

# Participation in a Parent-Child Group Intervention for Young Children with Autism Spectrum Disorder (ASD)

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## Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that involves global impairments in social skills and in verbal and non-verbal communication, as well as the presence of stereotyped patterns of behaviors and interests. ASD impacts society enormously as it leads to lifelong disability, high medical care, and increased mental health problems in caregivers. Research suggests that very early intervention started immediately after diagnosis during the first three years of life positively affects outcomes. Unfortunately, the majority of children in the United States starts intervention after 4 years of age or never receives ASD intervention. In our case report we describe outcomes of a young child with ASD after participating in a low intensity intervention. The intervention consisted in a 12-weeks parent-child intervention group for young children with ASD based on the Early Start Intervention Model (ESDM). The child demonstrated improvement in ASD symptoms as measured by the Behavior Observation of Social Communication Change (BOSCC). Moreover, the child's mother demonstrated fidelity in the implementation of the intervention strategies and indicated in a satisfaction survey that the intervention was very helpful. Results are discussed in terms of importance of low intensity intervention for communities with limited resources and families without sufficient ASD service benefits, as well as to provide a bridge as families are transitioning to and/or waiting for more intensive services to become available.

**Keywords:** Autism Spectrum Disorder (ASD); Early Intervention; Parent-Child Intervention

**Abbreviations:** ESDM: Early Start Intervention Model; BOSCC: Behavior Observation of Social Communication Change; ASD: Autism Spectrum Disorder; APA: American Psychiatric Association.

## Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that involves impairments in social skills and in verbal and non-verbal communication, as well as the

presence of stereotyped patterns of behaviors and interests (American Psychiatric Association, 2013). Epidemiological reports suggest that the number of ASD diagnoses are increasing [1]. ASD affects approximately 1 in 59 children in the United States, according to the Center for Diseases Control [2]. ASD impacts society enormously as it brings burdens including lifelong disability, high medical care, and increased mental health problems in caregivers. Early intervention started immediately after diagnosis during the first three years of life has high impact on outcomes [1]. Early

intervention has positive impact on verbal and nonverbal skills, adaptive skills, and quality of life of caregivers [3]. Unfortunately, on average children with ASD in the U.S. begin intervention at approximately 5 years of age or never receive ASD intervention. Therefore, most children with ASD miss the opportunity to improve outcomes.

The research and clinical communities agree that developing interventions that are appropriate to very young children and that can start immediately after diagnosis and thereby support the needs of parents at a very difficult time in their lives is a national and international priority [4]. Currently, research evidence indicates that high intensity, long term interventions are the most effective in supporting development and diminish ASD symptoms and associated disabilities [5-7]. One of these interventions, the Early Start Denver Model (ESDM) is particularly promising for improving child's outcomes [5]. ESDM focuses on the core areas of difficulties of ASD: verbal and nonverbal communication, joint attention, social engagement, imitation, play and cognition.

Although several insurances and state programs cover intensive interventions (25 hrs. per week), it is still very difficult for families of newly diagnosed children with ASD to access specialized services. Barriers involve scarcity of specialized providers as well as continuous increase in the number of diagnoses. Moreover, due to the high intensity of intervention currently recommended, it is hard for many children to find providers available immediately after diagnosis. Here we report the case of one young child diagnosed with ASD who could not access intensive intervention services due to restrictions in her insurance. However, the child and her mother participated for 12 weeks in a parent-child group intervention based on the principles of the ESDM. Accessing early intervention as early as possible is a significant concern for families faced with diagnosis of their young child (ren), and reflects a growing and critical public health issue. The intervention here reported has the potential to increase access to high-quality intervention for young children with ASD immediately after diagnosis.

## Case Presentation

For the purposes of this paper the child participant will be referred to by the pseudonym Mary. Mary is a Caucasian female who was between the ages of 24 and 27 months during the intervention period. Mary first presented to our outpatient child psychiatry clinic, housed within a large Midwestern university hospital, at the age of 23 months due to concerns about a lack of speech development, not responding to her name, adherence to rituals and routines, and a history of hand flapping. These concerns were first noted around 18 months of age. At 23 months, she was evaluated

by a multidisciplinary team including a social worker, clinical psychologist, and child psychiatrist. Additionally, she was evaluated just prior to 24 months by Occupational Therapy and at 25 months by Speech-Language Pathology.

Mary was born full-term via a vaginal delivery after an uncomplicated pregnancy. Her mother took Wellbutrin for smoking cessation during pregnancy. She was described as a happy, easy-going baby. She met motor milestones on time, but was delayed in speech and gestures. She started using "ma" and "da" at 6 months of age and variegated babbling at 12 months. At her intake appointment at 23 months she had limited gesture use and had just started using words, having only 10 distinct words at that time. There was a family history of Autism Spectrum Disorder in a maternal cousin and anxiety on the paternal side. With regards to further social developmental history, Mary's mother described her eye contact as generally okay, but avoidant at times. She had minimal gestures and did not alert caregivers to her needs consistently. For instance, she did not point to the refrigerator or otherwise let her caregivers know she was hungry or thirsty. She was noted to prefer playing by herself to playing with others, especially other children. She often engaged in repetitive play with a shape sorter or putting toys in a toy box. However, she did engage with peek-a-boo and pat-a-cake appropriately with her mother and enjoyed clapping when excited. Her mother denied repetitive motor mannerisms or clear restricted interests. Furthermore, she reported that Mary transitioned easily between activities. However, her mother did observe Mary to engage in some repetitive behaviors, especially during bedtime. She preferred doors to be closed and also engaged in some repetitive sensory seeking behavior, such as running her hands on walls and placing her fingers in the door latch. Mary also had tactile aversion to messy play and significant temper tantrums if expected to ride an elevator.

The Autism Diagnostic Observation Scale, 2<sup>nd</sup> Edition, Toddler Module [8]. was administered at 23 months of age. She demonstrated strengths in imitation and emerging eye contact. However, deficits were noted in the areas of language and communication, reciprocal social interaction and restricted and repetitive behaviors. She babbled regularly throughout the ADOS-2 administration, but most vocalizations were not directed. She did not point, nor use other gestures during administration. Although her eye contact was emerging, it was not regularly used to initiate, regulate, or terminate social interactions. She gave items to her father, but did not show items, and only rarely initiated joint attention, despite enjoying several tasks. She was able to play appropriately with several toys, including following the examiner's lead during the bath time routine. She engaged in brief finger posturing and had some sensory interests, often examining items close to her face or sniffing them. Taken as

a whole, Ashley scored a 17 on the Social Affect scale and a 5 on the Restricted Repetitive scale, placing her total score of 22 in the severe range for ASD. The Occupational Therapy evaluation noted weaknesses in self-care skills, fine and gross motor, and sensory aversions. Mary obtained a Standard Score of 86 on the Preschool Language Scale-5<sup>th</sup> Edition [9], with similarly developed receptive and expressive language scores. However, the speech-language pathologist felt she presented with a more moderate, rather than mild expressive language disorder, but testing was limited because of her young age.

## Treatment

Mary and her mother participated in a parent-child group intervention held in our outpatient child psychiatry clinic setting. The parent-child group intervention was based on the Early Start Denver Model [10-11]. An evidence based specialized intervention for young children with ASD. ESDM uses a child-centered, responsive interactive style and 10 foundational intervention themes, including:

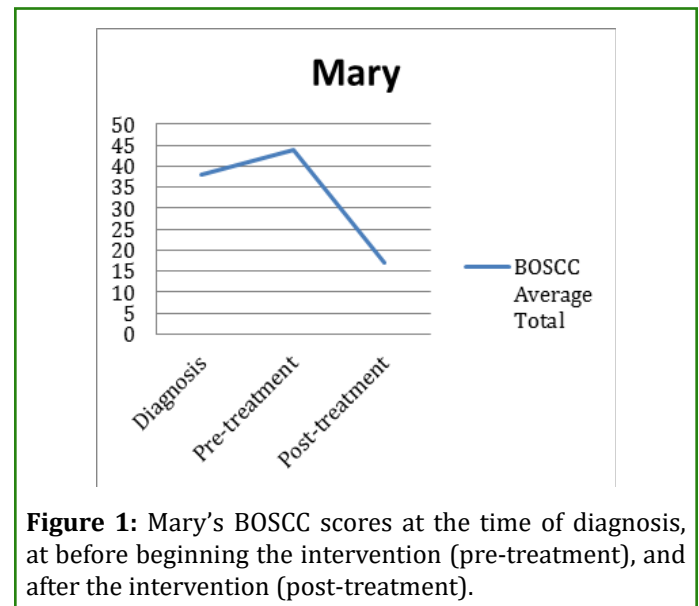
- Social attention and motivation for learning
- Sensory social routines
- Dyadic engagement
- Non-verbal communication
- Imitation
- Antecedent-behavior-consequences relationships
- Joint attention
- Functional play
- Symbolic play, and
- Speech development.

From session 2 to session 10, each strategy is the focus of one session in which the parent is taught to deliver the lesson in the context of a shared activity using age appropriate play materials. In session 1, we introduce the structure of the group to the participants. In session 12, all strategies were reviewed. During the first 45 minutes of the session two therapists met with the parents and covered one of the above themes while the children played with the supervision of 4 student research assistants. During the second phase, the parents were encouraged to implement the strategies learned during the first phase with the coaching of the interventionist. A total of 4 parent-child dyads, including Mary and her mother, participated in the parent-child group.

## Outcomes

ASD symptoms were evaluated through the Brief Observation of Social Communication Change (BOSCC) [2]. The BOSCC was developed as an outcome measure of symptoms associated with an Autism Spectrum Disorder (ASD) for young children. It is responsive to change in core ASD symptoms. Development of the BOSCC involved the expansion of codes

from the ADOS-2, in order to capture more nuanced variation. Inter-rater reliability, short-term test-retest reliability, and sensitivity of change over time using the BOSCC codes have been documented. The parents and the child are asked to play for 15 minutes with toys as they would normally do at their homes. Mary and her mother were administered the BOSCC during three time points, during the diagnostic evaluation, after three months before starting the intervention, and at the end of the intervention. Higher scores in the BOSCC are associated with higher ASD symptom severity. Mary's scores were 38 at the time of diagnosis, 44 before starting the intervention, and 17 at the end of the intervention (Figure 1). Thus, the child's ASD symptoms worsened from diagnosis to the beginning of the intervention and improved drastically after receiving the intervention. Additionally, Mary's mother learned the intervention strategies as she demonstrated to reach fidelity in the implementation of the intervention. Moreover, in a satisfaction survey Mary's mother indicated that she found the program very helpful.



**Figure 1:** Mary's BOSCC scores at the time of diagnosis, at before beginning the intervention (pre-treatment), and after the intervention (post-treatment).

## Discussion

Although several Insurances and State Programs cover intensive interventions (25 hrs. per week), it is nonetheless very difficult to families of newly diagnosed children with ASD to access appropriate services. Barriers involve a continuous increase in the number of diagnoses as well as scarcity of specialized providers. Moreover, due to the high intensity of intervention currently recommended, it is hard for many children to find providers available immediately after diagnosis. Accessing ASD intervention as soon as possible in life is a critical public health issue. While high intensity intervention currently represents the gold standard of services, it is clear that it cannot be accessed by all children with ASD in early development, immediately after

diagnosis. Parent based interventions have been successful in teaching children a variety of skills including verbal and non-verbal communication [11], social interaction [12], and play [13]. By learning intervention strategies through professional coaching, the parents may be able to implement therapy throughout the day [11]. Therefore, the limited time spent with the professional may multiply and lead to many productive hours of parent-child interaction during the day, outside of the therapist-child setting.

The case study here reported suggested that parents can learn helpful intervention strategies through a low intensity parent-child group program. Moreover, the child here described seemed to show a dramatic improvement in her ASD symptoms after participating in the intervention. By learning the intervention strategies, Mary's mother was able to implement treatment throughout the day. While intensive intervention is still to be considered the gold standard for young children with ASD, it is not realistic to administer intensive services to all children immediately after diagnosis. Our case study demonstrated how more children can receive effective intervention in low resource communities or in families without sufficient ASD service benefits.

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