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Developmental delay: An ambiguous term in need of change.

Background

- Mother to a six-year-old child with a severe intellectual disability, who was provided the interim diagnostic label “Global Developmental Delay” for her first five years.
- In contact with many parents, intervention therapists and medical specialists that provided anecdotal evidence that this term is thought of as ambiguous and misleading.

Why do we need a change?

- The term is ambiguous and misleading:
  - Difficult for medical professionals trying to provide a true picture of the situation
  - Difficult for parents/carers trying to understand the situation
- Is inconsistent with research about best practice in conveying diagnosis
- May interfere with the grieving process
- Does not allow for acceptance of the child as the person they are

What is 'Developmental Delay'?

- In Victoria, according to the Disability Act, 2006:
  - Developmental delay means a delay in development of a child under the age of six years which-
    > is attributed to a mental or physical impairment or a combination of both; and
    > is manifested before the age of six years; and
    > Results in substantial functional limitation in one or more of self-care, receptive and expressive language, cognitive development and motor function; and
    > Reflects the child’s need for special care, treatment or other services of extended duration.

No standardised diagnostic criteria

- DHS checklist to determine service eligibility
- Child has not met their expected milestones, eg. upper limit for being able to sit is 10 months, thus child is considered delayed if not sitting >11 months
- If a child is delayed by 25% and/or 2 SD from the mean in one or more development domains (Tervo, 2003)
- Researchers have used parameters of 1.5 SD from the mean (Shevell et al, 2005a & 2005b)

Multiple applications of the term

- As a euphemism for intellectual disability or as a way of avoiding the term intellectual disability
- Because a child scored low on a test of development and/or IQ
- To describe a delay in premature babies
- As a reference to any child with dev. problems
- As an interim diagnostic label
- As a symptom of a larger neurodevelopmental diagnosis (Petersen, Tube & Palmer, 1998)
Ambiguity of the label

- The word ‘delay’ is identified with a temporary state that will end in goal attainment.
- “rather like a train being delayed, but reaching its destination eventually” (Bosley, 2005, p. 875).
- The Oxford English Dictionary (1989) defines delay as:
  - The action of delaying: the putting off or deferring action; procrastination, loitering; waiting, lingering;
  - The fact of being delayed or kept waiting for a time; hindrance to progress

Developmental delay outcomes

- **Transient developmental delay**
  - Is the type of delay often seen in preterm babies or children that have medical problems that are the cause of their slower development: These children catch up
- **Persistent developmental delay**
  - Shevell et al. (2005a; 2005b) found that a preschool diagnosis of Global Developmental Delay was predictive of persisting developmental delay across individual domains of between 75% and 100% of children

Imparting news about diagnosis

- **Factors that contribute to satisfaction with the process include:**
  - Honesty about concerns and diagnosis provided as early as possible in a factual, compassionate manner
  - Accurate information about diagnosis and prognosis, available support, benefits and future educational opportunities
  - Immediate and ongoing support so that parents feel that they are doing something to help their child
  - Hope and possibilities for the future, despite their child’s disability

- **Factors that contribute to dissatisfaction with the process include:**
  - Withholding information
  - Ambiguous diagnosis and/or diagnostic labels
  - Lengthy process of diagnosis
  - A ‘wait and see’ approach is unhelpful because it means that parents have to source information and try to identify their child’s problems themselves

A new normal

“I found that all really confusing because I just loved him. When I was given the labels I knew that all my upbringing told me that I wouldn’t love a disabled child. Yet I loved him, there was never any doubt. But it was definitely a struggle to make sense of those mixed messages...he was so wrapped up in my love for him.”

Quote from a mother recounting a diagnosis of GDD (Goodley & Tegaskis, 2006)

An argument for change

- No standard diagnostic criteria
- Multiple applications of the term
- Ambiguity of the label
- Persistence of impairment
- Parental dissatisfaction with ambiguous diagnosis and/or diagnostic labels and withholding of information
- Provision of realistic hope to enable parents to move through the grief process and find a ‘new normal’ for themselves and their family
Recommendations

• Discussion and research into the appropriateness or otherwise of developmental delay as an interim term
• Development of standardised diagnostic markers and guidelines
• Development of a booklet for parents/carers that receive an interim diagnosis with information about what it means and likely outcomes
• Development of a strategy for adoption of change

A few key references