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SCIENTIFIC FORUM: COMMENTARY

Infants and toddlers with autism: The promise and the challenges

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Abstract

There has been a marked increase in interest in early identification of young children with and at risk for autism. This interest has reflected advances in research as well as an awareness of the potential for major changes in long-term outcome as a result of intervention. Several issues have complicated these efforts. There continue to be challenges to implementation of effective screening and diagnostic approaches in young children. Although the body of evidence-based research on treatment has increased, it remains limited. Despite these issues, important findings have emerged that may assist in fostering better approaches to screening, diagnosis, and documenting treatment impact.

Keywords: *Autism spectrum disorders, treatment, early intervention, screening, diagnosis.*

Introduction

In his lead article, Camarata (2014) raises a number of important issues. He rightly notes the increased emphasis on screening for autism and related conditions, but also underscores the differences between the UK and the US in this regard. His commentary also raises important questions about the efficacy of early intervention in light of the recent review by Warren, McPheeters, Sathe, Foss-Feig, Glasser, and Veenstra-Vanderweele (2011). In our brief comments we would like to focus on two, somewhat separate but ultimately connected, issues—early screening and the early diagnosis of autism and the effectiveness of interventions for it.

Diagnosis and screening in young children

Although the American Academy of Pediatrics formally recommended screening of 2-year-olds for autism in 2007 (Johnson, Myers, & American Academy of Pediatrics Council on Children With Disabilities, 2007), recommendations for such screening had been made earlier in practice guidelines from various specialty groups including paediatric neurology (Filipek, Accardo, Ashwal, Baranek, Cook, Dawson, et al., 2000; Filipek, Accardo, Baranek, Cook, Dawson, Gordon, et al., 1999) and child psychiatry (Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999). The importance of early diagnosis

was also underscored in the National Research Council (NRC) report (NRC, 2001), which further highlighted the importance of beginning early intervention as soon after a diagnosis as possible.

If autism, as Kanner (1943) suspected, is congenital or of early onset, why do delays in detection occur? Although many screening instruments have now appeared (see Ibanez, Stone, & Coonrod, in press), these vary in important ways, reflecting some of the diagnostic complexities in this population (discussed subsequently). Special challenges for screening include the relatively limited number of behaviours that appear before 18 months of age—at least for usual screening approaches. After that time a number of more directly observable, significant, and stable warning signs are observed (see Chawarska, Macari, Volkmar, Kim, & Shic, in press, for a discussion) although, even with more sophisticated diagnostic assessments, complex diagnostic situations arise.

Other obstacles arise given the broad range of severity and associated communicative and cognitive disability in autism (Volkmar, Reichow, Westphal, & Mandell, in press) and various external factors (lack of access to preventative healthcare, poverty, and psychosocial adversity) that may prevent screening in the first place. As with implementation of treatments, moving screeners from the academic centers where they are first developed to “real world” community settings can also be a major challenge. In one

study (King, Tandon, Macias, Healy, Duncan, Swigonski, et al., 2010) of a group of paediatric practices, many obstacles arose in the process from screening to referral and diagnostic assessment. As recently reviewed by Ibanez and colleagues, the advent of new approaches based on eye tracking, preferential listening, electroencephalography (EEG) response to faces, or even magnetic resonance imaging (MRI) based tasks may become more practicable, although there will be important issues of implementation in more typical practice settings that will need to be addressed (Ibanez et al., in press; Klin, Jones, Schultz, & Volkmar, 2005; McPartland, Wu, Bailey, Mayes, Schultz, & Klin, 2011; Paul, Chawarska, Fowler, Cicchetti, & Volkmar, 2007).

Diagnostic uncertainty, even after comprehensive assessment, reflects factors similar to those faced for screening. Although social dysfunction remains a, if not the, hallmark of the condition, assessment remains challenging. Again, various factors are involved. Although language delay is a frequent present complaint, some children (particularly those who are higher functioning) may have more subtle pragmatic language problems that are less likely to draw attention. Furthermore, some of the behavioural difficulties frequently seen in pre-school children with autism don't develop until between ages 2–3 (e.g., in pretend play, complex peer interactions, or unusual qualities of language). And, finally, often the more prototypic "resistance to change" criteria (e.g., stereotyped hand movements or body rocking) don't fully emerge until this period as well (although they may be preceded by unusual sensory interests or odd behaviours, see Chawarska et al., in press). Also, given the young age of the sample, the interpretation of behaviour has to take both age and developmental level into account, since behaviours that might not be unusual at one age (mouthing of toys or other materials) become so later on. Other issues arise given that up to 25% of parents report regression in skills—while this is often difficult to document it is sometimes very dramatic and it is quite possible that a child who passed a screener at age 2 years might develop a very classical autistic clinical presentation subsequently (see Volkmar, Reichow, et al., in press). It should also be noted that, although all the developmentally-based and diagnostic tests have their uses, they also have important limitations. In general, the many excellent diagnostic instruments (some of which require considerable training) appear to work best in somewhat older children and those with more 'mid range' levels of cognitive ability (challenges arise in younger and older individuals and for those who are higher and much lower functioning (Lord, in press). Yet another complication arises, as Camarata (2014) notes, from recent changes in nomenclature. These changes have been much debated (e.g., Huerta, Bishop, Duncan, Hus, & Lord, 2012; McPartland, Reichow, & Volkmar, 2012) and, although one of the rationales for change from

DSM-IV/ICD-10 was concern about diagnosis in younger children, several studies now suggest that the new diagnostic guidelines may be overly stringent for young children as well as older and higher functioning ones (see Barton, Robins, Jashar, Brenna, & Fein, in press; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012). As noted elsewhere, the increased awareness of genetic risk has presented issues of added urgency to screening in high risk populations, and the study of such populations, i.e., infant siblings of children with autism, has led to a substantive body of research (Szatmari, Jones, Holden, Bryson, Mahoney, Tuff, et al., 1996; Warren, Foss-Feig, Malesa, Lee, Taylor, Newsom, et al., 2012; Yirmiya, Gamliel, Pilowsky, Feldman, Baron-Cohen, & Sigman, 2006). Fortunately it does appear that by age 3 the diagnosis does become reasonably stable and, at least in the past, "movement" diagnostically tended to be from more severe autistic disorder to the broader autism spectrum and vice-versa (Chawarska et al., in press).

Interventions for autism in young children

The recent review by Warren et al. (2011) provided a systematic review of intervention for autism in children less than 12-years-old that included 34 studies (of which only two were randomized controlled trials). They noted considerable variability in the quality of the studies, with evidence strength ranging from difficult to establish to low, with some of the strongest support for two rather different model programs—the Early Start Denver Model (Rogers & Dawson, 2009) and the applied behaviour analytic approach pioneered by Lovass and Smith (1988). They also observed considerable variability in child response—a topic to which we'll return shortly. It is important to note that the Warren et al. (2011) review was not solely focused on young children and, as with all meta-analyses and systematic reviews, crucial decisions about inclusion/exclusion can have a significant impact on the results. It is also important to note that decisions on which criteria by which to judge the quality of the evidence can have major implications of interpretation (see Reichow & Volkmar, 2011).

Probably one of the most influential, if now somewhat dated, reports on the issue of early intervention in autism was provided by the NRC (2001). In this report a group of experts was asked to address the question of whether early intervention in autism was helpful. This report reviewed a number of programs, each of which had at least one peer-reviewed paper documenting the impact of its treatment model for young children with autism. These programs varied greatly from more behaviourally-based programs; for example, applied behaviour analytic approaches, such as early intensive behaviour intervention (e.g., Lovaas, 1987) and Pivotal Response Treatment (Koegel & Koegel, 1995) to

more developmental approaches like the Early Start Denver Model (Rogers & Dawson, 2009) and eclectic methods such as Division TEACCH (Schopler, 1997). The history of many of these models was similar in that many had started out as centre-based programs before moving to schools and home settings. Although the quality of information available for these programs were variable, the NRC report emphasized several important findings: for many (but not all) children with autism early intervention could make a major difference in outcome, with many areas of commonality, and some areas of difference, noted across the range of programs reviewed. There was consensus on the importance of comprehensive assessment of communicative, social, cognitive, and other relevant skills with a diagnosis established as soon as possible and appropriate follow-up provided. A number of important objectives for early intervention were highlighted including enhancing social and communication skills, organizational and motor skills, and play. This report recommended services to begin as soon as ASD was suspected and should be reasonably intensive (25 hours a week for 12 months a year). The report did note that not every child made progress and that a lack of progress was reason for a review of the program and its intensity.

Although the body of relevant evidence-based research in autism has increased markedly (Reichow, Doehring, Cicchetti, & Volkmar, 2011), it is the case that well-designed intervention work remains an area of great need. Warren et al. (2011) amply document the limitations of much of the available research, although clearly more work is becoming available. This has emerged both at the programmatic level (Rogers, Estes, Lord, Vismara, Winter, Fitzpatrick, et al., 2012), as well as relative to specific areas of intervention like social skills (Reichow & Volkmar, 2010). There are also many other systematic reviews, including multiple meta-analyses that have been recently published highlighting the emergence of evidence-based comprehensive programs for young children with autism (e.g., Reichow, 2012; Reichow, Barton, Boyd, & Hume, 2012; Rogers & Vismara, 2008). The recent advent of new approaches to assessing treatment outcome (including more basic measures of brain processing) is an exciting development (Rogers et al., 2012). Practice guidelines both in the US (Volkmar, Woodbury-Smith, King, McCracken, & State, in press) and abroad (McClure, in press) increasingly provide guidance for practitioners. Changes in outcome patterns suggest the importance of earlier intervention on improvements in outcome (Howlin & Moss, 2012). Given the costs of effective programs, economic issues must loom large in planning, although, on the other side, there are also considerable economic costs entailed in supporting individuals in residential treatment throughout their lives (Knapp, Romeo, & Beecham, 2009).

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