

# Identifying and supporting autistic preschoolers and their families



CPD 

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## Background

In Australia, preschoolers are being identified and diagnosed as autistic.

## Objective

The aim of this article is to describe the different paths preschool children and their families can take from identification of developmental or behavioural concerns to ongoing support, intervention and healthcare.

## Discussion

There are many ways in which general practitioners, working alongside other professionals and with relevant services, can assist each child and family.

**AUTISM** is a developmental condition that affects social communication and behaviour.<sup>1</sup> In Australia, significant progress has been made in the development of systems to detect autism early,<sup>2</sup> with most children now diagnosed during the preschool years.<sup>3</sup>

Parents (a term used in this article to refer to all primary caregivers), child care educators and healthcare professionals are well placed to monitor the achievement of language, motor and social/emotional milestones in preschoolers. When development is not progressing as expected, as seen in autism, identifying differences early can assist in providing advice, interventions and supports to families, leading to positive outcomes.<sup>4-6</sup>

Children with developmental or behavioural differences may present to a general practitioner (GP) in various ways. When seeing a child who may have autism, it is beneficial to adopt a holistic assessment approach, with all diagnostic possibilities considered. Key assessment elements should include language, social emotional and cognitive development, as the basis for understanding ability and behavioural differences. Consideration of environmental stressors and family dynamics is also important, as both can affect child development and behaviour. Depending on the severity and type of difficulties, there is a range of healthcare

professionals who can assess, intervene and support the child and family (Figure 1). The type of professionals involved and their setting (eg private, community health and hospital outpatient clinics) will vary according to local availability and parent resources. Advice, interventions and supports should be individually tailored to the child's and family's needs, including consideration of the wellbeing and support needs for parents and siblings. This approach will ensure best care, regardless of the diagnostic outcome. As discussed further in this article, GPs are integral to each step in a child and family's journey.

## Identification

In Australia, GPs are often viewed as the 'gatekeepers' for care and are therefore key decision makers in identifying and referring children to services.<sup>7</sup> When identifying children with neurodevelopmental differences, GPs are well placed to offer surveillance using standardised tools or to refer to Child Health Nurses (CHNs) for surveillance completion. Alternatively, GPs can be the first to hear of parents' concerns about their child or about concerns that have been raised by others, such as early years educators (eg preschool educators, day care staff), who are well placed to observe

child behaviour in social settings and identify developmental and behavioural differences.<sup>8</sup>

The role of CHNs in development and behaviour varies across Australia. With no agreement regarding a universal population surveillance policy, there are different views regarding whether the benefits are sufficient to justify autism surveillance.<sup>9,10</sup> As such, it is important that GPs are aware of their local surveillance services and how to access them when needed.

### Post-identification of neurodevelopmental or behavioural differences

As shown in Figure 1, there are multiple professionals involved in assessment,

intervention and support for children with developmental and behavioural concerns.

#### Assessment

Audiologists have a critical role in the early care pathway for autistic children.<sup>11</sup> If language is delayed or a child is not responding to cues from their parents, hearing impairment must be excluded. Less commonly, visual acuity requires assessment if there are concerns about vision as a reason for poor eye contact and visual engagement.<sup>12</sup> Ophthalmology referral is indicated for concerns about eye movements, strabismus, ptosis or a condition that has both vision and developmental difficulties.

If a child's developmental milestones are delayed or their behaviours are causing problems or are different than expected for

their ability, referral for further assessment by allied health providers is indicated. In the first instance, this could be with a care provider most directly relevant to the differences, such as a speech pathologist for speech, language and social communication; an occupational therapist for functional skills or sensory-motor difficulties; or a psychologist for cognitive skills and early behavioural or emotional support. If there are concerns about the child's environment, then social work expertise will assist, and if there are risks to the child, mandatory reporting should be completed. Detailed assessment in the aforementioned domains can provide key information needed for identifying intervention targets and assessing whether a child's behaviour is in keeping with, or different to, expectations for their age



**Figure 1.** The different levels that can indicate general practitioner involvement

\*As recommended in the relevant state or territory

<sup>†</sup>Tier 1: population surveillance including children with no identified concerns

<sup>‡</sup>Tier 2: surveillance of children with concerns identified

<sup>§</sup>Working in a community health, private or hospital outpatient setting

CHN, child health nurse; ECIS, Early Childhood Intervention Services; GP, general practitioner; NDIS, National Disability Insurance Scheme

and ability. Such assessments can occur prior to a diagnostic assessment, as part of public community health services, a National Disability Insurance Scheme (NDIS) plan or in private with funding support from mental health or chronic disease care plans, if criteria are met.

### Intervention and support

On the basis of assessment findings, allied health professionals can offer supports and interventions for the child and family (Figure 1). Allied health professionals can also assist families to access early childhood intervention from services funded by the National Disability Insurance Agency.<sup>3,13</sup> There is no need to delay access to interventions and supports while waiting for a diagnostic assessment, as entry is based on functional difficulties. Early childhood educators, other day care providers and kindergarten or preschool teachers have opportunities to support child behaviour and are well placed to implement strategies in the child's social settings.<sup>8</sup> Additional supports are also needed, such as assisting parents to identify their key goals, navigate services and seek interventions, alongside monitoring of a child's progress. Emerging evidence about parent coaching and stepped care provides guidance on how to implement structured and personalised care.<sup>14-17</sup>

It is important to recognise the stressful nature of the period in which a family begins to notice differences in development and to consider a potential diagnosis of autism for their child.<sup>17,18</sup> Regardless of whether a swift and affirming response or a 'watch and wait' with active monitoring and follow-up is deemed most appropriate, there is an opportunity to support families to deal with uncertainties and fears. Where monitoring and follow-up is planned, knowing the details of the plan will be reassuring for the family. Interventions and supports tailored to the needs of parents and siblings should also be considered. If parents develop or have pre-existing mental health needs, then a separate referral to support them is required.

The following case provides an example of a child who required assessment of speech and language

delays with some intervention, but where a full multidisciplinary team diagnostic assessment was not required.

#### CASE 1: NASIR

Nasir, aged two years and two months, attended his local general practice clinic because his mother was concerned that he was not talking and tended not to look at a person's face when making sounds. Nasir's mother had read about autism on the internet and was worried that Nasir was autistic. She wanted help as soon as possible but did not know which professional she should see.

Nasir's GP referred him to the CHN for surveillance. The results showed Nasir was behind in language but had met all his other milestones. The GP referred Nasir for a hearing assessment, which was normal. The GP also recommended child care and a speech pathology assessment to assess Nasir's communication and social skills. The speech pathologist identified an expressive language delay and saw Nasir for a short block of intervention, resulting in good progress. As his language improved, so did his eye contact, and he was discharged after four months. In this case, a referral to a paediatrician and other allied health services was not needed.

### Referral to a paediatrician and/or multidisciplinary assessment team

Referrals to secondary and tertiary service providers may occur at parental request, in collaborative decision making between the parents and GP, or be instigated by the GP or other health professionals following identification of developmental or behavioural concerns.<sup>19</sup> In Australia, there is a lack of standard information required for referral, and different services have different criteria and processes,<sup>15,20</sup> which means that GPs need to be familiar with their local services and referral requirements.<sup>21</sup>

Another common problem is extended waiting times for paediatric consultation or multidisciplinary assessments. This means that alternative strategies, as

described for interventions in Figure 1, are needed to ensure a child and their family are receiving intervention and support while waiting.

When discussing indications for referral, it is preferable to discuss the child's abilities using strengths-based language, to ensure conversations are family-centred and to consider the broader sociocultural context.

### Paediatrician roles

Paediatricians have an important role in symptom evaluation, case management and diagnosis. If a child is dysmorphic or there is a history of regression in development or neurological symptoms or signs, referral to a paediatrician is indicated. Exposures and complications during pregnancy (eg medication or substance use, gestational diabetes and hypertension) linked to differences in neurodevelopment should also trigger a paediatrician referral.<sup>22</sup>

Chromosomal microarray and fragile X testing is considered best practice for children presenting with developmental delay or intellectual disability, signs of autism and/or congenital abnormalities to investigate the possibility of genetic conditions.<sup>23,24</sup> Examples of genetic conditions associated with autism include tuberous sclerosis and fragile X syndrome.<sup>25</sup> When a child is diagnosed as autistic, referral to a genetic counsellor may be indicated so parents can be counselled regarding the recurrence risk for future children.

Paediatrician input for decisions about referral to a multidisciplinary clinic is also valuable and is required by some services. Paediatricians can also provide care coordination and long-term management for some children and their families.

### Diagnostic assessment

If there are concerns regarding development or behaviour that involve multiple domains, then assessments by multiple disciplines are needed. In addition, it is important to consider the relevance of findings in relation to the child's environment, whether difficulties occur in multiple settings, and the impact that difficulties are having on activities

and community participation.<sup>21</sup> There is no guidance for the minimum level or type of symptomatology to 'trigger' a referral for diagnostic assessment, but key factors for consideration would be significant differences from peers across more than one domain, a lack of response to community or privately accessed interventions, and family complexity.

A paediatrician or psychiatrist working in a private setting may commence a multidisciplinary assessment using Medicare Benefits Schedule items designed for that purpose. Alternatively, publicly funded hospital or community-based multidisciplinary teams are now available in many parts of Australia, but local knowledge is required about their location and intake criteria. A clinical description of the way assessment, intervention and support can be offered to an autistic child is provided in Case 2.

#### CASE 2: AMELIA

Amelia's father first brought her to the family general practice clinic at the age of four years because of concerns about Amelia's lack of interest in people, use of only two-word phrases, dislike for loud noises and interest in horses to the exclusion of everything else. Amelia also had difficulties falling asleep and with day and night time wetting. The GP arranged for Amelia to have a hearing assessment (which was normal), referred Amelia to a paediatrician working in private practice and supported the family to apply for early childhood intervention from the NDIS. The paediatrician arranged genetic testing and referred Amelia to colleagues for speech and language and cognitive assessments. Amelia was diagnosed with an intellectual disability and autism, with no genetic cause identified.

For the following 18 months post-diagnosis, Amelia was supported by the NDIS with an early intervention program including speech therapy and positive behaviour support, with an initial focus on improving sleep and achieving toilet training. Amelia attended a child care setting, and her NDIS early intervention team worked with the child care staff and family to ensure

consistency in visual schedules, use of visual aids and behaviour management.

Amelia made progress and was ready for school. Her family were supported by her NDIS team and child care professionals to approach mainstream and specialist schools and to make their selection. A paediatric review was also scheduled, where all assessment results were pulled together and further discussions about school placement and ongoing care provisions took place. A new report and recommendations were prepared for Amelia's family, school and the NDIS. This report and recommendations focused on both her strengths and difficulties to inform appropriate funding, education and care options for Amelia. This was also sent to the GP so that informed coordination of care and support could continue.

#### Post-diagnosis

Children diagnosed as autistic usually require some level of ongoing care coordination. This is more likely when there are associated medical conditions that require intervention and if activities and participation are reduced for the child. GPs are well placed to adopt care coordination,<sup>7,26</sup> with capacity to assist with NDIS plans, mental healthcare plans for co-occurring conditions and behaviour management, and chronic disease management plans if these are not already in place (Figure 1). GPs can also manage medication with guidance from relevant specialists and can assist with linking families with local support services.

The autism assessment and diagnosis process can trigger a range of emotions for families, adding to prior stressors.<sup>27</sup> Establishing positive relationships with parents allows for opportunities to monitor their wellbeing, provide diagnosis-related resources and offer referrals for individual and group-based supports as needed.<sup>28-30</sup>

#### Conclusion

GPs have an important role in identifying key developmental and behavioural differences; coordinating care through

care planning; organising referrals to relevant services for further assessment, intervention and supports; and providing ongoing care for each child and their family. Knowledge of the family's resources and of local services will inform decision making regarding the most appropriate accessible services. Much can be done prior to a diagnosis to assist children and their families and to ensure children's needs are correctly identified so they are able to access appropriate services at the most beneficial time.

#### Key points

- Preschoolers may present with developmental and behavioural differences.
- Primary healthcare providers are critical for identification and preliminary assessment.
- Health assessments, including hearing and developmental domains, guide best care.
- Autistic children require ongoing support, intervention and healthcare.

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