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Lack of Medicaid Funding for Occupational Therapy Serving the Autism Spectrum Disorder Population Ages 0-5 Years

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Running Head: Lack of Medicaid Funding for Occupational Therapy Serving the Autism Spectrum Disorder population ages 0-5 years

Lack of Medicaid Funding for Occupational Therapy
Serving the Autism Spectrum Disorder population ages 0-5 years
Occupational Therapy: A Needs Assessment Survey
Mary O'Donohue & Nadia Yala
Western Michigan University
Lee Honors College Honor's Thesis Project

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Abstract

The prevalence of autism in the United States is currently 1 in 68 children (Autism Alliance of Michigan, 2014). This is considered an epidemic. There are a variety of treatments available in the state of Michigan for children with autism, such as occupational therapy, speech therapy, physical therapy, and applied behavior analysis (ABA). Effective April 1st, 2013, Michigan increased their funding cap for ABA therapy for treating children with autism. However, there is a lack of knowledge within the community and amongst professionals in regards to the critical treatment occupational therapy practitioners provide and as a result, there is a lack of Medicaid funding for children with autism. The anonymous web-based survey will collect data from the parents/guardians of children with medical or educational diagnosis who have received occupational therapy and/or ABA services. The data collected will help support previous research in order to increase professional and community education on the services occupational therapy practitioner's provide for children with medical diagnoses. Lastly, the research conducted could ultimately work towards improving the effectiveness in treatment for autism in the state of Michigan.

Keywords: occupational therapy, autism, ABA, funding

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BACKGROUND

One in 68 children in the United States have Autism and moreover, Michigan has the 5th largest Autism population (Autism Alliance of Michigan, 2014). This disorder is primarily recognized with symptoms in the areas of communication, social interaction, restricted/repetitive behaviors, and sensory impairments. Due to these impairments, daily function and performance for child is affected significantly.

One third of all American children with autism use Medicaid as their primary source of health insurance coverage. Medicaid is a joint federal/state health care program for lower-income children, individuals with disabilities regardless of age, and other groups. The federal government and the states share the cost and responsibilities of running Medicaid. On April 1st, 2013 the Michigan Medicaid and MICHild Autism Benefit went into effect. This benefit provides Michigan Medicaid children ages 18 months to 5 years of age who have been diagnosed with Autism Spectrum Disorder (ASD) with coverage primarily for Applied Behavioral Analysis (ABA). ABA therapy receives a separate fund of \$21 million for the treatment of ASD in the Medicaid population. Other services that provide intervention for children with ASD such as occupational therapy, physical therapy, and speech pathology continue under the previous therapy cap of \$50,000 in combined services (Autism Insurance Portal, 2014).

ABA therapy aims to extinguish negative behaviors and reward positive behaviors until one skill is developed and then the process is applied towards a second skill set (Autism Therapies, 2014). There is a plethora of research conducted on ABA therapy compared to other practices and therefore, ABA therapy received the majority of funding for treating ASD in Medicaid populations.

Occupational therapists (OT) have a unique training in the areas of a child's daily occupations: play, education, and social interaction. OT's design treatment for ASD to promote development and interactions skills by engaging the child in meaningful activities and challenging them to adapt and respond to incoming sensory information from the environment. A child's inability to understand and process the sensory stimulation in their environment is one characteristic of ASD diagnosis. In a study with a sample population of 281 children ages 3-6 with ASD, 95% of the children were found to have some degree of sensory processing difficulties (Tomchek, 2005). The sensory-integration frame of reference is a specialized niche for occupational therapists.

OCCUPATIONAL THERAPY

Occupational therapy is defined as the therapeutic use of everyday life activities with individuals or groups for the purpose of enhancing or enabling participation. Participation is especially concerned with roles, habits and routines at home, school, workplace, or community settings. An occupational therapist can provide evaluation, intervention, and outcome measurements for children with ASD. Once an OT evaluates a child with ASD and gains a better understanding of the priorities of the child's performance and family members, they can provide purposeful and engaging treatment to help the child improve motor, sensory, and communication skills. Occupational therapists also provide the child and family with support by use of adaptive strategies to help maximize participation in daily activities (AOTA, 2011).

Occupational therapists have a unique education in the area of sensory processing. As a child typically develops, they learn to organize and process all of the incoming sensory information in the environment. Five to fifteen percent of the general population currently has

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difficulty organizing sensory information that can make adapting to different situations difficult for the child (AOTA, 2011). Occupational therapists evaluate these areas and base interventions on helping the child to identify their sensory needs and facilitate independence.

RESEARCH PURPOSE

The purpose of this survey and literature review is to provide further information on the effectiveness of occupational therapy intervention and continue to highlight evidence-based research for sensory integration treatment for children with Autism. There is lack of awareness of the occupational therapist's role in treating autism amongst parents of children with autism, as well as amongst legislation. This research will further support occupational therapy and sensory integration treatment for children with autism as well as advocate for the role of occupational therapy practitioner amongst society.

RESEARCH QUESTION

The following questions were addressed in this research: How satisfied are families with the occupational therapy services their child with Autism have been provided with? How effective have occupational therapy services been for a child with Autism? What are the common evaluation and intervention techniques used by occupational therapist in the treatment of Autism?

AUTISM

Autism is a developmental disability that is characterized by affecting someone's ability to communicate and have social interactions with others. Other common signs of Autism are repetitive movements, minimal eye contact, and difficulties processing various incoming senses (Autism Society, n.d.). Autism is presented in various degrees, however it can significantly

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impact a child's performance at home, in school, or in the community. Early intervention for Autism has been linked to improved development in cognition, language, and in the school setting (Mulligan & Prudhomme, 2012).

OCCUPATION

The American Occupational Therapy Association (AOTA) considers *occupations*, activities that support the health, well being, and development of an individual. For children, this includes activities that promote learning and general development, play, and self-care (AOTA, 2011).

THERAPUTIC APPROACHES

Over 75% of children with Autism have Sensory Processing Disorder (Tomchek, S.D. (2005). Occupational therapists use a frame of reference known as Sensory-Integration and many occupational therapists have training in sensory-integration intervention. This theory was developed by Dr. Jean Ayres and based on the theory that disturbances in the neurological system disrupt the construction of purposeful behaviors. (Case-Smith & O'Brien, 2010). Treatment consists of working within a controlled environment and exposing the child to various sensory stimulations that requires a child to develop an adaptive response in order to change neurological organization.

OCCUPATIONAL THERAPY PRACTICE FRAMEWORK

Occupational therapists have a widespread and diverse range of practice areas. In general, an occupational therapist is concerned with improving function and performance in everyday activities. For a child with autism, their main occupation is to play, socialize with peers, family members, attend school and basic self-care needs. An occupational therapist is trained to look at

the whole person. This means that they are responsible for taking into account the home environment, the school environment, the child's interests and the needs of the family. When seeing a child with autism, the occupational therapist will therapeutically observe and evaluate the child's sensory deficits, attention to task, social interaction and analyze standardized assessment scores (AOTA 2011).

A child with autism may present with a wide range of deficits that interfere with their participation in school, home and the community. Whether they have an aversion to olfactory and gustatory sensation that affects their eating or if they have aversion to tactile or auditory processing the occupational therapist can help. By exposing the child to the aversive stimuli and customizing strategies to adapt to the stimuli or manage behavioral responses, the occupational therapist can improve the child's performance in everyday life and ultimately improve their performance in school, with peers and integration with family. Furthermore, the child may have difficulty socially communicating, maintaining eye contact or attention to a task. Thus, an occupational therapist can develop intervention strategies or group therapy sessions to improve participation. Overall, an occupational therapist has a unique knowledge of symptoms, behavior patterns, and intervention approaches that can greatly aid a child with autism.

According to a research study conducted by Renee Watling and Jean Dietz regarding the Immediate Effect of Sensory Integration- Based Occupational Therapy Intervention on Children with Autism Spectrum Disorders, occupational therapists and caretakers noticed an improvement in 4 children's socialization, eye contact, choice making, compliance, flexibility and transitions between activities following sensory input. Although objective data yields inconclusive results, subjective data supports positive results in each child's performance and desired behaviors.

According to Jane Case-Smith and Marian Arbesman, sensory-based interventions, such as those that provide therapeutic touch, can decrease maladaptive behaviors, reduce hyperactivity, inhibit self-stimulation and stereotypic movements, and improve attention and focus. Furthermore, occupational therapists should pair sensory-based interventions with functional tasks in which the child practices the targeted performance outcome. Occupational therapy practitioners often combine sensory integration intervention with interactive play activities individually designed to enhance the child's play and social participation.

Lastly, according to Jane Case-Smith, deep pressure and massage during early intervention therapy can improve a child's on-task behaviors and reduce disruptive, stereotypical and aggressive behaviors. Occupational therapists can implement deep proprioceptive input in order to promote calming and focused attention to improve social play performance. Occupational therapists are advised to allow the child to select and pace activities in order to increase their motivation and attention to task. Furthermore, small group activities and the integration of technologies promote opportunities to practice social engagement and encourage social participation.

APPLIED BEHAVIOR ANALYSIS

Applied Behavior Analysis (ABA) therapy uses behavior principles to increase or decrease expected performance patterns. One such behavior principle is that of reward. When a child exhibits an expected behavior they are immediately given a reward to reinforce that behavior. ABA can be applied to any observable behavior such as aggression, self-stimulatory behaviors and self-injury. It can also be used to develop play or language skills that are all important for a child with autism. It is suggested that a child with autism see an ABA provider or

behavioral psychologist for at least 25 hours a week. This provider is responsible for evaluating and customizing a treatment approach that best suits the child's needs.

Overall, ABA therapy has gained widespread support as an effective means of therapy for children with autism. Currently, Autism Speaks funds research to continue to develop and validate the ABA principles and techniques. However, there are some limitations to the effectiveness of ABA therapy. Across multiple studies, some children exhibit little to no improvement in behavior patterns. Therefore, it is still unknown why some children respond more favorably to ABA therapy than others.

DISCUSSION

Although we recognize the effectiveness of ABA therapy and the evidence that is prevalent to support its positive effect on the behavior of children with autism, we also strongly advocate for the inclusion of more funding for sensory integration therapy and occupational therapy. Occupational therapists provide sensory integration during meaningful performance tasks to better regulate the child and enhance a transfer of learning. While studies show the relevance and effectiveness of ABA therapy, occupational therapists are uniquely trained to look at all areas of the client, their family, and their environments. Although ABA therapy may be more successful with older children or adults with ASD to develop appropriate and functional behavior patterns, young infants and children can benefit from receiving sensory integration therapy. Under Dr. Jean Ayres' Sensory Integration Model, the brain exhibits plasticity, especially at infancy. Therefore, it is crucial to implement deep sensory feedback to help develop and possibly mold or build new neural networks and responses. Overall, we would like to see occupational therapists working more closely with ABA psychologists. Because of their

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unique knowledge base, occupational therapists can consult on therapy intervention practices and vice versa.

METHODOLOGY

Subjects were recruited by a random distribution of emailing list. Subjects acquired an informed consent form to be signed at the initiation of the survey, in which they could not open and complete the survey without the initial consent form signed as page one on *surveymonkey.com*. Subjects received a link to the web-based survey on *surveymoney.com* and completed the 15-20 minute survey. The survey projected quantitative data reflecting the types of interventions subjects are receiving or have received, the effectiveness of intervention, and patient satisfaction. The design of the study included open questions, Likert scale, dichotomous yes/ no, and ranking. The analysis of the data was a comparison of needs request vs. satisfaction results.

PARTICIPANTS

Feedback was received and reviewed from 3 participants. Unfortunately, survey results were inconclusive for drawing evidence or support for occupational therapy servicing children with autism.

INCLUSION CRITERIA

In order to participate in the study, participants must have a child under the age of 6, with a medical diagnosis, live or reside in the state of Michigan, and be enrolled in Medicaid. We are limiting our research to this inclusionary criterion due to the lack of Medicaid funding available for children under the age of 6 receiving occupational therapy services for autism.

EXCLUSION CRITERIA

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Participants were excluded from this study if they did not meet the pre-stated criteria, predetermined definition of ASD or did not qualify for Medicaid funding.

RECRUITMENT PROCEDURE

Initial expectation for this study was to recruit approximately 500 subjects for this research with an expectation of 100 subjects to participate. In order to compile the necessary data we compiled a list of Michigan clinics serving the described population via Internet. We sent out an email and flyer to clinics explaining our research to advertise to potential subjects. We requested that if a clinic supervisor/therapist is interested in advertising this research to their clients that they contact us. We then sent out a link to our survey for the clinic supervisor to distribute to potential subjects. Potential subjects then completed the survey.

DATA COLLECTION PROCEDURE

Data was collected anonymously via an online survey. Informed consent was provided when the participant read the study protocol and purpose and agreed to proceed to the survey questions. Western Michigan Human Subject Institutional Review Board reviewed all stages of the data collection processed.

DEMOGRAPHICS

The sample population that was included in this study is parents or guardians of children with autism or ASD in Michigan who receive Medicaid funding for insurance purposes. This demographic is likely vulnerable and may not be receiving adequate funding, attention or therapy for their children's sensory and social needs.

DEFINITIONS

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For the purpose of this study, ASD refers to Autism Spectrum Disorder and includes Asperger's syndrome, Pervasive developmental disorder, not otherwise specified (PDD-NOS), and Autistic disorder (Autism Speaks, 2014).

ABA therapy refers to applied behavior analysis (ABA) and represents the use of techniques and principles to bring about meaningful and positive change in behavior (Autism Speaks, 2014).

LIMITATIONS

Limitations of our research are that we identified too small of a sample size to draw conclusive results about the importance of Medicaid funding for young children with autism.

FUTURE RECOMMENDATIONS

In conclusion, we identified that there needs to be more time and resources allocated to research supporting occupational therapy intervention so that federal and state legislation can better understand the positive effects of therapy to ultimately impact children and families dealing with autism spectrum disorders.

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Western Michigan University
Department of Occupational Therapy

Lack of Medicaid Funding for Occupational Therapy
Serving the Autism Population Ages 0-5 years

Principal Investigator: Joel Phillips, MS, OTR/L

Collaborating Investigator: Denise Hoffman, MSOT, OTR/L,

Student Investigators: Mary O'Donohue and Nadia Yala

You are invited to participate in a short survey research project to collect additional information of the treatment available for children with autism in the state of Michigan. This consent form will explain the purpose of this research project; will detail the procedures of the study, the risks and benefits of participation. Please read this consent form carefully and completely and please ask any questions if you need more clarification. Your participation is voluntary and will minimal to no risks involved.

What is the purpose of this study?

The purpose of this research study is to support occupational therapy treatment for autism spectrum disorders in the 0-5-age range for children in the Medicaid population. There is lack of awareness of the occupational therapist's role in treating autism amongst parents of children with autism, as well as amongst legislation. This research will further support occupational therapy and sensory integration treatment for children with autism as well as advocate for the role of occupational therapy practitioner amongst society.

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Who can participate in this study?

Participants must have a child under the age of 6, with a medical or educational diagnosis, live or reside in the state of Michigan, and be enrolled in Medicaid. We are limiting our research to this inclusionary criterion due to the lack of Medicaid funding available for children under the age of 6 receiving occupational therapy services for autism.

Where will the study take place?

You will be asked to take a Web-based, anonymous survey through a secure web link. You may take this from any computer.

What is the time commitment for participating in this study?

The online survey will take approximately 15-20 minutes to complete.

What will you be asked to do if you choose to participate in this study?

You will be asked to take a confidential online survey, and submit the results to the *Survey Monkey* site. After submitting the survey, there are no further demands required.

What information is being evaluated during the study?

Questions reflecting the types of interventions subjects are receiving or have received, the effectiveness of intervention, and patient satisfaction.

What are the risks of participating in this study?

There are no foreseeable risks associated with this survey. Participants will be protected through the use of an anonymous web survey program.

What are the benefits of participating in this study?

This research may benefit children in the state of Michigan under the age of 6 who are seeking to receive treatment for their autism spectrum disorder. The research may increase professional and

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community education on the services occupational therapy practitioner's provide for children with medical or educational diagnoses. The research conducted could ultimately work towards improving the effectiveness in treatment for autism in the state of Michigan.

Are there any costs associated with participating with this study?

There is no cost to the participant nor is there any compensation.

Is there any compensation for participating in this study?

There is no cost to the participant nor is there any compensation.

Who will have access to the information collected during this study?

Data collection will be anonymous to ensure the privacy of participating subjects and confidentiality of information. Informed consents will be collected by student investigators, Mary O'Donohue and Nadia Yala, however this information will not coincide with the anonymous data collected. All information will be kept completely confidential.

What if you want to stop participating in the study?

You can choose to stop participating in the study at anytime for any reason. You will not suffer any prejudice or penalty by your decision to stop your participation. You will experience NO consequences if you choose to withdraw from this study.

Should you have any questions prior to or during the study, you can contact the collaborating investigator, Denise Hoffman (269) 330-2113 or via email at dhoffmanot@gmail.com. You may also contact student investigators, Mary O'Donohue (248) 798-5752 or via email

mary.r.odonohue@wmich.edu or Nadia Yala (708) 822-5363 or via email

Nadia.Yala@wmich.edu.

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This study was approved by the Western Michigan University Human Subjects Institutional review Board (HSIRB) on October 8, 2014. Please do not participate in this study after October 7, 2015.

Participating in this survey indicates your consent to use the answers you supply.

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Western Michigan University

Occupational Therapy Department

Research Conducted by: Mary O'Donohue and Nadia Yala

PARTICIPANTS SOUGHT

This research is intended to collect data on the treatment available for children with autism in the state of Michigan. The purpose of this research study is to investigate the use of occupational therapy treatment for autism spectrum disorders in the 0-5-age range for children in the Medicaid population. Data is collected using a confidential online survey that asks questions regarding the types of interventions subjects are receiving or have received, the effectiveness of intervention, and patient satisfaction with autism intervention services.

Who: Parents/Guardians of children with Autism Spectrum Disorder ages 0-5 years using Medicaid funding.

What: Participate in an anonymous survey.

When: October 13th, 2014 -October 31st, 2014

Where: On any computer.

Why: To advocate for occupational therapy services for children with autism.

For additional information, please contact:

Mary O'donohue at mary.r.odonohue@wmich.edu or

Nadia Yala at nadia.yala@wmich.edu