Easter Seals' F.A.C.E.S. Program: families with autism in the community and engaging in society

Julia L. Hill

The University of Toledo

Follow this and additional works at: http://utdr.utoledo.edu/graduate-projects

This Capstone Project is brought to you for free and open access by The University of Toledo Digital Repository. It has been accepted for inclusion in Master's and Doctoral Projects by an authorized administrator of The University of Toledo Digital Repository. For more information, please see the repository's About page.
Easter Seals’ F.A.C.E.S. Program:
Families with Autism in the Community and Engaging in Society

Julia L. Hill

Site Mentor: Cheryl Chen, OTR/L, and Betsey White, OTR/L
Faculty Mentor: Beth Ann Hatkevich, Ph.D., OTR/L

Occupational Therapy Doctorate Program
Department of Occupational Therapy
The University of Toledo Health Science Campus
May 2009

Note: This document includes a capstone dissemination project developed over an individually planned semester under the supervisor of site and faculty mentors. The purpose of the capstone experience is to provide the occupational therapy doctoral student the opportunity to develop a project that he or she is personally invested in while demonstrating autonomous decision making and leadership qualities throughout the process.
# Table of Contents

Executive Summary...........................................................................................................6

Introduction

*Program Site..................................................................................................................7*

*Current Program...........................................................................................................7*

*Pre-Modification and Post-Modification Goals.................................................................8*

*Methods used for Needs Analysis....................................................................................9*

*Results of Needs Analysis.............................................................................................10*

*Literature Review..........................................................................................................12*

*Occupation-based...........................................................................................................17*

*Major Program Modification........................................................................................18*

*Relevant Model of Practice............................................................................................18*

Client/Patient Objectives and Program Modification Aims

*Pre-Modification Objectives.........................................................................................19*

*Post-Modification Objectives.........................................................................................19*

*Aims of Program Modification......................................................................................21*

Clients/Patients

*Post-Modification Pool of Participants..........................................................................22*

*Inclusion Criteria...........................................................................................................22*

Implementation to Achieve Aims

*Implementation of Easter Seals’ F.A.C.E.S. Program.......................................................23*

*Plan for Full Implementation........................................................................................25*

*Justification of Implementation.....................................................................................28*
Post-Modification Programming vs. Pre-Modification Programming

Documentation

Implications for Budgeting and Personnel

Easter Seals' Approval Process for Program Modification

Staff/Volunteer Training Procedures

Expected Revenue Generated & Financial Gain/Loss

New Personnel Credentials

Budgeting and Staffing

Personnel Costs

Family Training Costs

Community Outing Costs

Marketing Costs

Total Direct Costs

Indirect Costs

Total Budget

In-Kind Support: Items and Personnel

Program Modification Evaluation

Outcome Evaluation Procedures

Stakeholders to Evaluate Program Modification Aims/Process Evaluation

Formative Evaluation Procedures
Appendix R: Social Story: Bowling.................................................................89
Appendix S: Countdown to Bowling..............................................................97
Appendix T: Parent/Caregiver Survey of First F.A.C.E.S. Program.....................98
Appendix U: Results of Parent/Caregiver Survey of First F.A.C.E.S. Program...........99
Appendix V: Results of Survey: Satisfaction of Family Outings.........................100
Appendix W: Results of Survey: Strategies to Assist my Family Member with Autism within the Community.................................................................101
Appendix X: Easter Seals Therapeutic School and Center for Autism Research
F.A.C.E.S. Program Final Evaluation..............................................................102
Executive Summary

Autism spectrum disorder (ASD) is identified in approximately 1 in 150 children in the United States (CDC, n.d.). Areas of difficulty for individuals with ASD might include language and communication, relating to people and to the environment, responses to sensory stimuli, and developmental discrepancies (Janzen, 1996). A needs assessment was completed at Easter Seals Therapeutic School and Center for Autism Research to determine the needs of families who have students with autism. Based on the results, the occupational therapy program, Easter Seals’ F.A.C.E.S. (Families with Autism in the Community and Engaging in Society) program, was developed. The program goal focuses on increasing functional independent living skills and leisure occupations of students and families through family training programs and supported community outings. The F.A.C.E.S. program will be evaluated by surveys, documentation on community outings, observations, and informal meetings with stakeholders.
Introduction

Program Site

The site for this program will be Easter Seals Therapeutic School and Center for Autism Research. This site is part of Easter Seals which is an organization that provides services to individuals with disabilities or special needs as well as their families (see Appendix A for the organizational chart). The mission of Easter Seals is the following (Easter Seals Metropolitan Chicago, 2008): “In response to our communities, Easter Seals Metropolitan Chicago provides comprehensive services for individuals with disabilities or other special needs and their families to improve quality of life and maximize independence.” Some programs that they are involved in, specifically in Chicago, include autism therapeutic schools, adult vocational programs, after school programs, Head Start childcare, respite services, and senior community service employment. There are approximately 22,000 individuals served within the Easter Seals’ programs and 102 students currently served at the Easter Seals Therapeutic School and Center for Autism Research. The students that attend this school have an educational diagnosis of autism spectrum disorder, emotional disorders, and/or cognitive impairments. All of the students have been recommended for services by their school district and have “Therapeutic Day Placement” identified on their individualized education plan (IEP). The therapeutic school includes an extended school year, modified academic curriculum, speech therapy, occupational therapy, social work, nursing, behavior consultation, vocational and community training, on-site after school program, an on-site developmental training program, and other related services.

Current Program

The current program goal at Easter Seals Therapeutic School and Center for Autism Research focuses on empowering students to succeed academically, improve social, vocational,
and communication skills, and to successfully acquire functional living skills for independence within their community. Occupational therapy works collaboratively with each discipline to promote the overall program goal and focuses on ensuring that each student is able to access their individualized education plan and maximize their skills. In addition, within the overall program goal, occupational therapy assumes a lead role in teaching functional living skills within the community. Students receive occupational therapy services as determined by their individual education plan (IEP) and each student receiving services has individual goals that focus on his or her unique needs related to the overall goal of the occupational therapy program. There are currently four occupational therapists (three full time and one clinical coordinator) working at Easter Seals Therapeutic School and Center for Autism Research to provide these services.

The F.A.C.E.S. program will be an addition to the current occupational therapy program. It will provide the participating students the opportunity to refine and generalize their functional independent living skills and leisure skills with their families in actual community settings. It will also provide family members of the students the opportunity to learn strategies to assist their family member with autism to successfully engage in the community. These community outings will give the families the chance to engage in leisure occupations in a safe and supported environment in the hopes that this will provide families with the confidence and skills necessary to continue to engage in their community and enhance their overall quality of life.

*Pre-Modification and Post-Modification Goals*

The pre-modification goal of the Easter Seals Therapeutic School and Center for Autism Research, as mentioned earlier, focuses on empowering students to succeed academically, improve social, vocational, and communication skills, and to successfully acquire functional living skills for independence within their community. Occupational therapy works
collaboratively with each discipline to promote the overall program goal and focuses on ensuring that each student is able to access their individualized education plan and maximize their skills. In addition, within the overall program goal Easter Seals Therapeutic School and Center for Autism Research, occupational therapy assumes a lead role in teaching functional living skills within the community.

The post-modification goal of the occupational therapy program will expand upon the pre-modification goal. The goal of the F.A.C.E.S. program is to increase functional independent living skills and leisure occupations of students and families at Easter Seals Therapeutic School and Center for Autism Research through participation in a family training program to learn skills needed in community settings and engagement in supported family community outings.

Methods used for the Needs Analysis

The methods developed to determine the needs of students and families at Easter Seals were based on conversations held with employees at Easter Seals (specifically, Betsey White, OTR/L and Cheryl Chen, OTR/L), observations of students of Easter Seals during class and therapy sessions, and a literature review on autism and families’ needs. The following methods were used to complete a needs assessment at the Easter Seals Therapeutic School and Center for Autism Research: parent/caregiver surveys, employee surveys, and informal discussions/meetings with Easter Seals’ employees and administration.

The first method completed in the needs assessment was survey questionnaires (see Appendix C and Appendix F). These were developed for both parents/caregivers and employees at Easter Seals Autism Therapeutic School of Chicago based on the needs that were identified during conversations with Betsey White (Clinical Coordinator and Occupational Therapist), Cheryl Chen (Occupational Therapist), and other Easter Seals’ employees and a literature review
of needs of families with autism. The needs that were identified were the following:

parent/caregiver support, sibling support, family interaction and communication, leisure occupations for students, and socialization skills. The survey was relevant to both parents and employees in that it gave them the opportunity to have input in determining the main focus of the program. The parent/caregiver surveys were sent home with students and were given approximately two weeks to return the surveys. As an incentive to return surveys parents/caregivers were told that each student who had a parent/caregiver return a survey would be entered in a drawing for a class pizza party. The employee surveys were placed in staff mailboxes and were given approximately one week to return. The employees were asked to return the surveys to Cheryl Chen’s, OTR/L, mailbox so that they could be returned anonymously. Letters were attached to both surveys to further explain the purpose of the program and the surveys (See Appendix B and Appendix E). A reminder letter to return the surveys was also sent home to the parents a week after the surveys were distributed (See Appendix D).

The final method that was used in the needs assessment was informal meetings with employees of Easter Seals Autism Therapeutic School of Chicago. The discussions took place throughout the development of the program.

Results of Needs Analysis

A total of 14/94 (14.9%) employee surveys and 30/102 (29.4%) parent/caregiver surveys were returned. Based on the 14 employee surveys, the following needs were reported: sibling support (10/14; 71.4%), supported family interaction and/or communication (12/14; 85.7%), leisure occupations for students/families (9/14; 64.3%), student socialization skills (9/14; 64.3%), and student/family community outings (12/14; 85.7%).

The following comments were taken from employee surveys to emphasize the needs:
“Sometimes siblings get put aside (not purposefully) because their brother/sister requires so much of the parents’ time. I think they need something to help them understand and communicate their needs.”

“Many families are unable to provide leisure/rec opportunities for various reasons. May be helpful to offer alternatives that families (can) access.”

“These (leisure occupations) outings can make a family seem ‘normal’ where they do not have to worry about what other people are thinking.”

Based on the 30 parent/caregiver surveys, the following needs were reported: sibling support (9/30; 30%), supported family interaction and/or communication (9/30; 30%), leisure occupations for students/families (18/30; 60%), student socialization skills (25/30; 83.3%), and student/family community outings (22/30; 73.3%).

The following statements were taken from parent/caregiver surveys to emphasize the needs:

“Jason’s* brother Joe* doesn’t understand why Jason’s* behavior changes all of a sudden. We try to explain but he still ask(s) questions that sometimes I can’t even understand about his disability” (*names changed)

“Some parents are at a loss for how to interact…”

“Looking for age appropriate activities that he would enjoy – adulthood”

“I wish there was a group (social) that both boys could participate in on a regular basis”

“It would be nice if there could be Easter Seals Family Days at community venues – water parks, amusements, malls.”

“Trips/outings for families so students could interact and share interests with other families.”

Along with the surveys, informal discussions/meetings were held with Easter Seals’ employees and administrators to assess needs of students and families at Easter Seals Therapeutic School and Center for Autism Research. The previously listed needs were confirmed (i.e., sibling support, supported family interaction and/or communication, leisure occupations for...
students/families, etc.). Based on the needs assessment it is apparent that the families at Easter Seals’ would benefit from a family program that addressed as many of these needs as possible.

**Literature Review**

Autism spectrum disorder (ASD) is the second most common developmental disorder and is identified in approximately 1 in 150 children in the United States (CDC, n.d.). This new estimate of 1 in 150 in 2007 is an increase from the estimate of 1 in 166 children in 2004 (Autism Speaks, Inc., 2008); there is no known reason for this increase. It is estimated that 560,000 children between the ages of 0 – 21 in the United States have ASD (CDC & ADDM, n.d.) and that it is four times more likely in males (Autism Speaks, Inc., 2008). Autism spectrum disorder is known as a spectrum disorder due to its range of severity, onset, course of development, and incidence of features such as cognitive impairment or language delay (Shangraw, 2007). There is no known cause although hypothetical causes have been suggested. These include genetics, environmental factors, physiological abnormalities, or a combination of these factors (Shangraw, 2007).

As stated in the DSM IV (Morrison, 2001), a diagnosis of Autistic Disorder is given when at least six criteria are met under the categories of impaired social interaction (at least two), impaired communication (at least one), and activities, behaviors, and interests that are repetitive, restricted, and stereotyped (at least one). This diagnosis is typically given by the age of three and is based on evaluations such as clinical observations, parent interviews, developmental histories, speech and language assessments, and autism diagnostic tests (CDC & ADDM, n.d.). Autism spectrum disorder is seen in families of all racial, ethical, academic, and socioeconomic backgrounds (Case-Smith, 2005).
Symptoms of ASD vary for each individual. Common areas of difficulty might include language and communication (e.g., flat expressions, does not use gestures, repeats or echoes phrases), relating to people and to the environment (e.g., unresponsive, limited eye contact, repetitive play), responses to sensory stimuli (e.g., panic to specific sounds, flicks fingers before eyes, spins), and developmental discrepancies (e.g., learn skills out of sequence) (Janzen, 1996).

There is currently no cure for autism, although there are a number of interventions available. Janzen (1996) suggests that the best treatment is a “highly structured and specific educational program that addresses the predictable deficits of autism” (p. 11). More specifically, direct teaching or consultation by a special education teacher, speech therapy, occupational therapy, physical therapy, supportive counseling, and medication are available for families to consider when developing a treatment plan.

As this information has shown, autism impacts many aspects and occupations of daily life. One of these major areas, as mentioned earlier, is social skills and communication, which in turn affect the individual’s functional independent living skills, especially within the community and within the family. Many studies have begun to research social skills programs and occupational therapy services for individuals with autism in order to improve their and their families’ quality of life, and to determine the areas of need for these services (Chung, Reavis, Mosconi, Drewry, Matthews, & Tasse, 2006; Matson, Matson, & Rivet, 2007; Siklos & Kerns, 2006; Higgins, Baily, & Pearce, 2005; Benderix & Sivberg, 2007; Watling, Tomchek, & LaVessar, 2005).

A study by Chung, Reavis, Mosconi, Drewry, Matthews, and Tasse (2006) examined the benefits of a 12 week social skills training program for four boys ages six to seven diagnosed
with ASD. The results concluded from a pre- and post-test that intervention involving peer-mediated social skills training (e.g., structured group teaching, role-play, feedback, contingent reinforcement, and participation of typically developing peers) along with video feedback had a positive impact on the four participants although each area of social improvement was unique to the individual. The author reported that future research in social skills training for individuals with ASD was needed. This study is important in addressing the need for social skills programming for individuals with ASD.

Matson, Matson, and Rivet (2007) reviewed past studies regarding social skills interventions for children with ASDs and identified methods beneficial in teaching social skills. They also direct the reader to specific case examples in which these methods are used. The most common intervention approaches found throughout the literature review were: modeling and reinforcement with feedback given in regards to accuracy and appropriateness of responses, peer mediated intervention in which a peer tutor or volunteer model prompts appropriate social behavior, reinforcement schedules and activities, and the use of scripts and social stories. This study is beneficial in providing useful social skills interventions for individuals with autism.

Siklos and Kerns (2006) examined 88 participants who had either a child with ASD (n = 56) or Down Syndrome (DS) (n = 32) to determine what the parents’ needs were and what needs were unmet using a modified Family Needs Questionnaire (FNQ) (Marwitz, 2000). The parents rated the needs as being met by responding yes/no/partly and also rated the importance of the need by responding not important/slightly important/important/very important. While this study specifically examined the statistical significance of the correlations between the needs of the two groups, it also examined the unmet needs of each group. The authors reported a total of 27 out of the 40 “important” needs rated as “unmet” for parents who have a child with ASD. The
following list included the top ten “unmet” or “partly met” needs that were rated as “important” and the percentages of the parents who responded this way: financial support in order to provide my child with his/her therapies, treatments and care (93%); for my child to have friends of his/her own (82%); help dealing with my fears about my child’s future (79%); services continuously rather than only in times of crisis (79%); for my children’s friends to feel comfortable around my child (79%); weekend and after-school activities for my developmentally delayed child (77%); to have my child’s therapies continue throughout the summer months and school breaks (77%); information about special programs and services available to my child and my family (75%); to have consistent behavioral therapy for my child (75%); and to have consistent occupational therapy (73%). This study demonstrates that there are many areas of need for families and individuals with autism. It also identifies areas of social skills as unmet needs in the top ten areas reported by parents.

Higgins, Baily, and Pearce’s (2005) study included 52 participants who were caregivers of children with autism. A total of 134 surveys were sent out to caregivers (with only 52 returned completed) that measured general demographic characteristics and behavior characteristics of children with ASD, support services available for children with ASD and their families, family functioning using the Family Adaptability and Cohesion Evaluation Scale (FACES II), marital quality and marital happiness using the Quality Marriage Index (QMI), self-esteem using Rosenberg Self-Esteem Scale, and coping strategies using the Coping Health Inventory for Patients (CHIP). The results from this study concluded that the means of marital happiness (mean = 6.1), family adaptability (mean = 46.4), and family cohesion (59.2) were all lower than the norm group means (7.7, 49.9, and 64.9, respectively). The authors reported 41% of the caregivers experienced physical, emotional, financial, or marital relationship stress, 25%
described a negative effect on family life, and 22% reported that family, friends, teachers, and the community typically did not understand the behavioral characteristics of ASD.

Benderix and Sivberg (2007) interviewed 14 siblings ages 5 – 29 years to explore their past and present experiences of having a brother or sister with ASD and moderate to profound mental retardation. The interview included questions such as, “What is it like to have a brother or sister with autism?” or “What do you do together in your family?” Based on the interview seven categories were concluded by the authors. These categories were (Benderix & Sivberg, 2007):

1. Having a sense of precocious responsibility;
2. Feeling sorry for the brother or sister with autism;
3. Being exposed to frightening abnormal behaviors;
4. Having empathetic feelings for the child with autism;
5. Hoping that group home will be a relief for the family;
6. Physical violence on the family made the siblings feel unsafe and anxious at home;
7. Having a brother or sister with autism affects relationships with friends negatively.

This study’s findings suggest that a supportive treatment program, either individually or in a group session, may be beneficial to siblings who have a brother or sister with autism and moderate to profound MR.

A final article by Watling, Tomchek, and LaVessar’s (2005) is of great importance in defining the role and domains of occupational therapy with individuals with autism. It describes the individuals that the occupational therapist might work with (e.g., parents, caregivers, educators, and team members), a variety of settings that the occupational therapist might work with this population in (e.g., home, school, clinic, and community), and areas of focus for
intervention (e.g., activities of daily living, instrumental activities of daily living, education, work, leisure, play, and social participation). It is helpful in addressing the scope of occupational therapy practice.

It is clear from this review of research studies that a supportive program addressing the previously found needs for individuals with autism and their families is needed. One essential partner in developing this type of program is occupational therapy. “Occupational therapy practitioners work with individuals with autism as well as parents, caregivers, and other team members in a variety of settings, including the home, school, clinic, and community to assist the individual with ASD to engage in meaningful occupations.” (Schoen, 2006, p. 369) Since occupational therapists have experience with this population, are already working in these types of settings, and specifically develop interventions that address social skills and meaningful occupations it is logical that occupational therapists take a lead in developing occupation-based programs for individuals with ASD.

**Occupation-based**

The Easter Seals’ F.A.C.E.S. program is clearly an occupation-based program. As stated in AOTA’s Autism Fact Sheet (Scott, 2006, p.1), “occupational therapy services focus on performance of activities of daily living (e.g., feeding, dressing), instrumental activities of daily living (e.g., community mobility, safety procedures), education, work, leisure, play, and social participation”. The F.A.C.E.S. program focuses on independent living skills and leisure occupations within the community which falls under the domain and focus of occupational therapy.
**Major Program Modification**

The F.A.C.E.S. program is a major program modification from the current occupational therapy program. As mentioned previously, this program will provide the students and families with the opportunity to refine and generalize their functional independent living skills and leisure occupations within their own community. Currently there is not a program at Easter Seals that provides the families with this specific opportunity. There are opportunities for the students to go out into the community to practice specific functional independent living skills, but not with the focus on family leisure occupations within the community. This program will provide the families the opportunity to learn and practice functional independent living skills within a supported setting with an occupational therapist(s) and Easter Seals’ volunteers (possibly including other speech therapists, behavior specialists, social workers, teachers, etc.) and then take those skills and strategies out into the community with their families with the support of therapists and volunteers. The overall purpose of this program is that the families will learn the skills necessary to engage in leisure occupations as a family within their own community and thus enhance their overall quality of life.

**Relevant Model of Practice**

The model of practice that will be used in developing the F.A.C.E.S. program is the Model of Human Occupation (MOHO) (Kielhofner, 2004). This model focuses on the person as a whole and is applicable across all ages, cultures, and disabilities. Its central concept is that “engagement in activity or occupation itself will produce and maintain health” (Cole, 2005, p. 263). MOHO focuses on three main concepts within the client: volition (e.g., motivation towards occupational choices), habituation (e.g., occupational performance patterns), and performance
(e.g., performance skills and client factors). These concepts of the model are central to the purpose of the F.A.C.E.S. program (see program goal).

Client/Patient Objectives and Program Modification Aims

Pre-Modification Objectives

The following objectives of the pre-modified occupational therapy program at Easter Seals’ Therapeutic School and Center for Autism Research assess the gains of the students:

1. Increase independence with activities of daily living as demonstrated by achievement of quarterly benchmarks and annual goals as written by the occupational therapist and/or educational team.

2. Contribute to educational and vocational development through direct and/or consultative services addressing goals targeting fine motor, visual motor, visual perceptual, gross motor, and/or sensory processing skills with progressed measured via quarterly benchmarks and annual goals.

Post-Modification Objectives

The following objectives of the F.A.C.E.S. program were developed to assess gains of program participants:

1. Students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will demonstrate increased functional independent living skills and leisure skills within the community by requiring a reduced number of prompts (specific for each participant; see Appendix I) from first community outing to completion of fourth community outing.

2. Students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will demonstrate increased functional
independent living skills and leisure skills within the community by requiring a reduced number of prompts (specific for each student; see Appendix I) from fourth community outing to completion of eighth community outing.

3. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased satisfaction in family leisure occupations by increasing their score in the Satisfaction of Family Outings Survey (see Appendix J) from initial family meeting to completion of four community outings.

4. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased satisfaction in family leisure occupations by increasing their score in the Satisfaction of Family Outings Survey (see Appendix J) from completion of four community outings to completion of eight community outings.

5. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased knowledge of strategies to assist his or family member within the community by an increased score in the Strategies to Assist my Family Member with Autism within the Community Survey (see Appendix K) from the initial family meeting to completion four community outings.

6. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased knowledge of strategies to assist his or family member within the community by an increased score in the Strategies to Assist my Family Member with Autism within the Community Survey (see Appendix K) from completion of four community outings to completion of eight community outings.
Aims of Program Modification

The aims (measurable changes) of the program modification plan are to provide an optional family program to supplement the already existing occupational therapy program at Easter Seals and to hire an additional occupational therapist to direct the program. Initially the F.A.C.E.S. program will not be a part of the goals that are written by the occupational therapists during the school year. However, depending on the success of the program and each participating student’s goal(s) it is possible that future goals and/or benchmarks may involve the F.A.C.E.S. program. Another possible impact that the F.A.C.E.S. program may have on the occupational therapy program at Easter Seals is the need to hire an additional occupational therapist to direct the program. There are currently three full time occupational therapists (in addition to the clinical coordinator, Betsey White, who is also an occupational therapist) who have full case loads and may not have the time to take on the position as the director of the F.A.C.E.S. program.

These changes to the current occupational therapy program will be beneficial to the goals and objectives of the F.A.C.E.S. program. If goals and/or benchmarks on students’ IEPs (when appropriate) are integrated into the sessions and outings of the F.A.C.E.S. program then the director and volunteers of the program will have a better understanding of what that specific student needs to focus on. Hiring an additional occupational therapist that can focus his or her energy and attention to the F.A.C.E.S. program will be essential for both the families and the success of the program. The occupational therapist will have the time to develop beneficial training sessions, outings, train volunteers, complete documentation and program evaluations which will be essential to meeting the goals and objectives of the F.A.C.E.S. program and to the overall success of the program.
Clients/Patients

*Post-Modification Pool of Participants*

The post-modification pool of participants of the F.A.C.E.S. program will include students and families of Easter Seals Therapeutic School and Center for Autism Research. The students have diagnoses of autism spectrum disorder, emotional disorders, and/or cognitive impairments. The students that attend the school have been recommended for services by their school district and have “Therapeutic Day Placement” identified on their individualized education plan (IEP). Their ages range from 7 – 22 years. The students and families are from Chicago, IL and surrounding areas.

*Inclusion Criteria*

In order to participate in the F.A.C.E.S. program interested families are required to have a student attending Easter Seals Therapeutic School and Center for Autism Research. The families that participate are required to attend the training session in order to go on the family outing. The participating families are also asked to only include family members at the training sessions who will be also attending the community outing in order to best assist the families in the community.

For the pilot of the F.A.C.E.S. program the families that attended the informational meeting (all families were invited) along with others who indicated an interest in the program were contacted via a letter sent home with their student (see Appendix N) along with a follow up phone call (15 families total) to participate in the first session/outing. In the future, if the program is a success and grants are received, all families will be contacted each month about the F.A.C.E.S. outing.
Implementation to Achieve Aims

Implementation of Easter Seals’ F.A.C.E.S. Program

One session of the F.A.C.E.S. program has been implemented so far at Easter Seals. The session consisted of a family training which took place on March 28th, 2009 from 10:00 – 11:30am at Easter Seals Therapeutic School and Center for Autism Research and a community outing to the University of Illinois at Chicago (UIC) Bowling Center on April 4th, 2009 from 2:15 – 4:00 pm.

The family training consisted of seven families (a total of 18 participants), three Easter Seals’ volunteers (two teacher’s aides and one teacher), and one program leader (occupational therapy intern) with two supervisors (two occupational therapists). All families were provided with a packet, modified for their child, containing an informational letter explaining evidence-based strategies and techniques used during the family training (see Appendix O), a social story (see Appendix R for an example of a social story for a higher functioning student), and a countdown to bowling (see Appendix S for an example of a countdown calendar for a higher functioning student). Three families were interested in attending the outing, but were unable to make it to the training; therefore, a packet was sent home with the student with a letter explaining the packet’s contents. The family training session consisted of the following schedule:

- **10:00 – 10:10 am** Waiting for families to arrive
- **10:10 – 10:20 am** Introductions/Explanation of Packet
- **10:20 – 10:35 am** Split into three groups, depending on functioning level, to review social stories (i.e., students requiring use of flip book social story,
modified social story, and higher level social story) and to further discuss use of materials in preparation for the outing.

10:35 – 10:55 am  “Bowling”: Students and families split into three groups to practice bowling sequence in the hallways. Families were shown visual bowling sequence, possible “break” choices (i.e., sensory toys, going for a walk, break card, wall pushups, etc.) while waiting for their turn, and students and siblings practiced appropriate bowling skills (i.e., stopping at a line to bowl, rolling the ball (hand over hand or modeling/demonstration when necessary), waiting their turn, and cheering for their friends who were bowling (i.e., giving high fives, saying “good job!”).

10:55 – 11:10 am  Parents/Caregivers completed surveys (see Appendices H and J) regarding satisfaction of family outings and knowledge of strategies to use with their student on community outings. Students and siblings went to the playground with volunteers so that parents/caregivers could complete surveys.

11:10 – 11:30 am  Answered questions and discussed Saturday bowling at UIC. Refreshments were provided for families and time was provided for families to interact with other families and volunteers.

The community outing at the UIC Bowling center consisted of 8 families (a total of 19 participants), 10 volunteers (one OT, four aides, one speech therapist, one behavior specialist, one administrator, and two teachers), and one director (OT intern) with two supervisors (two
The families and volunteers met at the school and carpoled over to UIC using Easter Seals’ vans driven by certified drivers (volunteers). All family members were invited to participate in bowling with the students. To encourage participation and provide support (if needed) approximately one volunteer worked/bowled with each student/family. Visual schedules and materials reviewed at the family training were available for families and volunteers to use during the outing.

**Plan for Full Implementation**

The F.A.C.E.S. program will consist of 10 sessions per year including one family training and one family community outing per session. One session will be held each month on either a Saturday or Sunday excluding the months of June – August which will include only one session due to summer break. Depending on school holidays and activities days/dates may vary month to month. During family training the student and his or her family will learn the skills necessary to interact successfully in a specific community outing. The training is in preparation for the family community outing which will take place on a Saturday or Sunday within one to two weeks of the training each month. Each session will need to be modified according to the students that are attending. At the conclusion of each outing families will be asked what community outing they would like to go on for the next session of the F.A.C.E.S. program so that the outing will be more meaningful to them. Based on the majority of responses for a specific outing and the availability of that outing, the next session will be planned. Examples of possible family training sessions are listed in the chart below. Families will be supported as needed (i.e., providing visual schedules, suggesting sensory/behavior strategies) by volunteers/director during the outing.
<table>
<thead>
<tr>
<th>Outing</th>
<th>Materials Needed</th>
<th>Family Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowling</td>
<td>Visual schedules, countdowns, and social stories modified for each student, bowling sets (3), surveys, information letter on strategies/techniques used to prepare for the outing, sensory toys, visual sequence for bowling, tape, refreshments, money for bowling shoes and one bowling game for each family member, Easter Seals’ vans to carpool to bowling alley</td>
<td>(See previous section: Implementation of Easter Seals’ F.A.C.E.S. Program)</td>
</tr>
<tr>
<td>Zoo</td>
<td>Visual schedules, countdowns, social stories modified for each student, movie about “going to the zoo”, safe/not safe pictures about going to the zoo, refreshments, Easter Seals’ vans to carpool to the zoo, information letter on strategies/techniques used to prepare for the outing</td>
<td>The following techniques/strategies could be used for this training: visual schedules, social stories, and a countdown to the day of the outing; video modeling (watching a movie about going to the zoo), teaching socially appropriate behaviors at the zoo using safe vs. not safe activity (i.e., based on each student’s level of functioning; may including modeling of safe/unsafe behaviors by volunteers, safety cards, etc.). Families will be given the materials (e.g., social story, etc.) and encouraged to review these strategies prior to the outing.</td>
</tr>
<tr>
<td>Movie Theater</td>
<td>Visual schedule, countdowns, and social stories modified for each student, short movie, chairs to set up like a movie theater, popcorn/pop to “sell”, movie tickets, money for real movie tickets, Easter Seals’ vans to carpool to the movie theater, information letter on strategies/techniques used to prepare for the outing</td>
<td>The following techniques/strategies could be used for this training: visual schedules, social stories, and a countdown to the day of the outing; teach concrete rules for socially appropriate behavior (e.g., depending on level of student, use pictures/words to make rules for going to the movies; have volunteers and/or students model good and bad behavior at the movies, students have to figure out if the behavior was good or bad); model appropriate behavior for attending a movie (i.e., set up room to resemble a movie theater, have someone taking tickets — students have to wait in line, have someone “selling” popcorn, watch a short movie with previews at the movie theater)</td>
</tr>
</tbody>
</table>
beginning, etc.). Families will be given the materials (e.g., social story, etc.) and encouraged to review these strategies prior to the outing.

| Restaurant | Visual schedule, countdowns, and social stories modified for each student, menus for the actual restaurant and menus for the family training, food for the families to “order” at the training, Easter Seals’ vans to carpool, information letter on strategies/techniques used to prepare for the outing | The following techniques/strategies could be used for this training: visual schedules, social stories, and a countdown to the day of the outing; teaching simple scripts for common situations (i.e., script for ordering food); teach concrete rules for socially appropriate behavior (e.g., depending on level of student, use pictures/words to make rules for going out to eat); model appropriate interactions at a restaurant (i.e., practice “going out to eat” during the training; set up the practice to be as realistic as possible). Families will be given the materials (e.g., social story, etc.) and encouraged to review these strategies prior to the outing |

The sessions will be led by an occupational therapist who will also be the director/coordinator of the program. Volunteers will also assist with the sessions. The volunteers will be Easter Seals’ employees (i.e., teachers, aides, speech therapists, behavioral therapists, occupational therapists, administration, etc.) and therefore will be familiar with the students. The student to volunteer ratio will be approximately 1-2 families per volunteer depending on each family’s needs.

At the conclusion of each family training session the parents/caregivers will receive a handout reviewing what was learned during the session along with any resources that were used for their child during the training sessions (e.g., social stories, visual schedules, etc.). The families will be asked to continue to practice the skills with their student so that he or she will be prepared for the community outing.
Justification of Implementation

The focus of the F.A.C.E.S. program was developed based on past research studies and needs assessments that have examined the needs of families with autism (see previous literature review and needs assessment). The development of the family training sessions and community outings were based on evidence-based research studies that identified beneficial strategies to use to teach social skills to children autism, strategies to use during community outings, and the Model of Human Occupation (Kielhofner, 2004).

One specific study by White, Keonig, and Schall (2007) reviewed past literature of group-based social skills training programs for school age children and adolescents with ASD. From this study they reported a list of “promising” strategies to use in group-based social skills training programs for individuals with ASD in order to increase social motivation, social initiation, social responding, skill generalization, and to decrease interfering behavior. Some of these strategies include (White, Keonig, & Schall, 2007, p. 1864) “foster self awareness and self-esteem”, “intersperse new skills with previously mastered skills”, “make social rules clear and concrete”, “model age appropriate initiation strategies”, “teach simple scripts for common situations”, “reinforce positive behavior”, “review socially appropriate and inappropriate behaviors of the participant as a group via video or audiotape segments”, “reinforce response attempts”, “use modeling and role-play to teach skills”, “orchestrate peer involvement”, “use multiple trainers and individuals with which to practice skills”, “provide opportunities to practice skills in safe, natural settings”, and “use time between sessions to practice skills”.

A study by Matson, Matson, and Rivet (2007) also reviewed past studies regarding social skills interventions for children with ASDs and found similar methods beneficial in teaching
social skills. The most common approaches found throughout the literature review were:
modeling and reinforcement with feedback given in regards to accuracy and appropriateness of
responses, peer mediated intervention in which a peer tutor or volunteer model or prompts
appropriate social behavior, reinforcement schedules and activities, and the use of scripts and
social stories.

The benefits of using social stories to teach skills to children with autism was also
reported in a study by Quimbach, Lincoln, Feinberg-Gizzo, Ingersoll, and Andrews (2009). A
total of 45 participants diagnosed with ASD completed this study. The authors compared direct
social stories, standard social stories, and a control story to identify the effectiveness of each
method. Overall both groups who received social stories improved their ability to generalize and
retain the learned skills. One other important finding was that the social stories were highly
correlated to the child’s verbal comprehension. The social stories used in this study did not
include pictures and did not prove to be beneficial to children with low verbal comprehension.

A study by Koegel & Bimbela (1996) found that parent training using the method of
pivotal response training (PRT) was beneficial in teaching children with autism. This method
emphasized teaching key pivotal behaviors and on increasing the child’s motivation to the task.
New tasks were interspersed with previously learned tasks and any attempt at a correct response
was rewarded. Not only did the children improve their skills based on this method, but parents
reported being happier, less stressed, and more engaged with their child.

Two other studies that were helpful in providing families with strategies to use out in the
offered practical strategies for parents/caregivers to use out in the community such as: using a
visual schedule, showing and discussing a plan for what will happen during the outing, telling the child exactly what you expect of him/her (e.g., simply telling your child to be good does not help; tell your child in a concrete way what “good” looks like), take reinforcers or “tools” you might need during the outing (i.e., visual clock, toys, white board and marker to write messages/pictures, sensory toys, etc.), provide info about your child that others might need to know in order to communicate with your child (i.e., not necessarily giving your life story, can simply say “please give my child extra time to respond”), and make sure to give yourself plenty of time during the outing. Harchik & Ladew (2008) also provided good suggestions for families to use while out in the community such as gradually exposing the child to an outing or situation if it seems like it is difficult for him or her, make photos of the outing so that the child can see what might happen during the outing, pretend play or act out the situation so that the child will be less intimidated and anxious, take along something comforting for the child, plan ahead for how to deal with difficult behaviors, and try to pick a time to go on the outing when it is less crowded. These authors also emphasize the fact that avoiding situations because they are difficult for the child will only make the situation worse. This may only reinforce the difficult behavior and will prevent the child from learning necessary social skills to interact within the community.

The Model of Human Occupation, as mentioned earlier, focuses on the person as a whole and is applicable across all ages, cultures, and disabilities. The model’s wide use with a variety of populations and its focus on engagement in occupations to produce and sustain health (Cole, 2005) indicates that MOHO would be appropriate and valuable to the development of the F.A.C.E.S. Program. Two other central concepts of occupational engagement in MOHO which are applied in the F.A.C.E.S. Program include (Kielhofner, 2004, p.156):
1. “For doing to be therapeutic, it must involve an actual occupational form, not a contrived activity.

2. For the client to achieve change through doing, what is done must have relevance and meaning to the client.”

Post-Modification Programming vs. Pre-Modification Programming

As mentioned in the introduction, the post-modification programming, the F.A.C.E.S. program, is different from the pre-modification programming in a few ways. Easter Seals’ F.A.C.E.S. program is an addition to the pre-modified occupational therapy program. It will provide participating students the opportunity to refine and generalize their functional independent living skills and leisure skills with their families in actual community settings. It will also provide family members of the students the opportunity to learn strategies to assist their family member with autism to successfully engage in the community. There is currently not a program at Easter Seals that provides the families with this specific opportunity. There are opportunities for the students to go out into the community to practice specific functional independent living skills, but not with the focus on family leisure occupations within the community. This program will provide the families the opportunity to learn and practice functional independent living skills within a supported setting with an occupational therapist(s) and Easter Seals’ volunteers (possibly including other speech therapists, behavior specialists, social workers, teachers, etc.) and then take those learned and refined skills out into the community with their families with the support of therapists and volunteers.

Documentation

Documentation will be gathered during and after each family community outing. After each community outing volunteers (Easter Seals’ employees) will be filling out a student
documentation sheet (See Appendix I) to document the number and types of prompts (i.e.,
gestural prompts, indirect verbal prompts, etc.) required of each student they were assigned. The
volunteers will also be asked to add any additional comments concerning any strengths and
difficulties the student had during the outing. This documentation will be kept with other
confidential progress notes at Easter Seals Therapeutic School and Center for Autism Research.

Implications for Budgeting and Personnel

Easter Seals’ Approval Process for Program Modification

In order for a program modification plan (that requires funding) to be implemented at
Easter Seals there must be a need for the program and evidence-based support to demonstrate the
need. A literature review along with a needs assessment completed by stakeholders of the
program must be completed to demonstrate this need. A summary of the possible budget of the
program must also be completed. This information is presented to administration for review.
Once approved by administration, the program information is turned over to the grant writer at
Easter Seals in order to receive funding for the program.

Staff/Volunteer Training Procedures

Each volunteer will attend the volunteer meeting prior to the family training or outing he or she will be assisting. During the volunteer meeting the volunteers will review the program goals and his or her role in the program. No training on working with individuals with autism will be necessary since the volunteers are all employees at Easter Seals (e.g., teachers, speech therapists, occupational therapists, behavior specialists, student aides, etc.) and familiar with the students. Prior to each family training session each volunteer will be required to discuss and/or
review the plan for the training or outing that he or she is volunteering for with the director of the program.

**Expected Revenue Generated & Financial Gain/Loss**

The F.A.C.E.S. program will not initially generate revenue for Easter Seals. The start of the program was a pilot program in order to evaluate the potential success of the program. Families were not asked to donate any money for the first session of the F.A.C.E.S. program. A fundraiser was held prior to the first session and covered the expenses of the bowling outing. Other resources were borrowed or donated by Easter Seals (i.e., copies and laminate to make materials, bowling sets, etc.). Inexpensive or discounted outings were also sought out and will continue to be in order to decrease the initial financial loss for Easter Seals. The estimated financial loss for Easter Seals is minimal to none.

After the F.A.C.E.S. program is determined to be a beneficial program for Easter Seals’ families and receives a grant to continue the program there should be no financial loss to Easter Seals. The plan will be to apply for a grant for the first year to cover all costs of the program, including personnel, to further demonstrate the effectiveness of the F.A.C.E.S. program. After the first year of programming the F.A.C.E.S. program will strive to be self-sufficient. In order to be self-sufficient the F.A.C.E.S. program can obtain sponsors, incorporate a fee for service, and/or hold fundraisers to cover costs. Any of these or a combination of these possibilities will be much more likely after the F.A.C.E.S. program has had a year to prove its benefits to families with autism.
New Personnel Credentials

A part-time registered and licensed occupational therapist will be needed to direct Easter Seals’ F.A.C.E.S. program. The occupational therapist must have a minimum of a Bachelor’s degree in occupational therapy, have experience working with individuals with autism, and experience in a leadership position. He or she will need to be available two Saturdays or Sundays per month and must dedicate up to 30 hours per month to this program. The job requirements will include supervising volunteers, coordinating and directing family training, coordinating and directing community outings, communicating with stakeholders of the program (i.e., students, employees, caregivers, and volunteers), documenting progress, and program evaluation. See Appendices P and Q for a detailed job description and a sample advertisement.

The procedure to recruit an occupational therapist for this position will be to post the job description internally. The reason for this is that someone already working at the school is already familiar with the students and families and would be the best fit for this position. If no one internally applies for the position, then the job will be posted on the Easter Seals website.

Budgeting and Staffing

Personnel Costs

<table>
<thead>
<tr>
<th>Personnel</th>
<th>Amount</th>
<th>Cost</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part-time licensed and registered occupational therapist</td>
<td>1</td>
<td>$11,400.00</td>
<td>A part-time occupational therapist will be needed to supervise and run the F.A.C.E.S. program. An occupational therapist is best fit for this position because OT is a profession that focuses on occupational participation which is the essence of this program. The salary was determined based on an average OT salary, $72,619.50, in Chicago, IL (<a href="http://www.salary.com">www.salary.com</a>) and calculated to determine an hourly rate</td>
</tr>
</tbody>
</table>
(approximately $38.00/hour). Based on the job requirements the OT will work approximately 30 hours a month for 10 months out of the year.

| Fringe benefits for part-time OTR/L | 1 | $2850.00 | The fringe benefits are calculated as 25% of the part-time OTR/L salary.

Personnel Total $14,250.00

**Family Training Costs**

<table>
<thead>
<tr>
<th>Items</th>
<th>Amount</th>
<th>Cost per item</th>
<th>Total Cost</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social stories</td>
<td>100</td>
<td>$.08</td>
<td>$8.00</td>
<td>Research has shown that social stories are beneficial social skills teaching tools for individuals with autism. In preparation for each outing each family will be given a social story for the outing. A maximum of 10 families will be participating in each outing. There will be a total of 10 outings each year. Each social story consists of 8-10 pages. Therefore a maximum of 1000 pages will need to be printed. Color copies cost $.08 per page at <a href="http://www.docucopies.com">www.docucopies.com</a>. Easter Seals will be reimbursed this amount for use of their colored printers.</td>
</tr>
<tr>
<td>Community outing newsletters</td>
<td>100</td>
<td>$.05</td>
<td>$5.00</td>
<td>In order to keep family members informed/reminded about what was learned at the training sessions a newsletter will be sent home with the families after the session. A maximum of 10 families will be participating in each outing. There will be a total of 10 outings per year. Each newsletter will be one page long. Therefore a maximum of 100 pages will need to be printed.</td>
</tr>
</tbody>
</table>
Black and white copies cost $.05 per page at [www.docucopies.com](http://www.docucopies.com). Easter Seals will be reimbursed this amount for use of their copier.

<table>
<thead>
<tr>
<th>Item</th>
<th>Quantity</th>
<th>Price</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Digital camera</td>
<td>1</td>
<td>$82.88</td>
<td>$82.88</td>
</tr>
<tr>
<td>Pictures</td>
<td>300</td>
<td>$0.19</td>
<td>$57.00</td>
</tr>
<tr>
<td>Video camera</td>
<td>1</td>
<td>$184.88</td>
<td>$184.88</td>
</tr>
<tr>
<td>DVD blank discs</td>
<td>1 pack</td>
<td>$13.93</td>
<td>$13.93</td>
</tr>
</tbody>
</table>

A digital camera will be needed to take pictures of the community settings that the families will be attending in order to prepare the participant for the outing. A Kodak EasyShare C813 digital camera costs $82.88 at [www.walmart.com](http://www.walmart.com).

Pictures will need to be printed out in order for the families to be able to visualize the community settings that they will be attending. Pictures will also be taken during the outings. Over the course of 10 outings it is estimated that a total of 30 pictures will be taken per outing. A total of 300 pictures may be taken over a year. Pictures can be printed off at [www.walmart.com](http://www.walmart.com) for $.19 per picture.

Video modeling has shown to have positive effects in teaching individuals with autism social skills. A video camera will be a useful tool for the F.A.C.E.S. Program in teaching the families social skills in for a specific outing. A Samsung SC-DX103 Black video camera can be purchased at [www.walmart.com](http://www.walmart.com) for $184.88.

DVD blank discs will be needed so that the families can watch the recorded outings. Since there will be 10 outings that the families
will go on we will need at most 10 blank DVDs. These can be purchased at [www.walmart.com](http://www.walmart.com) for $13.93 by Maxwell 50-Pack 16x DVD+R Spindle.

<table>
<thead>
<tr>
<th>Snacks/Refreshments</th>
<th>10</th>
<th>$30.00</th>
<th>$300</th>
</tr>
</thead>
</table>

Snacks and refreshments will be provided for families after each training session. A total of 10 families may be at each session with approximately 2-4 individuals per family. Therefore a total of 40 family members may be at each session and approximately 10 volunteers. For each session the following items will be needed: drinks, snacks, 50 paper plates, and 50 plastic cups. It is estimated that approximately $30.00 will be spent per session to purchase these items.

<table>
<thead>
<tr>
<th>Construction paper</th>
<th>2 packs</th>
<th>.79</th>
<th>$1.58</th>
</tr>
</thead>
<tbody>
<tr>
<td>Velcro</td>
<td>1 pack</td>
<td>$55.98</td>
<td>$55.98</td>
</tr>
</tbody>
</table>

Another beneficial strategy for individuals with autism to use on outings is a visual schedule. The visual schedule consists of a series of pictures that depicts events that will occur during the outing. The visual schedule is constructed of one piece of construction paper, 1-2 Velcro strips, and 5-6 pictures of events (generally half a page printed from a computer). A total of 100 visual schedules will need to be made (10 families times 10 outings). Therefore 100 pieces of construction paper will be needed, 200 Velcro strips, and 50 pages of printed pictures will be needed. Construction paper and Velcro can be purchased at [www.discountschoolsupply.com](http://www.discountschoolsupply.com) for $.79 per pack and $55.98 (25 packs).
yards of hook fasteners and 25 yards of loop fasteners) per pack. Colored pictures cost $.08 at [www.docucopies.com](http://www.docucopies.com).

| Total cost of family training sessions | $713.25 |

**Community Outing Costs**

<table>
<thead>
<tr>
<th>Items</th>
<th>Amount</th>
<th>Cost</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Outings</td>
<td>10</td>
<td>$450.00</td>
<td>The F.A.C.E.S. program will provide the opportunity for Easter Seals’ families to participate in community outings 10 times per year. If a maximum of 10 families participate in each outing with 2-4 individuals per family, a maximum of 40 family members may attend along with up to 10 volunteers; a total of 50 participants/volunteers may attend. A maximum of $5.00 per person per outing may be needed for outings. Additional costs will be covered by fundraisers.</td>
</tr>
</tbody>
</table>

| Total cost of community outings | $450.00 |

**Marketing Costs**

<table>
<thead>
<tr>
<th>Items</th>
<th>Amount</th>
<th>Cost</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>F.A.C.E.S. Program monthly letters</td>
<td>1020</td>
<td>$.05</td>
<td>Each month a letter will be sent home with each student regarding the upcoming community outing/training sessions. There are a total of 102 students therefore a total of 102 letters will be sent home for each of the 10 outings. A total of 1020 letters will be sent home per year. Each letter will be one page long. Black and white copies cost $.05 at <a href="http://www.docucopies.com">www.docucopies.com</a>.</td>
</tr>
</tbody>
</table>

| Total cost of                                           | $51.00 |
Total Direct Costs

<table>
<thead>
<tr>
<th>Personnel costs</th>
<th>$14,250.00</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family training session costs</td>
<td>$713.25</td>
</tr>
<tr>
<td>Community outing costs</td>
<td>$450.00</td>
</tr>
<tr>
<td>Marketing costs</td>
<td>$51.00</td>
</tr>
<tr>
<td><strong>Direct Costs</strong></td>
<td>$15,464.25</td>
</tr>
</tbody>
</table>

Indirect Costs

Easter Seals Therapeutic School and Center for Research will be reimbursed for use of the building. These costs will include heat, air conditioning, and electricity. Indirect costs will be 25% of the total of the direct costs.

Total Budget

<table>
<thead>
<tr>
<th>Total of direct costs</th>
<th>$15,464.25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total of indirect costs (25% of the total of the direct costs)</td>
<td>$3866.56</td>
</tr>
<tr>
<td>Direct and indirect costs</td>
<td>$19,330.81</td>
</tr>
</tbody>
</table>

In-Kind Support: Items and Personnel

<table>
<thead>
<tr>
<th>Items</th>
<th>Amount</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Space for Saturday training sessions</td>
<td>1-2 rooms</td>
<td>The training sessions will be held in the Easter Seals Therapeutic School and Center for Research.</td>
</tr>
<tr>
<td>Volunteers from Easter Seals</td>
<td>200</td>
<td>Employees who work at the Easter Seals will be asked to volunteer their time during Saturday or Sunday training sessions and</td>
</tr>
</tbody>
</table>
during community outings. There will be a total of 10 training sessions and 10 community outings. A total of 10 volunteers (this will vary depending on the total number of participants) will be asked to assist with the sessions. A total of 200 volunteers will be needed over the year.

<table>
<thead>
<tr>
<th>Item</th>
<th>Quantity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Television</td>
<td>1</td>
<td>One television will be needed during the training session for the families to watch the video modeling of the community outing.</td>
</tr>
<tr>
<td>DVD player</td>
<td>1</td>
<td>One DVD player will be needed to play the video of the community outing.</td>
</tr>
<tr>
<td>Miscellaneous items needed to prepare for outing (i.e., bowling set, table/chairs to set up a “restaurant”, etc.)</td>
<td>Varies</td>
<td>The family training sessions will need specific items to prepare for each outing. These items can be borrowed from Easter Seals. For example, for the bowling outing we needed three bowling sets to practice bowling sequences for the outing. We were able to borrow these from Easter Seals rather than buy new ones.</td>
</tr>
</tbody>
</table>

Program Modification Evaluation

Outcome Evaluation Procedures

The following outcome evaluation procedures will continue to be followed as part of Easter Seals’ occupational therapy program:

1. Increase independence with activities of daily living as demonstrated by achievement of quarterly benchmarks and annual goals as written by the occupational therapist and/or educational team.
   a. Students with OT scripts have goals (as needed) related to increasing independence with activities of daily living that are measured by individualized quarterly benchmarks and annual goals. Occupational therapists measure progress towards these benchmarks/goals with daily
progress notes, observations, and discussions with teachers, parents, and others who work with that specific student. Meeting a quarterly benchmark(s) indicates that the student is making progress towards his or her annual goal(s).

2. Contribute to educational and vocational development through direct and/or consultative services addressing goals targeting fine motor, visual motor, visual perceptual, gross motor, and/or sensory processing skills with progressed measured via quarterly benchmarks and annual goals.
   a. Students with OT scripts have goals (as needed) addressing fine motor, visual motor, visual perceptual, gross motor, and/or sensory processing skills that are measured by individualized quarterly benchmarks and annual goals. Occupational therapists measure progress towards these benchmarks/goals with daily progress notes, observations, and discussions with teachers, parents, and others who work with that specific student. Meeting a quarterly benchmark(s) indicates that the student is making progress towards his or her annual goal(s).

The following outcome evaluation procedures will be followed based on the F.A.C.E.S. program (program modification):

1. Students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will demonstrate increased functional independent living skills and leisure skills within the community by requiring a reduced number of prompts (specific for each participant; see Appendix I) from the first community outing to the completion of the fourth community outing.
a. The students’ gains in functional independent living skills (specifically social interaction) and leisure participation will be measured by volunteers assigned to each student/family using the documentation sheet mentioned above (see Appendix I) after each community outing. Volunteers will be notified prior to the documentation regarding what skills they should be looking for during the outing. A decrease in scores from the first outing to the fourth outing will demonstrate improvement in functional independent living skills and leisure skills.

2. Students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will demonstrate increased functional independent living skills and leisure skills within the community by requiring a reduced number of prompts (specific for each student; see Appendix I) from fourth community outing to completion of eighth community outing.

   a. The students’ gains in functional independent living skills (specifically social interaction) and leisure participation will be measured by volunteers assigned to each student/family using the documentation sheet mentioned above (see Appendix I) after each community outing. Volunteers will be notified prior to the documentation regarding what skills they should be looking for during the outing. A decrease in scores from the fourth outing to the eighth outing will demonstrate that the student has continued to improve his or her functional independent living skills and leisure skills.

3. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased satisfaction in family leisure
occupations by increasing their score in the Satisfaction of Family Outings Survey (see Appendix J) from initial family meeting to completion of four community outings.

a. Families will complete the Satisfaction of Family Outing Survey during the initial family meeting and again after completing four community outings. This initial score will provide a baseline for overall satisfaction of participating in family outings. An increase in scores from the initial meeting to the completion of four community outings will demonstrate that the program has been successful in increasing family satisfaction in community outings.

4. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased satisfaction in family leisure occupations by increasing their score in the Satisfaction of Family Outings Survey (see Appendix J) from completion of four community outings to completion of eight community outings.

a. Families will complete the Satisfaction of Family Outing Survey again after the fourth and eighth outing. An increase in scores from the completion of four community outings to eight community outings will demonstrate that the program has continued to be successful in increasing family satisfaction in community outings.

5. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased knowledge of strategies to assist his or family member within the community by an increased score in the Strategies to Assist my Family Member with Autism within the Community Survey (see Appendix K) from the initial family meeting to completion four community outings.
a. Families will complete the Strategies to Assist my Family Member with Autism within the Community Survey during the initial family meeting and again after completing four community outings. This initial score will provide a baseline for overall satisfaction of knowledge in helping his or her family member with autism within the community. An increase in scores from the initial meeting to the completion of four community outings will demonstrate that the program has been successful in increasing the families’ knowledge of strategies to assist his or her family member with autism within the community.

6. Families of students of Easter Seals Therapeutic School and Center for Autism Research participating in the F.A.C.E.S. program will report increased knowledge of strategies to assist his or family member within the community by an increased score in the Strategies to Assist my Family Member with Autism within the Community Survey (see Appendix K) from completion of four community outings to completion of eight community outings.

   a. Families will complete the Strategies to Assist my Family Member with Autism within the Community Survey again after the fourth and eighth outing. An increase in scores from the completion of four community outings to eight community outings will demonstrate that the program has continued to be successful in increasing the families’ knowledge of strategies to assist his or her family member with autism within the community.

Stakeholders to Evaluate Program Modification Aims/Process Evaluation

As mentioned previously, the aims (measurable changes) of the program modification plan are to provide an optional family program to supplement the already existing occupational
therapy program at Easter Seals and to hire an additional occupational therapist to direct the program. The aim to provide an optional family program to supplement the OT program will be evaluated by parents/family members, students, staff, and administration of Easter Seals. These stakeholders will determine the direction of the program as well as the success of the program. The program will continually be reevaluated so that it is meaningful and purposeful to Easter Seals’ families and employees.

The second program modification aim (hiring an additional OT) will be evaluated by the clinical coordinator of Easter Seals, Betsey White, OTR/L and administration. After determining that the F.A.C.E.S. program fulfills a need for families at Easter Seals and the occupational therapy program at Easter Seals a grant may be written so that hiring an additional OT would be possible. The position would first be offered internally since the program would be more successful if it was given to someone who already knew the students and the families.

Formative Evaluation Procedures

Throughout the program there will be a number of formative evaluators to assess Easter Seals’ F.A.C.E.S. program. One way that the program will be evaluated will be through observations and informal conversations during family training sessions and community outings with families and volunteers. Another way that the program will be evaluated will be through an evaluation form that the volunteers and parents/caregivers will complete after the fourth community outing and again after the eighth community outing. This evaluation form will include statements related to their experience with the program, perceived benefits, the effectiveness of the program, and any suggestions or comments that they might have. Also, after each community outing each parent/caregiver will receive a survey to report how well they felt
the family training/community outing went for that particular session (see Appendix T). Based on the families comments and suggestions the next family training/outing session of F.A.C.E.S. will be planned. A final evaluator will involve an informal meeting with the volunteers after the fourth community outing and again after the eighth community outing to discuss the program and make adjustments as needed.

*Summative Evaluation*

Each student participant will be evaluated using a student documentation sheet recording the types and numbers of prompts required for social skills and leisure skills (see Appendix I) during each community outing. Documentation results will be evaluated every four months to determine whether or not a reduced number of prompts were required for each student participant. A reduced number of required prompts will indicate that the families and students are learning to interact more successfully during community outings.

Another way the program will be evaluated will be through survey scores on the satisfaction of family community outings and knowledge of strategies to use within the community with their family member with autism (see Appendices J and K). The families completed the surveys prior to their first community outing to get a baseline. After four months of participating in the program and again after eight months of participating in the program, families will complete the survey again. An increase in scores will indicate that the F.A.C.E.S. program has had a positive effect on the participating families’ satisfaction with family outings and knowledge of strategies to use with their child within the community.
Program Evaluation Results

During the first family training session the parents/caregivers completed the Satisfaction of Family Outings \((n = 9)\) and Strategies to Assist my Family Member with Autism within the Community surveys \((n = 9)\) (see Appendices H and I). The following questions had the two lowest average scores among the two surveys:

- I am happy with the amount of time my family spends together outside of the house.
- I feel satisfied with the number of strategies I know to help my family member with autism participate successfully within his or her community.

The results (see Appendices V and W for complete results) will be used as a baseline to judge whether or not families have improved in these areas of satisfaction and knowledge of strategies after participating in four F.A.C.E.S. sessions. Since surveys were completed anonymously and different families may be attending the outings at different times, the families will be asked to indicate on future surveys the number of sessions they have completed so that results will be accurate.

During the outing, volunteers were asked to complete the Student Documentation (see Appendix I) sheet to indicate the number and types of prompts that the student(s) they were working with needed during the outing. Since the volunteers were busy during the actual outing, they were told prior to the outing about the documentation and asked to stay a few minutes after the families left to complete the papers. If the volunteers needed to leave right away they were told they could take the paper home and return it the following Monday. This did not turn out well. Only one out of nine surveys was returned. It may work better if the importance of the surveys was stressed during the initial volunteer recruitment and more reminders were given to the volunteers during the outing.
Another survey, Parent/Caregiver Survey of First F.A.C.E.S. program, was completed by parents/caregivers following the community outing (see Appendix T). The survey basically asked the parents/caregivers for their input on how the program went, how beneficial it was to their family, and whether or not they had any suggestions for future sessions. The surveys were completed by 5/9 families. The results (see Appendix U) indicated that the families found the program successful and would like the program to continue.

A final way that the program was evaluated during the family training and community outing was through observations and informal discussions with volunteers, parents/caregivers, students, and supervisors. A number of parents questioned what the next program/outing would be during both the family training and the community outing. A few parents also mentioned that they would like to help out with the F.A.C.E.S. program to make sure that it continues. One parent reported that she felt like her family felt much more relaxed at the bowling outing being with other families and with volunteers who could help. The students and families also appeared to be enjoying themselves and many were enthusiastically participating in both the family training and bowling outing.
# Easter Seals’ F.A.C.E.S. Program Timeline

NA = Needs Assessment  
FT = Family Training  
CO = Community Outing  
PE = Program Evaluation

<table>
<thead>
<tr>
<th>Month</th>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb 2009</td>
<td>Complete NA</td>
<td>Review results of NA</td>
<td>Prepare for FT1 and CO1</td>
<td>Family Meeting</td>
</tr>
<tr>
<td>March 2009</td>
<td>Send home letter about CO1 to families</td>
<td>Volunteer Meeting</td>
<td>Prepare for FT1 and CO1</td>
<td>FT1</td>
</tr>
<tr>
<td>April 2009</td>
<td>CO1: Bowling; Student Documentation</td>
<td>Send home Parent/Caregiver Surveys</td>
<td>Easter Seals Spring Break</td>
<td>Prepare for FT2 and CO2</td>
</tr>
<tr>
<td>May 2009</td>
<td>Send home letter about CO2 to families</td>
<td>Volunteer Meeting</td>
<td>FT2</td>
<td>CO2; Student Documentation</td>
</tr>
<tr>
<td>June – Aug 2009 (summer session)</td>
<td>Send home letter about CO3 to families</td>
<td>Volunteer Meeting</td>
<td>FT3</td>
<td>CO3; Student Documentation</td>
</tr>
<tr>
<td>Sept 2009</td>
<td>Send home letter about CO4 to families</td>
<td>Volunteer Meeting</td>
<td>FT4</td>
<td>CO4; Student Documentation</td>
</tr>
<tr>
<td>Oct 2009</td>
<td>Send home letter about CO5 to families; Send home PE surveys</td>
<td>Volunteer Meeting</td>
<td>FT5</td>
<td>CO5; Student Documentation</td>
</tr>
<tr>
<td>Nov 2009</td>
<td>Send home letter about CO6 to families</td>
<td>Volunteer Meeting</td>
<td>FT6</td>
<td>CO6; Student Documentation</td>
</tr>
<tr>
<td>Dec 2009</td>
<td>Send home letter about CO7 to families</td>
<td>Volunteer Meeting</td>
<td>FT7</td>
<td>CO7; Student Documentation</td>
</tr>
<tr>
<td>Jan 2010</td>
<td>Send home letter about CO8 to families</td>
<td>Volunteer Meeting</td>
<td>FT8</td>
<td>CO8; Student Documentation</td>
</tr>
<tr>
<td>Feb 2010</td>
<td>Send home letter about CO9 to families; Send home PE surveys</td>
<td>Volunteer Meeting</td>
<td>FT9</td>
<td>CO9; Student Documentation</td>
</tr>
<tr>
<td>March 2010</td>
<td>Send home letter about CO10 to families</td>
<td>Volunteer Meeting</td>
<td>FT10</td>
<td>CO10;</td>
</tr>
</tbody>
</table>

*Informal evaluations will be completed during each community outing through discussions with caregivers, volunteers, siblings, and students.
Annotated Bibliography


The aim of this study was to describe the present and past experiences of 14 siblings from five families in terms of having a brother or sister with autism and mental retardation. Personal interviews were conducted with the siblings before their brothers or sisters were moved to a newly opened group home. Qualitative content analysis was used for the analysis of the transcribed texts. The analysis resulted in seven content categories: precocious responsibility, feeling sorry, exposed to frightening behavior, empathetic feelings, hoping that a group home will be a relief, physical violence made siblings feel unsafe and anxious, and relations with friends were affected negatively. The conclusion is that these siblings’ experience revealed stressful life conditions. Counseling for the family and for siblings is recommended to help them deal with their feelings and problems for the siblings in these five families, a group home was a relevant alternative as a temporary or permanent placement for the child with autism and mental retardation.

Fourteen siblings of five children with autism were interviewed to determine their experiences of having a brother or sister with autism. The following themes were found: “Having a sense of precocious responsibility, feeling sorry for the brother or sister with autism, being exposed to frightening abnormal behavior, having empathetic feelings for the child with autism, hoping that the group home will be a relief for the family, physical violence in the family made siblings feel unsafe and anxious at home, and having a brother or sister with autism affects relationships with friends.” The authors noted that it was important that siblings were able to feel free to express their feelings to parents and others and that a peer group for siblings could be a helpful support.


Parents of children with autistic spectrum disorders (ASDs) are more likely to experience serious psychological distress than parents of children with other developmental disabilities. To examine the impact of a range of factors on psychological wellbeing, interviews were undertaken with 68 mothers of children with ASDs to explore aspects of social support, mental health status, and satisfaction with services. Findings indicated that over half of mothers screened positive for significant psychological distress and that this was associated with low levels of family support and with bringing up a child with higher levels of challenging behavior. Mothers were more likely to report lower levels of support if they were a lone parent, were living in poor housing, or were the mother of a boy with ASD. The study also investigated areas of useful support and areas of unmet need, the latter including care breaks and advice needs.

Before reading this article I thought it could be helpful in understanding the needs of mothers who have children with autism, but after reading it I didn’t find it very useful. I didn’t end up using it for my needs assessment or literature review. The authors ran a large number of correlations but they were somewhat unclear as to what they were really getting at (e.g., the
authors found that greater levels of unmet needs were reported by parents whose house was considered more unsuitable). The discussion did not help to clarify these correlations and their meanings.


No Abstract.

This article was valuable in reporting the prevalence, symptoms, available services, and definitions of autism. In order to show a need for programming for individuals with autism it is necessary to explain the disorder with accurate information. The Centers for Disease Control is a government website that should have the most accurate and up to date information on these topics.


One of the most prevailing characteristics of children with autism is their deficit in social communication skills. The purpose of this study was to evaluate the effectiveness of a peer-mediated social skills training (SST) program combined with video feedback, positive reinforcement and token system in increasing social communication skills in young children and high-functioning autism. Four boys with high-functioning autism, ages 6-7 years, participated in the study. The social skills training, lasting 12 weeks, targeted six communication skills, selected after parent interviews and behavioral observation during a pre-training assessment period. One SST session was conducted each week, each session lasted 90 min and had six structured activities. The training effectiveness was evaluated through direct observation of a structured interaction period, using an observational coding system. Improvement was observed in three out of four children, although individual differences among children were seen for changes in two global scales as well as subscales. These results suggest that the social skills training were effective in improving social communication skills for some children with high-functioning autism. Clinical and research implications and future directions for social skills training as well as this study’s limitations are discussed.

This study is important in addressing the need for social skills programming for individuals with ASD. It examined the benefits of a 12 week social skills training program for four boys ages 6 to 7 diagnosed with ASD. The results concluded from a pre and posttest that intervention involving peer-mediated social skills training (e.g., structured group teaching, role-play, feedback, contingent reinforcement, and participation of typically developing peers) along with video feedback had a positive impact on the four participants although each area of social improvement
was unique to the individual. The author reports that future research in social skills training for individuals with ASD is needed.


This book was helpful in providing tips to teaching social skills. For example to teach social skills the authors suggest the following: explain everything, give concrete examples and cues, use checklists, use role playing or videos to show interactions, practice over and over, do not expect sudden changes, don’t talk in absolutes, and use multiple techniques in multiple environments. The authors also reported the system of least restrictive prompts. The following prompts are in order of most restrictive to least restrictive: hand over hand, direct verbal cue, indirect verbal cue, gestural prompts, and independent.


No abstract.

This book gave me a different perspective of understanding what it must be like to have autism. One quote that I especially liked and felt captured autism was the “experience of being alone in a strange country with little understanding of the local language and customs – every day of your life” (p., 25). It made me really think about the actions of individuals with autism. That if we can think of things from their perspective we might just understand, a little anyways. The author also gave some useful tips about preparing for change or for outings in to the community. She suggested that it is easier for individuals with autism to accept change if what remains the same is explicitly pointed out to him or her; that preparation for change should be as concrete as possible; and preparing for what to do if plans change to decrease anxiety. It was a very interesting book written from the perspective of a parent/professional.


No abstract. This book provided useful examples of behavior strategies, teaching social rules, social skills training, and crisis management. Some examples that the authors provided to teach social rules included: presenting rules in a very clear and concrete manner, presenting rules in a visual manner, use a highly structured, systematic approach, providing many opportunities for practice, building social rules into the person’s daily routines and rituals, and allowing for literal interpretation of language. The authors also provided numerous social skills training techniques: using direct instruction to teach social skills, modeling appropriate skills, matching skills to situations, practice in real life situations that are meaningful and functional with guidance and
feedback provided as needed, increasing opportunities for practice, videotape appropriate social
skills, avoiding too many verbal and physical prompts, etc.

community outings. The Exceptional Parent, 38, 75-77.

No Abstract. This article was helpful in giving parents tips to use when taking their child with
special needs out into the community. The authors remind the reader that avoiding taking a child
out in the community because of difficult behaviors is often reinforcing the poor behaviors and
preventing the child from learning the necessary skills to interact within the community. Some
tips the authors suggest include: desensitization (gradually exposing the child to a situation or
setting that is difficult for him or her), make photos of the event so that the child has an idea
about what will happen during the outing, pretend play or act out the situation or setting so that
once the child experiences it in real life it may not be so intimidating, take something comforting
for the child/reinforcers, plan ahead for dealing with behaviors, set a time limit for the outing,
and pick a time to go on the outing when it is less crowded.

coping strategies of families with a child with autism spectrum disorder, Autism, 9, 125 –
37.

A survey of parents/caregivers of a child with an autism spectrum disorder (ASD) was conducted
to examine the relationship between ASD characteristics, family functioning and coping
strategies. Having a child with ASD places considerable stress on the family. Primary caregivers
of a child with ASD from a regional and rural area in Victoria Australia (N = 53) were surveyed
cconcerning their child with ASD, family functioning (adaptability and cohesion), marital
satisfaction, self-esteem, and coping strategies. Results suggest that these caregivers had healthy
self-esteem although they reported somewhat lower marital happiness, family cohesion, and
family adaptability than norm groups. Coping strategies were not significant predictors of these
outcome variables. Results highlight the need for support programs to target family and
relationship variables as well as ASD children and their behaviors, in order to sustain the family
unit and improve quality of life for parents and caregivers as well as those children.

I used this article in my literature review to demonstrate the unmet needs of families with autism.
The study included 52 participants who were caregivers of children with autism. A total of 134
surveys were sent out to caregivers (with only 52 returned completed) that measured general
demographic characteristics and behavior characteristics of children with ASD, support services
available for children with ASD and their families, family functioning using the Family
Adaptability and Cohesion Evaluation Scale (FACES II), marital quality and marital happiness
using the Quality Marriage Index (QMI), self-esteem using Rosenberg Self-Esteem Scale, and
coping strategies using the Coping Health Inventory for Patients (CHIP). The results from this
study concluded that the means of marital happiness (mean = 6.1), family adaptability (mean =
46.4), and family cohesion (59.2) were all lower than the norm group means (7.7, 49.9, and 64.9,
respectively). The authors reported 41% of the caregivers experienced physical, emotional,
financial, or marital relationship stress, 25% described a negative effect on family life, and 22%
reported that family, friends, teachers, and the community typically did not understand the 
behavioral characteristics of ASD.

Autism and Developmental Disorders, 11*, 399 – 410

This study investigated sibling relationships of children with autism compared to children with 
Down syndrome and siblings of normally developing children. Ninety siblings (30 per group) 
between the ages of 8 and 18 participated in this study. Results indicated that sibling 
relationships in families of children with autism were characterized by less intimacy, prosocial 
behavior, and nurturance than those of the two comparison groups. Both siblings of children with 
autism and siblings of children with Down syndrome reported greater admiration of their sibling 
and less quarreling and competition in their relationships relative to normally developing 
comparison children.

This study was helpful in understanding relationships of 30 siblings of children with autism. The 
following results were found: siblings of children with autism may be less likely to report high 
levels of behavior, intimacy, and nurturance by their sibling; siblings did not report greater 
parental partiality towards their sibling with autism; and, siblings reportedly were less 
competitive and argued less than siblings with normally developing siblings.


Social interaction and understanding in autistic spectrum disorder (ASD) are key areas of 
concern to practitioners and researchers alike. However, there is a relative lack of information 
about the skills and competencies of children and young people with ASD who access ordinary 
community facilities including mainstream education. In particular, contributions by parents and 
their children have been under-utilized. Using two structured questionnaires, 19 children with 
ASD reported difficulties with social skills including social engagement and temper management 
and also reported difficulties with social competence, affecting both friendships and peer 
relationships. Parents rated the children’s social skill and competence as significantly worse than 
did the children themselves, but there was considerable agreement about the areas that were 
problematic. Using an informal measure to highlight their children’s difficulties, parents raised 
issues relating to conversation skills, social emotional reciprocity and peer relationships. The 
implications for assessment and intervention are discussed.

This study is significant in addressing the perception of social skills and social competence of 
individuals with ASD by the participant and his or her parent. Standardized assessments were 
used to compare parent report and participant report of social skills and social competence of 19 
participants (17 males with a mean age of 11 years 11 months and 2 females with a mean age of 
14 years 2 months) diagnosed with ASD, Asperger syndrome, high-functioning autism, or 
atypical autism. The results concluded that parents’ reports were statistically significantly lower
than participant reports of social skills and social competence. The results also concluded that in both social skills and social competence parents and participants scores were at least one standard deviation below typically developing young people ages 8 – 18. These results are important to the study of social skills of individuals with ASD because they demonstrate that individuals with ASD are aware of their areas of weakness in social skills, but they may not have completely accurate perceptions of their abilities (due to the differences of parent and participant scores).


Recent research suggests that using naturalistic teaching paradigms leads to therapeutic gains in clinic settings for children with autism and related disorders. More recent studies are demonstrating that implementing these strategies within a parent training format may produce collateral effects in other areas of family life. The present experiment assessed collateral effects of two very different parent training paradigms during unstructured dinnertime interactions in the family setting. One paradigm focused on teaching individual target behaviors (ITB) serially, and the other focused on a recently developed naturalistic paradigm that teaches the pivotal responses (PRT) of motivation and responsivity to multiple cues. Two groups of families were randomly assigned to each of the parent training conditions. Pre training and post-parent-training videotapes of dinnertime interactions were scored in a random order across four interactional scales (level of happiness, interest, stress, and style of communication). Results obtained for the four interactional scales showed that the families in both conditions initially scored in the neutral range, and the ITB training paradigm produced no significant influence on the interactions from pre training to post training. In contrast, however the PRT parent training paradigm resulted in the families showing positive interactions on all four scales, with the parent-child interactions rated as happier, the parents more interested in the interaction, the interaction less stressful, and the communication style as more positive.

This study involved 17 children with autism and their families. This study focused on examining parent training using two different methods: pivotal response training (PRT) and individual target behaviors (ITB). ITB taught the parent to provide treatment by selecting a skill to be taught and the stimuli to be used. The parent was then taught to present a series of discrete trials to the child, present clear instructions, select functional reinforcers, present reinforcers only when the child performed a correct response, and use principles of behavior shaping and prompting when the child did not initially provide a correct response. The PRT method followed similar procedures; however, the emphasis was on key pivotal behaviors and on increasing the child’s motivation and responsivity to multiple cues. The children had a choice in which teaching materials were used, were taught new tasks interspersed with previously learned tasks, and were rewarded for attempts to respond correctly rather than just for correct responses. The results demonstrated that both groups reported neutral parent-child interactions prior to treatment, but after treatment only the PRT group had a significant impact on the parent-child interaction. The
PRT group of parents reported being happier, more interested, lower levels of stress, and more engaged in communication/interaction with their child.


A social skills group intervention was developed and evaluated for young children with autism. Twenty-five 4- to 6-year-old (diagnosed) children were assigned to one of two kinds of social skills groups: the direct teaching group or the play activities group. The direct teaching group used a video modeling format to teach play and social skills over the course of the intervention, while the play activities group engaged in unstructured play during the sessions. Groups met for 5 weeks, three times per week, 1 h each time. Data were derived and coded from videotapes of pre- and post-treatment unstructured play sessions. Findings indicated that while members of both groups increased pro-social behaviors, the direct teaching group made more gains in social skills.

This study examined the effectiveness of video modeling when teaching social skills to young children with autism. The authors separated the children (n = 25) into two groups. Both groups followed a similar structured schedule throughout the group time; however, when the control group had supervised free time the other group received video modeling instruction followed by prompting to generalize the skills learned from the modeling. The video modeling tapes were performed by two young boys to teach simple and complex motor imitation, parallel play, ball play, taking turns, seeking play partners, partner pretend play, and appropriate use of play stations. The results showed that both groups benefited from the play groups. Both had improved social behaviors and improved learned readiness and group orienting behaviors from pre to post tests. The direct model group had significantly more gains in social skills (i.e., initiating behaviors, responding behaviors, and interacting behaviors) than the control group.


No abstract.

This article was one of my favorites even though it was only a page long. I felt like it offered very concrete examples for parents to use when they are taking their child with autism out into the community. She not only explains what could be used but why these tools or strategies will be useful. The author explains that children with autism need experiences outside of the home to learn and gain skills they will need in order to participate in this social world. Some of her suggestions included: using a visual schedule, showing and discussing a “game plan” before leaving home (i.e., using social stories, explaining what might happen), show exactly what you expect of your child (i.e., help your child understand what being “good” looks like; make a checklist, use a social script, role play), pack the “tools of the trade” (i.e., visual clock, small quiet toys, white board and marker to write messages/pictures, sensory toys, etc), provide info about your child that others will need in order to serve your child (i.e., doesn’t mean you need to
give your life story, just a simple “please give my child extra time to respond” might work), and give yourself plenty of time.


This paper presents findings from the final two years of a four-year study investigating a manualized social treatment program for high-functioning children with autism spectrum disorders. The study sought to (1) replicate and expand findings from years one and two; (2) compare outcomes of participants who received response-cost feedback versus non-categorical feedback; and (3) provide further evidence of program feasibility. Results indicated significant improvements in social skills and problem behaviors, however no significant differences for face emotion recognition. Measures of several socially-related behaviors yielded mixed results based on rater. While parent ratings did not appear to favor one feedback format, staff ratings appeared to favor the response-cost format on some measures. Results also provided support for program feasibility.

I found this study very interesting. This study included 54 children ages 6-13 diagnosed with high functioning autism, autism, or pervasive developmental disorder. The children took part in a social skills group program that lasted 6 weeks, 5 days/week, and 6 hours/day. Each of the children were in groups of 6 during the social skills treatment and participated in these sessions four times a day. The sessions consisted of a 20 minute structured social skills group and then ended with a 50 minute therapeutic activity to practice the social skills that were previously taught to them. The staff used the skillstreaming program to teach the social skills. This involved the following steps:

1. Define skill
2. Model skill
3. Establish trainee skill need
4. Select role-player
5. Set up role play
6. Conduct role play
7. Provide performance feedback
8. Assign skill homework
9. Select next role-player

All groups were structured the same way; however, the groups differed in the types of feedback they received. One group received response-cost feedback (RC) in which they received specific feedback along with a predetermined number of points for the social skill they demonstrated. If the student demonstrated a rule violation of a learned social skill then points could also be taken away. The points were added up at the end of the day to receive an edible reinforce and at the end of the week in order to participate in a field trip. The other group also received feedback however there was not a point system. Snacks and fieldtrips were awarded regardless. The results found significant social improvements and adaptive
behaviors in both groups regardless of the types of feedback. The group that received RC feedback demonstrated a greater positive impact on atypicality ratings.


Autism in children has increased significantly in the past 15 years. The challenges and stressors associated with providing services and caring for a child with autism affects families, educators, and health professionals. This descriptive study used a survey to collect data on parents’ perceptions of coping strategies and social support. Instruments included the Social Support Index and the Family Crisis Oriented Personal Evaluation Scales. One half of the families identified serious stressors in addition to autism. Acquiring social support and reframing were the most frequently used coping strategies. The school nurse is in a position to identify needs and refer families to local support groups and agencies, facilitating social support and development of coping strategies.

This study involved 18 families who had a child with autism. The focus of this study was to assess coping and social supports used by these families. The study found that in regards to acquiring social support, families with autism were similar to the norm. Families with autism were higher than the norm group when examining reframing (how families perceive a stressful event), ability to seek out community resources, and in passive appraisal (using avoidance or passivity as a coping strategy). Families with autism were lower than the norm group in seeking spiritual support. This study was useful in understanding the coping strategies and supports used by families with autism.


Background. Difficulties with social interaction and understanding lie at the heart of the communication disorder that characterizes the autism spectrum. This study sought to improve social communication for individuals with autism spectrum disorder (ASD) by means of a group work intervention focusing on social and emotional perspective-taking, conversation skills, and friendship skills. It also aimed to address some of the limitations of previous interventions, including a lack of generalization to other settings, so as to maximize inclusion in the community. Method. A group of 46 high functioning children and adolescents with ASD (38 boys, 8 girls, and age range 6–16 years) were allocated to one of 6 intervention groups. Each group met over a period of 12–16 weeks for a minimum of one 1K-hour weekly session aimed at promoting key areas of social interaction and understanding, supported by home-based practice. Results Significant gains were achieved in comparison with a normative population, and individual parent ratings showed marked and sustained changes in the key areas targeted in the group sessions. Conclusion. Social communication in children and adolescents with ASD can be enhanced through the use of a groupwork intervention addressing social interaction and understanding.

This study developed a social skills group program for individuals, ages 6-12, with high functioning autism. The children were separated into six groups of 7-8 individuals for a 12-16 week period. The three major themes focused on within the groups were social and emotional
perspective-taking, conversation skills, and friendship skills. The children were also give
opportunities to practice these skills outside of the group setting in order to generalize the skills
within the community and within their home. The results demonstrated that there were
significant increases from pre- to post-test scores of the four social skills questionnaires. Out of
30 parents who completed the follow-up interview, 28 found the group intervention helpful, and
two found no change in their child, however still reported being glad to have had their child
participate. This idea of learning skills in a supported environment and then taking the skills out
into the community to generalize the skills was used in developing my program for Easter Seals.


This book gave examples of how to prepare for specific outings. Not all of the examples applied
to the type of program being planned at Easter Seals, but one specifically was helpful. The type
of outing was a restaurant. The authors gave some of the following examples for how to prepare
for a restaurant outing: asking students to compare the differences between eating at home versus
eating at a restaurant, showing a video of people modeling appropriate skills, use a social story
with pictures from the actual restaurant, use menus from the actual restaurant, and use a picture
schedule to practice a simulated outing.


Marked advances in the treatment of children with autism spectrum disorders (ASDs) has
occurred in the past few decades, primarily using applied behavior analysis. However, reviews of
trends in social skills treatment for children with ASDs have been scant, despite a robust and
growing empirical literature on the topic. In this selective review of 79 treatment studies, the
authors note that the research has been particularly marked by fragmented development, using a
range of intervention approaches and definitions of the construct. Modeling and reinforcement
treatments have been the most popular model from the outset, with most studies conducted in
school settings by teachers or psychologists. Investigators have been particularly attentive to
issues of generalization and follow-up. However, large-scale group studies and comparisons of
different training strategies are almost nonexistent. These trends and their implications for future
research aimed at filling gaps in the existing literature are discussed.

This study is valuable because it reviewed past studies regarding social skills interventions for
children with ASDs and identified methods beneficial in teaching social skills. It also directs the
reader to specific case examples in which these methods are used. The most common
intervention approaches found throughout the literature review were: modeling and
reinforcement with feedback given in regards to accuracy and appropriateness of responses, peer
mediated intervention in which a peer tutor or volunteer model or prompts appropriate social
behavior, reinforcement schedules and activities, and the use of scripts and social stories.

**Objective.** Reports of large increases in autism prevalence have been a matter of great concern to clinicians, educators, and parents. This analysis uses a national data source to compare the prevalence of autism with that of other disabilities among successive birth cohorts of US school-aged children. **Design.** Comparison of birth cohort curves constructed from administrative data. **Setting and Population.** US children 6 to 17 years of age between 1992 and 2001. **Main Outcome Measures.** A disability category classification of autism, mental retardation, speech and language impairment, traumatic brain injury, or other health impairment, as documented by state departments of education and reported to the Office of Special Education Programs, US Department of Education. **Results.** Prevalence of disability category classifications for annual birth cohorts from 1975 to 1995 were calculated by using denominators from US Census Bureau estimates. For the autism classification, there were birth cohort differences, with prevalence increasing among successive (younger) cohorts. The increases were greatest for annual cohorts born from 1987 to 1992. For cohorts born after 1992, the prevalence increased with each successive year but the increases did not appear to be as great, although there were fewer data points available within cohorts. No concomitant decreases in categories of mental retardation or speech/language impairment were seen. Curves for other health impairments, the category including children with attention-deficit/hyperactivity disorder also showed strong cohort differences. **Conclusions.** Cohort curves suggest that autism prevalence has been increasing with time, as evidenced by higher prevalence among younger birth cohorts. The narrowing in vertical separation of the cohort curves in recent years may mark a slowing in the autism prevalence increase.

This article was useful to my literature mainly because their results, when using a national data base, found an increasing prevalence of autism over time. The study also found that this increase does not seem to be across the board for disabilities which is interesting to note. The rest of the article was very technical and not of great importance to my study.


**Background:** Social and emotional adjustment of siblings of children with autism was examined, to explore their risk or resilience to effects of genetic liability and environmental factors involved in having a sibling with autism. **Method:** Social-emotional adjustment, behavior problems, socialization skills, and siblings’ relationships were compared among 30 siblings of children with autism, 28 siblings of children with mental retardation of unknown genetic etiology (MR), and 30 siblings of children with developmental language disorders (DLD). Groups were matched by probands’ gender, siblings’ chronological age, gender, IQ, and birth order, and by family size, ethnicity, and parental income, employment, and stress level. **Results:** Four siblings of children with autism, three siblings of children with MR, and seven siblings of children with DLD received DSM—IV diagnoses. Nevertheless, most of the siblings were well adjusted.
Conclusions: The adjustment of siblings of children with autism is in sharp contrast to the severe social and emotional disabilities characteristic of autism, and is noteworthy considering the stress involved in having a sibling with autism.

This study included 30 siblings of children with autism (12 boys and 18 girls). Older siblings described their brother or sister more positively. Siblings of nonverbal children with autism had more behavior problems and lower socialization skills than siblings of verbal children with autism. The study showed that the greater stress there was on parents, the greater delay in children with autism’s socialization skills. The study also found that the larger the family the greater the delay in the child with autism’s socialization skills.


An increasing body of literature has indicated that social stories are an effective way to teach individuals diagnosed with autism appropriate social behavior. This study compared two formats of a social story targeting the improvement of social skills during game play using a pretest posttest repeated measures randomized control group design. A total of 45 children diagnosed with Autism Spectrum Disorder (ASD) ages 7–14 were randomly assigned to standard, directive, or control story conditions. Results demonstrated that the standard and directive story formats were equally as effective in eliciting, generalizing and maintaining the targeted social skills in participants who had prior game play experience and Verbal Comprehension Index (VCI) scores from the WISC-IV intelligence test in the borderline range or above.

The study examined the effectiveness of using social stories as a teaching strategy for individuals with autism. The study involved 45 children diagnosed with ASD between the ages of 7-14. The results found that using either a standard social story or a directive social story was beneficial and demonstrated significantly game playing skills than the control group who reviewed a story unrelated to social skills. One related factor to success in generalizing the social story to an actual play opportunity involved the child’s verbal comprehension. Since the social stories did not include pictures and including somewhat abstract/unfamiliar concepts, the stories were not beneficial to the children who had low verbal comprehension. Overall the study demonstrated that social stories were an effective strategy to be used when teaching a new skill, however, it is important to keep each individual child’s abilities in mind when creating the story.


Family systems theory was employed to study sibling relationships in 50 families with a child with autism. Typically developing siblings expressed satisfaction with their sibling relationships.
Parents were somewhat less positive about the sibling relationship than were the siblings themselves. As hypothesized, stress in marital relationships was associated with compromised sibling relationships. Informal social support buffered the deleterious effects of marital stress on positive, but not negative, aspects of sibling relationships. Contrary to predictions, families experiencing high marital stress who sought greater support from formal resources external to the family had typically developing siblings who reported a higher level of negative sibling behaviors than families who sought low levels of formal support. Findings reinforce the importance of considering family context as a contributor to the quality of the sibling relationship.

This study reviewed 50 families (49 mothers, 1 father) who had a child with autism (between the ages of 4 – 12) and a typically developing child (between the ages of 7 – 12). Based on self-report inventories and questionnaires the study showed as marital stress increases, sibling relationships decrease.


No abstract. This article was helpful in clearly identifying OT’s scope of practice with individuals with autism. The authors state that OT services might focus on “enhancing participation in and performance of activities of daily living (e.g., feeding, dressing), instrumental activities of daily living (e.g., community mobility, safety procedures), education, work, leisure, play, and social participation”. The authors also identify possible environments that OT’s might work in with individuals with autism (i.e., school, work, adult day care, etc.) and the info that OT’s can offer to families and teams that they work with.


Parents of children with autism frequently turn to the service delivery system to access supports designed to help adapt to the challenges of having a child with a life-long impairment. Although studies have suggested various supports and coping strategies that are effective for adapting, few studies have examined parents’ own perceptions of needs, and whether parents felt their needs were being met. In the present study the Family Needs Questionnaire (FNQ; Waaland et al., 1993) was modified to address needs for children with developmental disorders. A sample of fifty-six parents of children with autism and a comparison group of thirty-two parents of children with Down syndrome completed the FNQ. The groups did not differ significantly on the number of important needs reported nor the number of important needs being met. However, the two groups differed in the types of supports they most frequently endorsed as Important or Unmet.

This study was valuable in understanding the unmet needs of families who have children with autism. It was also a very helpful article to use as I developed by needs assessment and literature review. This study listed the top ten needs of families who had a child with autism based on the
completion of the FNQ. The following needs were reported as unmet: financial support in order to provide my child with his/her therapies, treatments and care (93%); for my child to have friends of his/her own (82%); help dealing with my fears about my child’s future (79%); services continuously rather than only in times of crisis (79%); for my children’s friends to feel comfortable around my child (79%); weekend and after-school activities for my developmentally delayed child (77%); to have my child’s therapies continue throughout the summer months and school breaks (77%); to have consistent behavioral therapy for my child (75%); and to have consistent occupational therapy (73%).


No Abstract. This article was helpful in describing sensory processing disorders that children with autism might have. The author clearly explained some of the different types of processing disorders: sensory defensiveness, sensory-seeking, and under-responsive. The author also mentioned that because a child with sensory processing disorders may have trouble regulating his or her own body they may exhibit behaviors such as anxiety, fight or flight reactions, irritability, fussiness, poor socialization, and difficulty forming relationships. It is important to consider these possibilities when you are working with a child with a sensory processing disorder. As an OT we can help these children regulate their senses so that they are at the just-right level to interact within their environment.


The study deals with strain on the family system, as well as the level of coping and types of coping behavior of the parents, in families with a child diagnosed as having an autistic spectrum disorder (ASD) as compared to families in a control group. Thirty-seven families and 66 parents were involved in each case, and four psychological tests were used. It was found that lower levels of coping were associated with higher levels of strain on the family system, that the level of strain on the family system was greater in the families with a child with an ASD, and that the two groups differed in their pattern of coping behavior. It is argued that limited contact between the child with an ASD and its parents, claimed earlier to be a cause of autism, can be explained in terms of strain on the family system and resulting pattern of coping.

This article was somewhat helpful in providing information on coping styles of families who have a child with autism. The study found that these families demonstrated more negative coping styles than the control group. These coping styles included distancing and escape to withdrawal from a stressful situation. The authors also reported a finding of high levels of intrusion felt by families with autism.


This article explores the perspectives of service providers and parents of children diagnosed with autism spectrum disorder regarding service systems. Transcripts from focus groups conducted at
national meetings sponsored by NECTAS were analyzed for emergent themes. A comparison of parent and provider focus group transcripts yielded points of convergence in the areas of collaboration, family support, financial issues, equity, early identification, advocacy, training, and inclusion. Divergent themes included access, home programming, the law (IDEA), best practice, and transition. Parents and providers agreed upon the importance of a coordinated, family-centered service delivery system that recognizes the expertise of both parties. Key words: autism spectrum disorder, families, parents, service delivery systems, service providers

I thought the idea behind this study was a great concept even though it is an older study. It would be interesting if the authors conducted this study again. In the study the author gathered parents of children with autism and service providers of children with autism together into focus groups to discuss their experiences of working with kids with autism. The focus group was centered on four main questions pertaining to hopes and expectations for serving children with autism, barriers to receiving service, positive experiences with services, and recommendations to others in similar roles. The results found eight common themes between the parents and providers: the need for family support, early identification, assistance with finances, training, collaboration between parents and providers, advocacy, inclusion, and equity. A few themes reported by parents differed from the providers: access, home-based programming, and law. Two themes reported by parents differed from the parents: quality programs/best practice and transition.


Introduction This study investigated the psychological adjustment of siblings of children with high functioning autism (HFA) in comparison with siblings of normally developing children in the domain of behavioral problems, social competence and self-concept. Method Twenty-nine siblings of children with HFA and 29 siblings of children without a disorder participated in the study. Standardized, written questionnaires were used. Results Siblings of children with HFA, especially brothers and sisters between 6 and 11 years old, had more behavioral problems than siblings of the control group. Sisters of children with HFA ascribed higher social competence to themselves. Sisters of children with HFA between 12 and 16 years old had a more positive self-concept. In both groups siblings with a more negative self-concept had less social skills and siblings with a more positive self-concept scored better in the social domain. Finally, in accordance with the control group, the perception of the siblings’ social competence of parents of children with HFA broadly matched the perception siblings had of them. Discussion Overall, siblings of children with HFA are not more susceptible to adaptation problems than siblings of children without a disorder. Implications for practice and further research are discussed.

This study examined psychological adjustment of 29 siblings of children with high functioning autism (HFA) in comparison to a control group of siblings of typically developing children. The authors specifically examined behavior problems, social competence, and self concept; the relationship of social competence and self-concept; and perceptions of social competence in siblings reported by siblings and by parents. Some findings that I found interesting are:
1. Siblings of HFA had more internalizing and externalizing problems than the control siblings.
2. Siblings of HFA scored higher on social skills behavior than the control group.
3. Sisters of HFA between the ages of 12-16 yrs had more positive self-concept than the control group.
4. Siblings of HFA between the ages of 12-16 yrs scored higher on the subscales Honesty-Trustworthiness and on verbal self-concept.
5. Relationship between self-concept and social competence was the same for both groups.


Objective. The purpose of this study was to examine the current practice patterns of occupational therapists experienced in working with children with autism spectrum disorders. Method. Occupational therapists experienced in providing services to 2-year-old to 12-year-old children with autism completed a mail questionnaire describing practice patterns, theoretical approaches, intervention techniques, and preferred methods of preparation for work with children with autism. Results. Of those contacted, 72 occupational therapists met the study criteria and returned completed questionnaires. Practice patterns included frequent collaboration with other professionals during assessment and intervention. Intervention services were typically provided in a one-to-one format with the most common techniques being sensory integration (99%) and positive reinforcement (93%). Theoretical approaches included sensory integration (99%), developmental (88%), and behavioral (73%). Evaluations relied heavily on nonstandardized tools and clinical observations. Educational methods identified as most helpful were weekend workshops (56%) and on-the-job training (52%). Conclusion. This study clarified the nature of current occupational therapy practice patterns for 2-year-old to 12-year-old children with autism. Additional studies are needed to examine the efficacy of current evaluation and intervention methods, as well as to explore the relevance of available standardized assessments for this population.

The information that I found the most relevant in this article was the table reviewing theories or frames of references used when working with individuals with autism. The table was based off of questionnaires returned by 72 pediatric OTs. The model most frequently used was sensory integration (99% rated using the model frequently or always), followed by developmental (88%), behavioral (73%), neuro (55%), coping (50%), MOHO (43%), and biomechanical (29%).


There is no abstract for this article. This article is of great importance in defining the role and domains of occupational therapy with individuals with autism. It describes the individuals
that the occupational therapist might work with (e.g., parents, caregivers, educators, and team members), a variety of settings that the occupational therapist might work with this population in (e.g., home, school, clinic, and community), and areas of focus for intervention (e.g., activities of daily living, instrumental activities of daily living, education, work, leisure, play, and social participation).


The purpose of this qualitative research study was to understand a family’s experiences with negotiating family daily life and the meanings they ascribed to these experiences when they and a child with severe autism. In-depth, semi-structured interviews were conducted with five family units. The interviews explored the meaning of the family’s participation in daily life activities. The transcribed interviews were analyzed with a phenomenological method. The results emerging from this study indicate that families with children with severe autism may experience difficulty engaging in daily activities that hold positive meaning and rely on stringent patterns of routines that revolve around the child with autism to meet the demands of daily life.

This study focused on understanding the experiences and feelings of families who have children with autism. The study found the following themes: whole family life revolves around autism (feelings of stress, anxiety), robbed as a family (i.e., robbed of dreaming about the future, enjoying days as a family), occupy and pacify, and fleeting moments of feeling like a family. It is important to understand these feelings when working with families who have a child with autism and when developing a program for these families. The author (an occupational therapist) stated that we need to “identify ways to help families construct ways of engaging in occupations that are satisfying, enduring, and fulfilling to the family” (p. 549).


Social reciprocity deficits are a core feature of the autism spectrum disorders (ASD). This review summarizes the state of research in group-based social skills training programs for school-age children and adolescents with ASD. All published studies of group social skills interventions between 1985 and 2006 were reviewed, as well as dissertations examining group-based social skills intervention programs. To assess the state of the science, a template developed by an NIMH work group was applied to 14 identified studies. Based on this review, the empirical support for this approach is incomplete, but promising intervention strategies were identified. Recommendations for the design of future treatment trails to guide clinical practice are offered.
“promising” strategies to use in group-based social skills training programs for individuals with ASD which will be helpful to use when developing a social skills program for individuals with ASD. For example, the following interventions were suggested as “promising” ways to increase social motivation: foster self awareness and self-esteem, develop nurturing, fun environments, intersperse new skills with previously mastered skills, and start with simple, easily learned skills.


In this article, we discuss findings of a hermeneutic phenomenological study that sought to describe the experiences of parents who have a child with autism. Qualitative interviews were conducted with parents from 16 families of children with autism residing in a western Canadian province. “Living in a world of our own” emerged as the essence of the parents’ experiences. In “living in a world of our own”, parents described a world of isolation. Three themes representing the essential challenging elements of the parents’ experiences included vigilant parenting, sustaining the self and family, and fighting all the way. Although much is known about the fundamental importance of support to parents of children with chronic conditions and or disabilities, findings from this study indicate that knowledge has not been adequately transferred to the care of children with autism.

This study looked specifically at the lived experience of being a parent to a child with autism. The study found that parents: society’s lack of understanding, missing a “normal” way of life, feeling disconnected from the family, and the unsupportive “system” (child related agencies and institutions; at times feeling like an outsider in their own child’s life). Three themes were also described in regards to the struggle the families dealt/deal with to remove isolation: vigilant parenting (i.e., acting sooner rather than later, doing all you can, and staying close to your gut feeling), sustaining the self and the family (i.e., working toward a healthy balance, cherishing different milestones, and learning to let go), and fighting all the way (i.e., becoming more direct, learning all you can, and educating others).
References


Appendix A

Easter Seals’ Therapeutic Day School Organizational Chart

- Director of Therapeutic Schools: Wendy Murphy
  - School Administrator
    - Program Coordinator
      - Senior Social Worker
      - Clinical Coordinator
        - SW, Art, Nurse, OT, SLP, BCBA
          - F.A.C.E.S. Program
Appendix B

Parent/Caregiver Letter

Parents and Caregivers:

My name is Julia Hill and I am an occupational therapy graduate student at the University of Toledo. I am working with Easter Seals to develop a program for siblings and families of students at the Easter Seals Therapeutic School of Chicago and would like your input regarding your needs as a family. Attached is a survey that will help to determine the main focus of this program. Your input would be greatly appreciated!

Please return the survey in the provided envelope by February 6, 2009 to your child’s classroom teacher.

Each student whose parent or caregiver has returned a survey will be entered in a drawing for a class pizza party!

Feel free to call Cheryl Chen, OTR/L, Betsey White, OTR/L, or Julia Hill, OTS at 312-432-1751 if you have any further questions.

Thank you for your time!

Sincerely,

Julia Hill OTS
Appendix C

**Parent/Caregiver Survey**

The purpose of this survey is to help determine if there is a need for a sibling and/or family program for the families of students at the Easter Seals Autism Therapeutic School of Chicago. Please return this in the provided envelope by February 6, 2009 to your child’s classroom teacher.

Please check the following areas to indicate a need. Feel free to explain the need further.

<table>
<thead>
<tr>
<th>Please check to indicate a need</th>
<th>Potential Needs</th>
<th>Explain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sibling support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Supported family interaction and/or communication</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Leisure occupations for students/families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Student socialization skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Student/family community outings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other needs?</td>
<td></td>
</tr>
</tbody>
</table>

Thank you for your help!
Appendix D

Parent/Caregiver Reminder Letter

Parents and Caregivers:

This is just a reminder to please return the surveys that were sent home with your children. Your feedback is greatly appreciated!

Please return the survey by February 6, 2009 to your child’s classroom teacher. Each student whose parent or caregiver has returned a survey will be entered in a drawing for a class pizza party!

Feel free to call Cheryl Chen, OTR/L, Betsey White, OTR/L, or Julia Hill, OTS at 312-432-1751 if you have any further questions.

Thank you for your time!

Sincerely,

Julia Hill OTS
Appendix E

Employee Letter

Easter Seals’ Employees:

My name is Julia Hill and I am an occupational therapy graduate student at the University of Toledo. I am working with Easter Seals to develop a program for siblings and families of students at the Easter Seals Therapeutic School of Chicago and would like your perspective regarding the needs of the students and families that you work with at Easter Seals. Surveys are also being sent home to parents/caregivers of the students.

On the back of this sheet is a survey that will help to determine the main focus of this program. Your input would be greatly appreciated!

Feel free to see Cheryl Chen, OTR/L, Betsey White, OTR/L, or Julia Hill, OTS if you have any further questions.

Thank you for your time!

Sincerely,

Julia Hill OTS

**Teachers: Enclosed are the parent/caregiver surveys, please send home with the students today. Thank you!
Appendix F

Employee Survey

The purpose of this survey is to help determine if there is a need for a sibling and/or family program for the families of students at the Easter Seals Autism Therapeutic School of Chicago. Please return this to Cheryl Chen’s mailbox by January 30, 2009.

Please check the following areas to indicate a need. Feel free to explain the need further.

<table>
<thead>
<tr>
<th>Please check to indicate a need</th>
<th>Potential Needs</th>
<th>Explain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supported family interaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and/or communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure occupations for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>students/families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student socialization skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student/family community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>outings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other needs?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Would you be interested in volunteering your time to assist with a sibling/family program…

once a month? : ________________________________

once a quarter? : _______________________________

Thank you for your help!
### Results of Parent/Caregiver Surveys

<table>
<thead>
<tr>
<th>Needs</th>
<th>Total</th>
<th>%</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling Support</td>
<td>9/30</td>
<td>30%</td>
<td>“Jon’s brother Jose doesn’t understand why Jon’s behavior changes all of the sudden. We try to explain, but he still ask(s) questions that sometimes I can’t even understand about his disability”</td>
</tr>
<tr>
<td>Supported family interaction and/or</td>
<td>9/30</td>
<td>30%</td>
<td>“Some parents are at a loss for how to interact or at a minimum communicate with their student”</td>
</tr>
<tr>
<td>communication</td>
<td></td>
<td></td>
<td>“A support group or gathering for families or caregivers of individuals with autism to come together and discuss concerns involving raising a child with autism”</td>
</tr>
<tr>
<td>Leisure occupations for students/families</td>
<td>18/30</td>
<td>60%</td>
<td>“It’s hard to find healthy activities for children with autism”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Looking for age appropriate activities that he would enjoy -&gt; adulthood”</td>
</tr>
<tr>
<td>Student socialization skills</td>
<td>25/30</td>
<td>83.3%</td>
<td>“I wish there was a group (social) that both boys could participate in on a regular basis”</td>
</tr>
<tr>
<td>Student/family community outings</td>
<td>22/30</td>
<td>73.3%</td>
<td>“Not to be afraid to try new things and go to new places”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Social gathering of any kind”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“It would be nice if there could be Easter Seals’ Family days at community venues”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Some of the students will not get out if the school doesn’t suggest something”</td>
</tr>
</tbody>
</table>

Other needs:
- “Listing of competent babysitters or caregiver services”
- “Anything to help our child and family member lose weight”
- “RESPITE!!!”
- “Appropriate sensory activities going into adulthood”
- “Someone to spend 1 or 2 hours per week socializing (with)”
- “Out of home respite”
Appendix H

Results of Employee Surveys

<table>
<thead>
<tr>
<th>Needs</th>
<th>Total</th>
<th>%</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling Support</td>
<td>10/14</td>
<td>71.4%</td>
<td>- “Sometimes siblings get put aside (not purposefully) because their brother/sister requires so much of the parents’ time. I think they need something to help them understand and communicate their needs.”</td>
</tr>
<tr>
<td>Supported family interaction and/or communication</td>
<td>12/14</td>
<td>85.7%</td>
<td>- “Many families are unable to provide leisure/rec opportunities for various reasons. May be helpful to offer alternatives that families (can) access.”</td>
</tr>
<tr>
<td>Leisure occupations for students/families</td>
<td>9/14</td>
<td>64.3%</td>
<td>- “These outings can make a family seem ‘normal’ where they do not have to worry about what other people are thinking.”</td>
</tr>
<tr>
<td>Student socialization skills</td>
<td>9/14</td>
<td>64.3%</td>
<td></td>
</tr>
<tr>
<td>Student/family community outings</td>
<td>12/14</td>
<td>85.7%</td>
<td></td>
</tr>
</tbody>
</table>

Total Survey Results

<table>
<thead>
<tr>
<th>Needs</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling Support</td>
<td>19/44</td>
<td>43.2%</td>
</tr>
<tr>
<td>Supported family interaction and/or communication</td>
<td>21/44</td>
<td>47.7%</td>
</tr>
<tr>
<td>Leisure occupations for students/families</td>
<td>27/44</td>
<td>61.4%</td>
</tr>
<tr>
<td>Student socialization skills</td>
<td>34/44</td>
<td>77.3%</td>
</tr>
<tr>
<td>Student/family community outings</td>
<td>34/44</td>
<td>77.3%</td>
</tr>
</tbody>
</table>
Appendix I

Student Documentation for F.A.C.E.S. Program

Name: ________________________________ Date: _________________________

Circle the type(s) of required prompts and indicate the approximate number of prompts per opportunity for the student.

<table>
<thead>
<tr>
<th>PP – Physical Prompt</th>
<th>HOH – Hand over hand</th>
<th>IV - Indirect Verbal</th>
<th>GV- Gestural</th>
</tr>
</thead>
</table>

1. Student demonstrated appropriate social skills (e.g., appropriate interactions with peers/family) and required ...

**Opportunity 1:**

<table>
<thead>
<tr>
<th>PP</th>
<th>HOH</th>
<th>DV</th>
<th>IV</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>___</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

Comments:
__________________________________________________________________________________________________
__________________________________________________________________________________________________

**Opportunity 2:**

<table>
<thead>
<tr>
<th>PP</th>
<th>HOH</th>
<th>DV</th>
<th>IV</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>___</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

Comments:
__________________________________________________________________________________________________
__________________________________________________________________________________________________

**Opportunity 3:**

<table>
<thead>
<tr>
<th>PP</th>
<th>HOH</th>
<th>DV</th>
<th>IV</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>___</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

Comments:
__________________________________________________________________________________________________
__________________________________________________________________________________________________

2. Student engaged in leisure activities during the community outing and required...

**Opportunity 1:**

<table>
<thead>
<tr>
<th>PP</th>
<th>HOH</th>
<th>DV</th>
<th>IV</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>___</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

Comments:
__________________________________________________________________________________________________

**Opportunity 2:**

<table>
<thead>
<tr>
<th>PP</th>
<th>HOH</th>
<th>DV</th>
<th>IV</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>___</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

Comments:
__________________________________________________________________________________________________

**Opportunity 3:**

<table>
<thead>
<tr>
<th>PP</th>
<th>HOH</th>
<th>DV</th>
<th>IV</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>___</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

Comments:
__________________________________________________________________________________________________
Appendix J

Satisfaction of Family Outings

Please answer each question using the following scale:

1 – Never  
2 – Hardly Ever  
3 – Sometimes  
4 – Most of the time  
5- Always

1. I feel comfortable going out in the community with my family to do things like go to the movies, go out to eat, go to the zoo, etc.

2. I am happy with the amount of time my family spends together outside of the house.

3. I look forward to spending time with my family outside of the house.

4. I can go out with my family without worrying about how my family member with autism will behave.

5. I am happy with the types/numbers of activities that my family can do together outside of the house.
Appendix K

Strategies to Assist my Family Member with Autism within the Community

Please answer each question using the following scale:

1 – Never    2 – Hardly Ever    3 – Sometimes    4 – Most of the time    5 – Always

1. I know how to help my family member with autism interact effectively during a community outing.
   1  2  3  4  5

2. I know what to do if/when my family member with autism has difficult behaviors out in the community.
   1  2  3  4  5

3. I know specific things that I can do to prepare my family member with autism to go out on a new outing.
   1  2  3  4  5

4. I know how to meet the sensory needs of my family member with autism during a community outing.
   1  2  3  4  5

5. I feel satisfied with the number of strategies I know to help my family member with autism participate successfully within his or her community.
   1  2  3  4  5
Appendix L

Employee/Volunteer Program Evaluation Survey

1. Please describe your experience working with the F.A.C.E.S. program.

2. Do you feel that this program is beneficial to the students and families of Easter Seals?

3. How well do you think that the sibling/student sessions prepare the student to successfully go out into the community?

4. Do you have any suggestions to improve the F.A.C.E.S. program?

Other Comments:

Thank you!
Appendix M

Parent/Caregiver Program Evaluation Survey

1. Please describe your experience with the F.A.C.E.S. program.

2. Do you feel that this program is beneficial to you and your family?

3. Which community outings have you attended?

4. How well do you think that the family training sessions prepared the student to successfully go out into the community?

5. Do you have any suggestions to improve the F.A.C.E.S. program?

Other Comments:

Thank you!
Appendix N

F.A.C.E.S. Program: Session 1 Letter

Parents/Caregivers:

Based on your interest in Easter Seals’ F.A.C.E.S. Program we would like to invite you to participate in the pilot of the first F.A.C.E.S. training session and community outing.

Our first outing will be at the UIC Bowling Alley on Saturday April 4th, 2009 from 2:30 – 4:00pm. A major part of this program is the preparation for the actual outing. This preparation will involve a family training session held prior to the outing. This first training session will be held at Easter Seals Therapeutic School and Research Center on Saturday March 28th.

In order for your family to receive the most benefits from this program there are a few things that we ask of you:

1. **At the training sessions please only include family members who will be going on the actual outing.** This will help us to help best prepare you for the outing.

2. **In order to attend the community outing your family MUST attend the training session prior to the outing.** The purpose of this program is to work with you and your family on valuable skills and techniques to use in the community. We need you at the sessions so your family can practice these skills in a supported environment.

3. **Please use the training sessions as a learning opportunity.** We have limited time to run the sessions and we want you to get as much as you can from them. We will provide families with the opportunity to interact and enjoy refreshments at the end of each training session.

We are very excited to get this program started and hope that it can be a great experience for your family! If your family is able to participate in this bowling training session and outing **please return the attached page by March 23rd, 2009**. If your family is unable to participate in this outing we will continue to keep you updated about upcoming outings.

Thank you!

Julia Hill, OTS, Betsey White, OTR/L, and Cheryl Chen, OTR/L

Please feel free to contact Julia Hill, OTS, Betsey White, OTR/L, or Cheryl Chen, OTR/L at 312-432-1751 if you have any questions or would like more information.
Easter Seals’ F.A.C.E.S. Program

_____ My family will be attending the family training session and community outing.

**Please include names/ages of family members attending the family training session held on March 28th and community outing held on April 4th for the F.A.C.E.S. Program.**

<table>
<thead>
<tr>
<th>NAME:</th>
<th>AGE:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(student)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix O

Information Letter: Family Training 1

Easter Seals’ F.A.C.E.S. Program
Family Training Session 1: Preparation for Bowling Outing

Preparing your child for an outing will help your child understand what is expected and reduce the anxiety that comes along with not knowing what will happen on that outing. There are a number of ways that you can help prepare your child for an outing. For this specific outing we will focus on the following techniques that have demonstrated positive effects for individuals with autism (White, Keonig, & Schall, 2007; Matson, Matson, & Rivet, 2007; Krummins, J., 2008):

1. **Social story** – Using pictures and written words, the social story concretely explains what will happen, how your child might feel, and ways that those feelings can be helped. (See “Going on a Bowling Outing” social story.)

2. **Visual Schedule** – A visual schedule may consist of pictures and/or words that show your child the sequence of events that will happen throughout the day. It will also allow your child to become more independent in his or her environment. For example, the visual schedule might look like a sequence of five pictures in order from top to bottom attached to the schedule by Velcro. After the child completes a step the step is then removed and placed in “finished” (i.e., a pocket located at the back or bottom of the schedule). A schedule has been developed for your child based on your child’s therapists’ knowledge of using a visual schedule with your child.

3. **Modeling** – Demonstrating or role playing a situation is another way to show your child what might happen during the outing. It provides your child with the opportunity to observe social interactions of others participating in the bowling activity, practice social skills he or she might need at that specific outing, and practice the visual sequence ahead of time. At this training we will go through a simulated bowling outing to give you and your family the opportunity to practice these skills.

Other strategies that you might find helpful as you participate in the outing and in future outings might include (Krummins, J., 2008): taking along “tools of the trade” (e.g., sensory toys – squishy balls, fabric, vibrating pens), a visual clock, paper/pen or whiteboard/marker to write messages to your child, or other comforting items, providing others with helpful information about your child (i.e., do not need to give life story, can simply say “Please give my child extra time to respond”), and give yourself plenty of time on the outing.

References


F.A.C.E.S. program

Appendix P

Occupational Therapy Job Description

A part-time registered and licensed occupational therapist will be needed to direct the Easter Seals’ F.A.C.E.S. (Families with Autism in the Community and Engaging in Society) Program. The occupational therapist must have a minimum of a Bachelor’s degree in occupational therapy. The program will be specifically for students and families with autism; therefore, experience working with individuals with autism is necessary. Also, leadership experience and enthusiasm for the program is necessary since this program is still in its beginning phases and will need a dedicated and knowledgeable leader. The occupational therapist will be expected to work 20 – 30 hours per month. He or she will need to be available to work two Saturdays or Sundays per month. The job requirements will include coordinating and directing family training sessions, directing and coordinating community outings, supervising volunteers, communicating with stakeholders of the program (i.e., students, employees, caregivers, and volunteers), and completing documentation and program evaluations.
Appendix Q

Sample Advertisement for an Occupational Therapy Position

**Exciting Opportunity for a Part-Time Occupational Therapy Position!**

Easter Seals’ Therapeutic School and Center for Autism Research is searching for a part-time occupational therapist to direct and supervise the new Easter Seals’ F.A.C.E.S. Program (Families with Autism in the Community and Engaging in Society).

**Required qualifications:**
- OTR/L
- Experience working with individuals with autism;
- Leadership experience;
- Self-motivated;
- Ability to work two Saturdays or Sundays per month; and
- Enthusiastic, committed, and ambitious occupational therapist!

**Position requirements:**
- Train and supervise volunteers;
- Direct and coordinate family training sessions;
- Direct and coordinate community outings for families of Easter Seals;
- Communicate effectively with students, families, volunteers, and employees of the Easter Seals’ Therapeutic School and Center for Autism Research; and
- Complete documentation and program evaluations.

Please mail resumes to:
Betsey White
Clinical Coordinator
Easter Seals’ Therapeutic School and Center for Autism Research
1939 West 13th Street
Chicago, IL 60608
F.A.C.E.S. program
Appendix R

Social Story: Bowling

Going to the Bowling Alley!
Going to the bowling alley with my family and friends is fun.
I get to wear special bowling shoes when I go to the bowling alley. I can tell the worker what size shoe I wear.
Sometimes the bowling alley gets noisy.

I can ask for a break when it is too loud.
When it is my turn to bowl I pick a bowling ball and walk to the lane. I make sure I throw the bowling ball in my lane.
When my turn is over I watch my friends bowl. I tell them they are doing a good job!
Sometimes I am sad when it is time to stop bowling...

BUT I know that I can come back to bowl later.
I can’t wait to bowl again!
Appendix S

Countdown to Bowling

<table>
<thead>
<tr>
<th>March 29</th>
<th>March 30</th>
<th>March 31</th>
<th>April 1</th>
<th>April 2</th>
<th>April 3</th>
<th>April 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sunday</td>
<td>Monday</td>
<td>Tuesday</td>
<td>Wednesday</td>
<td>Thursday</td>
<td>Friday</td>
<td>Saturday</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Bowling!</td>
</tr>
</tbody>
</table>
Appendix T

Parent/Caregiver Survey of first F.A.C.E.S. Program

Parents/Caregivers,

Thank you for participating in Easter Seals’ first session of the F.A.C.E.S. Program! Please answer the following questions so that we can continue to improve this program and prepare community outings that are meaningful to you and your family.

1. How well did you feel that the family training prepared your family for the bowling outing?

___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________

2. Did the family training introduce any new strategies or techniques that you felt were beneficial for the bowling outing or other outings that you and your family might go on?

___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________

3. Do you have any suggestions or comments on ways to improve the program?

___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________

4. What future community outings would you and your family like to go on?

___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________

Thank you!

We will continue to keep you updated on upcoming F.A.C.E.S. events.

Sincerely,

Julia Hill, OTS, Cheryl Chen, OTR/L, and Betsey White, OTR/L
## Results of Parent/Caregiver Survey of First F.A.C.E.S. Program

<table>
<thead>
<tr>
<th>Question</th>
<th>Comments (Received feedback from 5/9 families)</th>
</tr>
</thead>
</table>
| 1. How well did you feel that the family training prepared your family for the bowling outing? | • “Very good job preparing the kids for bowling. Excellent job of planning what would work for each individual student.”  
• “The training was great! It help(ed) me with some problem(s) we had before (when) we went bowling. Placing visual signs help (my child) focus more. Thanks.”  
• “Very well, the social story, visual schedule, and modeling were very helpful.”  
• “I feel it prepared my son well for the activity.”                                                                 |
| 2. Did the family training introduce any new strategies or techniques that you felt were beneficial for the bowling outing or other outings that you and your family might go on? | • “Yes, James knew what to expect. The sensory toys were helpful, squishy toys.”  
• “Social stories, pic schedule”  
• “Yes, the outlay for his tech speak (visual schedule) kept (my child) on task. I will program other outings in this manner.”  
• “I feel comfortable knowing bowling is something that (my child) will enjoy if we were to decide to do (it) again.”                                                                 |
| 3. Do you have any suggestions or comments on ways to improve the program? | • “Let’s do this again! With staff support the families felt more relaxed. We received support on what to do if...”  
• “The hardest part of any program is getting it started, so just keep it up. Also, continue to listen to the parents.”  
• “I thought the program was well planned.”  
• “Just think it’s great that the siblings were included. Thank you so much. Both of my sons enjoyed the day together. So did I!”  
• “The social story should also include going to the conference room not the classroom or explain in some way how we are going to school but not staying.” |
| 4. What future community outings would you and your family like to go on? | • “Movies, zoo, museums, restaurants, etc.”  
• “Movies, family picnic, carnival, amusement park, zoo, swimming, bowling; outings show be repeated for added reinforcement”  
• “Grocery shopping, movies, wait in line for any reason”  
• “Movies, parks, picnics, swimming”  
• “The bowling was great, anything that involves exercise. Also anything with music, maybe a college play or musical.” |
Appendix V

Results of Survey: Satisfaction of Family Outings

Results of Surveys by Question

*Satisfaction of Family Outings (n = 9)*

<table>
<thead>
<tr>
<th>Question</th>
<th>Total Score Out of 45</th>
<th>Mean Score Out of 5</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel comfortable going out in the community with my family to do things like go to the movies, go out to eat, go to the zoo, etc.</td>
<td>35</td>
<td>3.9</td>
<td>3 – 5</td>
</tr>
<tr>
<td>2. I am happy with the amount of time my family spends together outside of the house.</td>
<td>29</td>
<td>3.2</td>
<td>2 – 4</td>
</tr>
<tr>
<td>3. I look forward to spending time with my family outside of the house.</td>
<td>41</td>
<td>4.6</td>
<td>3 – 5</td>
</tr>
<tr>
<td>4. I can go out with my family without worrying about how my family member with autism will behave.</td>
<td>33</td>
<td>3.7</td>
<td>2 – 5</td>
</tr>
<tr>
<td>5. I am happy with the types/numbers of activities that my family can do together outside of the house.</td>
<td>32</td>
<td>3.6</td>
<td>3 – 5</td>
</tr>
</tbody>
</table>

Total Survey Results

*Satisfaction of Family Outings (n = 9)*

<table>
<thead>
<tr>
<th>Total Score out of 225</th>
<th>Mean Score Out of 25</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>170</td>
<td>18.9</td>
<td>15 – 23</td>
</tr>
</tbody>
</table>
Appendix W

Results of Survey: Strategies to Assist Family Member with Autism within the Community

Strategies to Assist my Family Member with Autism within the Community (n = 9)

<table>
<thead>
<tr>
<th>Question</th>
<th>Total Score Out of 40</th>
<th>Mean Score Out of five</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I know how to help my family member with autism interact effectively during a community outing.</td>
<td>33</td>
<td>3.7</td>
<td>3 – 5</td>
</tr>
<tr>
<td>2. I know what to do if/when my family member with autism has difficult behaviors out in the community.</td>
<td>34</td>
<td>3.8</td>
<td>3 – 4</td>
</tr>
<tr>
<td>3. I know specific things that I can do to prepare my family member with autism to go out on a new outing.</td>
<td>32</td>
<td>3.6</td>
<td>2 – 5</td>
</tr>
<tr>
<td>4. I know how to meet the sensory needs of my family member with autism during a community outing.</td>
<td>31</td>
<td>3.4</td>
<td>3 – 5</td>
</tr>
<tr>
<td>5. I feel satisfied with the number of strategies I know to help my family member with autism participate successfully within his or her community.</td>
<td>29</td>
<td>3.2</td>
<td>2 – 5</td>
</tr>
</tbody>
</table>

Total Survey Results

Strategies to Assist my Family Member with Autism within the Community (n = 9)

<table>
<thead>
<tr>
<th>Total Score out of 225</th>
<th>Mean Score Out of 25</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>159</td>
<td>17.7</td>
<td>15 – 23</td>
</tr>
</tbody>
</table>
Appendix X

Easter Seals Therapeutic School and Center for Autism Research

F.A.C.E.S. Program Final Evaluation

Prepared by:

(Mary E) Betsey White, OTR/L

Clinical Coordinator of Autism Therapeutic Schools

Easter Seals Metropolitan Chicago

May 4, 2009

In late 2007, Julia Hill, an OTD student from University of Toledo, contacted Easter Seals Therapeutic School and Center for Autism Research seeking an opportunity to work with us as she developed her capstone project for her OTD program. While she was open to suggestions and sought feedback as to what our specific program needs might be, she expressed an interest in focusing on family support and/or working with our students and their families. Her specific interest and focus seemed to be directly in line with Easter Seals overall mission and we agreed that her project would be valuable to our students and families.

Once it was agreed that Easter Seals would serve as the site for Julia’s Capstone project, she began communicating regularly with Cheryl Chen, MS, OTR/L and this writer, Betsey White, OTR/L to complete her needs assessment and narrow down her program objectives. This process was ongoing and continued even as she joined the team as an intern in January of this year. Ultimately, Julia established the F.A.C.E.S. program (Families with Autism in the Community and Engaging in Society).

When Julia began her internship at Easter Seals she was well prepared, organized, and highly focused on her end goal of piloting the F.A.C.E.S. program by the end of her 16-week placement. She demonstrated a great deal of initiative as she continued to collect additional information via staff surveys, parent surveys, literature reviews, and meeting directly with families to find out exactly what they might be looking for in such a program. Based on feedback from families it was determined that the program should focus not only on siblings, but also on parents/guardians and/or other interested family members.

Ultimately, F.A.C.E.S. evolved into a program that would provide students the opportunity to refine and generalize their functional independent living skills and leisure skills with their families in actual community settings via planned outings. The format for the program would include a training session on-site at the school one week, with the community outing taking place the following week. The training session would specifically focus on providing students and their family members with the appropriate tools and strategies to ensure a successful outing the following week.

The F.A.C.E.S. program was officially launched on Saturday, March 28, 2009 at Easter Seals Therapeutic School and Center for Autism Research with a training session that would ultimately prepare participating students, their families, and a team of staff volunteers for a bowling outing in the community the following weekend on April 4, 2009. Eight families attended both weekends, which was beyond expectations. Participating staff, students, and families appeared to have an enjoyable time and official program feedback
indicated that this was the case. Participants were engaged and there were little-to-no maladaptive behaviors observed.

Easter Seals intends to continue developing the F.A.C.E.S. program as developed by Julia. A committee has been formed and the next outing is being planned. The current plan is to conduct a second outing and gather additional feedback from staff and families before seeking funding opportunities to support the program for the long-term. There is a high level of support for this program from all of the families that participated in the pilot outing, as well as from the staff volunteers.

In summary, Julia did an excellent job preparing for her capstone experience and developing her project. She achieved her goal and developed a viable, sustainable, and much-needed program that will benefit a number of individuals with autism, as well as their dedicated family members. The level of professionalism and commitment that Julia has exhibited throughout this process has been exemplary. Ultimately, over the course of time, it is highly likely that the F.A.C.E.S. program will be offered at all 4 of Easter Seals Metropolitan Chicago’s Autism Therapeutic Schools in the greater Chicago area.