

Chapter 11

CYGNET Enhancing Support for Children With Autism Through Collaborative Engagement

Avgi Vitanidi

 <https://orcid.org/0009-0004-0732-7492>

Taxidi Stin Anaptixi, Greece

ABSTRACT

The Cygnet program is a structured initiative designed to empower parents and caregivers of children on the autism spectrum. By recognizing parents as the primary experts on their children, the program builds on their experiences while addressing unique challenges. Addressing the critical need for ongoing assistance, we examine parental self-confidence before, shortly after, and long after program completion, revealing that the benefits diminish over time. To enhance the program, we analyze feedback on thematic session content and propose extensions. Additionally, we advocate for the creation of a sibling-based intervention program derived from CYGNET sessions to provide comprehensive support for families. By addressing these challenges and proposing targeted interventions, our research aims to improve parental confidence and child well-being, thereby fostering a more effective support system for families navigating the complexities of ASD. The findings underscore the importance of sustained interventions and tailored programs for diverse family needs.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by deficits in social communication and the presence of restricted, repetitive patterns of behavior, interests, or activities. According to the American Psychiatric Association (2013), ASD is a spectrum condition, meaning that the severity and nature of symptoms can vary significantly from one individual to another. Prevalence rates have risen significantly, with the Centers for Disease Control and Prevention (CDC, 2020) reporting that approximately 1 in 54 children in the United States are diagnosed with ASD. This increase has amplified the need for understanding the challenges faced by children with ASD and their families.

Children with ASD face a wide range of challenges that affect various aspects of their lives. One of the core challenges for children with ASD is difficulty in social communication. Children with ASD often struggle with understanding social cues, maintaining eye contact, and engaging in reciprocal conversations (American Psychiatric Association, 2013). This can lead to social isolation and difficulties in forming peer relationships (Bauminger et al., 2003). Children with ASD may exhibit repetitive behaviors such as hand-flapping, rocking, or insistence on sameness (Kim et al., 2000). These behaviors can be disruptive in various settings, including school and home, and can sometimes lead to behavioral outbursts when routines are disrupted. Many children with ASD have heightened sensitivity to sensory stimuli, such as loud noises, bright lights, or certain textures (Ben-Sasson et al., 2009). These sensitivities can cause significant distress and interfere with daily activities. While some children with ASD may have average or above-average intelligence, others may experience cognitive delays. Additionally, children with ASD often have uneven learning profiles, excelling in certain areas while struggling in others (Landa & Garrett-Mayer, 2006).

Parents of children with ASD often experience unique and significant challenges. Parents of children with ASD frequently report higher levels of stress compared to parents of neurotypical children (Padden & James, 2017). This stress is often related to the demanding nature of caregiving, concerns about the child's future, and the emotional toll of managing challenging behaviors. The cost of therapies, special education, and medical care can place a significant financial burden on families (Cidav et al., 2012). Additionally, one or both parents may need to reduce work hours or stop working altogether to care for their child, further exacerbating financial strain. Parents often face challenges in accessing appropriate services for their children, such as finding qualified therapists, securing special education accommodations, and advocating for their child's needs within the healthcare and educational systems (Kogan et al., 2008). The demands of raising a child with ASD can strain parental relationships, leading to higher rates of marital discord and divorce (Hartley et al.,

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