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Review

The curious selection process of treatments for Autism Spectrum Disorders



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ABSTRACT

Treatments for Autism Spectrum Disorder (ASD) vary widely. The disorder is now considered treatable, but some interventions have extensive empirical support, while other interventions have none. Despite these stark differences in the evidence base for interventions, and efforts to educate the public, little correlation exists between what treatments work and what treatments parents choose. This review covers treatments, what people choose, and possible reasons choices are made, plus what factors may influence these choices. Data of this sort are important for clinicians and researchers, since multiple issues dictate treatment selection.

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1. Introduction

Autism Spectrum Disorders (ASD) are common, and present with life-long symptoms (Matson, Boisjoli, Rojahn, & Hess, 2009; Matson, Gonzalez, & Rivet, 2008). Core symptoms include social and communication deficits, and the presence of rituals and stereotypies (Ben-Sasson & Carter, 2013; Brooks & Ploog, 2013; Horovitz & Matson, 2010; Matson, Boisjoli, Hess, & Wilkins, 2010; Matson & Dempsey, 2008; Matson, Fodstad, & Mahan, 2009). More than perhaps any other problem in the field of mental health, the ASD literature is fraught with controversy (Matson & LoVullo, 2009). Issues such as how core symptoms should be defined have received a great deal of attention (Matson & Boisjoli, 2008; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; Matson et al., 2005; Rivet & Matson, 2011; Worley & Matson, 2012).

The type of comorbid symptoms and what causes them is also among these topics (Matson & Boisjoli, 2007; Matson, Dempsey, & Fodstad, 2009; Matson, Hess, & Boisjoli, 2010; Matson, Rivet, Fodstad, Dempsey, & Boisjoli, 2009; Mazzone et al.,

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2013). For example, intellectual disabilities are known to occur at high rates among persons with ASD (Cherry, Matson, & Paclawskyj, 1997; Matson, Wilkins, Smith, & Ancona, 2008; Paclawskyj, Matson, Bamburg, & Baglio, 1997). They can exacerbate a variety of problems such as feeding behaviors, self-injury, and other maladaptive behaviors (Kuhn & Matson, 2002; Matson, Cooper, Malone, & Moskow, 2008; Matson & Kuhn, 2001). These comorbid conditions can also further exacerbate core symptoms such as social skills (Matson, LeBlanc, & Weinheimer, 1999; Matson, Smiroldo, & Bamburg, 1998) and emotional disorders (Matson et al., 1999; Matson & Smiroldo, 1997; Wu, Desarkar, Palucka, Lunskey, & Liu, 2013). Challenging behaviors are also reported at high rates, and can markedly complicate the treatments used (Lane, Paynter, & Sharman, 2013).

2. Treatments

Easily, one of the most controversial of all topics in the ASD literature involves the types of treatments that are used and how they are selected. Medication, for example, is commonly used although little data exists to support its use, especially for the core symptoms of the disorder. Also, these drugs, especially antipsychotic medications, can produce chronic and debilitating side effects (Advokat, Mayville, & Matson, 2000; Matson et al., 1998). Similarly, there is debate about whether antipsychotic medications are effective for challenging behaviors among persons with developmental disabilities (Matson & Wilkins, 2008). Additionally, many psychological methods are also available (Bulkeley, Bundy, Roberts, & Einfeld, 2013; Lanovaz, Robertson, Soerono, & Watkins, 2013). Many are labor intensive and involve parental involvement, which often is not possible due to motivation, time constraints or other commitments, etc., (Matson, Mahan, & LoVullo, 2009).

An assumption often made by professionals is that more and better dissemination of information on what works and what does not work will result in better treatment selection. The amount of research on what works is expanding rapidly. Additionally, professional groups and state health departments have reviewed available interventions and developed guidelines on recommended treatments. To date, these efforts have not yielded particularly good results. For example, despite studies demonstrating that pharmacotherapy has little positive effect on the core symptoms of ASD and can cause significant side effects, usage is increasing (Goin-Kochel, Myers, & Mackintosh, 2007). This is just one example. Additionally, the measles, mumps, and rubella (MMR) vaccine has been shown to have no effect on ASD development in independent studies and legal decisions. Nonetheless, vocal groups within the ASD community continue to insist that the MMR vaccine is a cause of ASD. These groups are powerful. With assistance of major pharmaceutical companies and despite numerous studies showing the MMR vaccine does not impact development of ASD, the American Pediatric Association has developed a policy of choice where each of the three vaccines can be given separately rather than simultaneously. Delaying vaccination in this way will likely result in a greater number of insufficiently vaccinated children at a greater risk of developing preventable infectious diseases (Offit & Moser, 2009). Why are caregivers choosing methods that ineffective in treating ASD, and at times, capable of considerable harm? The answer is complex, but this paper explores some of the reasons why people think the way they do about ASD, and why parents make certain treatment selections.

3. Treatment selection: the more the merrier

It is evident that many parents employ multiple therapies with their children, with one study finding an average of 7–9 therapies per child (Goin-Kochel et al., 2007). There are a number of factors that may account for this state of affairs. Most importantly, the problem is pervasive across a range of behaviors and related disorders. Core symptoms in the areas of communication, social behaviors, and stereotypes and rituals are often also accompanied by restricted eating, gastrointestinal problems, challenging behaviors, mental health problems, fine and gross motor problems, seizures, and cerebral palsy, among other issues. No discipline has the expertise to treat such a diverse group of problems, and no one treatment would be applicable for so many concerns. It is the rare person with ASD who does not have one, if not several, of these comorbid problems. Thus, multiple therapies and therapists, generally, are necessary.

A second important issue is desperation. Parents hear of various claims made by developers of many treatments, most of which have little or no empirical support. Often parents are of the opinion that they should try any method that might have potential benefit. Thus, for example, there is little to no difference between parental educational level and whether they choose empirically supported treatments (Miller, Schreck, Mulick, & Butter, 2012). The claims made by developers of unsubstantiated treatment methods often consist of testimonials, not research or systematically collected data. Parents may be afraid of “missing out” on the latest purported treatments, thus trying a number of alternative interventions and sometimes keeping this information from doctors or other professionals for fear of criticism (Maurice, Mannion, Letso, & Perry, 2001; Metz, Mulick, & Butter, 2005; Simsek & Koroglu, 2012; Wong & Smith, 2006).

Third, a multitude of resources exist from which information can be obtained, including the Internet, other parents and caregivers, teachers, psychologists, physicians, occupational therapists, physical therapists, communication disorders specialists, and autism books and magazines. Even within professions, a wide range of difference in expertise, training, and experience can result in vastly different views about what works and what does not. Even a parent with considerable background and education could be easily confused and overwhelmed with the vast amount of information.

Fourth, age of the child dictates to some extent which treatment choices are made (Granpeesheh, Dixon, Tarbox, Kaplan, & Wilke, 2009). Intensive and/or behavioral treatments may be less available for very young children or for older children/adolescents (Mackintosh, Goin-Kochel, & Meyers, 2012). Researchers have found psychotropic drug use to be more common in adolescents as well as in children with Asperger's syndrome (Goin-Kochel et al., 2007).

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