Developmental delay

Identification and management

BACKGROUND Developmental delay occurs in up to 5% of children under 5 years of age. This includes delays in speech and language development, motor development, social-emotional development, and cognitive development. General practitioners are in an ideal position to play a central role in the early detection of developmental and behavioural problems in young children.

OBJECTIVE This article discusses the advantages and disadvantages of various methods health professionals use to assess children's development. It recommends ongoing developmental surveillance (rather than point-in-time assessment) and a multidisciplinary approach.

DISCUSSION In a busy general practice, obtaining parent reports of development is a good 'first line screen', and an efficient and effective way of selecting out children who require a more detailed assessment and/or referral. Early intervention is essential for optimising developmental progress in the delayed child.

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Case history – Jordan

Jordan is aged 4 years and 2 months. His mother Sarah brings him to see you with a number of concerns. His speech is not developing very well, and he does not mix well with other children. He is also a bit clumsy. His major developmental milestones were achieved age appropriately, but he seems slower than his sister Emily was at a similar age. Sarah says she can't put her finger on it, but she and her husband have been worried about him and feel he is 'just not quite right'.

Jordan attends kindergarten for three sessions per week. His teacher describes him as a 'bit of a loner'. He does not initiate conversations, preferring to quietly do his own thing.

Jordan has not been a particularly difficult child behaviourally, although he has been exhibiting some tantrums recently, which Sarah attributes to frustration at being unable to communicate his thoughts clearly. He likes playing with cars and trains, pushing them along tracks and making up a descriptive narrative to himself. His imagination does not seem to be as rich as that of other children his age.

You observe Jordan as you take the history. He appears anxious initially, and clings to his mother. When he seems to have warmed to you, you ask him some direct questions and he provides brief responses without elaboration. He seems to understand simple commands, eg. 'Could you please bring me the red book?' Although it contains many interesting toys, Jordan does not explore your consultation room.

Developmental delay occurs in up to 15% of children under 5 years of age.[1] This includes delays in speech and language development, motor development, social-emotional development, and cognitive development.

The evaluation of development in young children is an important component of general practice. Where the child's development seems to be delayed or atypical, a general practitioner's early referral for diagnostic assessment will expedite appropriate early intervention. This can make a significant difference to outcomes for both the child and the family.

Methods of early identification

It is has been estimated that only about half of the children with developmental problems are detected before they begin school.[2] Parents are usually the first to pick up signs of possible developmental delay, and any concerns parents have about their child's development should always be taken seriously; on the other hand the absence of parental concern does not necessarily mean that all is well.

Health professionals use a range of methods to evaluate children's development. Each has advantages and limitations, and most practitioners will use a combination of methods.

Checklist of developmental milestones

A developmental checklist based on children's skills may serve as a memory aid for the busy GP. However there is considerable individual variability in children's development, and there is a broad normal age range given on milestone checklists. Many children who are developing normally will not yet have acquired these particular skills, but may be making good progress toward their attainment. Furthermore, it is important not to place too much weight on a single delayed milestone, but rather to look at the pattern of groups of skills. Using milestones as the sole method for assessing development is therefore not recommended because of its potential inaccuracy.

Clinical judgment

All health professionals rely on a measure of clinical judgment to assess whether a child's development is delayed. Studies suggest however, that clinical judgment alone fails to detect development delay in many children.

Parental recall of milestones

Parental recall of their child's developmental milestones has been demonstrated in a number of studies to be inaccurate; though somewhat more reliable when milestones are significantly delayed.[3]

Parent report of current achievements

In contrast to parental recall of past milestones, parent reports of current attainment of developmental tasks has been shown to be accurate and reliable.[4] Utilising written questionnaires (see below) is preferable to asking questions informally during a consultation.

Developmental screening tests

The most commonly used test in Australia over many years has been the Denver Developmental Screening Test (DDST), or the Denver II. This screens for development in four domains:

- gross motor
- fine motor – adaptive
- language, and
- personal – social.

There are major reservations however, about whether the routine or regular administration of developmental screening tests is worthwhile, especially in populations of 'normal' children. Developmental screening tests have relatively low sensitivity (range 43–90%) and specificity (range 56–91%).[1] As a consequence, they are likely to miss significant numbers of children with developmental delay, and wrongly identify normally developing children as possibly having developmental delay.

Developmental screening fails to take into account the dynamic nature of child development. A child's performance on a screening test at one point in time is influenced by a myriad of factors. Development is a dynamic, complex process that is not linear; it is characterised by spurts, plateaus and even regressions. A single snapshot at one point in time – whether it is normal or abnormal – does not provide information about the child's developmental trajectory.

For this reason, developmental screening has gradually been replaced by the concept of developmental surveillance. This is much broader in scope, involves parents, takes note of context, and is a flexible, ongoing and continuous process. General practitioners elicit any concerns that parents may have, perform skilled observations on children each time they are seen, include measurement and recording of physical growth, assure that immunisation is up-to-date, and offer parents information and guidance on a range of age appropriate health and developmental concerns. A developmental screening test can be administered as part of developmental surveillance, but results are interpreted in the context of all of the activities described above, and no judgment about the child's developmental status is made simply on the basis of a single test administered at one point in time.

Parent evaluation of developmental status

Research suggests that one of the most effective ways of 'screening' for developmental delay in young children is via parent report.[4] In a busy general practice, obtaining parent reports of development is a good 'first line screen', and an efficient and effective way of selecting out children who require a more detailed assessment and/or referral.

The Parents' Evaluation of Developmental Status[5] (PEDS) is a 10 item parent questionnaire that covers the age range from birth to 8 years. Any parental concerns about the child's development are elicited by questions to which parents respond with a simple yes/no answer, with space for elaboration. Parent responses are then transferred to a score sheet and weighted, and then interpreted on an algorithm that provides a number of specific suggested actions.

The PEDS was developed as a formal screening

test, and has similar psychometric properties (especially sensitivity and specificity) as the commonly used developmental screening tests. However it has the advantage of involving parents, being flexible in its use, and needing no special equipment. Reports can be completed before the consultation – either at home or in the waiting room – or they can be given to parents during a consultation to be completed and returned later. It takes parents several minutes to complete, and practitioners several minutes to score, so that it is feasible for use in a busy practice. Even if it is not formally scored and used as a developmental screening tool, the PEDS is a very good way of eliciting parent concerns. Practitioners can then respond to these concerns in whichever way they feel is appropriate. The PEDS can be administered a number of times over the course of months or years, thus giving a more reliable indication of the child's developmental trajectory. An Australian version of the PEDS is available from the Centre for Community Child Health (http://rch.org.au/ccch/pub/index.cfm?doc_id=6472).

Assessment

Formal developmental assessment involves a synthesis of findings from the history, physical and neurological examination, as well as from detailed testing using standardised instruments. While the initial referral for a child suspected of having developmental delay is often to a paediatrician, detailed assessment of development is usually undertaken by a multidisciplinary team.

The paediatrician reviews the history and examination findings, looking for clues as to causative and potentiating factors. Investigations may include chromosomes, testing for fragile X syndrome, thyroid function tests and iron studies. In children with global developmental delay, the yield from tests such as brain imaging, electro-encephalogram and metabolic studies is very low in the absence of specific clinical indicators.[6] In most cases no specific cause is found.

A psychologist will administer standardised tests of development or cognition, depending on the age of the child. This testing is important to establish the child's cognitive capacity, and also to set a baseline for the future, and to document progress (or lack of it). Other disciplines are often involved, including speech pathology, social work, occupational therapy, physiotherapy, ophthalmology, and genetics.

The goal of the assessment is to develop an accurate developmental profile of the child's current strengths and weaknesses, and any continuing risk factors. It leads to a specific intervention plan that is individualised according to the needs of the child in order to achieve the best developmental outcome.

Opportunities and challenges in general practice

General practitioners are in an ideal position to play a central role in the early detection of developmental and behavioural problems in young children. They see young children on a regular basis, and often know and understand the family situation. They are ideally placed to provide support and guidance to parents, and can coordinate referrals and interventions within the broader health care sector. By encouraging parents to voice any concerns they may have, formally eliciting concerns through parent reports such as PEDS, and observing children during surgery visits, GPs can ensure that developmental concerns are appropriately addressed. In addition, they can identify and try to address any family risk factors that can impact on a child's developmental trajectory (eg. family stress, violence, substance abuse, harsh or otherwise inappropriate parenting, family breakdown, absence of a stimulating environment).

On the other hand, there are significant challenges for GPs to overcome in playing an active role in developmental monitoring and health surveillance. Barriers include a lack of time in a busy general practice, inadequate remuneration for long consultations, and lack of confidence because of perceived insufficient training and lack of expertise. These barriers are not insurmountable.

A practical approach for the busy GP

The approach outlined below consists of a series of graded steps. Some GPs will be interested in adopting all of these, while others may not go beyond the first several steps.

Elicit parent concerns and observe the child's development

Encourage parents to share any concerns they may have about their child's development or behaviour at each visit, and observe the child's development while taking a history or doing the physical examination.

Provide information for parents

Parents are always seeking credible information about their child's development and behaviour. General

practices can display and make available in the waiting room appropriate information. There is a multitude of parent information leaflets and handouts that can be easily sourced.

Referral and coordination

All GPs should have a list of allied health professionals they can use on a consultant basis for children with suspected developmental or behavioural problems. Often the first step in the process is referral to a general or developmental paediatrician. Most paediatricians would prefer to see children early rather than late; if development appears normal, then reassuring anxious parents is always rewarding. On the other hand if there is developmental delay, intervention at the earliest possible time can make a significant difference to outcome.[7]

Children who are at high risk for developmental problems should be referred early. This includes children with abnormal neurological signs, who have regressed developmentally, who are dysmorphic, or who have grossly delayed developmental milestones. It is useful to have information about where children can be referred for testing of vision and hearing, speech and language assessment, as well as maternal and child health nurses and other parental support services. Where parents are concerned about hearing or vision, these should be tested formally by a specialist used to assessing children.

Role of the GP beyond referral

Having a child with a developmental problem presents enormous challenges to the family. Many parents experience profound grief reactions relating to loss of potential and unrealised dreams for their child. The time and financial burden in caring for a developmentally disabled child is considerable, and marital relationships are often strained. Many families however, describe caring for a disabled child as enormously rewarding, promoting personal growth and adding richness and meaning to their lives.

The GP can play a significant role in the lives of families with a developmentally disabled child. The consistent, long term emotional and practical support of a family doctor is often highly valuable to families. Families' needs evolve and change as the child grows and develops. The interested GP will find the roles of listener, advisor and advocate extremely rewarding. Referral for respite support at appropriate times can be extremely helpful.

Case management – Jordan

Having taken a history and observed and interacted with Jordan you are unclear as to his developmental status. You ask his mother to complete the PEDS, and he comes out with one major concern (social development) and one minor concern (fine motor). You note his mother's comment that he is delayed compared to his sister at a similar age, and you decide to refer him to a general paediatrician.

You receive a letter back with the opinion that Jordan's development is within normal limits. His mother returns for his pre-school immunisations, and is evidently more confident about Jordan's progress. She asks for advice regarding school placement for next year, and you suggest that he may be happier in a smaller school given his reserved nature.

Summary of important points

- Developmental delays are common, and can involve different domains of a child's functioning.
- A combination of methods is required to detect cases of developmental delay.
- Early intervention provides the best opportunity for positive outcomes for the child and the family.
- The GP has an important role to play in early identification of developmental delays, appropriate referrals for detailed assessment, and ongoing family support.

Conflict of interest: none declared.

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