

About ACD

ACD is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by, and for, families of children with disability.

Our vision is that children with disability and their families have the same rights and opportunities as all children and families.

Since the rollout of the NDIS we have supported thousands of Victorian families to understand and navigate the NDIS with confidence. Their experiences inform this submission.

Adult centric culture of the NDIS

The NDIS has a strong adult centric bias that has an impact on participants who are children. Children are poorly represented throughout the NDIS consultations and decision-making structures. Current examples of the NDIS adult centric bias include:

1. Not prioritising early intervention for young children

The importance of the early years in child development is well established. Early childhood intervention builds on this critical developmental phase.

However, the NDIS has not undertaken market stewardship to ensure that young children can access early intervention as quickly as possible.

While the early childhood approach means that young children can access an NDIS plan relatively quickly (there has been significant improvement in this area) children can then spend months on waiting lists for services. The situation is particularly acute in areas with thin markets, such as the western suburbs of Melbourne, urban growth corridors and regional Victoria.

This issue is reflected in NDIS data that shows plan utilization for children aged 0 to 6 in Victoria is 59%, which is lower than any other age group.

2. Not ensuring children access best practice early intervention

The NDIS website refers to best practice in early intervention and highlights the importance of a family centered approach, building the capacity of families and supporting children in their every day settings. A key worker is an effective model to provide best practice.

However, while key workers are a line item in the price guide, this model is not prioritized over other less effective approaches. Families who are new to the world of early intervention are left to navigate services and thin markets. Families often don't know what is best practice and they are susceptible to dodgy providers who are offering a "cure" for their child.

This is in contrast to the information provided to families accessing universal early childhood education. The Australian Government Starting Blocks website enables families to search for early learning providers in their area, view accreditation ratings and vacancy status.

We are increasingly hearing from families whose NDIS funded therapists work one on one with children (without parents in the room) completely going against basic child safety principles and holistic approaches to family capacity building.

3. Lack of guidance on “parental responsibility”

The NDIS rules relating to “reasonable and necessary” include the following considerations for supports for children. These are commonly referred to as “parental responsibility”:

- That it’s quite normal for parents to provide substantial care for their offspring.
- Whether the child has additional needs compared to other children their age, because of their disability.
- Whether there is any risk to the wellbeing of family members or carers.
- Whether funding a support for the family would help build the child’s capacity or reduce any other risks to the child’s wellbeing.

Parental responsibility is one of the most common reasons given by Early Childhood partners, Local Area Coordinators and NDIS Planners as to why a support will not be funded.

These four dot points are the extent of the publicly available guidance on what constitutes parental responsibility.

Despite the agency producing detailed guidance on other areas of decision-making, parental responsibility is left to individual interpretation.

4. Not distinguishing between the role played by families of child and adult participants

The information for families and carers on the NDIS website makes the opening statement: “The role of families and carers is often essential in supporting people with disability to realise their goals, so it is important to include them in discussions about supports.” This tone continues in the NDIS language that refers to families as “informal supports”.

This ignores the fundamental role played by families of children and the importance of supporting families to care for their children. It is contrary to the approach taken by universal children’s services, such as schools and health care, that see families as the primary support for a child and seek to work in partnership with them.

Recommendations

Each of the examples above need to be addressed in collaboration with families and experts in childhood development.

With the announcement of the NDIS Review it is critical that children’s interests are represented and that recommendations from the review are considered from the perspective of what their effect will be on children and their families.

For more information

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