

AUTISM

[Archived] Autism Intervention: Comments on Harris, and Bruinsma, Koegel and Kern Koegel

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Introduction

The autism spectrum disorders are among the most serious of all childhood conditions and include autism, Asperger Syndrome and Pervasive Developmental Disorder (not otherwise specified). The condition is more common than previously thought and affects one in 165 children between birth and six years of age.¹ The outcome is poor² and the cost to both society and the family is enormous.³ In addition, the stress experienced by parents is considerable,⁴ especially as they search for a cause for their child's disability and an effective treatment that can alter that long-term outcome.

It is encouraging to note that there is now evidence that there are behavioural treatments for children with Autism Spectrum Disorders (ASD) that can lead to improvements in socialization, communication and cognitive abilities. The two reviews by Harris, and Bruinsma, Koegel and Kern Koegel nicely summarize and build upon data that are consistent with the National Research

Council Canada's⁵ recommendations for educating young children with autism. Both papers emphasize that early intervention for ASD children is needed and must start as early as possible. There is good scientific evidence that behavioural and educational intervention lead to gains in cognitive and language development and help compensate for some of the core deficits associated with the disorder. The outcome measures employed in studies have included cognitive, language and adaptive behaviour and behavioural measures and to a lesser extent, social and emotional measures.

However, these two reviews also emphasize that many questions remain unanswered. It is known that children's outcomes are variable in response to treatment; some children make substantial gains while others make slow progress. Very little is known about the child or family characteristics associated with this variation in outcome. Age and IQ seem to be important, but beyond that little is known. Harris and Bruinsma et al. recognize the difficulties with social-emotional functioning that children with autism experience. There are some single-subject design studies indicating that children with autism are able to learn to respond to and initiate social interactions with others, including peers, but the impact this will have on their development is yet unknown.

Harris emphasizes that children with autism need direct teaching in social and interpersonal skills. She clearly advocates for social inclusion programming with typical peers. Single-subject research has shown that specific social skills can be taught. Harris highlights the work of McGee, who taught young peers to request responses from children with autism, and Laushey and Heflin, who designed a peer buddy program to increase positive social interactions and increase the opportunities to generalize the skills to others. Specialized instructional methods such as script-fading, time delay and pivotal response training have been studied and used to teach necessary skills for play activities and found to be effective with some children. It is good to see an emphasis on social-emotional functioning as an outcome for SD children that is not mentioned in the reviews and that can have an impact on the implementation of these programs on a community-wide basis. It is important to remember that there is only a single Randomized Control Trial (RCT) that shows that approximately 25 hours per week of early Intensive Behavioural Intervention (IBI) is more effective than parent training. This study, by Smith Groen and Wynn,⁶ had a small sample size (N=28) and did not include children with ASD who also had severe developmental disability (i.e. IQ less than 35). This means that it is impossible to calculate the actual degree of treatment effect from the other studies. In the absence of an RCT, any estimate

of increase in IQ points in response to treatment is likely to be biased by the assignment of children to treatment or control groups. It is also not possible to compare this level of intensity or duration with other levels of intensity since only one level was compared to little or no treatment. Finally, it is not possible to generalize the findings to ASD children with severe developmental disability – that is, those with IQ below 35. Bruinsma et al. base their conclusions on the efficacy of early intervention on the several cohort studies and many single case studies that have been published, which is perfectly acceptable. But the lack of randomized controlled trials leads them to rely on these studies in an attempt to identify many child and parent characteristics associated with a better outcome. To be fully confident about the validity of these conclusions, these variables need to be tested as a priori hypotheses in RCTs.

It is also extremely important to draw a distinction between efficacy and effectiveness.⁷ Efficacy refers to evidence that a treatment works in the highly confined conditions of a lab setting, where there is strict control over who is admitted to the study, how well-trained the therapists are and how well the treatment is implemented. Effectiveness refers to how well a treatment works in community settings, where the conditions are very different. In effectiveness studies, inclusion criteria are very broad, therapists are trained as usual, and the treatment is implemented as it would be under normal circumstances. In this context, it may not be possible to ask a family to participate in 40 hours of treatment a week for four years. Neither review makes this important distinction.

Many questions remain; most studies lack measures that are sensitive to changes in social and emotional functioning. There is also a need for longitudinal studies of the impact of Intensive Behavioural Intervention across the lifespan. It is also important to emphasize that there are a range of interventions for children with ASD with strict ABA type discrete trial training that focus on teaching across all developmental domains at one end and more child-initiated developmental interventions that focus on social-communication skills at the other. Both are behavioural in the sense that complex cognitive and social skills are broken down into their component parts and are taught, but the methods of teaching are different. There is less evidence that these developmental methods are effective at present, but for some higher-functioning children this may be more cost-effective treatment than 40 hours a week of ABA for three to four years.

Implications

It is important to realize that children with ASD have a very severe developmental disability. Policy-makers must be aware that they have complex needs that may require a range of treatments and these must be distributed across the lifespan, not just concentrated in the early years so that there are no funds left over for school-aged children, adolescents and adults. Admittedly, there are fewer studies of interventions at older levels and these must be a priority for researchers.

It is certainly true that the field is progressing and it is no longer an issue whether intensive early intervention based on behavioural methods makes a difference. One of the key research goals must be understanding what form of treatment is most effective for what type of child at what developmental stage for what outcome goals. We have made a start in achieving this understanding but we have a long way to go. In the mean time, clinical judgment should rest on the solid foundation of available evidence and guide public policy while we wait for the new research to come in.

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