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Does Early Identification and Early Intervention for Autism work?

Introduction

There has been, over recent decades, increasing awareness and understanding in society about autism. Many more people receive a diagnosis of autism now than in earlier decades and the prevalence is typically judged to be between 1.8 and 2.6% of the population (Fombonne, 2018). The average age of diagnosis in the US is 4 years (Landa, 2018). However, the extent to which we should aim to identify autism in very young children, as young as 12 months, remains a matter of significant debate in research, policy and practice. This paper aims to summarise this extant debate and its potential implications for professionals and parents.

There are ongoing debates, reflecting wider arguments about how to conceptualize

inclusive practices in education (Mintz & Wyse, 2015), about whether autism should be considered as a) a developmental disability or category of special educational needs, or b) a different way that some people have of thinking and communicating, which has particular strengths such as attention to detail (Van Goidsenhoven, 2021). It is not my intention in this article to explore such debates in depth, but it is important to mention them as they can and do have an impact on how professionals and parents think about and work with autistic children, and about how we conceptualize early identification and intervention with young children.

From a developmental or psychological perspective, autism, is defined in the DSM-5 as being typified by "Persistent deficits in social communication and social interaction across multiple contexts" and "Restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric (Association, 2013). Volkmar (2016), who has been influential in work on autism diagnosis and treatment, has said of autism that ""It is first and foremost a disorder of social interaction associated with unusual patterns of learning and overengagement with the nonsocial world".

Early Identification

Over the last twenty years, there have been significant advances in the development of diagnostic tools which allow for early identification of autism in very young children. As summarised by Boyd (2010), retrospective studies, using early home video recordings of very young children (12 to 24 months) who went on to have a diagnosis of autism indicated early incidence of atypical behaviors allowed researchers to identify early warning signs which were correlated with later developmental delays. These warning signs include lack of coordinated eye contact, pre-occupation with particular objects, challenges with social smiling, looking at faces and responding to their name, engagement in high rates of stereotypic motor behaviors, or an intense focus on narrow interests (Baranek et al., 2005; Ozonoff, Heung, et al., 2008). As well, the presence of atypical object exploration and play at 12 months (Ozonoff, Macari, et al., 2008) and between 18 and 24 months of age (Morgan et al., 2008)—for example, object spinning or rotating, unusual visual exploration, preoccupation with certain objects—has been associated with lowerthan-age-expected scores on the Mullen Scales of Early Learning (Mullen, 1995) and increased autism severity at 3 and 4 years of age. Furthermore, researchers have associated (a) poor social-communication skills (e.g., inability to follow gaze or point), (b) limited use of vocalizations or gestures to regulate the behavior of others, and (c) minimal gains in the development of response to joint attention bids between 14 and 24 months with poorer receptive and expressive language skills at 30 or 36 months of age (Sullivan et al., 2007). This work has led to the development of specific screening tools. The Modified Checklist for Autism in Toddlers (MCHAT) has good sensitivity (i.e., proportion of children who screen positively and are later diagnosed with the condition) and specificity (i.e., proportion of children who screen negatively and are not later diagnosed with the disorder) between 16 and 30 months (Zwaigenbaum et al., 2009). The Quantitative Checklist for Autism in Toddlers (QCHAT) is effective at 18 to 24 months (Allison et al., 2008; Sturner et al., 2022). Landa's (2018) review of early identification and intervention in infants and young toddlers indicates that overall, the stability of autism diagnosis is high by 18 months, although as noted many children with signs of risk for autism will not be identified or diagnosed by this age.

The research on early warning signs has been translated in to tools for parents / teachers by some organisations especially in the US, - see for example "Learn the

Signs, Act Early from the CDC (https://www.cdc.gov/ncbddd/actearly/index.html) and "Learn the Signs of Autism" from Autism Speaks

(https://www.autismspeaks.org/signs-autism). Of course, just because such tools may be available does not mean that there are, in any particular territory or region, people trained to use them or necessary infrastructure for screening programmes to take place. Morin et al. (2021) have argued that the use of validated screening tools should be part of the standard training of teachers and related practitioners working in early childhood services. However, debates about whether increased early screening is in fact desirable, have led to reluctance on behalf of both professional associations and policy makers to commit significant funding to this issue in many areas (Landa 2018).

Is there Evidence for Early Intervention?

The rationale for the development of diagnostic tools, and the push for their wider adoption as an approach to screening some or even all children for a potential autism diagnosis (French & Kennedy, 2018), is based on the premise that a) earlier identification could lead to early intervention and that b) early intervention may better help children to overcome barriers to educational and social functioning in the medium or long term. This raises the question, however, as to what the evidence is that such early intervention would work in this way. As, if there is no evidence, then quite what would be the point of investing time and resources in early identification? This has been an area of contention in policy and practice over the last twenty years. The American Academy of Pediatrics, since 2016, has recommended universal screening for signs of autism of all children at 18 or 24 months during "well child visits" (French & Kennedy, 2018; Simon et al., 2016). However, the US Preventative Services Taskforce (USPSTF), an independent panel of experts which provides advice to the Department of Health at federal level has, since 2016, argued that current evidence does not support widespread screening where there are no specific concerns flagged by clinicians or parents (Siu et al., 2016). However, it should be noted that at time of writing their guidance on this area is under review. The extant debate on this topic up until recently is well expressed by Volkmar's (2016) summary that few if any interventions had robust double blind RCT evidence demonstrating efficacy. On the other hand, Howlin, another researcher whose work in the area has been seminal and influential, noted (Howlin, 2013) that despite the lack of such direct evidence, brain science research on autism has increasingly demonstrated the role of environmental factors and the plasticity of early brain development in the first 1,000 days, for all children. Howlin recommends, based on this premise, that early interventions might do best to focus on social communication development, mother/therapist interaction, parent-child synchrony and joint attention, and object exploration and symbolic play. Similarly, French and Kennedy (2018), in their review, argue strongly for early screening and intervention, arguing that "early treatment may have the best chance of alternating neural connectivity and a time of optimal brain plasticity".

However, the emerging evidence base in the last five years (Beaudoin et al., 2019; French & Kennedy, 2018; Fuller & Kaiser, 2020; Landa, 2018) has shown a shift in the weight of evidence supporting intervention, which I will attempt to summarise. However, it is worth noting that the role of evidence in the work of professionals and indeed of parents, with very young autistic children, as with the wider field of special educational needs, is itself somewhat contested. Biesta (2007) for example, as well as Thomas (2021) have argued that in professional fields such as education, there may be too much complexity and individual variation, to be confident that standardised approaches to evidence such as randomized controlled trials can properly represent that complexity. Biesta points out the individuality of professional to child interaction, and the specific knowledge that professionals (and of course parents) have about the unique child and their desires, motivations and needs. This is not to suggest that evidence of different types does not play an important role in decision making about working with young children, but rather that it informs rather than simply directs such decision making. Putting this another way, even without any "gold standard" evidence from RCTs, professionals and parents working with a child who has challenges with social interaction, still will feel the need (or indeed the moral imperative) to do their best to help that child meet these challenges. This is the messy, complex real world context in which teachers, psychologists, speech and language therapists and parents operate when making decisions about early identification and early intervention.

Types of Intervention

Broadly, interventions could be classified in to those that are "Naturalistic Developmental Behavior Interventions (NDBIs) (Schreibman et al., 2015) and those that are Early Intensive Behavioral Interventions (EIBI) (Smith, 2011). Landa (2018) typifies NDBIs as involving a "back-and-forth flow" of social interaction between child and professional or parent, with the adult responding to the child's play, communications or specific interests. Cues are provided to the child to promote specific behaviors with natural use of rewards or reinforcements. Everything happens within "naturalistic" contexts, i.e. the everyday interactions based on typical child activities for the day. EIBIs tend to be derived from specific behavioural and behaviourist interventions which can be traced back to Applied Behavioral Analysis (ABA). In these interventions, as Landa (2018) lays out, specific skills are taught in a specific order. The adult selects materials and tasks are usually adult initiated with specified reinforcement and reward schedules (Smith 2011).

Parental Involvement in Interventions

There is broad, although not complete agreement in the literature that effective interventions are likely to have significant parental involvement (Fuller and Kaiser 2020, Landa 2018). Van Goidsenhoven's (2021) encapsulation of early intervention as commonly meaning "giving instructions to parents to encourage their child's social- communicative development through play" is a fair assessment of the field.

The Strength of the Evidence

Green et al. (2017) undertook an RCT of a 12 session parent-mediated social communication intervention deliver at 9 to 14 months of age to children with familial high risk of autism in England. The intervention was "iBASIS-VIPP", a parent-mediated, video-aided feedback therapy which helps parents understand the unique abilities of their baby, and to use these strengths as a foundation for future development. Green et al.'s (2017) study indicated reduced severity of autism symptoms at three years of age. These findings were also replicated in a study by Whitehouse et al. (2021) in Australia.

Evaluation of the Preschool Autism Communication Trial (PACT) study using an RCT approach demonstrated reduction in symptoms of autism at follow up at ages 7 to 11 (Pickles et al., 2016). The intervention was low intensity training for parents of young children with autism. Again, using video feedback, therapists worked with

parents to increase the extent to which their communication was in step with that of their child. The intervention was carried out with young children (average age 45 months) and involved around 100 hours of coaching over a twelve month period.

The Early Start Denver Model (ESDM) is based on ABA, however it is applied within a naturalistic context, i.e. during natural play and everyday activities (Estes et al., 2015). Parents and therapists (who can be from a range of disciplines such as psychologists, speech and language therapists, occupational therapists) work closely with parents. The focus is on using play and joint activities to encourage interaction and communication. Estes et al. (2015) undertook an RCT involving evaluation of 36 children who underwent the intervention between ages of 18 to 30 months. Follow up at 6 years of age indicated improvements in core autism symptoms and adaptive behaviors. A more recent study by Beaudoin et al. (2019) also found improvements in motor skills and adaptive behaviors.

As French and Kennedy (2017) note, evidence like this that interventions can bring about sustained changes in autism symptoms over time is relatively new, and was previously considered difficult to demonstrate. It is this change in the evidence base that has shifted the argument more in favour of early identification, screening and intervention. However, not all studies have demonstrated impact on outcomes for children. Adaptive Response Teaching (ART) is a parent mediated naturalistic intervention aimed for infants identified at 12 months as being at risk for a later autism diagnosis (Watson et al., 2017), originally designed by Mahoney and MacDonald (2007) It focuses on "pivotal behaviors" – joint attention and engagement, intentional communication - as well as on developing parent-child reciprocity. ART involves a trained therapist coaching parents in child-responsive engagement strategies. These are suggestions to parents to vary the way they interact with their children – for example one strategy to encourage reciprocal engagement is "Take One Turn and Wait" (Mahoney and Macdonald 2007). Watson et a. (2017) undertook an RCT evaluation of 87 one year old children identified as being at risk for a later autism diagnosis. The intervention involved thirty sessions in the home across a six month period. Evaluation nine months after the end of the intervention indicated no impact on child outcomes however there was evidence of effects on parent responsiveness. This finding exemplifies Landa's (2018) conclusions reviewing at

similar studies, i.e. that there is evidence of impact on change in parental behaviors but not on sustained outcomes for children.

So, debates about the weight of evidence still persist. For example, two recent reviews of autism interventions for young children were both sceptical and viewed the efficacy of most interventions in altering developmental trajectories (i.e. having a sustained impact on outcomes) as being only small or moderate (Nahmias et al., 2019; Sandbank et al., 2020).

Debates about how early intervention is positioned in terms of the debate on disorder versus difference are also coming increasingly to the fore. Goidsenhoven (2021) notes that internationally, much of the autism community appears generally to support research on early intervention. However, at the same time, significant concerns have been raised about the assumptions of much research, particularly in relation to the use of concepts such as "early warning signs", "risk", and the deficit model associated with these terms. This can be, Goidsenhoven (2021) maintains, problematic in terms of how autistic children and adults are thought about in society.

What does this mean for practice?

It is difficult, given the range of evidence and views about that evidence, in the literature, to formulate clear guidance on implications for practice. Landa (2018) sets out a range of recommendations including: a) initiating intervention early, when signs of autism risk appear, b) provide coaching to parents for at least 9-12 months, c) use video feedback to help parents facilitate understanding of their child's social and communication development, and d) combining professional delivered interventions with parent mediated interventions. The range of literature considered in this paper does provide some support for professionals and parents to think about such approaches. It is true that the evidence base is uncertain, although the increasing weight of evidence is towards the potential of intervention to make a difference. Of course, issues of resourcing are also significant – different territories and regions have different levels of support that might be available to families in implementing any such interventions. As noted, even if there is not "gold standard" RCT evidence available on particular interventions, this does not mean that professionals and

parents cannot make judgements on how to work with children. Working with their understanding of what knowledge we have and, crucially their in-depth understanding of their children, they can make decisions on the use of potential strategies and interventions to help children maximise their potential. At the very least, parents and professionals should be encouraged to be aware of the possibilities, as well as the debates, around early identification and intervention.

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