Duquesne University Duquesne Scholarship Collection

Electronic Theses and Dissertations

Fall 1-1-2016

My Social Toolbox: Building a Foundation for Increased Social Participation Among Children With Disabilities

Brooke Willis

Follow this and additional works at: https://dsc.duq.edu/etd

Recommended Citation

Willis, B. (2016). My Social Toolbox: Building a Foundation for Increased Social Participation Among Children With Disabilities (, Duquesne University). Retrieved from https://dsc.duq.edu/etd/55

This Worldwide Access is brought to you for free and open access by Duquesne Scholarship Collection. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Duquesne Scholarship Collection. For more information, please contact phillipsg@duq.edu.

MY SOCIAL TOOLBOX:

BUILDING A FOUNDATION FOR INCREASED SOCIAL PARTICIPATION AMONG CHILDREN WITH DISABILITIES

A Doctoral Capstone Project

Submitted to the Rangos School of Health Sciences

Duquesne University

In partial fulfillment of the requirements for the degree of Occupational Therapy Doctorate

By

Brooke Willis

December 2016

Copyright by

Brooke Willis

MY SOCIAL TOOLBOX:

BUILDING A FOUNDATION FOR INCREASED SOCIAL PARTICIPATION AMONG CHILDREN WITH DISABILITIES

By

Brooke Willis

Approved November 8, 2016

Dr. Ann Cook, OTD, OTR/L Clinical Assistant Professor of Occupational Therapy (Committee Chair) Dr. Jaime P. Muñoz, PhD, OTR/L, FAOTA Associate Professor of Occupational Therapy (Committee Member)

Dr. Elizabeth DeIuliis, OTD, OTR/L Assistant Chair, Department of Occupational Therapy (Committee Member) Dr. Jaime P. Muñoz, PhD, OTR/L, FAOTA Chair, Department of Occupational Therapy Associate Professor of Occupational Therapy

Dr. Paula Turocy, EdD, LAT, ATC Dean, Rangos School of Health Sciences Associate Professor in the Rangos School of Health Sciences

ABSTRACT

MY SOCIAL TOOLBOX:

BUILDING A FOUNDATION FOR INCREASED SOCIAL PARTICIPATION AMONG CHILDREN WITH DISABILITIES

By

Brooke Willis

December 2016

Doctoral capstone project supervised by Dr. Ann Cook

Social participation is an important occupation for children that occupational therapists address. The benefits of participation include emotional well-being, life satisfaction, building friendships, psychological benefits and positive effects on overall health and development (Law, Petrenchik, King, & Hurley, 2007). Compared to their typically developing peers, children with disabilities are at an increased risk for decreased participation (Law et al., 2007). An expedited scoping review of the literature revealed key supports and critical barriers that impact the frequency and quality of social participation for children with disabilities. Children with disabilities and their families experiencing these barriers with resultant decreased levels of social participation could potentially lead to social isolation, decreased friendships, and negative psychological outcomes (Law et al., 2007).

A synthesis of the most current research informed the development of My Social Toolbox, a pilot program designed to alleviate the social participation disparities between children with and without disabilities. By addressing some of the barriers, as noted in the literature, My Social Toolbox aims to ease the social experience for the parents by providing them with the skills and resources they need to be successful, thereby facilitating increased social participation for their child, as well as enhancing the quality of interactions of their child. Thus, the My Social Toolbox program integrates the evidence supporting the effectiveness of parent-training programs in general and the important role parents play in the therapy process (Kaiser & Hancock, 2003; Kane, Wood, & Barlow, 2007).

This one-month pilot program consisted of weekly parent training sessions and a social event for the parents, their child, and other family members. The participants consisted of four mothers of children with disabilities. This comprehensive program addressed topics including the benefits of social participation, education about local resources, and teaching of strategies for enhanced social interaction skills. Multiple outcome measurement tools were chosen to measure the effectiveness of My Social Toolbox and program goal achievement, including the Participation and Environment Measure for Children and Youth (PEM-CY), the Child Occupational Self-Assessment (COSA), Goal Attainment Scaling (GAS), as well as tools created by the doctoral candidate to measure goal achievement and parent satisfaction with the program. Results of the program indicate parent's increased knowledge of the importance and benefits of social participation and parents' interest in programs helping them be able to best support their child socially. Knowledge of the current literature combined with the outcomes of My Social Toolbox can help guide the development of future programs addressing the participation disparities between children with disabilities and children without disabilities.

DEDICATION

I would like to dedicate this doctoral capstone project to my parents who have wholeheartedly supported my journey throughout the Duquesne University doctorate program.

ACKNOWLEDGMENT

I would like to thank the entire faculty at Duquesne University who has supported me not only through the Doctorate program, but also throughout my time at Duquesne in the occupational therapy program. All of your hard work has supported my journey and has helped the development of the new doctorate program at Duquesne.

Specifically, I would like to thank Dr. Jaime Muñoz and Dr. Ann Cook, my capstone mentor, for all the assistance and guidance you have provided me over the past year. All of the time and effort you put into providing me feedback and suggestions does not go unnoticed and is truly appreciated.

I would also like to thank Christine Goudy for enthusiastically serving as my site supervisor at my doctoral experiential site. Your energy and true passion for the school kept me motivated throughout my capstone project. Thank you for helping me with the logistics of the program so that My Social Toolbox could take place at your school. Lastly, I would like to thank Kathy Castrataro for serving as my external mentor and providing me with OT-specific knowledge and being readily available whenever I had a question.

Again, thank you to everyone who has supported the development and implementation of this capstone project. Without the help of each and every one of you, this capstone project would not have been accomplished.

TABLE OF CONTENTS

| ABSTRACT | iv |
|---|--|
| DEDICATION | vi |
| ACKNOWLEDGMENT | vii |
| TABLE OF CONTENTS | viii |
| LIST OF ABBREVIATIONS | ix |
| CHAPTER ONE: THE PRACTICE SCHOLAR CAPSTONE PROJECT | 1 |
| CHAPTER TWO: REVIEW OF RELEVANT LITERATURE 2.1 Doctoral Capstone Statement 2.2 Synthesis of the Literature 2.3 Summary | 5 |
| CHAPTER THREE: THEORETICAL FRAMEWORK | 13 |
| CHAPTER FOUR:DESCRIPTION OF PRACTICE SCHOLAR CAPSTONE PROJECT 4.2 Program Goals 4.3 Program Description 4.3.1 New/Existing 4.3.2 Theoretical Framework 4.3.3 Rationale for Program Design 4.3.4 Sample 4.3.5 Program Structure 4.3.6 Program Implementation 4.3.7 Program Evaluation | 16 17 18 18 19 21 23 |
| CHAPTER FIVE: RESULTS | |
| CHAPTER SIX: DISCUSSION | |
| CHAPTER SEVEN: SUMMARY BIBLIOGRAPHY | |
| APPENDICES Appendix A: Key Studies Informing the Program Approach Appendix B: My Social Toolbox Marketing Flyer Appendix C: My Social Toolbox Informed Consent Form Appendix D: PEM-CY Community Subsection Appendix E: Parent Social Participation Pre-Test/Post-Test Questionnaire Appendix F: Goal Attainment Scaling (GAS) Method Appendix G: The Child Occupational Self-Assessment (COSA) – Modified | 47 50 53 57 58 |
| Appendix H: Parent Participant Satisfaction Survey | 61 |

LIST OF ABBREVIATIONS

ASD Autism Spectrum Disorder

COSA Child Occupational Self-Assessment

ESY Extended School Year

GAS Goal Attainment Scaling

IEP Individualized Education Plan

MOHO Model of Human Occupation

OT Occupational Therapy

PEM-CY Participation and Environment Measure for Children and Youth

CHAPTER ONE

THE PRACTICE SCHOLAR CAPSTONE PROJECT

1.1 Problem Statement

Orange Schools enrolls students with disabilities such as autism spectrum disorders, learning disabilities, cognitive delays, and emotional, psychological, and/or physical disabilities. These students are at risk for restricted participation compared to children without disabilities (Law et al., 2007). The benefits of participation include emotional well-being, life satisfaction, building friendships, psychological benefits and positive effects on overall health and development (Law et al., 2007). Limited access to opportunities experienced by their typically developing peers (e.g., athletics, extracurricular activities) results in children with disabilities not experiencing these benefits, potentially leading to social isolation, decreased friendships, and negative psychological effects (Law et al., 2007). Currently, a majority of research findings indicate that programs for children with disabilities are limited and parents are not fully aware of the available programs or benefits of participation for their child (Law et al., 2007). At Orange Schools specifically, one program, the Extended School Year program, is offered to children with disabilities, thus, the availability of inclusive programs offered within the school is lacking.

1.2 Needs Assessment

Orange City Schools, hereafter referred to as Orange Schools, is a school district located in Pepper Pike, Ohio. Orange Schools serves students from preschool to high school and offers quality special education services, speech therapy, occupational therapy, physical therapy, and psychology services. In order to determine the needs of the site, a formal on-site needs assessment was organized via email with the Special Education Coordinator, Christine Goudy. One day was spent on site and this time was split between the Inclusive Preschool and the

Moreland Elementary School. A tour was provided of the elementary school and the doctoral candidate made observations of the occupational therapy services provided and attended an individualized education plan (IEP) meeting. A 30-minute interview was conducted with one occupational therapist and a 90-minute interview was conducted with the Special Education Coordinator. Both interviews focused on the perceived strengths of the school, the demographics of the population, strengths and weaknesses of current programming, and areas of need for improvement at the site.

Based on information gathered from the needs assessment, Orange Schools currently provides quality special education services and has a large campus with spacious and wellequipped facilities. Orange Schools offers many scholastic and athletic programs for their students. Though children with disabilities are not restricted access to these programs, per the Special Education Coordinator, it is evident that students with disabilities rarely participate in these programs. Currently, Orange Schools offers only one program specifically directed toward students with disabilities. This is a six-week Extended School Year (ESY) program and is only available for those whose needs qualify for the services. Students qualify based on data collected during the school year on their IEP goals and objectives. If a child demonstrates skill regression, such as academic, social, and/or behavioral, over vacations or weekends and a large amount of time is needed to recoup skills lost, or they are not recouped, then he/she may qualify. Students who do not show enough progress on critical IEP goals and objectives may also qualify. Participation in the ESY program is always a team decision and is determined each school year by the IEP team members. Often times, the students that qualify are the students in the multipledisability classrooms, indicating they have more challenging behaviors and require more handson assistance to complete tasks. Based on the interview with Christine Goudy, some of the

recommended needs of the students with disabilities enrolled in the school include providing programs for socialization, physical education, peer interaction, parent education and information about accessing community resources for children with disabilities.

According to Ideishi et al. (2013), "All people, regardless of abilities, should have access to, choice of, and an opportunity to participate in a full range of community activities" (p.1). Other than the Extended School Year Program, which is only offered to students whose needs qualify, Orange Schools does not currently offer programs specifically for children with disabilities. Children with disabilities are not excluded from participation in the current programs offered, but the Orange Schools Special Education Coordinator stated that these children rarely take the opportunity for a variety of reasons such as innate physical demands of the activities, psychological effects of negative attitudes toward the child or potential for not being included or accepted by other students, and low confidence in their ability to participate. Thus, children with disabilities have few opportunities for social inclusion, a limited range of choices for activities they feel they are able to engage in, and limited programs providing parent or peer education regarding social inclusion.

1.3 Aim and Purpose

The purpose of My Social Toolbox pilot program is to build a foundation for increased social participation among children with disabilities. There are four primary aims of this program.

- To identify the range of social opportunities available for children with disabilities within the surrounding community.
- 2. To increase parents' current understanding about the importance and evidence-based benefits of social participation for their child with a disability.

- 3. To teach parents the strategies they can use to promote increased social interaction and improved quality of social interactions in naturally occurring community activities for their child with a disability.
- 4. To increase parents' abilities to identify and access community resources that provides opportunities for their child's social participation in formal and naturally occurring community activities.

CHAPTER TWO

REVIEW OF RELEVANT LITERATURE

2.1 Doctoral Capstone Statement

Social participation and play are crucial occupations throughout childhood and into adolescence (AOTA, 2014). There are many children with disabilities enrolled in Orange Schools. The evidence that children with disabilities are at an increased risk for decreased participation compared to their typically developing peers is well documented (Law et al., 2007). A scoping review was completed to better understand the nature of various barriers and facilitators of social participation those children with disabilities and their families face and that contribute to this discrepancy in social participation levels. Research completed with persons with a variety of disabilities has improved general understanding of factors that can promote or inhibit participation. However, there is limited research on the efficacy of social participation programs, specifically parent education programs that seek to increase social participation in children with disabilities. A thorough review of the supports and barriers to successful participation helped inform the development of a program at Orange Schools with a focus on components contributing to increased social participation.

2.2 Synthesis of the Literature

There is a large disparity between children with disabilities and children without disabilities in regards to their levels of participation, as children with disabilities typically demonstrate decreased levels of participation (Law et al., 2007). Barriers and facilitators contributing to this disparity are well documented in the literature. From a parent's perspective, some of the barriers include family burden, such as time, cost (Anaby et al., 2014; Bedell et al., 2013; Fette & Estes, 2009; Heah et al., 200; Piskur et al., 2012; Shields & Synnot, 2016), and

environmental features and resources, including a lack of programs offered and/or a lack of information regarding the programs offered as well as a lack of equipment and supplies to fit their child's needs (Bedell et al., 2013; Coster et al., 2012; Fette & Estes, 2009; Piskur et al., 2012; Shields & Synnot, 2016). Other barriers include the mismatch between the child's abilities and the social, cognitive, and/or physical activity demands placed on the child within the services that are available (Bedell et al., 2013; Gorzkowski, Kelly, Klaas, & Vogel, 2011; Shields & Synnot, 2016), child factors such as poor self-esteem, (Bedell et al., 2011; Gorzkowski et al., 2011) frustration or loss of confidence when comparing their skills to those of their peers, and negative societal attitudes and prejudice towards persons with disabilities (Fette & Estes, 2009; Heah et al., 2006; Piskur et al., 2012; Shields & Synnot, 2016). All of these are factors contributing to the low levels of social participation of children with disabilities and need to be addressed in order to make any change and help solve this issue.

Despite these barriers, parents defined several factors that facilitate social participation for their children with disabilities. These included support, particularly the support from family and friends (O'Brien et al., 2009) as well as the ability to network with other parents (Heah et al., 2006; Piskur et al., 2012; Shields & Synnot, 2016). The availability of activities, including inclusive activities, and having a variety of activities that allowed parents to choose desired and meaningful activities were also felt to facilitate social participation (Heah et al., 2006; Shields & Synnot, 2016). Positive attitudes from community members and acceptance from the child's peers can greatly increase a family's desire and willingness to participate in social opportunities (Bedell et al., 2013; Shields & Synnot, 2016). Parents also identified the ability to have partnerships between their child's school, activity providers, and disability groups as a facilitating factor (Shields & Synnot, 2016). Such partnerships often ensured information and

resources regarding social opportunities were readily available and easily accessible within their child's current school.

There are well-structured studies that have helped define the factors that contribute to a parent's ability to support the ability of their child with a disability to participate. There is less research and evidence-based understanding about current programs addressing social participation in children with disabilities. Evidence regarding the implementation and effectiveness of a socialization program is sparse, specifically studies addressing the parents as crucial persons who have a significant effect on the child's social participation and social interaction skills. Thus, with a good understanding of those factors that both help or hinder a parent's ability to support their child in reaching their social potential, in addition to, literature outlining components of effective parenting programs, a basis for a quality program that fits the gap in current practices and literature can be developed.

Occupational therapists provide family centered care. When occupational therapy (OT) services are offered to children, a family perspective is utilized. It is very important to also include the parents and understand the critical role they play in the therapy process because "parents are their children's first and most enduring teachers" (Kaiser & Hancock, 2003, p. 9). "Parent training is now considered an essential component of successful intervention programs for children with autism" (Ingersoll & Dvortcsak, 2006, p. 79). Though this statement is specific to children with autism, it can also apply more broadly to children with a variety of disabilities. Ingersoll and Dvortcsak (2006) tested a parent training module which "[focused] on teaching families naturalistic intervention techniques to increase their child's social—communication skills during daily activities and routines" (p. 80). In this study, parents' knowledge of intervention techniques to increase their child's social-communication skills increased by 46% with the

training, overall parent satisfaction ratings were positive, and parents felt more optimistic about their ability to positively impact their child's development (Ingersoll & Dvortcsak, 2006, p. 84). Steiner et al. (2012) also documented parents' ability to learn strategies to effectively teach their children across a variety of areas, including social skills. The parent training sessions can help bring the issue of decreased social participation to the forefront of the parent's minds and provide them with information regarding current social participation opportunities within the community. This information can illustrate to the parents how incorporating some of the recommendations or opportunities provided can be a way that they, as parents, can help positively influence their child's health and development.

Parenting programs can also be helpful and beneficial to parental and family functioning (Barlow & Stewart-Brown, 2001; Kane, Wood, & Barlow, 2007). In semi-structured interviews, parents involved in a Family Links Nurturing parenting program reported that the opportunity to be in a group setting with other parents, receive support from other parents, and exchange ideas with one another were valued components of the experience (Barlow & Stewart-Brown, 2001; Kane et al., 2007; Steiner et al., 2012). These features are integrated into the proposed program which is designed to allow parents opportunities to be in a group setting, discuss barriers to participation that they face with their child, and work together to help problem solve some of the challenges they face. The group setting allows parents to network and create relationships with one another, while simultaneously offering a supportive and accepting environment with others experiencing similar situations (Barlow & Stewart-Brown, 2001; Steiner et al., 2012). Parents also communicated that they benefited from being supported in the parenting role, rather than being taught how to raise their children and be a parent (Barlow & Stewart-Brown, 2001). Thus, for program implementation, a partnership model appears to be a good approach. Steiner et al.

(2012) highlighted that "when interventionists used a partnership approach, defined as making more collaborative rather than directive statements to parents about treatment recommendations, improvements in parent stress and confidence were found, in addition to child improvement" (p. 5). A partnership approach can help ensure that the information is being conveyed positively both by the doctoral candidate and the parents. Information and goals can be tailored based on their input. Lastly, the parents engaging in the parenting program noted the benefit of having new ways to support their child's development and having new tools to use in the role of a parent (Barlow & Stewart-Brown, 2001). With this new acquisition of knowledge, parents can experience an increased sense of control and confidence (Kane et al., 2007).

The topics of the parent training sessions within the My Social Toolbox program all relate to increasing social participation for a child with a disability, some of which focused specifically on strategies parents could use to improve their child's social interaction skills. Carter and Hughes (2005) completed a review of the literature explaining various intervention approaches utilized to increase social participation between youth with intellectual disabilities and their typically developing peers. This review included articles with study participants between seventh and twelfth grade with the interventions focused directly toward the students. While the children of the parents in the My Social Toolbox program will be younger than this population, closer to elementary school age, the ideals and strategies presented in this review are deemed valuable and can be used to educate and train the parents on various methods to promote increased social interaction between their child with an intellectual disability and his or her typically developing peers. These will include both skill-based and support-based interventions that the parents can easily incorporate into their lifestyle, helping their child's social development. In Carter and Hughes' (2005) review, skill-based interventions involved teaching

participants with disabilities skills to increase their social interaction with peers. In the My Social Toolbox program, the skills were taught to the parents of the children with disabilities, rather than the children themselves in the hopes that the parents utilizing these skills would, in turn, have a positive effect on their child. Support-based interventions focus on arranging aspects of the environment to promote or support peer interaction (Carter & Hughes, 2005). Information on how to adapt the environment to support their child's needs and help make them the most successful in their environments, such as a child with sensory processing difficulties, were provided.

With evidence supporting the implementation and benefits of parenting programs, Kaiser and Hancock (2003) specified ways that professionals can optimize parent teaching, including strategies that should be considered when planning for interventions with parents to improve their effectiveness. First, it is important that participants are willing, ready, and interested to participate and learn new strategies (Kaiser & Hancock, 2003). Thus, this helped support recruitment efforts into the program, emphasizing voluntary participation ensuring all the information about the content and format of the program was provided to allow parents the opportunity to make informed decisions. Kaiser and Hancock (2003) noted the importance of having the parent and parent educator "set collaborative goals with the parent for themselves, the family, and the child" (p. 12). In a review completed by Steiner et al. (2012), a collaborative approach to goal setting between the parent educator and the parent was also emphasized. Collaborative goal setting was, therefore, incorporated into the program plan in order to help the parens set meaningful and achievable goals for themselves and their children in relation to an aspect or multiple aspects of social participation that were presented throughout the program. Some other strategies Kaiser and Hancock (2003) suggested for educating parents include

incorporating practice in implementing the procedures with the child, giving the parent feedback for support, and teaching across settings. These approaches were utilized to optimize the parent's learning and transfer of knowledge, with the hopes in increasing the effectiveness of the My Social Toolbox sessions. Parents were encouraged to practice implementing some of the social interaction strategies provided that best fit their parenting style and child's needs into their daily routine and day-to-day interactions within the context of their home and community settings. Also, parents also had the opportunity to practice some of the strategies taught in the final session during the social event, giving the parents the opportunity to practice these skills, increasing the potential for the generalization of skills and sustainability of the effects (Kaiser & Hancock, 2003). Parents were provided feedback in the group setting based on observations and were offered the opportunity to receive individual feedback as well if requested. Lastly, Kaiser and Hancock (2003) suggest to "invite formal and informal feedback from parents at frequent intervals" (p. 14). Requesting feedback from the parents helped the doctoral candidate determine if the program was helpful and to know if adjustment of teaching style or teaching methods were required for a better understanding of the information being provided.

Knowledge of the barriers and facilitators to social participation faced by families with a child with a disability combined with evidence supporting program components supported the development of My Social Toolbox content and design in an effort to maximize the parent's ability to help initiate and support their child's social experiences. Though evidence regarding the implementation and effectiveness of socialization programs is sparse, a combination of effective program components found in current research was used to design the program. This includes the parents as participants as they are crucial persons impacting the development of their child with a disability, as well as, their ability and positive outlook toward learning

intervention techniques to increase their child's social skills. The group setting of the parent sessions allows parents to receive support from other parents and exchange ideas with one another who are in similar situations and the collaborative goal setting allows the program goals to be individualized for each unique family's needs. Lastly, education of social interaction strategies will include both skill-based and support-based interventions, both teaching skills to the parents to increase the child's social interaction with peers and education on arranging aspects of the environment to promote or support peer interaction. Refer to Appendix A to view information about the articles utilized to support various program components.

2.3 Summary

Research shows that children with disabilities, on average, engage in social participation less frequently than their typically developing peers. Current literature regarding social participation for children with disabilities is dominated by documentation of the barriers and facilitators affecting a child's ability to engage in social participation as well as the barriers and facilitators parents face regarding their child's engagement in social participation. There is a lack of evidence regarding programs related to social participation, especially programs that have the child's parent(s) as the program participants. Neither is the effectiveness of programs focusing on social participation well documented. Designing and testing the outcomes of My Social Toolbox can contribute to the current literature by describing the effectiveness of a community-based pilot program for parents of children with disabilities and their ability to increase their child's level of social participation and facilitate quality social interactions of their child with other persons, given appropriate supports.

CHAPTER THREE

THEORETICAL FRAMEWORK

The Model of Human Occupation (MOHO) is the theoretical framework guiding the development of My Social Toolbox. MOHO utilizes the concept of the open system cycle and states that there is interdependence among many factors that influence a person's, in this case, the parent's, motivation, behaviors, and performance (Cole & Tufano, 2008). Kielhofner identifies four components within the human system that contributes to the success and/or the disruption to a person's occupational engagement, which include input, throughout (the person), output (skilled action or occupational performance), and feedback (the environment) (Cole & Tufano, 2008). More specifically, input is any external information a person takes in using their senses, which they then internally process, the throughput. When the information is processed, the person takes some form of skilled action, or output, which is a goal-directed action that can be externally witnessed (Cole & Tufano, 2008). Lastly, the environment provides feedback based on the action or occupational response that the person chose (Cole & Tufano, 2008).

The Model of Human Occupation (MOHO) was utilized as the overarching theoretical framework to guide this program. According to MOHO, the three subsystems that comprise the person include volition, habituation, and performance capacity and are all crucial components to consider when understanding a child with a disability's ability to successfully engage in social opportunities (Kielhofner & Burke, 1980). Each of these components can inhibit or support a child's social participation. Volition can be supported via positive societal attitudes, whereas it can be diminished as a result of negative societal attitudes towards the child with a disability, causing them to have poor self-esteem and loss of confidence (Bedell et al., 2011; Gorzkowski et al., 2011). In regards to the parents, having an awareness of the impact they can make when increasing engagement of their child in quality social participation can support the parent's

volition or motivation to make the effort to support their child's social participation, and thus, the education provide in the My Social Toolbox sessions is crucial. The educational process of collaborative goal setting helped the parents set meaningful goals that are relevant to their needs as well as their child's, supporting their sustained motivation to participate in the program. The social event helped develop the parent's belief in self and belief in their skills by allowing them the opportunity to practice these in a safe and supportive environment.

Habituation includes both habits and roles (Kielhofner & Burke, 1980). In terms of habits, habituation is hard to achieve in terms of getting children involved in regular social participation if there are a lack of programs available and/or a lack of knowledge about the programs available (Bedell et al., 2013; Coster et al., 2012; Fette & Estes, 2009; Piskur et al., 2012; Shields & Synnot, 2016). Implementation of this program helps parents to easily access social participation opportunities for their children as well as social interaction strategies that can be habituated and incorporated into their family's lifestyle, for example, taking the extra time to allow their child to complete task components more independently or introduce themselves when meeting new people. In terms of roles within the subsystem of habituation, parents play an important role as catalysts, creating opportunities for their child to engage in social participation. This program also has the potential to broaden the parenting role for those who participate. Parents may be provided opportunities to habitually practice skills with other parents and even other children who have be encountering similar difficulties.

Lastly, it is important to address performance capacity as it is crucial to determine which activities best fit the needs and abilities of the child in order to help them be successful, ensuring that the demands placed on them are appropriate for the child's current level of functioning and are not above their capabilities. In regards to the parents, My Social Toolbox works with parents

to enhance their performance capacity in their ability to engage their child or others in interactions with their child. Similarly, it is important to address the parents' limitations and the demands placed on them, including time, cost, and the increased stress parents of children with disabilities encounter. My Social Toolbox emphasizes the social, physical, and cognitive performance of the child and the parent to varying degrees.

Using MOHO, it is also important to consider various aspects of the environment, physical and social, and the occupational performance factors, such as body structures and functions and motor, process, and social interaction skills, that contribute to the outcome. When considering the theoretical constructs of MOHO, the environment both affords opportunities and presses for behavior (Kielhofner & Burke, 1980). Generally speaking, the social and environments press for behaviors that are extremely difficult for children with disabilities, inhibiting their ability to successfully engage. My Social Toolbox seeks ways to approach the environment in a way that it could help these children engage in social activities they want and need to engage in. Thus, the comprehensive nature of My Social Toolbox fits nicely with the theoretical concepts addressed in MOHO. According to MOHO, "Any shift in one part of a person's open system cycle will result in a change in one's overall dynamic" (Cole & Tufano, 2008, p. 99). Specifically in this case, a positive change in the child's community, school, or home environment, the child themselves, or the activities in which they participate, will help lead the child toward improved overall performance and participation.

CHAPTER FOUR

DESCRIPTION OF THE PRACTICE SCHOLAR CAPSTONE PROJECT

4.1 Title of Project

My Social Toolbox

4.2 Program Goals

Goal 1: 85% of the parents who participate in parent training sessions will demonstrate an increased understanding of the importance of social participation in children evidenced by increased scores from pre-test to post-test scores within 3 months.

- i. *Objective 1a:* 70% of parents who participate in parent training sessions will be able to communicate the importance of at least 3 potential, positive benefits of social participation during childhood/adolescence in 1 month.
- ii. *Objective 1b:* 70% of parents who participate in parent training sessions will be able to communicate at least 2 strategies to promote social interaction between their child and a typically developing peer within 2 months.
- **Goal 2:** 85% of the parents who participate in parent training sessions will initiate engagement in more social opportunities for their children evidenced by initiating a minimum of 2 social opportunities within 4 months after the event.
 - i. *Objective 2a:* 70% of parents who participate in parent training sessions will report continued use of the PowerPoint presentations as a reference for social participation opportunities evidenced by referring back to the presentation a minimum of 2 times within 3 months after the event.

- ii. *Objective 2b:* Within one month after the event, 70% of parents who participate in parent training sessions will initiate contact with at least 1 local resource that the family does not normally attend via phone or e-mail.
- iii. *Objective 2c:* 70% of parents who participate in parent training sessions will report continued use of the at least 2 social interaction strategies to promote social interaction between their child and a peer within 2 months.

Goal 3: 85% of students will demonstrate improved positive benefits (life satisfaction, positive psychological benefits, and children's overall development and health) of increased social participation opportunities evidenced by parent report within 5 months after the event.

- i. Objective 3a: 85% of students will report increased satisfaction with engagement in social events evidenced by an increase in pre-post scores on a modified version of the Child Occupational Self-Assessment (COSA) within 3 months after the event.
- ii. *Objective 3b:* 70% of parents who participate in parent training sessions will report improved social interaction skills in their child evidenced by positive changes on a researcher-created ordinal rating scale within 3 months.

4.3 Program Description

4.3.1 New/Existing

My Social Toolbox was a new program being introduced at Orange City Schools in Pepper Pike, Ohio.

4.3.2 Theoretical Framework

The Model of Human Occupation (MOHO) was chosen as the theoretical framework to guide the development of My Social Toolbox. The idea of the open system cycle described within this theory states relies on interdependence among many factors that influence a person's motivation, behaviors, and performance (Cole & Tufano, 2008). This fits nicely with the background and development of My Social Toolbox as the literature demonstrates the contribution of a wide array of factors that can either facilitate or hinder a child's ability to successfully engage in social participation. The parents received education and resources, the input, thought about which social opportunities and/or social interaction strategies best fit the needs and interests of their child, the throughput, and, in turn, chose a social participation opportunity or opportunities to attend or a specific social interaction strategy to implement with their child, the output. Based on the child's reaction and engagement in these various social experiences, parents receive either positive or negative feedback, which, in turn, acts as a new input for the parent, allowing him/her to adapt and modify their approach in order to enhance their child's overall social engagement.

4.3.3 Rationale for Program Design

A good understanding of the factors that both help or hinder a parent's ability to support their child in reaching their social potential and a synthesis of the literature outlining components of effective parenting programs helped establish a basis for developing a quality program that fit the gap in current practices and literature. My Social Toolbox was designed using a combination of clinical reasoning skills, the current literature about the social participation barriers and facilitators, and evidence-based research supporting specific program implementation and service delivery models. Implementation and evaluation of this program brought about an

understanding of the effectiveness of a community-based pilot program for parents of children with disabilities in increasing their child's level of social participation and the quality of their social interactions with other persons and can contribute to the current body of literature.

Specifically, My Social Toolbox was built upon the evidence supporting parent-training programs. A partnership approach was used within the context of a group setting for the parents to gain trust and support from each other and the doctoral candidate (Barlow & Stewart-Brown, 2001; Kane et al., 2007; Steiner et al., 2012). Kaiser and Hancock (2003) and Steiner et al. (2012) emphasized the importance of collaborative goal setting with the parents, and thus, such collaboration was incorporated into the program design. Lastly, skill-based and support-based intervention techniques described in a review completed by Carter and Hughes (2005) that can be used for addressing the child's social interaction skills with their peers were taught to the parents and how these can be easily incorporated into the family's lifestyle.

4.3.4 Sample

The target population for My Social Toolbox was between three and ten parents of children with disabilities. This targeted number was chosen to ensure an appealing group setting where the parents would feel comfortable sharing personal information and so that the doctoral candidate could provide adequate support, feedback, and attention when needed, such as when writing personalized goals or providing personalized strategies that may be beneficial for a unique child's needs. My Social Toolbox was marketed to all parents of children enrolled in the Extended School Year (ESY) program at Orange Schools in the summer of 2016 as well as the parents who are members of the Orange Parent Education Network (OPEN) through Orange Schools. OPEN is a community of parents in the Orange School District, though not all children of parent members of OPEN are enrolled at Orange Schools. Through collaboration, advocacy

and education, OPEN seeks to empower and bring academic and life success to students with learning and attention differences. With the goal of bringing parents, educators, students, and community professionals together to better serve the needs of their children, OPEN hopes to reach all families, especially those whose children (from preschool through high school) have special needs, learning or attention differences, 504 Plans, or Individual Education Plans (IEP).

Secondary to challenges and allowances with physical access to the parents and the lack of ability to receive the target parents' phone numbers, recruitments strategies were limited. For the parents of children enrolled in the ESY program, the marketing flyer created by the doctoral candidate was sent home to all parents four weeks prior to the start of My Social Toolbox via their child's take home folder at school. One week later, a staff member working with the ESY program at Orange Schools forwarded a personalized email from the doctoral candidate to each of these parents. The email included an electronic copy of the marketing flyer as well as an introduction to the doctoral candidate, an overview of My Social Toolbox, the purpose and benefits of the program as well as contact information of the doctoral candidate should the parent request more information about participation or want to RSVP to the program. In regards to the parent members of OPEN, the president of the organization posted a copy of the marketing flyer on the organization's Facebook page four weeks prior to the start of My Social Toolbox. In addition, the same personalized email referred to above was also sent out individually to each member via email directly from the doctoral candidate.

There were some general inclusion criteria for participation in the My Social Toolbox program. Participants of the program had to speak English and be able to read and write. Once participants RSVP'd to the doctoral candidate via email, each parent received a welcome packet in the mail. The welcome packet included a welcome letter from the doctoral candidate, a copy

of the informed consent form, and the pre-test assessment tools (PEM-CY community subsection, modified version of the COSA, and the parent social participation pre-test/post-test questionnaire) to be filled out and brought to the first parent training session. Information explaining each of the assessment tools and how to correctly fill them out was also included in the welcome packet. Refer to Appendix B and Appendix C to view the specific recruitment documents utilized.

4.3.5 Program Structure

My Social Toolbox consisted of four, once weekly, group parent-training sessions and a social event that took place during the final group session. Each parent training session was one hour long. The following are specifics regarding the content and process of the parent training sessions:

- a. Parent Training Session 1: Overview of the My Social Toolbox, outline of events, and topics to be covered; Goal Attainment Scaling (GAS) to set personal and measurable goals for each parent based on their needs in relation to their child's social participation; Parent education regarding the importance of social participation as well as the evidence about benefits to the child as a result of engagement in social opportunities. This took on a psychoeducation approach, which is designed to teach parents knowledge-based content (Steiner et al., 2012).
- **b.** Parent Training Session 2: Education of various social participation opportunities available in the local community (summer camps available for children with disabilities, networking opportunities or support groups for parents of children with disabilities, etc.); Discuss and problem solve community barriers these families currently face that inhibit social participation with their child with a disability;

Discuss strategies for locating peers and setting up play dates and community outings; Following the session, an electronic copy of the PowerPoint listing all available community opportunities was emailed to the program participants for easy reference to facilitate and promote engagement outside of the school setting.

- c. Parent Training Session 3: The focus of this parent training session included education and discussion of intervention strategies parents can utilize to facilitate increased levels of social interaction as well as improve quality of social interactions for their child with a disability with his/her peers and other persons (i.e. initiating and maintaining social interactions/conversations, use of and interpretation of nonverbal communication, etc.). This session was more directly focused on a parent education approach, in which the primary focus "is that of teaching discrete skills that are designed to aid parents in managing problem behavior, teaching skills to their child, and improving the quality of the parent-child relationship" (Steiner et al., 2012, pp. 2-3). This approach seeks to enrich or facilitate parenting behaviors, ultimately shaping positive developmental outcomes in their children (Steiner et al., 2012). Specific activities that parents can practice with their child were discussed, including ways of incorporating various strategies and activities into routine daily life, thereby decreasing family stress and burden. Within all of these sessions, a partnership approach was the overarching model and support and problem solving from group members was encouraged. Following the session, an electronic copy of the PowerPoint was emailed to the program participants for easy reference.
- **d.** Parent Education Session 4: Discussion on the utilization of social interaction strategies parents implemented in the home and the community settings as well as any

challenges that may have been addressed during practice. Parents were encouraged to bring their child and other family members for a small-scale, informal social event to take place during session four where the child can interact with other persons. The social event gave parents the opportunity to practice implementing strategies to help facilitate social interactions with the other children present. A review and discussion of goals formulated from the GAS during the initial parent training session took place. Parents completed parent satisfaction questionnaires and post-test measures including the PEM-CY community subsections, modified version of the COSA in collaboration with their child, and the researcher created pre-test/post-test questionnaire.

4.3.6 Program Implementation

To accommodate for parents' schedules, a morning option and a night option were offered for My Social Toolbox. The morning option of My Social Toolbox took place for four consecutive Wednesdays at 9:30 in the morning in the Board Room at the Orange Inclusive Preschool beginning July 13th, 2016 and ending on August 3rd, 2016. The night option of My Social Toolbox took place for four consecutive Thursdays at 6:30 in the evening beginning July 14th, 2016 and ending on August 4th, 2016. The night option sessions took place in a meeting room at the Orange Branch of the Cuyahoga Public Library, located across the street from the Orange Inclusive Preschool, due to the doctoral candidates lack of access to the Orange School facilities after working hours. Both the Board Room at the Preschool and the meeting room at the library are equipped with a projector and screen to display the PowerPoint presentations. The parents signed in with the doctoral candidate upon arrival. The doctoral candidate's personal computer was used to access the PowerPoint presentations. There was no budget for

implementation of My Social Toolbox this year. Printing materials, utilized for hard copies of the assessment tools, were available through the Orange Inclusive Preschool.

4.3.7 Program Evaluation

My Social Toolbox was evaluated using both outcome and process evaluation methods. Outcome evaluation was gathered in order to systematically measure the effectiveness of My Social Toolbox on the parent's knowledge of the importance of social participation for their child, the child's level of social participation, the parent's ability to facilitate social interactions for their child, and the child-specific benefits received secondary to program implementation. Process evaluation was gathered to measure the parents' subjective opinions on the components of My Social Toolbox that were the most and least beneficial to their learning and the effectiveness of the group setting and collaboration with other parents. For both the process and outcome evaluations, a mixed-methods approach was utilized, incorporating both quantitative and qualitative methods.

Quantitative and qualitative data was gathered simultaneously using a concurrent triangulation design, in which neither of these designs were designated as the core method (Corcoran, 2006). This allowed the doctoral candidate to pursue interesting developments as they occurred, though the maintenance of the methodological integrity of both quantitative and qualitative designs had to be adhered to simultaneously (Corcoran, 2006). If adequate consideration of the method of combining both quantitative and qualitative methods was not strategically planned, issues of validity could have been introduced and been problematic (Corcoran, 2006). One advantage of using a mixed methods design is that the strengths of both quantitative and qualitative designs can be emphasized, and thus, compensate for the inherent limitations in each of these designs (Corcoran, 2006). Other advantages of using a mixed

methods design is that the doctoral candidate had the opportunity to examine the results from different perspectives to gain a more holistic understanding of the outcomes of the program while also validating the results due to the fact that they were confirmed through multiple data collection techniques (Corcoran, 2006). Specifically for outcome evaluation, the Participation and Environment Measure for Children and Youth (PEM-CY) community subsection, a modified version of the Child Occupational Self-Assessment (COSA), a Parent Social Participation Pre-Test/Post-Test Questionnaire, and Goal Attainment Scaling (GAS) were used and completed by the participants pre-test and post-test. For process evaluation, a parent satisfaction questionnaire was completed after the program. Refer to Figure 1 to see a graphic of the evaluation process.

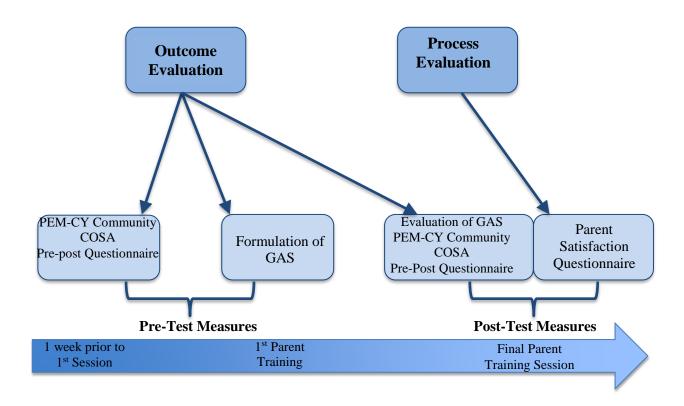


Figure 1. Program Evaluation Schematic Timeline.

One outcome evaluation measure that was used was the Participation and Environment Measure for Children and Youth (PEM-CY), which is a parent-report measure that evaluates participation (i.e. how often, level of involvement, and desire/interest in change) and environmental factors (i.e. environmental factors and activity demands and resources) within each the home (10 items), school (5 items), and community (10 items) contexts that support or challenge the child's participation (Coster et al., 2011). The measure also asks the parents about their strategies to promote participation for each setting (Coster et al., 2011). For purposes of this program, only the community context subsection will be evaluated as this most closely relates to social participation and the overall goals of participation in My Social Toolbox. The PEM-CY is designed for children between 5-17 years old and takes about 30 minutes to complete when all three settings are evaluated (Coster et al., 2011). The PEM-CY is a good fit for the proposed program because it measures both frequency of participation as well as elicits current strategies the families are using to try to help promote participation in their children. This aligns nicely with the program components of My Social Toolbox and will help to better plan and adapt intervention for the parent training sessions based on current strategies being used and helping the families to strengthen these and/or provide them with new strategies that may be beneficial for them. The PEM-CY also showed moderate to good psychometric properties based on a large sample (n=576) with a diverse population including age and diagnosis (Coster et al., 2011). Internal consistency coefficients (ICC) for participation frequency were 0.59-0.70, 0.72-0.83 for participation involvement, and 0.83-0.91 for environment supportiveness across home, school, and community settings, translating to moderate to very good scores (Coster et al., 2011). Testretest reliability estimates for participation frequencies were good for the community setting (ICC=0.79) (Coster et al., 2011). All reliability estimates for the environment scores were above

0.80, indicating good agreement across occasions in each setting (Coster et al., 2011). In regards to validity of the PEM-CY, there was a significant negative correlation between 'desire for change' score and environmental supportiveness (-0.42 to -0.59) for each setting (Coster et al., 2011). A similar pattern was found in both the disability and no disability groups, in addition to, for the sample as a whole (community, -0.53) (Coster et al., 2011). Refer to Appendix D to view this measurement tool.

The parent social pre-test/post-test questionnaire is a brief, one-page questionnaire, which utilizes a Likert-scale and open-ended responses to assess other aspects of social participation, specifically addressing goals of My Social Toolbox. The questionnaire assesses the parents' knowledge about the importance of and benefits of social participation, knowledge of social interaction strategies, assesses whether the parents have observed a change in their child's social interaction, and the parent's level of confidence in facilitating positive social interactions for their child. The parent participants will complete this questionnaire one week prior to the start of the program and after completion of the final parent training session. Refer to Appendix E to view this measurement tool.

Goal attainment scaling was used as an evaluation method by collaborating with the parent participants to set between one and two individualized goals that can be quantifiably measured (Mailloux et al., 2007). The doctoral candidate provided the parents with example goals to help facilitate the goal making process. Goals were defined at the beginning of the first parent-training session and reviewed for outcomes following completion of the program. GAS goals are scaled using a five-point scale ranging from -2 to +2 (Mailloux et al., 2007). An outcome score of zero indicates the expected level of performance, a +1 indicates somewhat more than expected performance, and a +2 indicates significantly more progress than the

expected outcome, with -1 and +2 respectively paralleling the opposite end of the spectrum (Mailloux et al., 2007). When used appropriately, the distance between each numeric on the scale "is equal and equally distributed around the predicted level of performance" (Mailloux et al., 2007, p. 255). Refer to Appendix F to view the GAS form parents completed and sample goals that were provided to the parents during the first session when formulating individualized goals. At the end of the program, the parents were asked to rate their personal GAS goals based on the above rating scale.

Another outcome evaluation measure that was used is the Child Occupational Self-Assessment (COSA), a self-report questionnaire that takes approximately 10-20 minutes to administer and was completed by each child whose parent participated in the My Social Toolbox parent training sessions (Schultz-Krohn, 2007). The COSA is "designed to collect data on the individual's self-perception of occupational competence, the importance of occupational functioning, and environmental adaptation" (Schultz-Krohn, 2007, p. 47). This outcome measure is used for children between the ages of 8-13 years old (Schultz-Krohn, 2007). For the purposes of this program, the COSA was modified to only include the questions that related to social participation or social interaction skills. The COSA was a good fit for evaluating the child's selfperception of participation for My Social Toolbox because it has a short implementation time and is a self-report questionnaire, eliminating the potential for administrator bias. Also, the questionnaire was fitting as it could be sent home and completed with the parent. The COSA rating form with symbols was used as it utilizes pictures to help the child understand the meaning of questions, thus making it more appropriate for this population. The parents were encouraged to have their child complete the assessment on their own or were able assist their child as needed. The COSA has moderate to good reliability scores and reported internal validity. According to

Schultz-Krohn (2007), the COSA "adopted a 4-point scale to improve reliability" (p. 47). The COSA was examined to have ICCs for the competence (ICC = 0.717) and value (ICC = 0.772) total scores were good (Ohl, Crook, MacSaveny, & McLaughlin, 2015). The COSA was determined to be a valid measure of occupational self-assessment and rasch analysis supports internal validity as no item misfits were noted (Schultz-Krohn, 2007). Thus, it can be said that the COSA is measuring what it is intended to. Refer to Appendix G to view the modified social participation version of the COSA that was used as an outcome evaluation measure for this program.

A parent self-report satisfaction questionnaire was utilized for process evaluation measurement. The doctoral candidate created this satisfaction questionnaire, as current available measures do not address the particular variables of interest related to specific components of the My Social Toolbox program. This questionnaire was completed at the end of the fourth parent training session. The questionnaire included an ordinal Likert-style measurement scale that consisted of two sections relating to the effectiveness and parent's opinions regarding the different process components of the program including the parent training sessions and the social event, which took place during the fourth parent training session. This measurement scale required the participant to have an opinion, as there was no neutral option offered. It also allowed the doctoral candidate to analyze the rank order of various statements included and compare across participants in order appropriately modify the program for future program implementation. The parent self-report satisfaction questionnaire also included qualitative openended questions regarding the parents' perspectives on the components of the program they believe were most and/or least beneficial, areas for improvement on program implementation, and whether or not they believe their child's social interaction skills have improved or not following participation in this program. This questionnaire was completed anonymously in order to ensure participant confidentiality and increase the likelihood of the participants providing true, honest responses knowing their identity on the questionnaire was not known. Names were not included on the assessment and, though it was a small sample size, parents were comfortable completing the assessments knowing their children could not be identified in any of the published material. Refer to the Appendix H to view the questionnaire that was utilized as part of the evaluation process.

CHAPTER FIVE

RESULTS

The sample consisted of five parents of children with disabilities. Four of these parents attended on a consistent basis. All parents were mothers. Their children were all males and ranged in age from 7-13 years old with a mean age of 9.4. Four of these parents' children were diagnosed with Autism Spectrum Disorders and the fifth parent's child had a diagnosis of Angelman Syndrome and was nonverbal. Refer to Table 1 for a detailed description of the sample. Assessment data was only collected for participants 1-4 who attended three or four of the My Social Toolbox sessions. Participant 5 wrote initial GAS goals and will be discussed for research purposes where applicable.

Table 1. Participant Characteristics

| Participant | Child's Age (years) | Child's Diagnosis | Sessions Attended | Time of Sessions Attended (Morning/Night) | Attended Social Event (session 4) |
|-------------|---------------------------|--------------------------------------|----------------------|---|---|
| 1 | 7 | Autism | 1, 2, 3 | Morning | No |
| 2 | 7 | Autism | 1, 2, 3 | Morning | No |
| 3 | 10 | Angelman Syndrome (non-verbal) | 1, 2, 3, 4 | Night | Yes (parent and child) |
| 4 | 10 | Autism | 1, 2, 3, 4 | Night | Yes (parent and child) |
| 5 | 13 | Autism; Anxiety | 1 | Night | No |

All five parents used Goal Attainment Scaling to write two personalized goals for themselves to complete by the end of the fourth session of the My Social Toolbox program. The mothers wrote goals centered around trying a new community/social event with their child and family (n=3), setting up a play date with peers (n=2), and making a list of social participation options that would be feasible for their family and of interest to their child (n=2). Other less frequently listed goals include trying two different social interaction strategies discussed during

My Social Toolbox sessions with their child while in the community (n=1), getting their child to instigate a 'hang out' with a peer (n=1), and one mother wrote that she wanted to find parents with children with similar difficulties to host a community outing together (n=1). Refer to Table 2 for the results of GAS scoring. Note that of the four parents who consistently attended the My Social Toolbox sessions and rated their GAS goals, six of the eight goals were either reported as an expected outcome (0), meaning they met their goal, or as better than expected (+1), meaning they exceeded their goal. All four mothers met or exceeded at least one of their goals with one parent, participant two, exceeding both of her goals. Only two goals were rated as slightly less than expected (-1) and were reported by two different parents. Though participant three rated 'try 2 social interaction strategies with their child in the community' as a -1, meaning that she did not meet her goal, she still made improvements. This mother commented that she tried one new social interaction strategy with her child in the community, and thus, even though her goal was not met, she still made positive improvements, incorporating the information gained from the My Social Toolbox sessions outside of the context of the program. 'Set up a play date with peer(s)' was the other goal rated as a -1 and was rated by participant one secondary to scheduling conflicts within the short timeframe. Both of the goals that were rated as -1, less than expected, can be considered the two more challenging of the goals to have been met within the time frame compared to the other composed goals.

Table 2. Goal Attainment Scaling (GAS) Results

| Goal | Participant | Outcome Score |
|--|-------------|---------------|
| Try new community/social event | 1 | 0 |
| | 2 | +1 |
| | 4 | 0 |
| Set up play date with peer(s) | 1 | -1 |
| | 2 | +1 |
| Make list of social participation options | 3 | 0 |
| feasible for their family | 4 | 0 |
| Try 2 social interaction strategies with | 3 | -1 |
| their child in the community | | |
| Get child to instigate a 'hang out' with a | 5 | X |
| peer | | |
| Find parents with children with similar | 5 | X |
| difficulties and host community outing | | |
| together | | |

^{*}X = Outcome data was not gathered.

The results of the Parent Social Participation Pre-Test/Post-Test Questionnaire show overall improvements in the parents' knowledge of the importance and benefits of social participation as well as the understanding of social participation strategies they can use to help their child engage socially. Three of the four parents were able to list three benefits of social participation pre- and post-test, while one parent was only able to list two benefits pre-test, but three benefits post-test. Each of the three parents who were able to list three benefits initially all had one different benefit listed post-test, all three of which were discussed throughout the program. Three of the four parents were able to list two strategies for social participation pre-test and post-test, while the last parent was unable to list any social strategies pre-test. This parent was able to list two strategies at post-test, following the My Social Toolbox sessions. Two of the parents who were able to list two social interaction strategies pre-test list one different strategy post-test. These results are comparable to the first two Likert-style questions regarding similar information. Refer to Table 3 to view the results of the Likert-scale portion of the questionnaire. On the five-point Likert-scale ranging from one, meaning strongly disagree, to five, meaning

strongly agree, the average scores for 'have a strong understanding of the importance of social participation' and 'able to articulate the importance and benefits of social participation' were 4.75 and 4.5, respectively. Note that the responses for both of these questions improved to five, strongly agree, post-test. The final three statements included in the Likert-style chart did not show differences pre-test to post-test, illustrated by only one documented score in Table 3. Note that even though the scores did not improve pre-test to post-test for these three items, the lowest mean score from the participants was a 3.75, indicating moderate to good scores.

Table 3. Parent Social Participation Pre-Test/Post-Test Questionnaire Likert Responses

| Statement | | | | cipant 2 | | cipant 3 | Partic | cipant 4 | Mean Scores | |
|---|--------------|---------------|--------------|---------------|--------------|---------------|--------------|---------------|----------------|---------------|
| | Pre- Test | Post- Test | Pre- Test | Post- Test | Pre- Test | Post- Test | Pre- Test | Post- Test | Pre- Test | Post- Test |
| I have a strong understanding of the importance of social participation for my child with a disability. | 5 | 5 | 5 | 5 | 4 | 5 | 5 | 5 | 4.75 | 5 |
| I am able to articulate the importance and benefits of social participation for my child with a disability. | 5 | 5 | 4 | 5 | 4 | 5 | 5 | 5 | 4.5 | 5 |
| I am able to successfully facilitate positive social interactions for my child with their peers. | | 5 | 3 | 3 | 2 | 2 | | 5 | 3. | 75 |
| I use a variety of strategies when helping my child interact with their peers. | | 5 | 4 | 1 | | 3 | | 5 | 4. | 25 |
| I feel confident in facilitating positive social interactions for my child with their peers. | | 5 | | 3 | | 3 | | 4 | 3. | 75 |

PEM-CY scores pre-test (week one) and post-test (week four) did not show any change. 100% of the parents said that they want to change their child's participation in at least 7/10 various community activities included in the assessment, some of which include neighborhood outings, community events, non-school sponsored classes and lessons, both organized and

unstructured physical activities, getting together with other children in the community, and overnight visits. This percentage (70%) may have been higher; however, some of the included community activities were not applicable to the parents and/or children, such as working for pay and religious/spiritual gatherings. When asked how involved their child was when they engage in these community activities, answers ranged from five (very involved) to one (minimally involved). Specifically, the average score of involvement in the topic of 'community events' was 2.75 (less than somewhat involved) and the average 'getting together with other children in the community' was 3.25 (just above somewhat involved). Another important data point is that 100% of the parents stated that 'the social demands of typical activities (communication, interaction with others)' usually makes it harder for their child to engage in activities in the community. This was the only option that all parents agreed makes community participation harder for their child. Lastly, the parents' responses varied from 'usually, yes' to 'usually, no' in regards to if there are available and/or adequate programs and services for their child as well as available and/or adequate information about activities, services, and programs.

Similar to the results of the PEMC-CY, the results of the Child Occupational Self-Assessment remained consistent pre-test to post-test as this assessment is not receptive to minimal changes. One assessment was completed solely by the child, one assessment was completed by the child with assistance from their parent, and the other two assessments were completed solely by the parent due to busy schedules and having the time to complete it with their parent. The parents who completed the assessment in lieu of their child responded to the prompts with their best efforts how they thought their child would rate themselves in the regards to the given statements. In general, the responses varied across the spectrum based on the each child's personal strengths and weaknesses. 15 out of 24 responses (62.5%) were rated either 'I do

okay with this' or 'I am really good at this' and the same percentage responded to the importance either 'really important to me' or 'most important of all to me' in regards to the six socially-relevant statements provided.

Three of the four Parent Satisfaction Questionnaires were returned from the participants. Only one of the parents that returned this questionnaire attended the Social Event. In regards to the statements about the positive benefits of the parent training sessions specifically (excluding the social event), 96% of responses were rated either 'agree' or 'strongly agree,' demonstrating positive results. There was only one response from one parent that was rated 'disagree' to the statement, 'I find myself reviewing the information provided in the PowerPoints following the completion of the sessions.' This could be attributed to the mother's ability to remember the information from the recent presentation of the material. The one parent who completed the Parent Satisfaction Questionnaire as well as attended the Social Event rated all seven statements specifically related to the Social Event either 'agree' or 'strongly agree,' demonstrating positive results. When asked their opinions of the most beneficial aspects of the program, participant one stated "community resources; video modeling and how it can help;" participant two stated, "the specific strategies, games, and resources were very helpful;" and participant three stated, "the importance of reducing anxiety for my child in new social situations and to prepare him more ahead of time for what we will be doing and who we will be seeing and why." In the open-ended response inquiring about the child's social interaction skills following participation in My Social Toolbox, 100% of the parents responded that they had not had the chance to implement the strategies yet, but planned on implementing them in the near future for the benefit of their child. Lastly, 100% of parents stated that they would recommend My Social Toolbox to other parents in the future. Participant one specified that the program was "extremely helpful" and participant three stated "Yes it's important for parents to connect with each other and to realize the importance of kids learning to establish and maintain relationships with peers."

CHAPTER SIX

DISCUSSION

The findings described in this capstone project represent the only article the doctoral candidate is aware of examining the effectiveness of a program designed to increase social participation for children with disabilities using parents as program participants, acting as catalysts of change in their child's life. Preliminary data from this pilot program show positive results and support the continued research on programs similar to My Social Toolbox to determine its effectiveness in increasing children with disabilities' social participation. Implications can drawn from the various assessment tools utilized for this community-based pilot program and are discussed below.

The use of goal Attainment Scaling and the creation GAS goals assisted the families in thinking about how they could incorporate the information obtained from the My Social Toolbox program to their daily life to support their child's social participation. It can be noted, though, that all the parents identified goals directly from the list of examples provided to them by the doctoral candidate. Thus, this brings up the debate of whether or not providing the parents with examples of goals helped the process of determining goals or hindered the parent's creation of goals that are truly meaningful to their family's and child's needs and lifestyle. An alternative approach to the facilitation of the creation of meaningful GAS goals with parents could be to begin with having the parents think about and share some of the most difficult situations they encounter when trying to engage their child in social participation opportunities or with peers. From this, parents could reflect on their personal struggles and the resultant goals they want to set for themselves that would help them to overcome these challenges faced. The approach of having the parents think about and reflect on difficult times they face may help them be more open and reflective when creating their GAS goals and not as highly focused on the example

goals. This recommended approach would likely maximize the congruence of the GAS methodology with the client-centered occupational therapy philosophy, meaning that intervention goals and outcomes are specifically relevant to the mothers and their families (Mailloux et al., 2007). Another suggestion for future research is to have parents consider the child's perspective on what they want and need as well when determining their GAS goals. Incorporating the child-perceived struggles can help the parents address issues they have difficulty with as well as their child's difficulties, in the hopes of enhancing social participation outcomes. As an example, the child's perspective could be obtained by looking at the results of a self-report assessment tool designed for children such as the COSA, as was used in the current pilot study.

The Parent Social Participation Pre-Test/Post-Test Questionnaire indicates that, in general, parents have a good understanding of the importance and benefits of social participation and are able to articulate this. Responses on the ordinal Likert-style scale range from two to five on a five-point scale, with five being the best outcome. In general, responses that were rated higher related to knowledge of the importance and benefits of social participation for their child with a disability, whereas the lower rated scores were typically in response to statements regarding the ability of the parents to implement social interaction strategies for their child during social opportunities with peers and their confidence in doing so. Thus, the parents' responses may indicate that knowledge of the importance and benefits of social participation as well as social interaction strategies may not translate to successful implementation of these in a real-life context. Thus, programs developed with the goal of increasing children with disabilities' social participation needs to emphasize the transfer of knowledge and skills to routine tasks and community events in which the families engage.

The PEM-CY was used to gather the parents' perspective of current participation functioning and factors affecting participation. The responses to this assessment did not change pre-test to post-test. This can likely be attributed to a combination of the set-up of the program and the chosen assessments. For example, questions relating to social interaction strategies and the parents' trial of these and/or integration of such strategies into social opportunities likely did not show much improvement because only one week had lapsed between the time these strategies were discussed in session three and the time the post-test measures were administered at the conclusion of the program in session four. Regarding the PEM-CY, specifically, many responses request information about typical participation over week or month time frames. This factor made it difficult for the results to be responsive to minimal changes in participation because only one to three weeks passed by the time this information was assessed post-test. Future endeavors should use the PEM-CY as an outcome measure for more long-term testing of outcomes. Programs developed with a shorter timeframe, such as My Social Toolbox, should locate an assessment that is more responsive to minimal changes. Though quantitative data from this assessment cannot support the effectiveness of My Social Toolbox, the parents' responses add to the growing literature of the need for socialization programs to help children with disabilities become more involved, in addition to, increasing the quality of their social interactions. All four parents rated at least seven of the 10 community opportunities listed in the PEM-CY as wanting their child's participation in each given activity to change either by doing the activity 'more often,' 'be more involved' during the activity, and/or 'be involved in a broader variety of activities' within the respective category of activity. Some of the other responses to activities were not scored because they were not applicable to the family or the child, such as religious events and working for pay. Three of the four participants reported that social demands

usually make the activity harder, suggesting a need for education on how to support the parents and child when engaging in these socially complex activities. This data shows that parents do want to improve their child's participation and that they may need help facilitating these efforts.

The results of the COSA were consistent from pre-test to post-test. These findings should be interpreted carefully as all responses were not obtained from the child's perspective, as intended. Similar to the timing limitation noted above in the PEM-CY, this may have also had an effect on post-test scores received. For example, there was only one week between the session focused on social interaction strategies and the post-test data collection. Therefore, if the parents had not had a chance to implement these strategies within the week timeframe, then the child would not have experienced any of the resultant benefits from the use of the social interaction strategies at that point in time. More long-term and follow-up data is warranted to determine if the children of the parent participants perceived any of the benefits from their parent's participation in the My Social Toolbox sessions.

The results of the Parent Satisfaction Questionnaire indicate parents' increase in their knowledge about social participation and their confidence in supporting their child with the use of the information provided. Though short-term and/or long-term benefits, specifically relating to the benefit of the social interaction strategies discussed, cannot be determined since they were not yet implemented, all parents were planning on, at minimum, trialing these in order to help support their child. With all of the parents noting that they would recommend this program to other parents, this is a good indicator that parents enjoy and benefit from being in a group setting with other parents where they can be supported, share experiences and ideas with each other, as well as learn of new social strategies and community opportunities available for them and their

child. Further research should be conducted in order to understand the long-term benefits of this parental support in the form of a parent training program.

The results of this capstone project demonstrate promise regarding the benefits of and the need for socialization programs assisting parents of children with disabilities to help their child be able to engage socially. Post-test information gathered from the parents parallels current literature that being in a group setting with other parents and receiving their support as well as exchanging ideas with each other are beneficial and valued (Barlow & Stewart-Brown, 2001; Kane et al., 2007; Steiner et al., 2012).

The present results of this capstone project should be considered within the limitations of the study. The results of this study may not be generalizable to other parents of children with disabilities as there was a small sample size, all of who resided in one geographical location. Also, the majority (80%) of the children had a diagnosis of Autism Spectrum Disorder. Future research is required to determine if this type of program intended to increase children with disabilities' social participation using parents as the catalysts of change would be beneficial for parents of children with varying diagnoses. Another limitation of this study is the lack of follow-up data. Further research is warranted to determine if this type of capstone project has lasting, long-term benefits for children with disabilities and their families.

CHAPTER SEVEN

SUMMARY

Occupational therapists' roles include addressing social participation in order to support a person's engagement in desired activities in various contexts and those involving family, peers, and/or friends (AOTA, 2014). Comprehensive occupational therapy services for children include the parents/caregivers as they are with the child more than any service provider and can provide frequent implementation of intervention strategies for their child, increasing the generalizability of the skill(s) (Steiner et al., 2012). My Social Toolbox included wide-ranging topics in order to make the largest impact and address many parents' and children's needs. These session topics included the importance and benefits of social participation, resources for locating available social activities for their child, and strategies to improve overall social interaction skills, including interactions with peers. This program took place in a supportive environment where parents could support, network, and share ideas with each other. By addressing barriers that families encounter and focusing on the parents' ability to facilitate social participation, My Social Toolbox pilot program was designed to begin to remediate the issue of decreased social participation in children with disabilities. Results from participation in My Social Toolbox indicate that parents increased their knowledge of the importance and benefits of social participation of their child, felt more confident in implementing social interaction strategies with their child in order to promote higher quality social interactions and community engagement, valued the support and exchange of ideas from other parents of children with disabilities, and would recommend this program to other parents of children with disabilities in the future.

BIBLIOGRAPHY

- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(1), S1–S48. http://dx.doi.org/10.5014/ajot.2014.682006
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L. & Teplicky, R. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Archives of Physical Medicine and Rehabilitation*, 95, 908-917.
- Barlow, J. & Stewart-Brown, S. (2001). Understanding parenting programmes: Parents' views.

 *Primary Health Care Research and Development, 2, 117-130.
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y.C., Teplicky, R., Anaby, D. & Khetani,
 M. (2013). Community participation, supports and barriers of students with and without
 disabilities. Archives of Physical Medicine and Rehabilitation, 94, 315-323.
- Carter, E. W. & Hughes, C. (2005). Increasing social interaction among adolescents with intellectual disabilities and their general education peers: Effective interventions.

 *Research and Practice for Persons with Severe Disabilities, 30(4), 179-193.
- Cole, M.B. & Tufano, R. (2008). Applied theories in occupational therapy: A practical approach. Thorofare, NJ: SLACK Incorporated.
- Corcoran, M.A. (2006). Using mixed methods designs to study therapy and its outcomes. In G. Kielhofner (Ed.), *Research in occupational therapy: Methods of inquiry for enhancing practice* (pp. 411-419). Philadelphia, PA: F.A. Davis Company.

- Coster, W., Bedell, G., Law, M., Khetani, M.A., Teplicky, Liljenquist, K., . . . Kao, Y. (2011).

 Psychometric evaluation of the participation and environment measure for children and youth. *Developmental Medicine & Child Neurology*, *53*, 1030-1037.
- Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y.C., Khetani, M., & Teplicky, R. (2012). School participation, supports and barriers of students with and without disabilities. *Child: Care, Health, and Development, 39*(4), 535-543.
- Fette, C.V. & Estes, R.I. (2009). Community participation needs of families with children with behavioral disorders: A systems of care approach. *Occupational Therapy in Mental Health*, 25(1), 44-61, doi: 10.1080/01642120802647584
- Gorzkowski, J., Kelly, E. H., Klaas, S. J. & Vogel, L. C. (2011). Obstacles to community participation among youth with spinal cord injury. *The Journal of Spinal Cord Medicine*, 34(6), 576-585.
- Heah, T., Case, T., McGuire, B., & Law, M. (2006). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*, 74(1), 38-47.
- Ideishi, R., D'Amico, M., & Jirikowic, T. (2013). Fact sheet: Supporting community integration and participation for individuals with intellectual disabilities. Bethesda, MD: American Occupational Therapy Association.
- Ingersoll, B. & Dvortcsak, A. (2006). Including parent training in the early childhood special education curriculum for children with autism spectrum disorders. *Journal of Positive Behavior Interventions*, 8(2), 79-87.
- Kaiser, A.P. Hancock, T.B. (2003). Teaching parents new skills to support their young children's development. *Infants and Young Children*, 16(1), 9-21.

- Kane, G.A., Wood, V.A., & Barlow, J. (2007). Parenting programmes: A systematic review and synthesis of qualitative research. *Child: Care, Health and Development, 33*(6), 784-793.
- Kielhofner, G. & Burke, J.P. (1980). A model of human occupation, part 1: Conceptual framework and content. *American Occupational Therapy Association*, 34(9), 572-581.
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 88, 1636-1647.
- Mailloux, Z., May-Benson, T.A., Summers, C.A., Miller, L.J., Brett-Green, B., Burke, J.P., . . . Schoen, S.A. (2007). The issue is Goal Attainment Scaling as a measure of meaningful outcomes for children with sensory integration disorders. *American Journal of Occupational Therapy*, 61, 254-259.
- Piskur, B., Beurskens, A., Jongmans, M. J., Ketelaar, M., Norton, M., Frings, C. A., Hemmingsson, H. & Smeets, R. (2012). Parents' actions, challenges, and needs while enabling participation of children with a physical disability: A scoping review. *BCM Pediatrics*, 12(177), 1-13.
- Shields, N. & Synnot, A. (2016). Perceived barriers and facilitators to participation in physical activity for children with disability: A qualitative study. *BCM Pediatrics*, *16*(9), 1-10.
- Steiner, A.M., Koegel, L.K., Koegel, R.L., & Ence, W.A. (2012). Issues and theoretical constructs regarding parent education for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(6), 1-15.

APPENDICES

Appendix A: Key Studies Informing the Program Approach

a) Table of Research Studies

| Citation (1st author & year) | Study Purpose/ Research Question | Design | Sample | Data Collection Strategies | Findings that Inform This Study |
|------------------------------|---|--|---|---|---|
| Barlow (2001) | Evaluate the effectiveness of a school-based parenting program and to gain a better understanding of parents' experiences of a parenting program | Pilot cluster randomized controlled trial (the qualitative data collected as part of a large study where participants were randomly allocated to 4 groups) | 450 typically developing children ages 4-7 years old and 34 parents | Grounded theory approach; Semistructured interviews with 11 parent participants | 3 ways parents benefited from the program include: 1. Support received from other parents, including a mirroring of problems 2. Regaining of a sense of control in parental role 3. Increased ability to empathize and identify with their children, and a better understanding of the factors which motivate children's behaviors |
| Ingersoll (2006) | Examine parent training in an effort to improve the quality of education for students with autism | Pilot training programs in 2 Regional Program Autism Training Sites (RPATS) classrooms | 12 families of children with autism | Pre-post knowledge quiz, parent satisfaction survey, teacher satisfaction survey | Increase in parent knowledge following the training, positive satisfaction survey results |
| Kaiser (2003) | Explain the skills that parent educators need in order to be effective; Discuss a model for preparing professionals to teach parents | Qualitative study that draws on empirical data and anecdotal examples from the authors' ongoing research on teaching parents naturalistic language intervention strategies | Parents of children with developmental disabilities | Checklists; Parent- report | Parent are good as program participants when they are interested, choose to participate, are supported by others, and have sufficient time and energy Beneficial for parent teachers and parents to collaborate in goal setting Parent teachers should create safe learning environment, teach for generalization, and include practice |

b) Table of Review Studies

| Citation | Review Purpose/ | Design | Sample | Conclusions from the Review |
|-------------|---------------------|------------------------|------------------------------|--|
| (1st author | Research | | | |
| & year) | Question | | | |
| Carter | Analysis of | Qualitative | 26 articles | Primary focus of interventions were either skill-based |
| (2005) | interventions aimed | systematic review | selected that met | interventions (teaching participants with disabilities skills to |
| | at promoting social | and analysis | inclusion criteria; | increase their social interaction with peers) or support-based |
| | interaction among | | focus on youth in | interventions (arranging aspects of the environment to |
| | adolescents with | | middle school | promote or support peer interaction) |
| | intellectual | | and high school | |
| | disabilities and | | | Many social interactions and behaviors are responsive to |
| | their typically | | | interventions |
| | developing peers | | 4 11: | |
| Kane | Examine parents' | Systematic review | 4 qualitative | Acquisition of knowledge, skills and understanding |
| (2007) | experience and | of 4 qualitative | studies included | Feelings of acceptance and support from other parents |
| | perceptions of | studies; Meta- | following inclusion criteria | Parents able to regain control and feel more able to cope. |
| | parenting programs | ethnographic method | and critical | |
| | | illetilot | and critical | |
| Steiner | Overview of parent | Narrative review | 113 articles | Further research required to define most effective method to |
| | education programs | with qualitative | utilized in | complete parent education sessions |
| (2012) | for young children | findings; 26 | creation of this | complete parent education sessions |
| | with autism and | empirical social | review; Parents | Collaborative models in which the parent educator and parent |
| | details data-driven | interaction | of children with | work together to develop treatment goals are emphasized |
| | procedures | interventions were | autism | work together to develop treatment goals are emphasized |
| | associated with | analyzed | | Strengths-based approach may increase hope |
| | improved parent | | | Suchguis-based approach may increase nope |
| | and child outcomes | | | |

Rease join us for a series of 4 Parent Training Sessions during the summer of 2016!

My Social Toolbox

Building a Foundation for Increased Social Participation Among Children with Disabilities

| Session Topic | Morning Option | Night Option |
|-----------------------------------|-------------------------------|-------------------------------|
| Session 1 | July 13 th , 2016 | July 14 th , 2016 |
| The Importance and Benefits of | 9:30am | 6:30pm |
| Social Participation | Orange Inclusive Preschool | Orange Public Library |
| Session 2 | July 20 th , 2016 | July 21 st , 2016 |
| Opportunities Available for | 9:30am | 6:30pm |
| Children with Disabilities in the | Orange Inclusive Preschool | Orange Public Library |
| Local Community | | |
| Session 3 | July 27 th , 2016 | July 28 th , 2016 |
| Social Interaction Strategies | 9:30am | 6:30pm |
| | Orange Inclusive Preschool | Orange Public Library |
| Session 4 | August 3 rd , 2016 | August 4 th , 2016 |
| Social Event; Bring Your Child! | 9:30am | 6:30pm |
| | Orange Inclusive Preschool | Orange Public Library |

Who?

Any parent of a child with a disability enrolled in the Extended School Year Program or a member of the Orange Parent Education Network (OPEN) committee through Orange Schools!

All sessions will run approximately 1 hour long.



Hosted By:

Brooke Willis, Occupational Therapy Doctoral Candidate at Duquesne University

Cost:

There is **no cost** to participate!

If you would like to be a participant or learn more information about the program, please contact Brooke Willis at willisb@duq.edu or (440) 487-6160 for more information.



My Social Toolbox

32000 Chagrin Boulevard ◆ PEPPER PIKE, OH 44124

CONSENT TO PARTICIPATE IN A CAPSTONE PROJECT

TITLE: My Social Toolbox

PROGRAM DEVELOPER: Brooke Willis, Occupational Therapy Doctoral Candidate

Duquesne University willisb@duq.edu

ADVISOR: Christine Goudy, Special Education Coordinator

Orange City Schools cgoudy@orangecsd.org

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the

requirements for the clinical doctoral degree in occupational therapy at Duquesne University.

PURPOSE: You are being asked to participate in a capstone project that

is designed to evaluate the impact of a parent training program designed to increase the level of social participation and quality of social interaction in their

children with disabilities.

In order to qualify for participation, you must be a parent of

a child with a disability. Participants must be English

speaking and be able to read and write.

PARTICIPANT PROCEDURES:

To participate in this study, you are asked to attend four parent-training sessions each lasting approximately one hour. Throughout these sessions, you may be encouraged to share personal experiences and speak/collaborate with other participants. You are asked to complete two measures

before and after your participation in these training sessions

that focus on your child's participation in social

environments and the impact of social participation on your

child. You will also be asked to assist your child in

completing a rating form before and after your participation in the program that focuses on your child's self-perception of participation. During the first session, you will be asked

to create individualized goals for yourself during the program, which will be reviewed during the final session. Example goals and assistance will be provided. During the final session, you will be encouraged to bring your whole family to participate in a social event. Lastly, you will be asked to complete a satisfaction survey used to gather data on the effectiveness of components of My Social Toolbox, including the parent training sessions and the social event. If you are unable to attend all four sessions, you will be asked to complete the parts of the assessment tools that relate to the sessions you are able to attend. These are the only requests that will be made of you.

RISKS AND BENEFITS:

There are no more risks associated with this participation than those encountered in everyday life. Benefits for participation in My Social Toolbox include increased knowledge of the importance of social participation, resources about community opportunities for your child and knowledge of social interaction strategies you can use with your child.

COMPENSATION:

Participation in the project will require no monetary cost to you.

CONFIDENTIALITY:

Your participation in this project and any personal information that you provide will be kept confidential at all times and to every extent possible.

All forms and project materials will be kept secure. Any project materials with personal identifying information will be maintained until the end of December 2016 after the completion of the doctoral candidate's schooling and then destroyed.

RIGHT TO WITHDRAW:

You are under no obligation to participate in this project. You are free to withdraw your consent to participate at any time by contacting Brooke Willis. Data collected prior to the time of withdraw from the program will be kept by the doctoral candidate for research purposes unless specifically requested by the participant for all data to be destroyed.

VOLUNTARY CONSENT:

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I

| | project. | to participate in this capstone |
|-------------------------|--------------------------|--|
| | my participation in this | I have any further questions about project, I may call Brooke Willis at willisb@duq.edu. |
| Participant's Signature | | Date |
| Researcher's Signature | | Date |

| COMMUNITY Participat | tion | | | | participate in 1 or more activities of this type? | | | | | | pai act | C) Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY | | | | | | | | | | |
|---|-------------|---|----------|----------------|---|------------------|-------------|-------------|--------------|-----------|------------|--|------------|-------------|-----------|------------|----------|---------|--------|--|--|---|
| | \s\display. | - | Jimes av | NEET LEET LEET | Little 5 art | Tother Les & Few | times in or | ast four no | A STANTONIOS | resitor C | / / 55 | The Math | Lidued Ari | / July live | Starte de | do note of | SO LES X | of Tes. | Tes be | ed la di a di la d | | / |
| 1) Neighborhood outings (e.g., shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore) | | | | | | | | | | | | | | | | | | | | | | |
| 2) Community events (e.g., attending a play, concert, sports game, parade) | | | | | | | | | | | | | | | | | | | | | | |
| 3) Organized physical activities (e.g., sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics) | | | | | | | | | | | | | | | | | | | | | | |
| 4) Unstructured physical activities (e.g., nature trail walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, playing pick-up games like basketball) | | | | | | | | | | | | | | | | | | | | | | |
| 5) Classes and lessons (not school-sponsored) (e.g., music, art, languages, computers) | | | | | | | | | | | | | | | | | | | | | | |

C

Appendix D: PEM-CY Community Cont

COMMUNITY Environment

| Do the following things <u>help or make it harder</u> for your child to participate in activities in the community? CHECK ONE RESPONSE ☑ | Not an Issue | Usually helps | Sometimes helps; sometimes makes harder | Usually makes harder |
|---|-----------------|------------------|---|----------------------------|
| 1. The physical layout or amount of space outside and inside buildings (e.g., distances to stores, presence of sidewalks, availability of ramps or elevators) | | | | |
| 2. The sensory qualities of community settings (e.g., noise, crowds, lighting) | | | | |
| 3. The physical demands of typical activities (e.g., strength, endurance, coordination) | | | | |
| 4. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving) | | | | |
| 5. The social demands of typical activities (e.g., communication, interacting with others) | | | | |
| 6. Your child's relationships with peers | | | | |
| 7. The attitudes and actions of other members of the community towards your child (e.g., shopkeepers, instructors, coaches, other families) | | | | |
| 8. Outside weather conditions (e.g., temperature, climate) | | | | |
| 9. The safety of the community (e.g., traffic, crime, violence) | | | | |

| Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE | Not needed | Usually, yes | Sometimes yes; sometimes no | Usually, no |
|---|---------------|-----------------|--------------------------------------|----------------|
| 10. Access to personal transportation to access community activities (e.g., family car, bicycle) | | | | |
| 11. Access to public transportation to access community activities (e.g., bus, train, subway) | | | | |
| 12. Programs and services (e.g., inclusive sports programs, personal support worker) | | | | |

Appendix D: PEM-CY Community Cont

COMMUNITY Environment

| Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE ✓ | Usually, yes | Sometimes yes; sometimes no | Usually, no |
|---|-----------------|--------------------------------------|----------------|
| 13. Information (e.g., about activities, services, programs) | | | |
| 14. Equipment or supplies (e.g., sports equipment, craft supplies, reading materials, assistive devices or technology) | | | |
| 15. Do you (and your family) have enough time to support your child's participation in the community? | | | |
| 16. Do you (and your family) have enough money to support your child's participation in the community? | | | |

| what are some things that you or other family members do that help your child participate successfully in activities in the community? |
|--|
| PLEASE LIST UP TO 3 STRATEGIES |
| 1. |
| 2. |
| 3. |

Appendix E: Parent Social Participation Pre-Test/Post-Test Questionnaire My Social Toolbox:

Parent Social Participation Pre-Test/Post-Test Questionnaire

| 1 | |
|--------|--|
| 2 | |
| 3 | |
| elopin | ocial interaction strategies that can be used to help your child interact with a typically g peer. If you do not know of any social interaction strategies, please write "unsure." ou do not have to be currently utilizing these strategies to list them below) |
| 1 | |
| | |

- 3. Using the scale below, please circle the number that best presently corresponds to the statements below.
 - 1 = Strongly Disagree
 - 2 = Disagree
 - 3 = Neither Agree Nor Disagree
 - 4 = Agree
 - 5 =Strongly Agree

| Statement | Please circle the appropriate number | | | | iate |
|---|--------------------------------------|---|---|---|------|
| I have a strong understanding of importance of social participation for my child with a disability. | 1 | 2 | 3 | 4 | 5 |
| I am able to articulate the importance and benefits of social participation for my child with a disability. | 1 | 2 | 3 | 4 | 5 |
| I am able to successfully facilitate positive social interactions for my child with their peers. | 1 | 2 | 3 | 4 | 5 |
| I use a variety of strategies when helping my child interact with their peers. | 1 | 2 | 3 | 4 | 5 |
| I feel confident in facilitating positive social interactions for my child with their peers. | 1 | 2 | 3 | 4 | 5 |

Appendix F: Goal Attainment Scaling (GAS) Method GAS Form for Parents to Complete

Please choose 1-2 goals to be worked on by the completion of My Social Toolbox.

| Goal Attainment Scaling Form | | | | |
|---|---------|---------|--|--|
| Level of Attainment by the completion of My Social Toolbox (1-month timeline) | Goal 1: | Goal 2: | | |
| -2 Much less than expected | | | | |
| -1 Somewhat less than expected | | | | |
| 0 Expected level of outcome | | | | |
| +1 Somewhat more than expected | | | | |
| +2 Much more than expected | | | | |
| Comments: | | | | |

Appendix F: Goal Attainment Scaling (GAS) Method Cont

Example GAS Goals Provided to Parents

Listed below are example goals for your reference. These are listed for your references and do not have to be chosen. They can be edited to fit your and your child's needs. All goals will be set for a one-month timeframe during the duration of My Social Toolbox.

Goals for Increasing Social Participation:

- I will make a schedule to plan out specified time periods designated to social participation opportunities for my child.
- I will make a list of social participation options that would be feasible for my family and that my child is interested in, using the My Social Toolbox reference guides or other sources.
- I will try 2 new social participation events/outings with my child.
- I will initiate contact with at least 2 local resources that my family does not normally attend via phone call or email.
- I will reference the My Social Toolbox reference guide when searching for social participation opportunities for my child.

Goals for Promoting Social Interaction/Utilizing Social Interaction Strategies:

- I will try 2 different social interaction strategies discussed during My Social Toolbox with my child while out in the community setting (i.e park, playground, zoo, etc.).
- I will utilize a social interaction strategy with my child during 3 consecutive social outings in the community.
- I will try a technique to facilitate social interaction between my child and a peer (community facility/community event, school, local playground, etc.).
- I will set-up at least 1 social outing for my family and a family with a similar-age child to encourage social interaction for my child and utilize social interaction strategies.

Note: It is recommended you make these goals as specific to you and your family as possible. For example, if a goal indicates use of a social interaction strategy, specify which one you intend to use. If a goal states, "in the community," try specifying actual community events and/or places.

Appendix G: The Child Occupational Self-Assessment (COSA) – Modified

| Parent Name: | | Child Gender: M \square F \square | Child Date of Birth: | |
|--------------------|---------|---------------------------------------|----------------------|--|
| COSA completed by: | Child □ | Child and parent □ | Parent □ | |

Directions: Here are some sentences that tell about everyday things that kids do. For each one, ask yourself "Is this a problem for me? If so, how much of a problem is it for me?" Mark the face(s) that best match how you feel. Also think about how important things are to you. Please tell how important these items are to you, not your parents or teachers. Mark the number of the stars that best matches how important something is to you.

There are no right or wrong answers. This is not a test. I want to know what answer best describes how you feel about these activities

| Myself | I have a big problem doing this | I have a little problem doing this | I do this ok | I am really good at doing this | Not really important to me | Important to me | Really important to me | Most important of all to me |
|---------------------------------------|---|---|-----------------|--------------------------------------|-------------------------------|--------------------|------------------------------|---|
| Choose things that I want to do | | | \odot | | \searrow | | | |
| Get around from one place to another | | <u>:</u> | \odot | (i) | $\stackrel{\wedge}{\searrow}$ | $\sim \sim$ | | *** |
| Keep my mind on what I am doing | | <u>:</u> | \odot | ○ ○ | \searrow | | | *************************************** |
| Do things with my family | © © | <u>:</u> | \odot | : | \nearrow | | | *** |
| Do things with my friends | © © | <u>:</u> | \odot | : | \searrow | | | *** |
| Make others understand my ideas | ○○○ | <u>:</u> | \odot | \odot | $\stackrel{-}{\searrow}$ | | | *** |

Appendix H: Parent Participant Satisfaction Survey

Participant Satisfaction Questionnaire

Results of this survey are anonymous and will be used to inform future program development.

Please rate the following statements by checking the appropriate box on the right.

| Please rate the following statements by checking | tne appro | priate box | on the rigi | 1t. |
|--|-----------|------------|-------------|----------|
| Statement: | Strongly | Disagree | Agree | Strongly |
| Parent Training Sessions | Disagree | | | Agree |
| 1. The parent training sessions were beneficial in | | | | |
| increasing my understanding of the importance | | | | |
| of social participation for my child. | | | | |
| 2. The parent training sessions helped me become | | | | |
| more aware of local, social participation | | | | |
| opportunities available for my child. | | | | |
| 3. The content provided in the parent training | | | | |
| sessions was informative. | | | | |
| 4. I feel confident with the content provided to me | | | | |
| in parent training sessions. | | | | |
| 5. I have a better understanding of strategies I can | | | | |
| use to promote improved social interaction skills | | | | |
| in my child. | | | | |
| 6. I feel confident in implementing the social | | | | |
| interaction strategies learned in the parent | | | | |
| training sessions with my child. | | | | |
| 7. Support from other parents of a child with a | | | | |
| disability who were present at the sessions was | | | | |
| beneficial to my learning. | | | | |
| 8. I find myself reviewing the information provided | | | | |
| in the PowerPoints following completion of the | | | | |
| sessions. | | | | |
| 9. I take more initiative in finding and planning | | | | |
| social participation opportunities for my child. | | | | |

| Statement: | Strongly | Disagree | Agree | Strongly |
|--|----------|----------|-------|----------|
| Social Event | Disagree | | | Agree |
| 1. I enjoyed attending the social event for my child. | | | | |
| 2. My child enjoyed attending the social event. | | | | |
| 3. The social event was organized and run smoothly. | | | | |
| 4. The activities included in the social event were appropriate for my child. | | | | |
| 5. This event provided my child an opportunity to interact with other peers at an appropriate level. | | | | |
| 6. I would attend the same or a similar event in the future. | | | | |
| 7. I would recommend this event to other families. | | | | |

Appendix H: Parent Participant Satisfaction Survey Cont.

Please respond to the following questions:

| 1. What did you find to be the most beneficial components of this program? Least beneficial? |
|--|
| |
| |
| 2. What would you change and/or add about the program to increase your understanding of the importance of social participation or your knowledge of the local opportunities available? If you do not have any ideas, please write 'not sure' below. |
| |
| |
| 3. Do you feel as though your child demonstrates improved social interaction skills secondary to your participation in My Social Toolbox? Why or why not? (If you have no had a chance to implement a social interaction strategy, do you feel that the content provided in the parent sessions will be beneficial to improving your child's social interaction skills?) |
| |
| |
| 4. Would you recommend this program to other parents in the future? Why or why not? |
| |
| |
| 5. Please add any additional comments you have about My Social Toolbox below. |
| |
| |
| Thank you for your participation in this survey. Your feedback is appreciated. For questions or concerns about this survey, contact Brooke Willis at or willisb@duq.edu |