيكون تدخلي فقط في بعص الاحيان اضطراريا اذا لزم الامر. ساسجل بالفيديو جميع جلسات التدريب وسيكون التركيز فقط على كيفية استخدام الايباد مع مراعاة استبعاد ظهور الوجهه في التسجيل. عن النتهاء من الجلسات التدريبية لك امكانية الاحتفاظ بالايباد للتمكنو من الكلام مع بعضكم. جميع الاوراق والتسجيلات الصوتية والفيديو ستكون محفوظة في مكان امن ومقفل عليها في سواء في درج او على جهاز الكمبيوتر. ايضا سيتم التعامل باستخدام اسماء مستعارة لجميع الافراد لضمان سرية المعلومات وعدم التعرف على الشخصية المشاركة. اخيرا سيتم ايتلاف جميع الاوراق والتسجيلات عند اتمام البحث والانتهاء منه.

اتوقع ان هنالك سيكون اضرار ضئيلة الحدوث اثناء مشاركتك في البحث من خلال مشاركتك في الانشطة والكلام. " مثل التحدث عن الابنه البالغة وسولكها وقدرتها على التواصل ربما يجعلك تشعرين بالحزن او الغضب. فاذا اردتي يمكنك التوقف عن اتمام المقابلة في اي وقت". كذلك المشاركة في هذا البحث سيساعد الابنه البالغة على الكلام اكثر وبطريقة افضل ايضا. وسيكون هنالك تسجيل صوتي وتصوير فيديو عن كيفية استخدامكم للايباد دون التركيز على وجوهكم. وجميع التسجيلات ستحفظ في مكان خاص وسري.لضمان السرية الشخصية سيكون استخدام الرموز العددية عند الاحتفاظ بجميع الملفات على جهاز الكبيوتر بدلا من ستخدام الاسماء الحقيقية لكم. كذلك اسمائكم لن تظهر في اي تقرير سيعمل لهذا البحث.

رجاء يمكنكم الاتصال بي لاي استفسار او سؤال عن هذا البحث. وارجو كذلك الاحتفاظ بصورة من هذه الاستماره في ملفاتكم الشخصية. مع جزيل الشكر لمساعدتكم لي في تطبيق هذا البحث.

المشاركة في هذا البحث تطوعية. يمكنك لابنتك البالغة الانسحاب من هذا البحث وعدم المشاركة في اي وقت. قرارك سيكون بعين الاعتبار وليس مؤثرا لخسارة اي نفع. بعد القراءة والاطلاع على ماتقدم والاستفسار عن اي شيء ارجو التكرم بتوقيع اسفل الصفحة اشعارا بالموافقة على المشاركة في هذا البحث. سيتم تزويدك بنسخة من هذه الاستماره بعد توقيعها كمرجع لك في المستقبل. واذا لديك اي استفسار عن اختيارك وتعاملك في هذا البحث كمشارك ارجو الاتصال بـ شيري ماي. رئيسة مكتب لجنة الاير بي، مبني كبنر، جامعة شمال كلورادو، قريللي، كلورادو، 80639، 970-351-1910.

______________________	______________________
اسم الابنه البالغة كاملا	تاريخ ميلادها (شهر/يوم/ سنة) بالميلادي
______________________	______________________
توقيع الوالده/او الشخص المسؤول	التاريخ
______________________	______________________
توقيع الباحثة	التاريخ

APPENDIX E

INTERVIEW QUESTIONS IN ENGLISH AND ARABIC

Interview Questions (English Version)

Demographic questions:

1. What is your relationship to _________ (child’s name)?
2. Are you in charge to take care of ___________?
3. Are you employed? What is your job?
4. Do you have a child with a disability, and if so, what is the disability?
5. When did you first learn about this disability, and how did you learn about it?
6. What health issues has your child experienced?
7. How has the child’s disability impacted your family life?
8. Describe your child’s development over her lifetime. Tell me about her when she was younger.
9. What do you think your child learned when she was in school?
10. How satisfied were you with your child’s progress in school? Were there any problems, and if so, how were they addressed?
11. Has _________ received special education and/or other services after she finished elementary school? If yes, what are these services and for how long?
12. How old is _________ now?
13. How long has she been living at home since she finished school?
14. What does she do during a typical day?
15. What is she most interested in, how much time does she spend with this/these interest, and how does she express this/these interests?

Primary Interview Questions for First Interview:

1. Tell me about how important you think good and appropriate communication is in your family.
2. How do you think different family members affect ___________’s communication?
3. What are your goals and dreams about communication between different family members with _____________?
4. Do you think the communication ability affects ______ to engage with any kind of special services, therapies, or any other kind of activities?
5. How would you describe your communication with __________ at home?
6. What are your concerns about ______________ and the way she communicates at present?
7. What are your dreams for ____________ regarding communication?

8. Describe your family’s current communication interactions with ____________, how and when this interaction takes place, what happens during this interaction, your feelings and other family members’ feelings about this interaction?
9. Describe some specific examples of ____________’s communication and examples of family members communicating with her in different kinds of activities.
10. How would you describe ___________’s communication ability to interact with others outside of the home environment?
11. How satisfied are you with your communication in interacting with _______ in the home? If not, how would you like to communicate with her?
12. What are the worst problems that __________has in communication and behavior? (If she responds with several, have her prioritize them)
13. How does _________ currently communicate her needs or wants to you?
14. How do you think ___________’s communication style could affect her behavioral skills during daily activities?
15. Does ____________ exhibit in some inappropriate behavior when you do not understand her communication language?
16. Have you any experience in using technology like an iPad? If yes, how have you used it and for what?
17. Has _________ used any technology such as iPad in her daily activities? If yes, what does she use it for?
18. Have you heard anything about using an iPad as communication tool to improve communication and interaction skills for ____________?
19. How do you feel about the idea of introducing the use of an iPad as a communication tool to _____________?
20. What type of words and phrases do you hope ___________ could use to improve her communication skills and reduce her inappropriate behavior?
21. What type of activities does ____________ like to engage in during her daily life?
22. What else would you like to tell me about __________, her communication with family members, how you would like things to change, and how you could imagine an iPad helping ___________?

Primary Interview Questions for Second Interview:

1. How do you think different family members affect ___________’s communication now?
2. What are your goals and dreams about communication between different family members with _____________ now?
3. Do you think the communication ability affects ______ to engage with any kind of special services, therapies, or any other kind of activities?
4. How would you describe your communication with __________ at home now?
5. What are your concerns about ______________ and the way she communicates at present?
6. What are your dreams for ____________ regarding communication?
7. Describe your family’s current communication interactions with ____________, how and when this interaction takes place, what happens during this interaction, your feelings and other family members’ feelings about this interaction?
8. Describe some specific examples of ____________’s communication and examples of family members communicating with her in different kinds of activities.
9. How would you describe ___________’s communication ability to interact with others outside of the home environment?
10. How satisfied are you with your communication in interacting with _______ in the home? If not, how would you like to communicate with her?
11. What are the worst problems now that __________has in communication and behavior? (If she responds with several, have her prioritize them)
12. How does _________ currently communicate her needs or wants to you?
13. How do you think ___________’s communication style could affect her behavioral skills during daily activities?
14. Does ____________ still exhibit in some inappropriate behavior when you do not understand her communication language?
15. What type of words and phrases do you now hope ___________ could use to improve her communication skills and reduce her inappropriate behavior?
16. What type of activities does ____________ like to engage in during her daily life?
17. Have you noticed any changes in _______________’s communication, with you or with other family members? If so, please describe what these changes are?
18. What do you think about the training process in teaching _____________ to use the iPad? What do you think was most helpful? Least helpful? What else would you like to know about using the iPad to help ________________ in communicating?

19. How likely do you think you are to continue using the iPad?
20. How do you see _______________ using the iPad in the future?
21. What else would you like to tell me about ___________ and her communication with family members now?

Interview Questions (Arabic Version)

اسئلة المقابلة الاولى

الاسئلة الشخصية:

1. ماهي علاقتك الشخصية _______ (اسم الابنة)؟
2. هل انت من يعتني _______ مباشرة؟
3. هل انت موظف؟ ماهو نوع عملك؟
4. هل لديك من طفل من ذوي الاحتياجات الخاصة؟اذا نعم، ماهي اعاقته/اعاقتها؟
5. هل _______ تتلقى تعليم خاص او اي نوع من الخدمات الخاصة بعد انتهائها من المرحلة الابتدائية؟ اذا نعم؟ ماهي هذه الخدمات وكم هي المدة التي تتلقى فيها الخدمات؟
6. ماهو عمر _______ الزمني؟

اسئلة المقابلة الرئيسية:

1. حديثيني عن اهمية التواصل بين افراد العائلة في منزلكم.
2. كيف تعتقدي ان الاختلاف بين افراد العائلة يؤثر على التواصل مع ـــــــــ؟
3. ماهي اهدافك واحلامك بالنسبة للتواصل بين افراد العائلة مع ـــــــــــــ؟
4. هل تعتقدي ان قدرة _______ من ذوي الاعاقات الشديدة او المتعددة على التواصل تؤثر على دمجها في خدمة التعليم الخاص او اي من الخدمات الطبية الاخرى؟
5. كيف يمكن لك ان توصفي كيفية تواصلك مع _______ في المنزل؟
6. كيف يمكن لك ان تصفي قدرة _______ على التواصل خارج محيط المنزل؟
7. ماهو قلقك علي ـــــــ وكيف لها ان تتواصل مع افراد عائلتها؟
8. ماهي احلامك اتجاه تطوير مهارات التواصل لـ ـــــــــ؟
9. ماهو مدى رضاك عن تفاعلك اثناء تواصلك مع _______ في المنزل؟ اذا لم تكوني راضية، كيف تفضلي ان تتواصلي مع _______؟
10. ماهو اسوء شيء يمكن ل_______ ان تبديه في مهارتها على التواصل ويظهر في سلوكها؟اذا كان اكثر من مظهر ، ماهي؟
11. اوصفي لي بعض الامثله عن تواصل ـــــــــ مع افراد عائلتها من خلال بعض الانشطة المختلفة؟
12. ماهو نوع اللغة التي تستخدمها _______ للتواصل معك، على سبيل المثال: لغة الرضع، اصوات للكلمات، كلمات محدودة، او لغة الاشارة؟
13. كيف تعتقدي اسلوب التواصل ل_______ يمكن ان يؤثر على مهاراتها السلوكية خلال الانشطة اليومية؟
14. هل تظهر _______ بعض السلوكيات غير المرغوب فيها عندما تبدين لها عدم فهمك للغة تواصلها؟
15. هل لديك اي خبرة في استخدام التكنولوجيا مثل جهاز الايباد؟ اذا نعم، كيف تستخدميه ولاي غرض؟

16. هل سبق ل ______ وان استخدمت التكنولوجيا كجهاز الايباد من قبل خلال الانشطة اليومية؟ اذا نعم، لاي غرض كانت تستخدمه؟
17. هل سبق وان سمعت عن استخدام جهاز الايباد كجهاز للتواصل لتنمية مهارة التواصل والتفاعل الاجتماعي ل______؟
18. ماذا تشعري عن استخدام جهاز الايباد كاداة للتواصل لتنمية مهارتالتواصل لدى ______؟
19. ماهي الكلمات والعبارات التي ترغبي ان تقولها ______ لتنمي لديها مهارة التواصل وتقلل من المشاكل السلوكية لها؟
20. ماهي انواع الانشطة التي ترغب ان تخوض فيها ______ خلال حياتها اليومية؟
21. ماذا تريدي ان تضيفي او تخبريني عن ـــــــ وتواصلها مع افراد العائلة؟
22. كيف يمكن لك ان تغيري او تتخيلي تواصل ـــــــ مع الايباد سوف يكون؟

اسئلة المقابلة الثانية

١) كيف تعتقدي ان مختلف افراد الاسرة يؤثرو على تواصل الاء الان؟

٢) ماهي اهدافك واحلامك بالنسبة للتواصل بين افراد الاسرة والاء الان؟

٣) هل تعتقدي قدرة الاء علي التواصل تؤثر على دمجها في انشطة الحياة اليومية؟

٤) كيف ممكن توصفي تواصلك مع ......في البيت الان؟

٥) ما هو قلقك على ....وطريقة تواصلها الحالية؟

٦) ما هي احلامك لـ.......... بالنسبة للتواصل؟

٧) اوصفي لي كيف يتفاعل افراد الاسره حاليا مع ....؟ وكيف ومتى يكون هذا التفاعل في اي وقت او موقف؟ ماذا يحدث خلال هذا التفاعل الاسري؟ ماهو شعورك وشعور افرلد السرة يالنسبة لهذا التفاعل مع ....؟

٨) اوصفي لي بعض الامثلة من تواصل ....؟ وامثلة على تواصل افراد الاسره مع .... خلال الانشطة المختلفة؟

٩) كيف يمكن ان توصفي قدرة ....على التواصل والتفاعل مع الاخرين خارج محيط المنزل؟

١٠) ما هو مدى رضاك عن التواصل والتفاعل مع ..... في البيت؟ اذا كنتي غير راضية كيف تفضلي ان تتواصلي معاها؟

١١) ما هي اسوأ مشكلة لدى ..... في تواصل او سلوك الان؟

١٢) كيف تتواصل معاك ...... لطلب احتياجاتها ومطالبها؟

١٣) كيف تتوقعي انه طريقة .... على التواصل تؤثر على سلوكها خلال اليوم؟

١٤) هل تبدي....... اي سلوك غير مرغوب عندما لاتفهمي لغتها في التواصل؟

١٥) ماهي الكلمات والعبارات التي تحتاج لها ......لتطور مهارة التواصل لديها وتقلل من المشاكل السلوكية؟

١٦) ما هي انواع الانشطة اليومية التي ترغب فيها .... ان تندمج فيها؟

١٧) قد لاحظتي اي تغييرعلى تواصل .... معاك او مع احد افراد الاسرة؟ اذا نعم، هل ممكن ان تصفي لي هذه التغيرات؟

١٨) ماذا تعتقدي عن خطوات تطبيق ورشة العمل عن استخدام جهاز الايباد كوسيلة للتواصل لـ...... ؟ ماهو اكثر شي كان مساعد لك؟ وما هو اقل شي مساعدة؟ ماذا تفضلي ان تضيفي لتطوير استخدام الايباد مع.......؟

١٩) ما مدى رغبتك في استمرارية استخدام الايباد مع ...... ؟

٢٠) كيف تتوقعي استخدام الايباد مع ...... في المستقبل؟

٢١) ماذا ترغبي ان تضيفي عن تواصل ...... معاك او مع افراد العائلة؟

APPENDIX F

DATA SHEET

Subject: Date: Duration:
Situation:

Physical Behaviors:	**Frequency**	**Notes**
Keeps Head Down		
Sits Up Straight		
Maintains Eye Contact with communication Partner		
Smiles/Laughs		
Frowns		
Aggression (P=pushing items/people away, H=hits, K=kicks)		
Drools		
Cries		
Communication Behaviors:		
Initiates Communication (G=gesture, V=verbal/word, S=sound)		
Responds to Communication (G=gesture, V=verbal/word, S=sound)		
Uses Words (C=correct word/name, I=incorrect word/name)		
Uses Sounds (Vocalization, Grunt, Singsong)		
Uses Yelling/Screaming		
Gestures with Hand to Request (Attention, Glass of Water, Remote Control, Phone)		
Gestures with Hand to Respond (Yes, No, Indicate Needs)		
Gesturing with Head to Request/Respond		
Quiet/withdrawn from Communication Partner		
Active/Engages with Communication Partner		

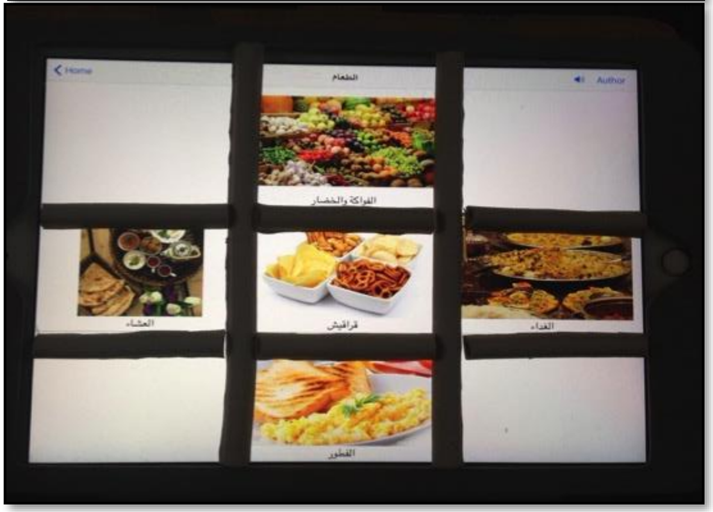
Definition of the Behaviors on the Tables

Physical behaviors:
Keeps head down
Sits up straight
Maintains eye contact with communication partner
Gestures with hand to request (attention, glass of water, remote control, telephone)
Gestures with hand to respond (yes, no, indicate needs)
Gesturing with head to request/respond
Smiles/laughs
Frowns
Aggression (P=pushing items/people away, H=hits, K=kicks)
Drools
Cries
Communication behaviors:
Initiates communication (G=gesture, V=verbal/word, S=sound)
Responds to communication (G=gesture, V=verbal/word, S=sound)
Uses words (C=correct word/name, I=incorrect word/name)
Uses sounds (vocalization, grunt, singsong)
Uses yelling/screaming
Quiet/withdrawn from communication partner
Active/engages with communication partner

APPENDIX G

SCREEN SHOTS FROM REEM'S iPAD

Opening Screen



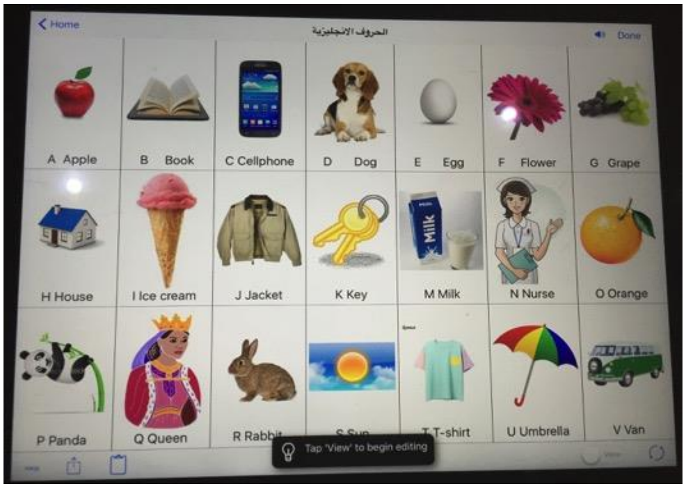
Food Folder

Dairy Drinks Folder

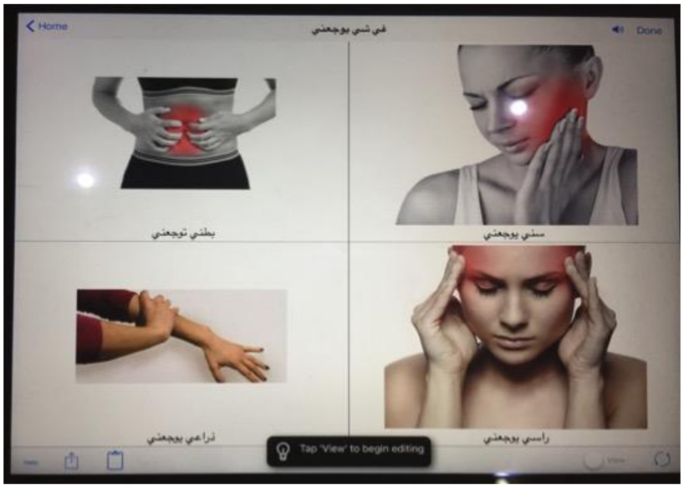
APPENDIX H

SCREEN SHOTS FROM ALAA’S iPAD

Opening Screen



English Alphabet Folder



Pain Feeling Folder

APPENDIX I

SCREEN SHOTS FROM ROAA’S iPAD

Opening Screen

Cold Drinks Folder

T.V Folder