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# Helping Parents Navigate Occupational Therapy in the IEP Process

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Matrix Capstone Project  
Helping Parents Navigate Occupational Therapy in the IEP Process

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A Culminating Project Submitted in Partial Fulfillment of the Requirements for the  
Degree Masters of Science in Occupational Therapy  
School of Health and Natural Sciences  
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This project, written under the direction of the candidates' faculty advisor and approved by the chair of the master's program, had been presented to and accepted by the Faculty of the Occupational Therapy department in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy. The content, project, and research methodologies presented in this work represent the work of the candidates alone.

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\*Supplemental Material: Resource Manual..... Access at [http://matrixparents.org/wp-content/uploads/2015/01/OT\\_ResourceGuide\\_forASD\\_Students.pdf](http://matrixparents.org/wp-content/uploads/2015/01/OT_ResourceGuide_forASD_Students.pdf)

### **Abstract**

At the request of Matrix Parent Network and the Marin Autism Collaborative, the project developers have gathered information in order to help parents of children with Autism Spectrum Disorder (ASD) better understand Occupational Therapy (OT) in the school setting. The development of the resource guide consisted of three needs assessments to identify areas of occupational therapy in which parents required further clarification. After meeting with the director of parent services from Matrix Parent Network, and receiving the online survey results from twenty-eight parents in Marin County, who have children with ASD, the project developers identified areas of OT to focus on. The identified areas include OT assessments, goals, terminology and role in the IEP process. School based OTs in Marin County were consulted through an online survey in order to identify common assessments, interventions, and goals, along with any tips for parents in the IEP process. A resource guide was then created in order to organize and distribute this needed information to parents in Marin County. The information gathered from both surveys was used to help determine the content of the resource guide. The final resource guide was sent to parents and school-based occupational therapists in Marin County in order to be critiqued. Based on the positive feedback received, the project developers were successful in creating a booklet that succinctly conveys integral information to parents in Marin County. The information provided in the resource guide will allow parents to further understand OT in the IEP process, and in turn be a resource for advocating for their child with ASD. When knowledge of OT in the school setting is gained, the parents may feel more comfortable advocating for a positive change in their child's life. The resource guide PDF will be available for download on the Matrix Parent Network website in January 2015.

## **Introduction**

The prevalence of autism spectrum disorder (ASD) is rising, and parents are seeking information in order to support and encourage their child's success more than ever. Occupational therapy is an important service for children with ASD (Tomcheck, LaVesser, and Watling, 2010). For school aged children to receive occupational therapy services through their school district, children must qualify for special education and receive an assessment administered by a qualified occupational therapist. Once a child qualifies for service, an Individualized Education Plan (IEP) is written, which articulates the goals and the used methods for meeting those goals. The IEP process can be confusing and difficult for parents. The confusion may be due to cultural and language barriers, complex medical or educational jargon, unclear documentation, or unclear explanations of documentation. Information and resources explaining occupational therapy services, occupational therapy assessments, and ways to navigate the IEP can support and empower parents. The aim of this paper and accompanying resource guide to provide information on ASD, review current interventions in occupational therapy, outline occupational therapy assessments, and examine the importance of parent advocacy in the IEP process.

## **Literature Review**

Autism spectrum disorder is the fastest growing serious developmental disability in the United States (Autism Speaks, 2013). Due to the rise in prevalence, ASD is a growing issue within the United States. Since the number of children affected by this disorder is growing, so is the amount of services being provided to support children with ASD. This literature review examines the current research about ASD, current assessments used for children in the school systems, interventions used with children with ASD, and reviews the IEP process and how it can be enhanced by parent advocacy.

### **Autism Spectrum Disorder**

Autism spectrum disorder is a neurodevelopmental disorder that can cause challenges in communication, behavior, and social skills (Autism Speaks, 2013). Behavioral difficulties are a challenge for children with ASD. According to recent findings, many children with ASD exhibit repetitive behaviors. Repetitive behaviors include ritualistic behavior, repetitive motor movements, preoccupation with parts or objects, restricted interests, and repetitive speech (Stratis & Lecavalier, 2013). Examples of these repetitive behaviors include hand-flapping, arranging objects, and repeating words or phrases (Autism Speaks, 2013). There is a positive correlation between those who demonstrate repetitive behaviors and those who also have high anxiety and depressive symptoms (Zandt, Prior, & Kyrios, 2007).

Children with ASD communicate less, both verbally and nonverbally, than typical children (O'Haire, McKenzie, Beck, & Slaughter, 2013). Children with ASD may fail to respond to their names, and often avoid eye contact with other people. Children with autism tend to focus on the mouth of the person speaking, if looking at the individual at all (Press, & Richman, 2009). Often, children with ASD have difficulty interpreting what others are thinking or feeling



due to the inability to understand social cues, such as tone of voice or facial expressions, and do not watch other people's faces for clues regarding appropriate behavior (Autism Speaks, 2013).

Social communication is a primary deficit in ASD.

Many children with ASD have co-existent anxiety disorder, most commonly a social anxiety disorder (Chang, Quan, & Wood, 2012). Social anxiety for children with ASD may originate from bullying, which can occur because many children with ASD communicate differently than typical children of their age. Between 6-46% of children with ASD are bullied, which leads them to becoming more anxious in social situations (Chang, Quan, & Wood, 2012). Bullying negatively affects the way children with ASD perform in school due to the social environment at school.

Autism Spectrum Disorder is a condition one is born with, however it may not be diagnosed until much later in life (Autism Speaks, 2013). A diagnosis of ASD can be made as early as eighteen months old, however diagnosis by age two is considered more reliable (CDC, 2014). Presentation of ASD changes with each phase of life, for example school-aged children may withdraw from social interactions. There is a plethora of different developmental categories that may be affected for those with ASD. These categories include intelligence (intellectual disability to gifted), social interaction (not interested in interacting with others to having a variety of friendships), communication (nonverbal to verbal), maladaptive or disruptive behaviors(intense to mild), sensory dysregulation (hypersensitive to hyposensitive), and fine and gross motor (uncoordinated to coordinated) (Case-Smith, & O'Brien, 2010). Children may excel in some categories, yet struggle in others. Severity depends on the amount of support needed, which is easily identified in school-aged children (Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012).

Recent changes in the Diagnostic and Statistical Manual of Mental Disorders (DSM) have impacted the way that ASD is now diagnosed. Using the fourth edition of the DSM, individuals could be diagnosed with one of the four separate disorders under the ASD umbrella. The diagnoses include autistic disorder, Asperger's disorder, childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS) (American Psychiatric Association, 2000). Recent changes in the DSM occurred to improve consistency made in the diagnosis (American Psychiatric Association, 2013). Under the DSM-V, ASD will be considered the primary axis I diagnosis and includes diagnosis of Asperger's syndrome, autism, CDD, or PDD-NOS instead of each of these considered separate diagnostic categories. Having one general term for the diagnosis is thought to improve the diagnostic process, without changing the number of those who were previously diagnosed (American Psychiatric Association, 2013). The big issue is that in many states and districts Autism automatically qualified a child for services but Asperger's and PDD-NOS did not. It is not clear how these categories are going to be handled in terms of service provision.

### **Assessments in Occupational Therapy**

School aged children with ASD have functional limitations that impact their main occupations of school and play. Both of these areas rely heavily on socialization, which is difficult for those with ASD. Also, learning in general may be difficult if the child is intellectually disabled, or has issues with maladaptive behavior and sensory processing. Identifying and addressing these difficulties for each individual child can help them optimize their school experience and reach their full potential. Occupational therapists often assess these key areas and determine the child's skills and function.

Evaluation allows occupational therapists to accurately determine areas of strengths and weaknesses, and help guide intervention planning. Multiple assessments are available to occupational therapists working in school settings. In a survey completed by 219 school-based therapists in the Southwestern United States, researchers found The Peabody Developmental Fine Motor Scale (PDMS-2) and Bruininks-Oseretsky Test of Motor Proficiency (BOT-2) were used most frequently by occupational therapists (Burtner, McMain & Crowe, 2002) although this varies by state. Researchers also found a trend toward more functional school-based assessments since the Individuals with Disabilities Education Act (IDEA) came into existence. The appropriate test for the individual child is an important aspect in the assessment process. Due to the wide array of assessments available, it is important to look at the validity and reliability of the test. Examination of the PDMS-2 and the BOT-2 show the positive validity and reliability of each test.

The PDMS-2 is a developmental motor test that evaluates both fine and gross motor skills for ages birth to five years old. A study conducted on eighteen children, who were identified with fine motor problems and had non-neurological disorders, examined the reliability and validity of the Fine Motor Scale of Peabody Developmental Motor Scales – second edition (PDMS-FM-2). The Peabody was found to be a good determinant of fine motor ability. The study examined children with and without fine motor delays and found that test-retest reliability and inter-rater reliability met acceptable criteria for the fine motor tasks, except for in-hand manipulation. (VanHartingsveldt, Cup & Oostendorp, 2005).

The BOT-2 assesses many different client factors of the child including fine motor, gross motor and visual motor skills. The BOT-2 is a standardized and norm referenced test for ages 4-21 years. Looking at several studies, internal consistency has been reported as high (Deitz,

Kartin & Kopp, 2007; Wuang & Su, 2009). Another study reported the need for more research in order to determine usefulness of the BOT-2 for children with ASD (Bruininks & Bruininks, 2005). Although extensive research has been conducted on the use of specific tests for general delays in children, limited research has been done about current practice of occupational therapy assessments for children with ASD. An older study, regarding occupational therapists in the United States, revealed that therapists used several different assessments to evaluate children with ASD (Watling, 1999). Researchers found The Informal Sensory Processing History, which is not a test but a process, was used most frequently, with 69% of therapist reporting using it frequently. The Sensory Profile was also used frequently with 50% of therapist reporting its use.

Current research completed in Australia about current practice with children with ASD found that the two areas most assessed by occupational therapists were fine motor skills and sensory processing (Kadar, et al., 2012). The Sensory Profile was the most frequently used, with 80.3% of occupational therapists frequently using it. Since the use of the Sensory Profile is commonly used with children with ASD, it is important to look at the efficacy of the assessment with this specific population.

Several studies have reported the effectiveness of the Sensory Profile and Short Sensory Profile in children with ASD. A study completed by Tomcheck and Dunn (2007) found that the Short Sensory Profile was effective in identifying sensory processing disorders in children with ASD. Furthermore, a study found The Sensory Profile is accurate in identifying discrepancies in sensory processing in children with ASD (Brown, Leo & Austin, 2008). Discrepancies were found in children with ASD using the Sensory Profile in the Sensory Seeking, Emotional Reactive, Low Endurance/Tone, and Oral Sensitivity, Inattention / Distractibility, Poor Registration and Fine Motor / Perceptual categories (Watling, Deitz & White, 2001).

Due to the rise in ASD diagnoses, new occupational therapy assessments for children with autism are being established. Development of new assessments looking at specific components of ASD are important, especially when some components are not assessed by current occupational therapy assessments. Kramer, Coster, Kao, Snow and Orsmond (2012) examined the need for substitute methods of assessing adaptive behavior in children with autism. Researchers looked at elements of the Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT), and strength based assessment, to see if alterations in the assessment would accurately display the performance of children with ASD. Inclusion of the specific modifications and environmental supports that were previously in place for children with ASD enhanced the performance of children with autism on the assessment. The inclusion of established environmental supports created a more accurate representation of function in children with ASD. Another modification involved adjusting the scaling systems and creating a more parent friendly assessment. This created an opportunity for parents to give feedback about their experience. With interviewing parents, the study found that parents preferred assessment formats to be quick, simple, and uncomplicated. Parents preferred the assessment in which they could focus on their child's strengths. This is in contrast to developmentally appropriate performance, which may not allow the child to demonstrate their individual assets. Assessments provide a foundation to determine appropriate intervention and goals for children with ASD. When developing this individualized intervention, it is essential to assess the performance and behaviors of the child with ASD in order to acquire a successful outcome (Case-Smith, 2008). With most interventions, the occupational therapist considers the child's strengths and areas for improvement.

## **Occupational Therapy Interventions**

The predominant characteristics of ASD can lead to significant barriers to full engagement in daily occupations. Occupational therapists are among the health care practitioners who are trained and well qualified to intervene with children with ASD in order to increase participation in various environments, including the child's school setting. The domain of occupational therapy services address participation in meaningful occupations including activities of daily living, instrumental activities of daily living, education, work, leisure, play, and social participation. In the school setting, the occupational therapist main concern is regarding the child's ability to participate in school-related activities, including classroom activities, lunchtime, after school activities, and recess. An occupational therapist will address the occupational barriers that ASD presents to a child through the use of occupation-centered activities that take into account the child's contexts and physical environment (Case-Smith, 2008). Occupational therapists assess the child with ASD and then work directly with the child, as well as the parents, caregivers, educators, and other team members to best determine a successful intervention (Tomcheck, LaVesser, and Watling, 2010).

While informative guidelines have been developed to address the practice of occupational therapy at the individual level, little research has been done regarding specific occupational therapy intervention within schools. When working collaboratively with children with ASD, occupational therapists primarily focus on areas of attention, behavioral and emotional regulation, social skill development, sensory processing, motor function, play participation, and self-care skills (Tomcheck, LaVesser, and Watling, 2010). When working for an organization, such as a school, the occupational therapists may also focus on improving the structure, resources, and services to best address the needs of the child with ASD (2010). At the

organizational or individual level, occupational therapy intervention may also involve adaptation of the environment and use of assistive technology (Asher et. al., 2010). The physical, social, and cultural contexts are also considered when implementing the intervention. The occupational therapist intervenes with children diagnosed with ASD through the use of sensory integration and sensory-based interventions, relationship-based interactions, developmental skill based interventions, and behavioral management strategies (Case-Smith, 2008).

### **Sensory-Based Interventions.**

Sensory processing disorder (SPD) is common among children with ASD (Dovydaityene, Vaitiekute & Nasvytiene, 2013). Children with ASD tend to have more difficulty with auditory, visual, vestibular, tactile, and oral sensory processing skills (2013). All of these sensory difficulties can significantly impact the child's engagement in meaningful occupations, especially in the school setting. Unusual sensory responses to stimuli have been reported in 42-88% of children with ASD (Baranek, 2002), making this issue common and important to address. With sensory processing disorders, the occupational therapist plans an intervention in hopes of accomplishing improved sensory modulation, and improved ability to integrate sensory information to form improved perceptual skills, attention, behavior, academics, and social skills.

Originally developed by A. Jean Ayres (Ayres,1976) , sensory integration interventions are implemented to enhance modulation, organization, and integration of environmental stimuli primarily through activities that engage the somatosensory and vestibular senses (Baranek, 2002). With this enhancement, the child is expected to improve adaptive responses. When using the sensory integration approach, an occupational therapist will often use play as a basis for the intervention. Incorporating activities provides intrinsic motivation for the child (Baranek, 2002).

Sensory integration therapy is one of the most common intervention strategies implemented for children with ASD. Researchers determined that 99% of 72 occupational therapist participants working with children with ASD regularly deliver this intervention (Watling, Deitz, Kanny, and McLaughlin, 1999). Previous research regarding the effectiveness of sensory integration has mixed conclusions (Watling, Deitz, Kanny, and McLaughlin, 1999). Sensory integration therapy has received some criticism due to its questionable assumptions, such as a hierarchically organized nervous system (Baranek, 2002). The assumption however, that senses have a great effect on an individual's learning, is accepted (Baranek, 2002). Atypical reactions to sensory stimuli, such as ear covering, yelling, and evident hearing loss, may be associated with auditory hypersensitivity or hyposensitivity (Sinha, Silove, Hayan, & Williams, 2011). Auditory processing difficulties are also common among children with ASD, with one study noting 100% of the participants exhibiting this difficulty (Greenspan & Wieder, 1997). Occupational therapists often provide an intervention that addresses this issue. Interventions, such as auditory integration training (AIT) and therapeutic listening have been developed to target various features of ASD. Both auditory integration training and therapeutic listening™ involve listening to individualized, electronically modified music delivered by headphones on a daily schedule (Miller-Kuhaneck, 2004). Research has found that atypical sensitivity or insensitivity, regardless of hearing ability, is associated with learning and behavior issues of individuals with ASD (Al-Ayadhi, 2013). In a study conducted in 2013, seventy-two children with ASD received a two-week auditory integration training for thirty minutes, two times per day. All participants demonstrated improvement in social awareness, social cognition, speech, and communication at a 6-month follow up (Al-Ayadhi, 2013).



**Relationship-Based Interventions.**

Occupational therapists will frequently facilitate relationship-based interventions in order to develop and improve peer interactions. The interventions will often incorporate social games and play, and are ideally performed in a school setting (Hwang and Hues, 2000). In the school setting, the occupational therapist will design a structured activity with the child and peers in order to promote social interaction. The goals for relationship-based interventions are used to address difficulty with socialization and peer relationships (Asher et. al., 2010). To achieve the best outcome, the occupational therapist will promote environments that encourage positive social interaction and cooperative play.

Relationship development intervention™ (RDI ) is a specific intervention that aims to help children with ASD develop stronger social skills and build social connections (Gutstein & Gutstein, 2009). In this process, the occupational therapist trains the teacher or caregiver to provide daily opportunities for successful completion of graded tasks by incorporating adult scaffolding. The intervention consists of gradually introducing the child with unpredictable and increasingly challenging situations, in hopes to increase the child's flexibility and adaptability. The parents are encouraged to incorporate this strategy into the child's everyday routine. The objectives for RDI™ include learning from the emotional experience of others, controlling behavior, and improving adaptive thinking. Other objectives include improved rational information processing, ability to anticipate a situation, and expressive language (Gutstein, Burgess, and Montfort, 2007).

Children with ASD often exhibit difficulties with social interaction and communication skills, which can be addressed through Floor Time Play (FTP) (Greenspan & Wieder, 2006). Floor Time Play, developed by Stanley Greenspan, is an intervention approach that takes place in

the child's environment, and is centered on the child's preferred occupations (Dionne & Martini, 2011). During this process, the therapist will engage the child at their level and present the child with activities that the child enjoys, while establishing back and forth play. This method is provided to increase shared attention, engagement, and problem solving. There are few published research articles regarding the effectiveness of the intervention. However, in a study conducted in 1998, 58% of children had good to outstanding outcomes (Greenspan & Wieder, 1998). The occupational therapist will often educate the child's family and caregiver in order to integrate this method into the child's daily life.

According to Asher et al. (2010), elements of successful intervention with children with ASD are time intensive and include early involvement, actively involved families, and highly trained staff. Also, the intervention plan should be a carefully designed, relevant, research-based intervention that will contribute to generalization and maintenance of skills. Before starting such interventions, the occupational therapist will complete an evaluation of strengths and limitations, and subsequently relate the implications of the findings to daily occupations. Once the barriers are clearly understood, the occupational therapist and IEP team will identify an individualized intervention with the objective of maximizing the child's function in daily occupations.

### **Individualized Educational Plan**

The U.S. Department of Education (2004) defines an IEP as a written document that is created for a student who is or will be in Special Education programs. An IEP highlights student's learning goals that will be achieved over the year as well as teaching strategies, special services and resources that will be provided to achieve this goal (Prunty, 2011). Through the Individuals Disabilities Education Act (IDEA), Special Education law has authority to mandate the IEP process (Lewis, 2005). State regulations vary across the United States in how guidelines

are determined for qualifying students for special education (Foster, 2012). The IDEA of 2004 mandates that free and appropriate education be provided for those who meet the criteria for eligibility and requires the inclusion of information such as the students present level of function, measurable goals, and accommodations that will be implemented following the write up of the IEP. In addition, the IEP includes objective criteria, schedules and evaluation method for determining if goals have been achieved (Lewis, 2005). Individualized education plans are reviewed annually and signed by parents in order to receive special education services. The IEP process has specific steps to ensure the most appropriate placement and services are provided for each student.

The first step of the IEP process is a pre-referral that documents the student's challenges, examines the student's progress, and tests for effectiveness of classroom accommodations and modifications (Lewis, 2005; Ruble, 2010; Smith, 2011). The next step is the referral that can come from parents, doctors, nurses or social service agencies (Lewis, 2005; Ruble, 2010; Smith, 2011). This step is often associated with identifying children that are at risk or have signs of a disability. The third step involves evaluations that are conducted to determine if in fact the student has a disability (Lewis, 2005; Ruble, 2010; Smith, 2011). The fourth step is identifying the eligibility for the student to special education services. Next, the development of the IEP may be conducted in which the IEP team begins to outline the most beneficial programs and services that the student is eligible to receive (Lewis, 2005; Ruble, 2010; Smith, 2011). Following this, the team works toward the goals and objectives that the IEP team has made an agreement upon. The final step of the IEP process is the evaluation and review of the plan (Lewis, 2005; Ruble, 2010; Smith, 2011). In most states, the student's IEP is reviewed once a year. The review step is crucial to the IEP process because it determines how effective the programs and services have

been and what gains the students have made towards their goals (Smith, 2011). The revision of the IEP allows for the IEP team to adjust goals and assess effectiveness and alternatives to the student's academic well being.

### **Barriers for Parents in the IEP process**

The IEP process is complex and is made up of many aspects that can be challenging for parents to comprehend. This complexity creates barriers that often restrict parent involvement. Parents whose English is their second language, or who have immigrated to the United States can be presented with barriers that restrict their involvement in the IEP process (Prunty, 2011). Parents of different cultural backgrounds often value the relationship between the parents and the educator and feel it is not their right to question the academic plans that the professions have designed for their child (Harry, 1992). Parents, in this case, often remain passive in the IEP process, fearful that speaking up may result in conflict with the teacher and concern that the teacher might in turn "take it out" on their child. As a result, parents often feel that they don't have as much of a say as the other contributors of the IEP (Harry & Jung, 2011). This may leave the parent feeling isolated and as though they are not being heard. In turn, this may cause difficulties addressing what they believe is best for their child.

The language used in IEP meetings can also present as a barrier for parental involvement, especially if English is not the parent's first language (Jung, 2011). Parents, therefore, may not fully understand the process of the IEP or what the plan is for their student. Translation may not be adequate and information may not be communicated to the parents in a way they understand. Although translators are provided by the school district to parents who are not primary English speakers, words and concepts are often lost in translation. Additionally, translators working with the school district may not have the child's best interest in mind but rather their alliance to the

school district (2011). Primary information about the child's strengths and weakness is commonly received from the parents. However, if the parents are not able to relay the information in their own language, essential aspects of their child's strengths and weakness may not be expressed, which may result in inappropriate placement or inadequate services.

Language presents as a barrier to parental involvement not only for native speaking parents but also for parents who speak English as their first language. Even when parents are proficient in English they can still become perplexed with the educational jargon and acronyms used, which adds to their lack of understanding of the school system (Prunty, 2011). During the IEP process, parents often become overwhelmed and uncertain about what the best outcome is for their child creating a sense of vulnerability and feelings of inferiority. It is important for school districts to provide parents with supports to allow them to actively participate as members in the IEP team to contribute relevant information and allow for the more appropriate placement of the student.

### **Parent Advocacy**

Gartin et al. (2002) defines advocacy as presenting an argument that coordinates with a cause to assist in guiding a decision. Studies have shown that parental involvement in their student's education positively affects their academic achievement (Epstein, 1995; Heyman & Earle, 2000). The IDEA of 2004 gives parents the right to make educational decisions for their child (Foster, 2012). In order for a parent to effectively advocate for their child they must know the child and understand the disability. Parents must take an active role in the IEP process to represent the child's best interest by communicating their child's strengths and challenges (2012). Parents should be well informed of both the special and general educational laws in order to make the best decision for their child. By asking questions and seeking further

knowledge, parents can truly advocate for their child (Kalyanpur, Harry & Skritic, 2002).

Advocacy for students with special needs begins by seeking further knowledge of programs and services and continues to parental consent before assessment of the child's and implementation of the IEP.

Education is a key factor to enhance parent advocacy in the IEP process. In a study by Fish (2008), 44% of parents surveyed gained information about the IEP process through self-education and 31% of these parents desired more information. Results showed that parents who were more educated around the IEP process had better meeting outcomes and the IEP more effectively served their children's special education needs. Stoner et al. (2005) found that providing parents research-based information was a key aspect in improving IEP experiences. This information shows that informed parents are better equipped to successfully navigate the IEP process and feel empowered to help their child receive the resources they need.

### **Statement of Purpose**

ASD is a disorder that impacts behavior, social interactions and communication of children. These factors can affect the development of the child, as well as functional behavior throughout his or her education. Under IDEA 2002, children with disabilities are required to receive education with accommodation and modification as needed. This process allows children with ASD to undergo the IEP process, in which appropriate services are allocated for each individual child.

In Marin County, empowering parents of children with ASD to advocate for the needs of their child can be an important aspect in receiving specialized services. One way to empower parents is to educate them on the specific methods to determine service, particularly surrounding occupational therapy services and the IEP created for children with ASD in public school districts. A resource guide was developed for parents of children with ASD to supplement their knowledge about the occupational therapy assessments, goals, interventions, terminology and role in the IEP process in order to further empower them when advocating for the educational needs for their children. The objectives for the project that were addressed are as follows: 1) Develop an easily accessible web-based resource guide for parents and other interested members of the community to gain information about the Individualized Education Process in Marin County; 2) Develop a web-based resource guide that informs parents of the basic occupational therapy assessments, goals, interventions, and terminology which are being used by school-based occupational therapist for children with ASD.

## Theoretical Framework

In order to direct the resource guide toward the parents of children with ASD, extensive research and knowledge regarding the effectiveness of learning strategies for adults is necessary. Adult learning theory, and specifically the development of andragogy, addresses the importance of developing an educational program that is geared toward effective adult learning. Adult learning theorists provide research to explain how adults assimilate knowledge, skills, and attitudes (Abela, 2009).

The term andragogy, first developed by Alexander Kapp in 1833, is used to describe the normal process by which knowledge is gained by adult learners (2009). For many years, this theory was largely disregarded in the United States. It was not until the 1980's, when Malcolm Knowles supported and expanded this theory, did the United States take note of this elaborated concept (2009). The comprehensive explanation addressing the development of knowledge with adults makes this theory beneficial for the parents, who are the intended population of consumers for the resource guide.

Andragogical theory is based on four assumptions, all of which differ from pedagogy, or the learning process for children (Knowles, Malcolm & Elwood, 2011). These four assumptions describe the learner's change in self-concept, role of experience, readiness to learn, and orientation to learning (2011). The four assumptions will help guide the development of the web-based resource guide, and provide a basis for organization and educational approaches. The assumption regarding the individual's self-concept describes the adult as independent and self-directing. As an individual enters adulthood, he or she takes on new roles and responsibilities. The roles and responsibilities reflect the adult's right to autonomy and self-determination. Many parents of children with ASD will often search for relevant information in



order to gain confidence when advocating for their child. If the parent does not have the educational background, he or she may lack the confidence to ask for the entitled accommodations or services. The adult also experiences a desire to be perceived by other individuals as independent and self-directing (2011). Consequently, adults tend to be resistive to learning situations that involve being treated like children (2011). The resource guide is age-appropriate, and available upon request or for self-directed search. Adult learning methods, combined with the necessary information, is desirable in order to help achieve parent empowerment.

Knowles's second assumption considers the personal experience of the individual. As a person ages, he or she gains experience that acts as a resource for learning (Henry, 2011). The adult's experience is a broad foundation on which to build novel learning. According to Knowles, because of the great amount of life experience, adults have fixed habits, routines, and patterns of thought. As a result, adults have the tendency to be less open minded than children (2011). Knowles also believed that adults have a tendency to strongly rely on their own experience when defining their own identity (2011). Since the adult's experiences are strongly valued, it becomes increasingly important to relate the educational content with the consumer's personal life situations. The completed resource guide is accessible on the Matrix Parent Network and Resource Center website. Individuals visiting this website are often parents of children with special needs, including ASD, searching for resources to aid the process of advocating for their child. The needs assessments for this project helps to determine the areas of the IEP process and occupational therapy services that are most problematic for the parents. The information incorporated in the resource guide, therefore, is relevant to the parent's life experience regarding their child.

According to Knowles, the adult's readiness to learn also depends on the designated social roles (Knowles, Malcolm & Elwood, 2011). The desired information that is actively sought by the adult learner is dependent on his or her social roles (2011). The roles can stem from various contexts such as work, family, or any other relevant organization. The individuals seeking additional information by using the resource guide will likely be a parent or caregiver of a child with ASD who has expressed a need for further information about occupational therapy and the IEP process. The information provided in the resource guide is a reflection of the parent's needs. The needs assessment of this project, a parent survey, sought to identify the primary concerns of the parents of children with ASD regarding the IEP process and occupational therapy assessments. The information provided in the resource guide is based on the results of the parent survey to assure relevance to the parent's current needs.

The fourth assumption in Knowles's theory describes the orientation to learning. According to Knowles, adults tend to seek information based on the challenges he or she is currently having (2011). As stated by Knowles et al. (2011), "He wants to apply tomorrow what he learns today (p.61)." The needs assessment for this project, distributed to the parents of children with ASD, sought to discover the gaps of knowledge regarding the IEP and occupational therapy assessment process. Since the results from the needs assessments helped to determine the information provided in the resource guide, parents or caregivers are expected to benefit from the finished product. The provided information guides the learners through the process of problem solving.

The theory of andragogy helps to guide the project process and implementation. Adult learners view education as a progression toward developing increased competence in order to further their potential in life. The information provided in the resource guide will allow parents

to further understand the IEP and occupational therapy process, and in turn be a resource for advocating for their child with ASD. When knowledge of the IEP and occupational therapy process is gained, the parents may feel more comfortable advocating for a positive change in their child's life.

## **Methodology**

### **Design**

The design of this project was chosen based on the needs of the Matrix Parent Network and Resource Center (Matrix). The project developers chose to create a web-based resource guide to empower parents by providing knowledge related to occupational therapy in the IEP process. The resource guide includes information on specific occupational therapy assessments used in school-based treatment, deficits the occupational therapist addresses in a school based setting, ways to create an effective alliance with an occupational therapist and other team members, general steps in the IEP process for children with ASD, and receiving occupational therapy services. In order to gain information about specific areas of knowledge parents of children with ASD were lacking, to understand assessments utilized by school-based occupational therapist, and determine how an effective alliance can be created between parents and occupational therapist, the project developers sent out one web-based survey for school-based occupational therapist in Marin County and one web-based survey for parents of children with ASD. The information provided was utilized to inform the design of the project regarding areas of focus as well as to gain relevant information for the parent guide. The final resource guide is available on the Matrix website.

### **Agency Description**

Matrix is a non-profit organization that empowers parents to advocate on behalf of their children with special needs. The focus of Matrix is to provide information and support to parents. This is done in several ways including parent-to-parent support groups, family resource centers, and family empowerment centers in which parents collaborate with professionals to gain training and information (Matrix Parent Network and Resource Center, 2012).

## **Target Population**

This project was developed for parents or primary caregivers of children with ASD, and parent advocates in the IEP process. Due to the variety in services, IEP process, and funding for each school district, we chose to focus on Marin County schools. Although Matrix provides services for parents in Sonoma and Solano Counties in addition to Marin County, all information available in the resource guide may not be applicable to Sonoma and Solano school districts.

## **Project Development**

Several steps were taken in the development of this project. First, a meeting was held with a representative from the Matrix organization. From this meeting we were able to identify ideas for what would most benefit the parents at Matrix. Consequently, two main themes were identified as being most important to the organization; understanding occupational therapy goals and services and how to collaborate with occupational therapist in the IEP process. Next, two online needs assessments were created, one for parents of children with ASD and one for occupational therapists working within the identified school districts. In order to find eligible participants for the surveys several methods were used. Snowball sampling via email was utilized to get in touch with occupational therapist working in the surrounding school districts, beginning with a known occupational therapist. An online survey of eight questions was distributed. The aim was to identify current interventions and assessments being used with children with autism, as well as ways in which parents could improve communication and collaboration with occupational therapist in the IEP process. The results showed that the BOT-2, Sensory Processing Measure and Sensory Profile were the most used assessments (Appendix A). The surveyed occupational therapists identified several intervention methods they currently use with children with ASD. Results varied greatly among therapists but general trends included the

used of modification and accommodation of both the school environment and specific tasks, as well as fine and gross motor activities, and handwriting interventions. When asked what advice they would give to parents, a common theme among respondents was helping parents understand what interventions can be provided by school-based occupational therapy as compared to outpatient occupational therapy. Another theme was communicating with both school based and outpatient OTs, while including both in the IEP process.

To connect with participants for the parent survey, the Marin Autism Collaborative and Matrix distributed an email requesting participation in a 12-question mixed-methods online survey (Appendix B). Some participants in the occupational therapist survey were also asked to distribute the survey to parents who may be interested in participating. Inclusion criteria for participants was that they had a child with ASD who had gone to school in the identified school districts. In total, twenty-eight parents responded. The ages of the children ranged from 3-20 years old, went to a variety of schools in the districts, and all but one family had received occupational therapy services.

Seven Likert scale questions were presented to the parents, each including a comments section pertaining to the question. Parent responses about their general knowledge regarding the IEP process and their general understanding of occupational therapy role, intervention, and assessment process were positive with more than 50% responding agree or strongly agree for each question (Appendix A). However, qualitative responses varied greatly from the Likert-scale answer. Only two respondents stated “strongly disagree” for the above questions, however both had children who were too young to enter the public school system. This indicated that providing appropriate education before entering the IEP process could be beneficial to parents with ASD.

Qualitative results varied greatly from the responses found on the likert scale. Three common trends were found within the qualitative results. The first was confusion about the IEP process and all the information given in the beginning. Three participants, commented that getting outside help from a source, such as a legal advocate, attorney or Matrix, made a difference in their understanding of the IEP process. However, when asked if they were able to successfully advocate in IEP meetings, several participants indicated their discouragement of the process, as seen in comments such as, "...basically they make all the decisions and I don't really have much say" and "it does not matter, districts do as they please." The second was the need for hiring an educational advocate, a lawyer or seeking an advocacy organization, such as Matrix Parents Network, to help understand the IEP process and have an expert advocate for their child's needs. The third was a feeling of frustration, both at the lack of availability of services and not being able to receive services for an extended time period. One parent stated, "It frustrates me that my child doing well hinders services." These three trends in the needs assessment demonstrated a greater need for increased education in the beginning of the IEP process for parents of children with ASD.

The project developers targeted the parents of children with ASD associated with the Matrix organization. The goal was to establish an easy to use manual to help parents understand occupational therapy in IEP process. Using adult learning theory as a guide, the project developers then looked to create the guide. By using the information that was gathered from the needs assessment, as well staying in communication with local occupational therapists who are working in the schools, the content of the guide was formed. It was important for the project developers to speak with a local school based occupational therapist to gain a better understanding of the different assessments used in the school districts. Once the manual was

completed, it was presented to the parents of Matrix and an online version was sent to the director of parent services to be posted on the Matrix website. Lastly, a post-assessment was given to determine the effectiveness of the product as well as its ease of use.

### **Ethical Considerations**

There are minimal ethical considerations in the proposed project. One component that was of utmost importance was the ability to provide an informational guide complied with current terminology and standards of practice within the educational and occupational therapy communities. Another aspect to consider was keeping all information from the needs assessment confidential. Although specific names were not requested, email addresses were asked for voluntarily. The email addresses were used to identify potential post-evaluation volunteers. Although there are few considerations at this time, as concerns arise, confidentiality and anonymity of our participants will be at the forefront of this project.



## **Project Implementation**

In order to connect with participants for the parent survey, the Matrix agency distributed an email requesting participation in an online survey. Two surveys were available online (Appendix C). One survey was completed by the local school based occupational therapy, while parents who are affiliated with the Matrix agency and have children who are diagnosed with ASD completed a separate survey. The survey asked the parents which areas they would like more clarity on during the IEP process, as well information on the assessments that are frequently done in the schools. The needs assessment was completed and submitted by twenty-eight parents and seven occupational therapists, and results were sent to the project developers.

Once the needs assessments were collected, the project developers assessed each question to determine which areas of the IEP process and what assessment to include in the resource manual. Eight parent participants expressed how difficult it is to understand what the IEP process and occupational therapy can truly offer their child. One participant stated, "It was very hard in the beginning to understand all the process." The majority of the parent participants expressed frustration regarding how they are unaware what the school district can provide for their child and what the assessments are really measuring. Collectively, the participants wanted information about; occupational therapy goals, assessments, and what occupational therapist can work on with their child in the school setting.

After reviewing the needs assessments from both the parent and occupational therapist participants, the program developers decided to include the trends found in the surveys. These trends include commonly used assessments, evaluations and interventions used in the school settings, understanding occupational therapy goals and how to collaborate with their child's occupational therapist. Program developers broke down each section with charts and examples

to ensure ease of readability. The most commonly used OT assessments in a school setting were broken into four sections; “Type of assessment,” “Specific assessment name,” “specific skills examined,” and “how this assessment administered?” Occupational Therapy intervention was broken down into three sections. The first sections defined what the skill was, the second was, “importance in a school setting,” the third, “how will this skill transfer to everyday life,” and the final “example interventions.” Occupational therapy goals were broken down into two sections, “example of annual goal,” and “relation to school performance.” The final section of the resource manual, “collaborating with your occupational therapist” was broken down to three sections labeled, “how can I better understand OT lingo?” “What questions should I ask my occupational therapist,” and “How can I support my child’s occupational therapy at home. Program developers also included a brief overview of what occupational therapy is, what occupational therapist can do in a school setting, how their child can benefit from therapy, and how their child may be able to obtain services from the school district.

The program developers then researched and compiled information about each section. Information for the resource manual was obtained through peer-reviewed evidence-based practice articles using American Journals of Occupational Therapy and the Dominican University of California Library databases. Keywords such as “occupational therapy,” “autism,” “Individual Educational Plan” and “school assessments,” and “school-based interventions” were used in each search engine to obtain studies conducted over the past five years.

Once the resource manual was completed, electronic copies were sent out to the thesis advisor, Matrix organization, Marin Special Education Local Plan Area (SELPA), and parent participants for review. The project developers made changes based on the feedback given.

Once this process was completed, the final resource guide was sent electronically to Matrix in December 2014 to be published on the website in January 2015.

The purpose of this project was to develop an evidence-based resource manual that clearly outlined key information about what occupational therapist can do in the schools, (assessments, interventions and goals) along with including information about the IEP process so parents can have a better understanding of their rights and what occupational therapist and the school district can do for their child. This resource manual can be beneficial for parents of children with autism as well as occupational therapists working in the school district.

## Project Evaluation

Program developers developed and administered a resource guide evaluation to the participants (Appendix C). The participants were asked to review the resource guide and complete an evaluation of the guide. The purpose of the resource guide evaluation was to examine if the resource guide included valuable and educational information for the parent of children with autism as well as the occupational therapist who treat children with ASD in the school setting.

The program developers designed a ten question Likert Scale, in which the participants were asked to rank different aspects of the resource guide by selecting; “strongly disagree” “disagree,” “undecided,” “agree,” or “strongly agree.” Participants were also encouraged to include comments to determine if the resource guide was resourceful and educational in aspects such as understanding goals, assessments and documentation, and understanding the IEP process. Participants were encouraged to include any comments or suggestions not included in the evaluation that they would like to bring to the program developers attention.

Program developers received nine evaluations at the conclusion of a two-week review period. Nine parents of children with Autism completed evaluations. Eight out of nine parents answered that they “strongly agree” that they clearly understand the role of the occupational therapist in their child’s education. Respondent 2 expressed that parents new to OT and the IEP as well as “veteran” parents would benefit from the guide and is a great starting point. Respondent 7 expressed the importance to remember “some parents may need the IEP and assessment process explained and reviewed several times before they grasp its concepts and method of delivering info.” After reading the resource guide, the majority six of the seven respondents selected “disagreed” or “neutral” in regards to adding other components to the guide

would enhance understanding of occupational therapy goals, assessments and documentation, and IEP process. The remaining two respondents commented with remarks such as, “ I believe most of the areas of uncertainty were well covered in the manual.”

### **Discussion, Summary, and Recommendations**

As discussed in the design section of this paper, the planning and implementation of this project was reliant on The Matrix Parent Network. In working with this agency, the importance of communication was learned. To achieve the projects goal of providing an accurate manual for parents, caregivers, or teachers to explain occupational therapy and the IEP process in the school setting, common and necessary themes had to be addressed. For example, it was crucial for the project team to know what concepts in the IEP process were confusing for parents so the manual would provide the information parents were seeking. It was important that the information was written in an understandable and straightforward manner. In addition, when doing a large project such as this one, changes will occur during the course of the project, new research will arise, project demands will change, expectations of the recipient may fluctuate, and all of this in turn may result in a minor or drastic change to the project. There were no major changes to the project, however with every bit of feedback received, minor changes were made, in order to produce a clear and comprehensive guide.

Based on the feedback the resource manual received in the surveys done by parents, feedback from local Marin county occupational therapists, and the feedback received from practitioners and attendees of the Occupational Therapy Association of California (OTAC) conference in October 2014, the resource guide was well received and perceived as a very useful tool. An exit survey was posted online and distributed via email to the same parents that participated in the initial project survey. Of the twenty-nine parents who did the initial survey, nine of them did the exit survey. In this exit feedback survey, after reading the resource guide only one person felt there were additional components needed to enhance their understanding of occupational therapy goals, IEP, and assessments and documentation, however those

components were not identified. Comments such as, “I feel the guide is successful at it's stated objective,” and “After 8 years with ASD in our lives and 5 in the school system, I have yet to see the subject material presented here, offered or even spoken of in such a succinct manner. I would recommend it to anyone facing an IEP,” and “Really great guide, even for "veteran" parents” were received. Comments such as these draw upon the conclusion that the guide will be well-received and enjoy by many. Additionally, our contact from The Matrix Parent Network was thrilled with the end product and is excited to see how the guide will be received by others at Matrix.

The result of this project is a multidimensional resource guide for parents of children with autism to help them navigate the IEP process with a focus on school based occupational therapy in Marin county. The implications of this project are for parents and caregivers to better understand the services their child may be eligible to receive through the school system, what they can do to help their child, and the clarification for jargon that may be confusing to them. The resource guide aims to help the profession as a whole, through empowering parents and consequently allowing them to support their children’s therapeutic goals. Another result of this project is hopefully the parents feel more confident in their knowledge of the system and will be better prepared to advocate for their child.

Although the majority of the feedback received was positive, there were a few recommendations for future projects. At the OTAC conference an attendee stated she would like to see the guide expanded to fit other diagnoses, especially diagnoses that can sometimes get overlooked. A next step to this project may be to add more to this guide to include other diagnoses or to make complimentary guides that cover a variety diagnoses. Another future step

for this project may be to make the guide for school districts. This guide is specific to the Marin county area and the guide would benefit more people if it could be more widely distributed.

Limitations of the research guide include interviewing a limited number of occupational therapists in the areas. Identifying a wider network of therapists and building rapport before the study may have enhanced the feedback and allowed us to gain more feedback from therapist currently working in the school districts. Additionally, the parent feedback that was received was from a small number in a specific area. Both of these elements limit the generalization of the resource guide and the views and opinions stated might not be representative of the greater population. In order to make the guide benefit a larger population a larger and more diverse sample of both therapists and parents would need to be sampled.



## Conclusion

Current data shows an increase of ASD among children (CDC, 2014). Due to the rise in ASD, there are more children than ever that need specialized services. In order to receive these services, parents must navigate IEP meetings and advocate for their children. However, barriers such as use of jargon or unclear documentation can affect a parent's ability to understand the rights of their child (Prunty, 2011; Donaldson et al, 2004). Because parent advocacy can be such a crucial component of a child's education, it is important to empower parents by providing them with information. A critical aspect of empowerment is educating parents, however parent education may be overlooked and underestimated. Education can be a critical way in which parents are provided the knowledge to advocate for their children and help them reach their academic goals. Research shows that parents who are more educated about the IEP process help better serve their children's educational needs (Fish, 2008).

As a means to create a comprehensive guide, gaps in parents' knowledge surrounding the IEP and occupational therapy process were determined, so that the guide can accurately inform parents and provide them with the informational basis needed to advocate for their child. This proposal sought to provide parents with an overall guide to understand the IEP process, occupational therapy assessments and goals, and the role of occupational therapy within the treatment of ASD.

## References

- Abela, J. (2009). Adult learning theories and medical education: A review. *Malta Medical Journal, 21*(1), 11-18.
- Al-Ayadhi, L., Majeed Al-Drees, , Abdul, & Al-Arfaj, A. (2013). Effectiveness of auditory integration therapy in autism spectrum disorders--prospective study. *Autism Insights, (5)*, 13-20. doi:10.4137/AUI.S11463
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Ashar, A., Collins, A., Crabtree, L., Demchick, B., George, B., Harrington-Kane, E., . . . Watling, R. (2010). What is occupational therapy's role in supporting persons with an autism spectrum disorder? *The American Occupational Therapy Organization*,
- Autism Speaks. (2013). What is autism? Retrieved September/28, 2013, from <http://www.autismspeaks.org>
- Ayres, A., & Robbins, J. (1979). *Sensory integration and the child*. Los Angeles, Calif.: Western Psychological Services.
- Bakken, N., Calton, K., Hyland, M., Landau, S. & Wilbarger, J. (2014). Understanding occupational therapy in the school setting. Retrieved from [http://www.matrixparents.org/1-information/otherguides/pdfs/OT\\_ResourceGuide\\_forASD\\_Students.pdf](http://www.matrixparents.org/1-information/otherguides/pdfs/OT_ResourceGuide_forASD_Students.pdf)
- Baranek, G. T. (2002). Efficacy of sensory and motor interventions for children with autism. *Journal of Autism & Developmental Disorders, 32*(5), 397-422.

- Brown, T., Leo, M., & Austin, D. W. (2008). Discriminant validity of the sensory profile in Australian children with autism spectrum disorder. *Physical & Occupational Therapy in Pediatrics, 28*(3), 253-266.
- Bruininks, R. H., & Bruininks, B. D. (2005) *Bruininks-oseretsky test of motor proficiency, second edition* Pearson, 19500 Bulverde Road, San Antonio, TX 78259
- Burtner, P. A., McMain, M. P., & Crowe, T. K. (2002). Survey of occupational therapy practitioners in southwestern schools: Assessments used and preparation of students for school-based practice. *Physical & Occupational Therapy in Pediatrics, 22*(1), 25-39.
- Case-Smith, J. & O'Brien, J.C. (2010). Developmental disabilities. *Occupational therapy for children* (6th ed., pp. 168-171). Maryland Heights, Missouri: Mosby Elsevier.
- Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. *The American Journal of Occupational Therapy, 62*(4), 416-429.
- Center for Disease Control. (2014). Autism: Data and statistics. Retrieved April 26, 2014, from <http://www.cdc.gov>
- Chang, Y., Quan, J., & Wood, J. (2012). Effects of anxiety disorder severity on social functioning in children with autism spectrum disorders. *Journal of Developmental & Physical Disabilities, 24*(3), 235-245. doi:10.1007/s10882-012-9268-2
- Deitz, J. C., Kartin, D., & Kopp, K. (2007). Review of the bruininks-oseretsky test of motor proficiency, second edition (BOT-2). *Physical & Occupational Therapy in Pediatrics, 27*(4), 87-102.

Dionne, M., & Martini, R. (2011). Floor time play with a child with autism: A single-subject study. *Canadian Journal of Occupational Therapy*, 78(3), 196-203.

doi:doi:10.2182/cjot.2011.78.3.8

Dovydaityene, M., Vaitiekute, G., & Nasvytiene, D. (2013). Sensory processing and emotional and behavioral difficulties in children with autism. *Special Education*, (1), 20-31.

Epstein, J. L. (1995). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappan*, 76 (9), 701-12.

Foster, A., Rude, D., & Grannan, C. (2012). Preparing parents to advocate for a child with autism. *Phi Delta Kappan*, 94(4), 16-20.

Gartin, B.C., Murdick, N. L., Thompson, J. R., & Dyches, T. T (2002). Issues and challenges facing educators who advocate for students with disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 37(1), 3-13

Gibbs, V., Aldridge, F., Chandler, F., Witzlsperger, E., & Smith, K. (2012). Brief report: An exploratory study comparing diagnostic outcomes for autism spectrum disorders under DSM-IV-TR with the proposed DSM-5 revision. *Journal of Autism & Developmental Disorders*, 42(8), 1750-1756. doi:10.1007/s10803-012-1560-6

Greenspan, S., & Weider, S. Developmental patterns and outcomes in infants and children with disorders in relating and communicating. A chart review of 200 cases of children with autistic spectrum diagnosis. *Journal of Developmental and Learning Disorders*, 1, 87.

Greenspan, S., & Wieder, S. (2006). *Engaging autism: Using the floortime approach to help children relate, communicate, and think*. Cambridge, MA: Da Capo Lifelong Books.

- Gutstein, S. E., Burgess, A. F., & Montfort, K. (2007). Evaluation of the relationship development intervention program. *Autism: The International Journal of Research and Practice*, 11(5), 397-411.
- Gutstein, S., & Gutstein, H. (2009). *The RDI book: Forging new pathways for autism, Asperger's and PDD with the Relationship Development Intervention program*. Houston, Tex.: Connections Center Pub.
- Henry, G. (2011). *Malcolm shepherd knowles : A history of his thought*. New York: Nova Science Publishers.
- Harry, B. (1992) *Culturally diverse families and special education system: Communication and empowerment*. New York: Columbia University Press.
- Hwang, B., & Hughes, C. (2000). The effects of social interactive training on early social communicative skills of children with autism. *Journal of Autism & Developmental Disorders*, 30(4), 331.
- Jung, A. W. (2011). Individualized education programs (IEPs) and barriers for parents from culturally and linguistically diverse backgrounds. *Multicultural Education*, 18(3), 21-25.
- Kadar, M., McDonald, R., & Lentin, P. (2012). Evidence-based practice in occupational therapy services for children with autism spectrum disorders in victoria, australia. *Australian Occupational Therapy Journal*, 59(4), 284-293. doi:10.1111/j.1440-1630.2012.01015.x
- Kalyanpur, M., Harry, B., & Skritic, T. (2002). Equality and advocacy expectations of culturally diverse families' participation of special education services. *Focus on Autism and other Developmental Disabilities*, 18(2) 1, 10-36.

- Knowles, M., Malcolm, S., & Elwood, F. (2011). *The adult learner: The definitive classic in adult education and human resource development* (6th ed.). Burlington, MA: Elsevier Inc.
- Kramer, J. M., Coster, W. J., Kao, Y., Snow, A., & Orsmond, G. I. (2012). A new approach to the measurement of adaptive behavior: Development of the PEDI-CAT for children and youth with autism spectrum disorders. *Physical & Occupational Therapy in Pediatrics*, 32(1), 34-47.
- Lewis, A. C. (2005). The old, new IDEA. *The Education Digest*, 70(5), 68-70.
- Miller-Kuhaneck, H. (2004). "Alternative and complementary interventions for the autism spectrum disorders." In H. Miller-Kuhaneck (Ed.). *Autism: A Comprehensive Occupational Therapy Approach*, (2nd ed). Baltimore: AOTA.
- National Institute of Mental Health. (2013). Autism spectrum disorder. Retrieved September 28, 2013, from <http://www.nimh.nih.gov>
- O'Haire, M. E., McKenzie, S. J., Beck, A. M., & Slaughter, V. (2013). Social behaviors increase in children with autism in the presence of animals compared to toys. *Plos One*, 8(2), 1-10. doi:10.1371/journal.pone.0057010
- Press, L. J., & Richman, J. E. (2009). The role of optometry in early identification of autism spectrum disorders. *Optometry & Vision Development*, 40(3), 141-149.
- Prunty, A. (2011). Implementation of children's rights: What is in 'the best interests of the child' in relation to the individual education plan (IEP) process for pupils with autistic spectrum disorders (ASD)? *Irish Educational Studies*, 30(1), 23-44. doi:10.1080/03323315.2011.535974

- Sinha, Y. (2011). Auditory integration training and other sound therapies for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*, (12)
- Stratis, E. A., & Lecavalier, L. (2013). Restricted and repetitive behaviors and psychiatric symptoms in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(6), 757-766. doi:<http://dx.doi.org>
- Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the short sensory profile. *The American Journal of Occupational Therapy*, 61(2), 190-200.
- Tomchek, S., LaVesser, P., & Watling, R. (2010). The scope of occupational therapy services for individuals with an autism spectrum disorder across the life course. *American Journal of Occupational Therapy*, 64, S125-36. doi:10.5014/ajot.2010.64s125-64s136
- U.S. Department of Education. (2004). Retrieved from <http://idea.ed.gov/explore/view/p/,root,dynamic,TopicalBrief,9>,
- Van Hartingsveldt, M. J., Cup, E. H. C., & Oostendorp, R. A. B. (2005). Reliability and validity of the fine motor scale of the peabody developmental motor scales--2. *Occupational Therapy International*, 12(1), 1-13.
- Watling, R., Deitz, J., Kanny, E. M., & McLaughlin, J. F. (1999). Current practice of occupational therapy for children with autism. *American Journal of Occupational Therapy*, 53(5), 498-505.
- Watling, R. L., Deitz, J., & White, O. (2001). Comparison of sensory profile scores of young children with and without autism spectrum disorders. *American Journal of Occupational Therapy*, 55(4), 416-423.

Zandt, F., Prior, M., & Kyrios, M. (2007). Repetitive behaviour in children with high functioning autism and obsessive compulsive disorder. *Journal of Autism & Developmental Disorders*, 37(2), 251-259. doi:10.1007/s10803-006-0158-2



## APPENDIX A

**Survey Questions and Results of Occupational Therapists**

Below are the questions and results of the original online needs assessment survey of occupational therapist currently working in schools, powered by SurveyMonkey.com.

**School District:**

**Results:** All respondents reported working within schools in Marin and Sonoma Counties.

**City:**

**Results:** All respondents reported being in cities in Marin and Sonoma Counties.

**What are the common assessments used when working with children with autism in the school setting?****Sample Answers:**

Sensory Processing Measure Sensory Profile Bruininks-Oseretsky 2 Clinical and classroom observations Peabody Developmental Motor Scales Parts of the Sensory Integration and Praxis Tests VMI Print Tool - Handwriting without Tears

Respondent #5 - 12/16/2013 2:39 PM

After a review of records, this will depend on child's level of cognitive ability and age. Infant/Toddler, Preschool, Kindergarten, First Grade= PDMS, Pre-K,K, and older= Beery VMI, 1st grade and older= Goodenough Draw a Person, Bus & Airplane subtests of Gardner HWT K-1 and grade school= DTVP-2, SI Postural and Clinical Observations= all ages, SPM= Preschool, K. Parent & Teacher questionnaire. Dunne's Sensory Profile= Pre-K, K, and older. Parent & Teacher Sensory Profile @ K level and above. Older students w/ low cognitive skills= GOAL and SFA for functional skills. K, 1, and above=BOT2 Brief

Respondent #3 - 12/3/2013 9:06 PM

**What are common interventions used with children with autism?****Sample Answers:**

Accommodations and modifications within the school setting esp. where it impacts their focus, attention and engagement. Such as providing opportunities and tools for regulation as per their individual needs. Sometimes adaptive tools are needed to address challenges writing, etc. - Respondent #4 - 12/4/2013 8:32 AM

Address sensory processing through sensory motor/integration, build strength/coordination using yoga ball and exercises, practice visual tracking skills with pencil and paper tasks or ball skills, handwriting.- Respondent #1 - 11/21/2013 11:45 AM

### **What are common goals for children with autism?**

#### **Sample Answers:**

It can run the gamut depending on what areas of need arise with all assessments. OT attaches/supports educational goals that are developed in collaboration with their case manager which is usually the teacher. Areas usually addressed are fine motor, self-care with the component of self-regulation always being considered with regard to its impact on the student's engagement, focus and follow-through. - Respondent #4 -12/4/2013 8:32 AM

SENSORY - Student will has access to sensory strategies to remain calm and attend to task Student will be able to participate in typical preschool messy play FINE MOTOR - Student will show age appropriate grasp patterns Student will complete visual motor tasks such as cut on line, trace, connect items, copy forms Student will be able to write name, UC or LC letters MOTOR PLANNING -Student will be able to sequence a multi-step sensory motor, fine motor or craft activity BALANCE/POSTURAL CONTROL - Student will show improved balance while engaged in simple eye hand coordination SELF CARE - Student will be independent with fasteners during dressing Student will be able to tie shoes Student will use utensils PLAY/SOCIAL -student will share a piece of equipment (swing), take turns, throw to another peer, etc - Respondent #5- 12/16/2013 2:39 PM

### **What do parents of children with autism need to know about OT to successfully navigate the IEP process?**

#### **Sample Answers:**

It takes a VILLAGE and a good supportive TEAM working together to help a child with ASD succeed. Each profession is important. A combination of "push in" services, "pull out" services and "group therapy services" seems most effective when it comes to OT. Districts are starting to go towards therapy minutes per year vs. weekly minutes, which I think is a good model. This allows for individual therapy as well as group or push in or consult, as needed for the child. Groups allow for social and behavioral modeling. Individual sessions allow time to address unique individual needs. Push in services keep the student a part of the class and helps them learn how to successfully perform adapt in the school environment. Regular consultation with the team is needed for consistent carry over in all environments. Respondent #3 -12/3/2013 9:06 PM

OT is an additional service that helps students to increase independence on academic related goals. If the academic environment meets the student's needs, OT is not needed. -

Respondent #7 -12/19/2013 8:41 PM

**Additional Comments:**

**Sample Responses:**

Some parents supplement school based OT services with private therapies, which is fine in my opinion. School based OT is intended to address only academic concerns. Sometimes a child w/ ASD needs to work on dressing skills or needs more intensive sensorimotor integration activities which the school setting is not suited to provide. Sometimes OT's use different therapeutic approaches and may have different opinions about approaches. OT practices are intended to be evidenced based and backed by research. Some school districts do not support use of all therapeutic interventions and a parent may need to search out private therapy for a certain desired treatment modality. If parents have questions, they should ask the practitioner about the research supporting their approaches and how this might help towards achieving set goals. Should parents decide to supplement w/ private OT, collaboration w/ IEP team would be most beneficial.

Respondent #3-12/3/2013 9:06 PM

Some schools offer OT consult to teachers as an intervention to students who are "at risk" or identified at STI (pre IEP meetings). Some students may be "on the radar" of OT's but not officially on their caseload. OT's sometimes assist in classrooms with students who are at risk- especially Kindergarten/1st grade. Most districts discontinue OT services in 3rd/4th grade.

Respondent #1- 11/21/2013 11:45 AM

## APPENDIX B

**Needs Survey Questions and Results Analysis- Parents**

Below are the questions and results of the original online needs assessment survey for parents of children with autism, powered by SurveyMonkey.com.

**How old is your child?**

**Results:** Respondents stated that their children ranged from three-years-old to 20-years old.

**Child's School:**

**Results:** Respondents all responded with schools within Marin County and Sonoma County

**I am knowledgeable in regards to the IEP process:**

| <b>Answer Choices</b> | <b>Responses</b> |           |
|-----------------------|------------------|-----------|
| Strongly Agree        | <b>25%</b>       | <b>7</b>  |
| Agree                 | <b>50%</b>       | <b>14</b> |
| Neutral               | <b>17.86%</b>    | <b>5</b>  |
| Disagree              | <b>7.14%</b>     | <b>2</b>  |
| Strongly Disagree     | <b>0%</b>        | <b>0</b>  |

**I am able to successfully advocate for my child in the IEP process:**

| <b>Answer Choices</b> | <b>Responses</b> |           |
|-----------------------|------------------|-----------|
| Strongly Agree        | <b>14.29%</b>    | <b>4</b>  |
| Agree                 | <b>50%</b>       | <b>14</b> |
| Neutral               | <b>25%</b>       | <b>7</b>  |
| Disagree              | <b>10.71%</b>    | <b>3</b>  |
| Strongly Disagree     | <b>0%</b>        | <b>0</b>  |

**Has your child ever received occupational therapy (OT) services?**

**Results:** Of the respondents 27 of 28 reported receiving OT services.

**I have a clear understanding of the OT role in my child's education:**

| <b>Answer Choices</b> | <b>Responses</b> |           |
|-----------------------|------------------|-----------|
| Strongly Agree        | <b>28.57%</b>    | <b>8</b>  |
| Agree                 | <b>42.86%</b>    | <b>12</b> |
| Neutral               | <b>17.86%</b>    | <b>5</b>  |
| Disagree              | <b>7.14%</b>     | <b>2</b>  |
| Strongly Disagree     | <b>3.57%</b>     | <b>1</b>  |

**I am knowledgeable in regards to the OT intervention process:**

| <b>Answer Choices</b> | <b>Responses</b> |           |
|-----------------------|------------------|-----------|
| Strongly Agree        | <b>14.29%</b>    | <b>4</b>  |
| Agree                 | <b>50%</b>       | <b>14</b> |
| Neutral               | <b>21.43%</b>    | <b>6</b>  |
| Disagree              | <b>10.71%</b>    | <b>2</b>  |
| Strongly Disagree     | <b>3.57%</b>     | <b>1</b>  |

**I have a clear understanding of the OT goals for my child:**

| <b>Answer Choices</b> | <b>Responses</b> |           |
|-----------------------|------------------|-----------|
| Strongly Agree        | <b>17.86%</b>    | <b>5</b>  |
| Agree                 | <b>46.43%</b>    | <b>13</b> |
| Neutral               | <b>17.86%</b>    | <b>5</b>  |
| Disagree              | <b>7.14%</b>     | <b>2</b>  |
| Strongly Disagree     | <b>10.71%</b>    | <b>3</b>  |

**I have a clear understanding of the OT assessment results and documentation provided for my child:**

| <b>Answer Choices</b> | <b>Responses</b> |           |
|-----------------------|------------------|-----------|
| Strongly Agree        | <b>14.81%</b>    | <b>4</b>  |
| Agree                 | <b>40.74%</b>    | <b>11</b> |
| Neutral               | <b>25.93%</b>    | <b>7</b>  |
| Disagree              | <b>14.81%</b>    | <b>4</b>  |
| Strongly Disagree     | <b>3.70%</b>     | <b>1</b>  |

\*One participant omitted response to this question

**Additional comments name and best way to contact you:****Sample Responses**

I am a English learner but I can totally give you a better explanation in Spanish. I know OT it's a very important part for my child to be success in the rest of the areas that we are working too. If he doesn't get enough OT he won't improve at school because his poor fine and gross motor skills even I'm his social skills because he rejects to do things that are hard for him to do

-Respondent #27

1/11/2014 11:39 AM

I found that when I was in initial stages of my childs diagnosis and education at a different school (not an NPS) it was harder to obtain the initial services for OT for my child, however once he started receiving it, it made a substantial difference in his ability to regulate and to make him available to learn without exhibiting the extremely severe behaviors that would happen prior too. Hindsight would have me pursuing OT first and not last for my child.

-Respondent #4

11/22/2013 6:19 AM

## APPENDIX C

**Evaluation Survey Questions and Results- Parents**

Below are the questions and results of the original online evaluation survey for parents of children with autism, powered by SurveyMonkey.com.

**How old is your child?**

**Results:** Respondents stated that their children ranged from three-years-old to 20-years old.

**Child's School**

**Results:** Respondents all responded with schools within Marin County and Sonoma County

**I am knowledgeable in regards to occupational therapy goals for my child:**

| Answer Choices    | Responses |   |
|-------------------|-----------|---|
| Strongly Agree    | 44.44%    | 4 |
| Agree             | 44.44%    | 4 |
| Neutral           | 11.11%    | 1 |
| Disagree          | 0%        | 0 |
| Strongly Disagree | 0%        | 0 |

**I am knowledgeable in regards to occupational therapy assessments and documentation for my child:**

| Answer Choices    | Responses |   |
|-------------------|-----------|---|
| Strongly Agree    | 55.56%    | 5 |
| Agree             | 33.33%    | 3 |
| Neutral           | 11.11%    | 1 |
| Disagree          | 0%        | 0 |
| Strongly Disagree | 0%        | 0 |



**I clearly understand the role of the occupational therapist in your child's education:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>88.89%</b>    | <b>8</b> |
| Agree                 | <b>11.11%</b>    | <b>1</b> |
| Neutral               | <b>0%</b>        | <b>0</b> |
| Disagree              | <b>0%</b>        | <b>0</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

**I am able to successfully advocate for my child in the IEP process:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>44.44%</b>    | <b>4</b> |
| Agree                 | <b>44.44%</b>    | <b>4</b> |
| Neutral               | <b>0%</b>        | <b>0</b> |
| Disagree              | <b>11.11%</b>    | <b>1</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

**I knowledgeable in regards to the IEP process:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>44.44%</b>    | <b>4</b> |
| Agree                 | <b>55.56%</b>    | <b>5</b> |
| Neutral               | <b>0%</b>        | <b>0</b> |
| Disagree              | <b>0%</b>        | <b>0</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

**I clearly understand the role of occupational therapy in my child's education:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>66.67%</b>    | <b>6</b> |
| Agree                 | <b>33.33%</b>    | <b>3</b> |
| Neutral               | <b>0%</b>        | <b>0</b> |
| Disagree              | <b>0%</b>        | <b>0</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

**After reading the resources guide, do you feel there are additional components that would enhance your understanding of occupational therapy goals:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>0%</b>        | <b>0</b> |
| Agree                 | <b>11.11%</b>    | <b>1</b> |
| Neutral               | <b>33.33%</b>    | <b>3</b> |
| Disagree              | <b>33.33%</b>    | <b>3</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

\*Two participants chose to leave comments instead of use likert scale.

**After reading the resources guide, do you feel there are additional components that would enhance your understanding of occupational therapy assessments and documentation:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>0%</b>        | <b>0</b> |
| Agree                 | <b>11.11%</b>    | <b>1</b> |
| Neutral               | <b>33.33%</b>    | <b>3</b> |
| Disagree              | <b>33.33%</b>    | <b>3</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

\*Two participants chose to leave comments instead of use likert scale.

**After reading resources guide, do you feel there are additional components that would enhance your understanding of the IEP process:**

| <b>Answer Choices</b> | <b>Responses</b> |          |
|-----------------------|------------------|----------|
| Strongly Agree        | <b>0%</b>        | <b>0</b> |
| Agree                 | <b>11.11%</b>    | <b>1</b> |
| Neutral               | <b>33.33%</b>    | <b>3</b> |
| Disagree              | <b>22.22%</b>    | <b>2</b> |
| Strongly Disagree     | <b>0%</b>        | <b>0</b> |

\*Two participants chose to leave comments instead of use likert scale.

**Do you have any other comments, questions, or concerns?**

**Sample Responses**

I really appreciate the diligence and effort put into this document and think when it is complete it should be shared everywhere.

-Respondent #7

12/4/2014 1:14 PM

I feel the guide is successful at its stated objective. Other materials are available for more in depth study of specific topics concerning IEPs. After 8 years with ASD in our lives and 5 in the school system, I have yet to see the subject material presented here, offered or even spoken of in such a succinct manner. I would recommend it to anyone facing an IEP.

-Respondent #3

12/1/2014 7:53 PM