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EXECUTIVE INDEX

AUTISM SPECTRUM DISORDERS

The earlier that children with an Autism Spectrum Disorder (ASD) receive referral, diagnosis and intervention, the better the long-term results are for those children and their families (Barbaro & Dissanyake, 2009; Wiggins et al., 2006; Mandell et al., 2005).

Primary health care professionals, such as child and family health nurses and GPs, can listen to parent concerns and be alert to the signs of developmental delay in infancy and early childhood to facilitate early referral and diagnosis. Indeed, Barbaro & Dissanayake state that primary health care professionals, given their extensive knowledge and training on developmental milestones, are the best placed – and most expert – to observe young children's development and to identify early signs of ASDs (2010:377).

ASD IN AUSTRALIA: AN OVERVIEW

ASD is the term used to refer to three types of developmental disorder: Autism, Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). A diagnosis of one of the three indicates a developmental deficit of varying severity in the areas of:

1. communication
2. social skills and/or
3. behaviour.

No two children with an ASD are the same, as they each have varying degrees of developmental deficit in the above three areas. This is why the term 'spectrum' is used when describing the disorder. In this article we will use the term ASD when referring to the all three of the disorders.

Diagnoses of ASD have increased markedly since the 1990s. Prior to this, children were generally diagnosed with Global Developmental Delay or intellectual disability. Williams et al. (2008) found that:

- The current rate of prevalence in Australia is estimated at 1 in 160.
- Rates of diagnosis vary by state and territory due to differences in the way a diagnosis can be reached.
- Australian data show that about four boys are diagnosed with ASD for every one girl.

The cause of ASD is not known, but is thought to be a combination of genetic and environmental factors. It is not caused by anything the family does or does not do.

Despite the recognition that signs of ASD can appear in infancy, one study from America found that the average age of diagnosis is around three or four years old (Mandell et al., 2005). In specialist centres, diagnoses can be made for some children as early as 24 months, and rarely earlier. Significant research is being done to try and reduce the average age of diagnosis as this may lead to an earlier intervention. In turn, earlier intervention could help improve developmental outcomes for children and their families and lessen the long-term impact of an ASD for an individual child (Barbaro & Dissanyake, 2009).

Children with Asperger's Syndrome are generally diagnosed later than children with

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other ASDs, often between seven and eight years of age (Mandell et al., 2005). This is because language development is usually normal for these children and any additional developmental deficits are often less severe than in other ASD cases (Barbaro & Dissanyake, 2009). Most cases of Asperger's Syndrome are not identified until the children move into a school or preschool setting when their developmental deficits become more apparent (Barbaro & Dissanyake, 2009).

Early diagnosis is challenging and it is likely that not all children with an ASD can be diagnosed early. In some children, development appears to be normal and they reach their milestones for communication and social skills up to approximately 15-21 months. They then start to regress, losing skills they had previously demonstrated, most commonly they language skills (Barbaro & Dissanyake, 2009).

AREAS OF DEVELOPMENTAL DEFICIT IN ASD

ASD is characterised by developmental deficits of varying severity in the following areas:

Social skills

- being content to be alone
- ignoring bids for attention
- lack of use of gestures or eye contact
- dislike of physical contact
- lack of social smiles

Communication skills

- lack of speech or speech that isn't functional, fluent or used with intent to communicate
- repetition of others' speech (echolalia)

Behaviour

- repetitive, non-functional behaviours such as hand flapping, rocking, twirling or finger movements
- persistent and restricted attachments to objects (not toys)
- little or no imaginative play (Johnson & Myers, 2007).

Children with ASD will have developmental deficits in one, two or all three areas and the extent of these deficits will also vary from child to child.

There are particular behaviours that have been identified by the American Association of Pediatrics as 'red flags' and these should trigger immediate referral:

- no babbling, pointing or other gesturing by 12 months
- no single words by 16 months
- no two-word spontaneous (not echolalic) phrases by 24 months
- loss of language or social skills at any age (Johnson et al., 2007).

Around three quarters of children with Autism (one of the three types of ASD) are also intellectually disabled (Barbaro & Ridgway, et al., 2010; RCH Quality and Care, 2008). The area of developmental deficit that is most severe or most apparent will influence the referral pathway provided to the child and family.

EARLY IDENTIFICATION OF SIGNS OF ASD

It is vital that practitioners pay attention to concerns reported by parents. A study by Barbaro & Dissanyake (2009) found that some parents will express concerns about the child's developmental trajectory before 12 months and many more will have concerns by 24 months (Frith and Soares,1993). The Parents Evaluation of Developmental Status (PEDS) is a widely used parent-report screening instrument that has shown to be a valid way of eliciting developmental concerns held by parents (Glascoe, 2000).

There is also a number of tools that have been specifically developed to screen children for ASDs and while their validity is not addressed here, they include:

- First Year Inventory
- Checklist for Autism in Toddlers (CHAT) and its modified version M-CHAT
- Infant Toddler Checklist
- Early Screening of Autistic Traits Questionnaire (Barbaro & Dissanayake, 2009, 2010).

Examples of the items covered by these tools can be found on the M-CHAT which can be downloaded from www.firstsigns.org/screening/tools/rec.htm

A recent Australian study found that child and family health nurses are well placed to observe a child's

developmental trajectory and as a result can identify the need for further ASD assessment in children between the ages of 12 and 24 months (Barbaro and Dissanyake, 2010). Therefore, with training and resources, it appears that it is possible to identify early many children with ASD (Barbaro et al., 2010 in press). Having trained child and family health nurses means that surveillance and screening for ASD can be a part of a family's regular well-baby visits.

Some practitioners may be concerned about the balance between the need to refer early to maximise developmental outcomes and the desire to wait to ensure that any signs are persistent and not simply a function of normal developmental variations. However, several studies have found that between 85 and 90 per cent of children diagnosed with an ASD between two and three years old retained their diagnosis at later ages (Lord, 1995; Turner, 2006; Charman et al., 2005).

Barbaro et al. (2010) advise that 'the main factor associated with parental satisfaction in the diagnostic process is early diagnosis'. Similarly, the Centre for Community Child Health advises that the literature overwhelmingly advises professionals to listen carefully to parental concerns. The Centre recommends the approach be to report the aspects of the child's development that are of concern followed by a thorough assessment as necessary.

HOW ARE CHILDREN DIAGNOSED WITH ASD?

Parents who have raised concerns with their child and family health nurse might want the nurse to provide a diagnosis, or might question whether their child has ASD, particularly given raised levels of community awareness about ASD. This can be difficult to manage, but it is best to explain to parents that there is no single, simple test for ASD and that a child and family health nurse is not able to provide a definitive diagnosis.

The child and family health nurse or the family's GP will refer a child to a professional based on the area of observed developmental deficit that is most acute, as well as existing protocols and the availability of health and allied health professionals in the area. This first point of referral is likely to be a speech therapist, psychologist or a paediatrician.

From here, a team is generally assembled that may include occupational therapists and child psychiatrists in addition to the professionals listed earlier. At times, a paediatrician or child psychiatrist will make a diagnosis alone.

While Australian states and territories have different approaches to the process of diagnosing children with an ASD, it is most common for a team to assess the child and makes a diagnosis. The multidisciplinary assessment process may include:

- paediatric medical and developmental assessment
- psychiatric assessment
- speech and language assessment
- observation of behaviour and a psychosocial assessment
- cognitive skills assessment
- audiology assessment
- completion of an autism checklist

(Autism Victoria, 2010 www.autismvictoria.org.au/diagnosis/; Raising Children Network, 2009; CCCH, 1997).

While diagnosis of ASD or other developmental delay needs to be done by a team of health professionals with experience in the area, detailed referral information from a child and family health nurse provides the diagnostic team with useful information about the child.

The path between initial concerns and referral for diagnosis and intervention can be a long one. Families without access to the private health system or in rural or remote areas may encounter particular and lengthy difficulties in accessing the range of services needed for diagnosis.

Given the importance of introducing therapies and intervention as early as possible in the life course of a child with an ASD, the time spent on waiting lists can be intensely frustrating for families. However, families do not have to wait for a diagnosis from an assessment team to start making contact with support services; parents and families should be encouraged to explore multiple avenues (see over page for suggested resources). Families should also be made aware that the Australian Government, through its Helping Children with Autism Package, has committed significant funding to assisting families with the cost of interventions following diagnosis.

WORKING WITH PARENTS AND FAMILIES

There are significant challenges when working with parents and families who have a child with a diagnosed or a suspected developmental deficit. Learning that their child has or may have a developmental disorder can be overwhelming and it is important to offer families support and information.

It is important to acknowledge parental concerns about their child. Consider:

- offering support to and for the family, including links to community services, respite options and professional input
- identifying the particular areas that indicate developmental delay and the behaviour that causes the parents the most concern and/or distress
- addressing the parents' concerns systematically
- referring for assessment and diagnosis (CCCH, 1997).

PRACTICE RESOURCES

There are many online resources for families with a child who has an ASD. Many of these resources contain quality information, but some provide information that is misinformed and potentially harmful. Directing families towards reputable and evidence-based resources can help them acquire good-quality information. Families can also be guided to sites outlining financial support services that are available from the federal government through the Helping Children with Autism package and sites that provide guidance in how to choose an appropriate early intervention source.

State and territory-based ASD organisations

Each state and territory has its own ASD organisation that can provide families with support and links to relevant local services. They can be found online at:

Autism Asperger ACT: www.autismaspergeract.com.au

Autism Spectrum Australia (NSW): www.autismspectrum.org.au/a2i1i1l445l487/welcome.htm

Autism Northern Territory: www.autismnt.com.au

Autism Queensland: www.autismqld.com.au

Autism SA: www.autismsa.org.au

Autism Tasmania: www.autismtas.org.au

Autism Victoria: www.autismvictoria.org.au/home

Autism Association of Western Australia: www.autism.org.au

ASPECT – Autism Spectrum Australia: www.aspect.org.au

Government

FaHCSIA's Autism portal: www.fahcsia.gov.au/sa/disability/progserv/people/HelpingChildrenWithAutism

Hospital-based resources

The Royal Children's Hospital Melbourne: www.rch.org.au/kidsinfo/factsheets.cfm?doc_id=12216

Children's Hospital Westmead: www.chw.edu.au/parents/factsheets/autism_spectrum_disorder.htm

Monash University, ACTNOW Fact Sheets: www.med.monash.edu.au/spppm/research/devpsych/actnow/factsheet.html

Other online resources

Early Days: www.earlydays.net.au

My Time: www.mytime.net.au

Child Inclusive Learning and Development Australia: www.rucsn.org.au (formerly Resource Unit for Children with Special Needs)

First Signs, including M-CHAT: www.firstsigns.org/screening/tools/rec.htm

RAISING CHILDREN NETWORK

The Raising Children Network has extensive resources for families of a child with an ASD. You might like to direct families towards:

Contact information for government-funded diagnostic services:
http://raisingchildren.net.au/articles/autism_spectrum_disorder_funded_diagnosis_services.html/context/1033

ASD therapies and services:
http://raisingchildren.net.au/therapies_services/asd_therapies_services.html

ASD services pathfinder, including available financial support:
http://raisingchildren.net.au/services_pathfinder/services_pathfinder.html

How to find community support in your area:
http://raisingchildren.net.au/articles/autism_spectrum_disorder_support.html/context/1034

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Go to www.rch.org.au/ccch/resources.cfm?doc_id=10888

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