

The value of early intervention for children with autism

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Abstract

Autism is a heterogeneous neurodevelopmental condition characterised by difficulties in social communication and social interaction, along with a range of impairing sensory interests or aversions, and repetitive and stereotyped behaviour. Prevalence estimates vary from approximately 1 to 2 in 100. Diagnosis may be as early as 2 years of age, but this is influenced by a range of factors such as the symptom severity, family circumstances and professional factors. Interventions for young children with autism spectrum disorder primarily aim to promote social communication and basic core skills through a number of different behavioural approaches. These may be administered by professionals but also often involve parents as co-therapists. Behavioural interventions primarily incorporate either a developmental approach, based on an understanding of the way that language and communication emerge in typical development, or approaches based on applied behavioural analysis. The evidence base for the effectiveness of interventions for children with autism is limited but a number of randomised control trials have shown benefits across a number of outcome measures, including early social communication in children and parental communication style within parent-child dyads. Emerging findings suggest that earlier and more intensive treatment may result in more favourable outcomes.

Keywords autism spectrum disorder; diagnosis; early intervention; screening

Introduction

Autism spectrum disorder

Autism spectrum disorder (ASD) is a heterogeneous neurodevelopmental condition characterised by impairments in social communication, social interaction, and sensory, stereotyped and repetitive behaviour. Estimates of prevalence have typically ranged from approximately 1%–1.5%, although a recent US study suggests that prevalence may be as high as 2.24%. Estimates of ASD prevalence have increased over time, mostly as a result of a wider understanding of the manifestation of ASD, and also as an artefact of different approaches used in epidemiological studies. The majority of individuals with a diagnosis of ASD are male, with male – female ratios increasing in relation to higher levels of intellectual ability. There has been great interest of late in the profile of girls and women with ASD, the possibility that females may be more adept than males at ‘camouflaging’ the

symptoms of autism and the likelihood that many remain undiagnosed.

Both ICD and DSM systems previously incorporated diagnostic subtypes, including Asperger syndrome, but DSM-5 now specifies a single concept of autism spectrum disorder. Individual differences are defined by descriptions of cognitive and language ability, sensory impairment and any known comorbidities. Although the genetic basis of autism was clearly established via twin studies several decades ago, and it is certainly the case that autism tends to run in families, the search for the specific genes involved in autism has been unsuccessful.

Age of diagnosis

The age of diagnosis of ASD varies partly in relation to the combination of intellectual ability and severity of autistic symptomatology. Children identified as having moderate-to-severe degrees of intellectual impairment or who have been diagnosed with congenital conditions may receive an autism diagnosis before two years of age. Regardless of intellectual ability, children showing clear and impairing difficulties associated with autism, including insistence on elaborate or rigid routines, resistance to change and strong sensory interests or aversions, will tend to raise concerns in parents, who may then discuss these concerns with early years professionals. However, according to a large American study, compared to parents of children with learning disability or developmental delay without ASD, parents of children with autism alone may initially be met with reassuring, less proactive responses.

Preschoolers attending nursery and children entering formal education may attract concerns relating to ASD due to delayed onset of speech, unusual features of language, including the use of stereotyped and repetitive words and phrases, or difficulties engaging with their peers. More able individuals and those whose symptoms are less profound may not attract concerns until later in primary school, after starting secondary school or even later, with difficulties becoming more evident as expectations in enhanced social sophistication increase with age. Attention deficit hyperactivity disorder (ADHD) is recognised as a common comorbidity of ASD, and the focus on the symptoms and treatment of ADHD may distract from the identification of autism. In adolescence and adulthood anxiety, depression, eating disorders and other psychiatric conditions may co-occur with ASD, especially in the absence of a formal autism diagnosis.

Early intervention

The value of early intervention for children with autism is considered here in relation to the following issues:

- Early identification of autism
- The range of interventions for young children with autism
- Evidence for the effectiveness of early interventions
- How early is ‘early’?

Early identification of autism

Screening: In the absence of validated biological markers, the identification of ASD depends on the observation and assessment of individuals’ skills, difficulties and needs. As suggested above, the age at which diagnosis is made varies according to a number

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of factors pertaining to the individual, although this is also influenced by other issues, including the resources available through local services, waiting times for referrals, and demographic and family circumstances. Over the past 30 years researchers and clinicians have attempted to design screening instruments to identify toddlers at risk for later autism diagnosis, particularly for use in a primary, whole population, setting. In the UK, an initial screening measure, the Checklist for Autism in Toddlers (CHAT) was designed to be used in the context of a regular 18-month check-up, typically administered by a health visitor or GP. Certain aspects of early social communication skills and pretend play, believed to be part of the prodrome of ASD, were assessed via parent report and professional observation. Although early results appeared promising, with all children who screened positive receiving an autism diagnosis, a longer term follow-up showed that the sensitivity of the CHAT was very poor, with approximately 80% of children subsequently diagnosed with ASD being missed by the screener.

Subsequently a number of screening instruments, mostly in the form of parent questionnaires, have been developed, although none have proved to have sufficient sensitivity and specificity to warrant implementation in a community-wide context. Screening instruments may be more effective when used as part of an ongoing surveillance programme, or in order to distinguish autism from other conditions in children about whom general developmental concerns have been raised. The systematic use of screening instruments for ASD is not currently recommended by the UK National Screening Committee.

Red flags: There are a number of early developmental features and behaviours believed to be early manifestations of ASD, often referred to as 'red flags'. These include:

- Poor or absent engagement and interaction during early infancy
- Lack of babbling by 12 months
- Late onset of speech, including no single words by about 18 months or short phrases by 24 months
- Absence or reduced use of socially-motivated nonverbal behaviours, such as gestures, pointing and showing
- Loss of language or other social and communication skills once clearly established

Knowledge of these red flags amongst early years professionals, including GPs, health visitors, speech and language therapists and nursery staff, can help to precipitate the identification of children who might warrant attention from specialist professionals and teams. Information about the early prodromal signs of ASD may be included as part of initial training and continuing professional development, and is also available via the websites of statutory and voluntary sector organisations, such as NHS Choices, the National Autistic Society and Autism Speaks.

Familial risk: The highly heritable nature of autism means that it often runs in families. The recurrence rate in younger siblings of children with ASD may be as high as 10%, and research investigating the development of younger siblings at familial risk suggests that the recurrence rate may be higher. The fact that siblings are at elevated risk for ASD means that local early year's services may monitor these children more closely, with a view to identifying potential symptoms as early as possible.

The range of interventions available for young children with autism

Interventions for toddlers and preschoolers with a diagnosis of ASD (and those for whom ASD is strongly suspected) broadly fit into one of three broad approaches. Some specific interventions fit very clearly within one of these approaches, whilst others incorporate elements of more than one. There is very limited evidence to enable professionals to match a specific intervention to a given child's profile of strengths and needs in order to promote optimal outcomes. Decisions about intervention depend on a number of factors, including parental preference; limited options within a statutory service provision; child characteristics, such as intellectual ability and age; family profile and resources; and the relative costs of different interventions.

The three main categories into which most interventions for young children with autism fall are:

- Developmental pragmatic approaches
- Applied behaviour analysis (ABA)
- Comprehensive environmental systems

Developmental pragmatic approaches: Developmental pragmatic approaches include a range of general and specific programmes that are based on a perspective on how language and communication are facilitated in typically developing children. The focus is primarily on the transactional nature of reciprocal interaction and intentional communication between children and their caregivers during the first year or so of life. For children with language and communication delay or disorder the to-and-fro nature of the interaction can break down as the child may not be able to initiate and reciprocate communicatively. In this situation parents may become more directive or over-talkative, in an attempt to 'fill in the gaps'.

A common focus for these interventions is to encourage parents to be more responsive in their communication style, following their child's interests and chosen activities. Given the emphasis on the parent-child dyad, the majority of these programmes focus on working with parents as 'co-therapists'.

These interventions were originally developed to support parents of children with language delay and disorder, and have been adapted to be applied to the needs of parents of children with ASD. Many approaches follow the model originally presented by the Hanen programme, which offers courses to small groups of parents over a number of weeks, providing information about the nature of language and communication disorder, and demonstrating a range of techniques parents can employ in order to enhance their young child's communication environment. Professionals visit the parents at home and video examples of parent-child interaction. Parents can then observe and analyse their own communication and extend their positive communicative engagement. In addition to group-based provision, this approach is also delivered on an individual basis, both through specific, manualised programmes and more general 'parent-child interaction' sessions, often delivered by speech and language therapists.

A growing body of evidence supports the effectiveness of this approach. Short-term follow-ups show that parents can change their style of communication, adopting the skills and techniques taught by the professionals. This enhanced communication environment has been shown to have positive effects on

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