

SCIENTIFIC FORUM: COMMENTARY

The importance of early identification and intervention for children with or at risk for autism spectrum disorders

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Abstract

There has been a dramatic rise in the number of children being diagnosed with autism spectrum disorders (ASD), which has led to increased attention paid to assessment and intervention issues. This manuscript agrees with Camarata (2014) that the evidence base for early assessment and intervention should be expanded. However, it disagrees with Warren et al.'s (2011) assumption that there are not empirically validated early interventions. Reliable diagnosis has been documented during infancy and toddlerhood, and evidence suggests that the earlier the onset of intervention, the greater likelihood of an improved developmental trajectory. It is argued that early intervention is more cost and time efficient than a “wait and see” approach. With regard to published studies, the large amount of heterogeneity in the ASD population supports the use of rigorous single case experimental design research. It is an error to limit empirical evidence for treatments to only randomized clinical trials, which have the weakness of masking individual differences. Single case experimental designs examine the effects of intervention beyond typical maturation by allowing for clear estimations of developmental trajectories prior to the onset of intervention, followed by evaluation of the impact of the intervention. This commentary discusses the short- and long-term benefits of early diagnosis and intervention.

Keywords: *Autism spectrum disorder, early identification, early intervention.*

Introduction

This manuscript discusses Dr Stephen Camarata's article entitled “Early identification and early intervention in autism spectrum disorders: Accurate and effective?” We wholeheartedly agree with Dr Camarata that there is a “clear need to expand the evidence base” in the area of early diagnosis and intervention services for children with autism spectrum disorder (ASD) (Camarata, 2014, p. 8). There is a worldwide increase in the prevalence of children being diagnosed with ASD (Blumberg, Bramlett, Kogan, Schieve, Jones, & Lu, 2013; Kim, Leventhal, Koh, Fombonne, Laska, Lim, et al., 2011) and, thus, intervention programs are crucial. Camarata primarily discusses the need for accurate early identification and early intervention. We continue the discussion by addressing issues that are essential to understand these areas. Our article includes a discussion of the changes in the definition of ASD, the categorical exclusion of different types of experimental designs, and the harmful consequences of limiting “acceptable” designs to only randomized clinical trials when evaluating treatment outcomes for children with ASD and their families.

Early identification

DSM-5 changes in the diagnosis of autism

Since Kanner's (1943) first description of autism, diagnosis continued to encompass the three general categories of communication difficulties, social deficits, and restricted interests/repetitive behaviours. However, when the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) was introduced in May 2013, the three core domains of autism were pooled into two categories (social communication and restricted interests) and several of the sub-classifications were removed including Asperger Disorder, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (APA, 2000, 2013). This could likely affect the incidence rate of ASD (McPartland, Reichow, & Volkmar, 2012; Worley & Matson, 2012), but may not immediately affect the prevalence as the recommendation is to not re-evaluate individuals already qualifying for ASD under various classifications (Hyman, 2013).

This complicates the diagnostic process, as it is difficult to understand why two children with identical symptoms may have different diagnoses based solely on the date of diagnosis. Thus, only one child would receive ASD specific interventions while the other would not even have the diagnosis according to the DSM-5 guidelines.

Adding to the issues of diagnosing ASD is the fact that it is indeed a spectrum disorder. Individuals diagnosed with ASD who have fewer support needs may present similarly to other developmental disorders, and even those with significant support needs may have symptoms that overlap with other disorders (e.g., language delays, non-verbal learning disorder, social communication disorder). Related, the addition of social communication disorder (SCD), which is not considered within the autism spectrum, will also likely affect the incidence of ASD. Children diagnosed with SCD previously may have qualified under the autism spectrum. In an attempt to address the “spectrum” issue, the DSM-5 has provided, albeit vague, severity levels of symptoms in the two domains.

The variability in both symptoms and severity of ASD has led many to argue that ASD should not be viewed as a single disorder (Geschwind & Levitt, 2007); its symptoms are complex depending on individual characteristics and environmental contexts. However, studies have documented high reliability of diagnosis at age 18 months if the examiner is highly trained in ASD (Chawarska, Klin, Paul, & Volkmar, 2007). Further, retrospective and prospective studies are suggesting that social deficits are present during the child’s first year of life, and therefore the current state of the art is leaning toward an even earlier diagnosis.

In summary, the rationale for changing the DSM is multi-fold, including improvement in the precision of the diagnosis, characterization of common ASD symptoms within a single name, and description of severity level (APA, 2013). The consequences of these changes are not yet known and there has been great concern regarding whether the new criteria threaten service delivery and eligibility. For example, despite that children with less severe symptoms of ASD are often amenable to intervention and greatly benefit from increased support, many of these individuals may no longer qualify for ASD services (Rondeau, Klein, Masse, Bodeau, Cohen, & Guilé, 2011). Current research suggests that some individuals with a DSM-IV diagnosis of autism may no longer meet criteria for ASD in the DSM-5. While there is likely to be an inherent increase in the number of children diagnosed with ASD, the overall rate will decrease because of the dropped classifications (Taheri & Perry, 2012). Thus, Camarata’s (2014) discussion relating to concern about accurate diagnosis is certainly shared by others and it is an important area to consider.

Early intervention

Improved outcomes

Many of us who were in the field of autism in the 1960s and 1970s are well aware of the poor outcomes for children with ASD before numerous comprehensive interventions were available. Almost all children with ASD were placed in mental institutions by adolescence, with some placed as early as toddlerhood. Anyone who spent time observing the locked wards of these hospitals would attest to the undesirable living conditions these children had to endure. Each decade since has provided a rich and accumulating database documenting hundreds of effective interventions for children with ASD ranging from parent education to school interventions, behaviour management techniques (Baker-Ericzen, Stahmer, & Burns, 2007), methods to improve communication (Koegel, Camarata, Koegel, Ben-Tall, & Smith, 1998; Smith & Camarata, 1999), socialization (Harper, Symon, & Frea, 2008; Koegel, Werner, Vismara, & Koegel, 2005), academics (Koegel, Koegel, Frea, & Green-Hopkins, 2003; Koegel, Singh, & Koegel, 2010; Robinson, 2011), pragmatics (Kaiser & Warren, 1985), and so on. Many researchers feel that ASD is *not* necessarily a life-long disabling condition (Koegel & Koegel, 2012; Koegel, Koegel, Shoshan, & McNeerney, 1999), and most research clinics report that, with intervention, most children will be included in regular education classrooms, and as many as 25% of children will lose the diagnosis completely (Cohen, Amerine-Dickens, & Smith, 2006; Helt, Kelley, Kinsbourne, Pandey, Boorstein, Herbert, et al., 2008; Lovaas, 1987; Sallows & Graupner, 2005). Despite some methodological concerns with the Lovaas (1987) study, most researchers feel that the interventions and resulting outcomes for children with ASD are much improved today over previous methods. In fact, prior to Lovaas (1987), Prizant (1983) showed that, even with the best available interventions, a staggering number (~50%) of children diagnosed with autism remained non-verbal throughout their lives. In contrast, research today shows that fewer than 10% of individuals with ASD will remain non-verbal with intervention (Koegel, 2000). Moreover, data suggest that children who are completely non-verbal who begin intervention in the early pre-school years are far more likely to become verbal than children who begin intervention over the age of 5-years (Koegel, 2000). The majority of the field agrees that intervention must start at the earliest point in time (Landa, 2007; Reichow, 2012; Rogers, 1996). The “wait and see” method for early intervention of ASD is likely to have significant negative consequences on children with ASD (National Research Council, 2001).

Prevention of secondary symptoms

Individuals with ASD often exhibit aggression, tantrums, and self-injury. These behaviours are not in the diagnostic criteria for ASD, but are secondary symptoms that develop when primary symptoms are not addressed. Almost all disruptive behaviours (secondary symptoms) exhibited by children with ASD have a communicative function (Carr & Durand, 1985; Iwata, Dorsey, Slifer, Bauman, & Richman, 1994) and, thus, are often avoided, reduced, or eliminated, with early intervention focused on teaching functionally-equivalent replacement behaviours (FERBs) (Horner, Carr, Strain, Todd, & Reed, 2002). Similarly, co-morbid symptoms, such as depression and anxiety (common in adolescents and adults with ASD; Bauminger & Kasari, 2000; Howlin, 2000) are often directly related to difficulties with socialization, and recent research suggests that co-morbidity may be reduced if the core social area is treated (Koegel, Ashbaugh, Koegel, Detar, & Regester, in press). Alternatively, failing to provide intervention for these symptoms due to inaccurate or lack of diagnosis may result in grave consequences. Early intervention techniques to address core symptoms of ASD may prevent secondary symptoms and reduce the need for more substantial and expensive interventions later in life.

Fiscal issues

Early intervention leads to fiscal savings, as untreated symptoms of ASD become more abundant and severe later in life, requiring more costly interventions (Chasson, Harris, & Neely, 2007; Jacobson & Mulick, 2000; Jacobson, Mulick, & Green, 1998). Further, these potential lifelong costs are prohibitive for individuals with ASD that need lasting support. Jacobson et al. (1998) discussed a cost-benefit model for early intensive behavioural intervention for children who received 3 years of early intervention between the age of 2 years and school entry. In this model, cost savings were estimated in the range (in US dollars) of \$187 000–\$203 000 per child aged 3–22 years and \$656 000–\$1 082 000 per individual aged 3–55 years. Furthering the financial benefits of early treatment, many interventions for infants have shown that parents can be effective change agents with as little as 1 hour per week of professional support (Koegel, Singh, Koegel, Hollingsworth, & Bradshaw, 2013; Steiner, Gengoux, Klin, & Chawarska, 2013). By recruiting parents as active interventionists in the habilitation process at the earliest point in time, a much less costly intervention can be implemented.

Parent stress

Parents are generally the first to notice and report a developmental problem in their children (Johnson & Myers, 2007). Along with this perspicacious ability

of parents to identify a problem very early in life is the coinciding stress that is almost universally present in parents with a child with a disability (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker-Ericzn, Brookman-Fraze, & Stahmer, 2005). Without tools to address atypical behaviours, such as is the case with ASD, anxious parents are likely to further descend into deeper levels of health problems, such as depression (Dumas, Wolf, Fisman, & Culligan, 1991; Hastings & Brown, 2002), possibly interfering with their ability to effectively parent (Durand, Hieneman, Clarke, Wang, & Rinaldi, 2013). In contrast, providing parents with tools to address symptoms at the earliest point in time is likely to give them self-confidence and empowerment (Durand, Hieneman, Clarke, & Zona, 2009; Koegel, Bimbela, & Schreibman, 1996), thereby improving their own mental health along with their child's behaviour. In short, including parents in early intervention treatment has significant benefits for both the child and the parents' well-being.

Overcoming a disability with early intervention

Although Camarata (2014) suggests that some consider ASD a lifelong disabling condition, many researchers in the field have documented case examples of children who have eliminated their symptoms to the point where the individuals fit within the typical range (Koegel & LaZebnik, 2004; Lovaas, 1987), and almost half can eventually function without the need for special support. However, without early intervention this is unlikely. Most parents and professionals have the goal of alleviating symptoms that could negatively affect the child's ability to engage in leisure activities and gain employment. Early intervention increases the likelihood of improved long-term outcomes.

Barriers to early intervention funding

As Camarata (2014) points out, an increasing number of states have passed legislation requiring private insurance companies to cover intervention services for ASD. Despite the intent of the initiatives, the autism legislation has been accompanied by numerous class action lawsuits for denial of services (e.g., Cigna, Philadelphia; Kaiser, California; Providence, Oregon). Few would disagree that third party payers are infamous for denial of claims. Again, this often delays or eliminates the possibility of early intervention, and magnifies the costs of intervention in later years.

Methodology

Some of the insurance denials along with some recent publications have suggested that autism (Applied Behaviour Analysis, or ABA) therapy is "experimental"

and that there is a lack of empirical evidence for behavioural intervention approaches (Warren, McPheeters, Sathe, Foss-Feig, Glasser, & Veenstra-VanderWeele, 2011). The primary rationale relates to the lack of randomized controlled trial (RCT) studies. Quite candidly, we (as well as judges that ruled in favour of the individuals with ASD) believe that there are many scientifically validated interventions available. While RCTs are often considered the gold standard for clinical trials (such as drug evaluations), there are problems when this methodology is applied to behaviour interventions for individuals with ASD. First, the heterogeneity of individuals diagnosed with ASD makes it difficult to ascertain which participants respond to a specific intervention and to what degree. For example, a non-verbal child with ASD may not respond as well as a verbal child with ASD to a particular intervention. However, if the study's participants include both verbal and non-verbal children, one may mistakenly believe the intervention will help all children with ASD when the significance was analysed at the group level. Second, unlike medication studies where some participants are given a placebo, it may be impossible to have a non-intervention control group for young children with ASD. That is, parents who suspect a delay will seek out services for their child, which limits the possibility of a control group. While an argument could be made that the "treatment as usual" (TAU) in the community is sub-par, there is variability in community services and, therefore, it would be a challenge to compare an experimental and TAU group. Third, because of the heterogeneity of individuals diagnosed with ASD (as well as the difficulty of finding a non-treatment group), often the treatment effects are not significant in a group design. Next, and taking the perspective that there are not enough RCTs to support the effectiveness of early intervention, this leads us to question why more behavioural treatment RCTs are not being funded by the US federal government. One simply has to look at funded research in the US to see that a disproportionate amount of funding is being spent on physiological research relative to psycho-educational research in the area of ASD (Singh, Illes, Lazzeroni, & Hallmayer, 2009). Moreover, the research-to-practice gap from when a scientific discovery is made until it is practiced is often more than a decade. This means that even if a RCT were started today, a child would be well past the early intervention age by the time it was ready for implementation (Greenwood & Abbott, 2001; Morris, Wooding, & Grant, 2011). We believe that no one would argue in favour of denying early intervention services until more RCTs are conducted.

The value of rigorous single case experimental designs

A single case research design is a well-accepted, rigorous, experimental approach for documenting

treatment effects, and more than 45 journals publish studies with this highly regarded methodological design (Kratochwill, Hitchcock, Horner, Levin, Odom, Rindskopf, et al., 2013). Several hundred studies have shown the positive effects of early intervention through single case designs (National Autism Center, 2009). Highly regarded volumes on empirically supported treatments for many different disorders, including ASD, have reported the outcomes of a wide range of rigorous experimental designs (e.g., Weisz & Kazdin, 2010). With regards to external validity, single case studies can use procedures that have been replicated in multiple settings and by multiple independent investigators to improve confidence in generalizability. Further, single case experimental designs, by virtue of their repeated measurement time series analyses, control for any changes that might be attributable to maturation alone. In short, single case experimental designs provide a systematic and methodologically sound approach to conducting research on early intervention for ASD.

Treat behavioural functioning

There has been some concern that diagnosing a child with ASD may result in some false positives, particularly in the more mild cases or very young children (Rondeau et al., 2011). However, given the potential effects of ASD on the individual, the family, and the larger community, and the success of early intervention, it seems unwise and potentially detrimental to delay intervention or adopt the "wait and see if ASD develops" approach. Because of the heterogeneity in the diagnosis of ASD, a more intelligent and sensible approach may be to provide treatment for behavioural functioning rather than a diagnostic label. For example, if a child is not talking at 2 years of age and is uninterested in social interaction, it makes more sense to teach the parents some procedures to evoke first words in a social context rather than wait to see if the child is a "late talker" or will develop ASD. Similarly, if a child exhibits excessive tantrums, teaching appropriate replacement communicative utterances would be advisable. Even if there are some false positives, the risks of *not* providing early intervention can be far more serious, and contrasts negatively with the positive effects of parent education and attention to specific symptoms at the earliest possible age. In other words, not addressing all of the symptoms because of a reluctance to diagnose the child with ASD may place him or her at a disadvantage.

Summary

As Hart and Risley (1992) pointed out over 2 decades ago, developmental trajectories are well established by the pre-school years, and delays in

communication are very likely to result in a lifetime of challenges in many other areas. Approaches to studying social dysfunction in infants have become quite sophisticated, and the negative consequences of social dysfunction can be profound (Klin, Jones, Schultz, Volkmar, & Cohen, 2002). Promising interventions are available for infants within the first year of life (Koegel et al., 2013), as well as early in the infant's second year of life (12–18 months) (Steiner et al., 2013). These interventions draw from well-established empirically-validated treatments that have been effective with older children (Koegel & Koegel, 2012) and rely heavily on the parents as primary change agents, making early intervention both time- and cost-effective, while simultaneously reducing parent stress. We strongly encourage symptoms to be addressed at the earliest point in time so that parents learn effective strategies to help their children improve socially and communicatively and to decrease the possibility of more severe secondary symptoms. Warren et al. (2011) did not include any single subject design studies, and only discussed studies with 10 or more participants. A more comprehensive evaluation may be found through the National Standards Project (National Autism Center, 2009) and the National Research Council (2001). Camarata (2014) points out the importance of evidence and substantiated approaches to treating ASD. This is essential. Given the high numbers of children currently being diagnosed with ASD (Blumberg et al., 2013) undoubtedly this should be one of the nation's highest priorities. However, discounting research that uses single subject designs (that have been used for over 40 years and are accepted by over 45 professional peer-review journals) would, in essence, deny effective services to millions of individuals with ASD that could benefit from these interventions. As a society, we cannot ethically deny intervention to a child when many scientifically sound studies exist, showing remarkable intervention results for both decreasing undesirable behaviours and improving desirable behaviours (Eldevik, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009; Horner et al., 2002). Stating that an accurate diagnosis is not possible or that not enough group studies exist will result in the failure to provide services for many needy children. A more intelligent approach would involve individualizing specific empirically-validated interventions (either through group or single subject research designs) based on an infant or child's unique behavioural, environmental, and family characteristics, and then to carefully document the child's response to intervention (RTI) (Fuchs & Fuchs, 2006) to understand whether the intervention is effective for that child. RTI allows us to change, modify, discontinue, or continue a particular intervention. As Lovaas (1987) showed, if a child is responding to intervention, a larger "dose" may result in the ability of a child to be indistinguishable from his or her peers. The

potential positive outcome of early detection and intervention is not something that should be denied to any child or family, and will ultimately have a positive impact on society.

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