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**Developmental delay: An ambiguous term in need of change.**

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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.**

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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**

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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.

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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)**

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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)

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### 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 (Piper & Howlin, 1992; Quine & Rutter, 1994)

### Imparting news about diagnosis

- **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**

(Goodley & Tregaskis, 2006; Piper & Howlin, 1992)

### 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 & Tregaskis, 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

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