



Response to the Consultation
on
Developing a Guide to the
Guiding Principles under
Australia's Disability Strategy
2021 - 2031

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*Professionals and Researchers in Early
Childhood Intervention (PRECi)*

About PRECI

PRECI is a new and unique Australian research-to-practice network specifically focussed on the area of young children with developmental disabilities.

The purpose of PRECI includes:

- advancing excellence and equity in services for young children with developmental disabilities and at risk of developmental delay in Australia
- providing a national network connecting early childhood intervention practitioners and early childhood intervention researchers, with a focus on supporting collaborative research, knowledge sharing and peer support in relation to practices relating to the provision of quality early childhood intervention services for young children with developmental disabilities and their families
- providing early childhood intervention professionals, community organisations, researchers, higher education institutions and policy makers with an authoritative source of information about best practice in early childhood intervention
- identifying, developing, promoting, and raising awareness of advances in effective models of service delivery to ensure consistent implementation of best practice for young children and families
- promoting a national approach to coordinated and comprehensive pre-service, in-service and postgraduate training opportunities for professionals working with children with developmental delay and disability, and their families and related mainstream services, on contemporary and evidence-informed practices
- developing a national research framework and conducting research projects
- promoting interdisciplinary collaborations to ensure advances in research and translation of research into practice

PRECI response

Introduction

Professionals and Researchers in Early Childhood Intervention (PRECI) welcomes the opportunity to comment on the Guiding Principles under Australia's Disability Strategy 2021-2031 (ADP). We also welcome the inclusion of a principle specifically focused on children. Guiding Principle, No 8, which is '*respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities*', is a significant recognition of the importance of children's development. We also recognise the importance of the first Targeted Action Plan focused on Early Childhood.

PRECI's expertise is in young children with developmental disabilities aged from birth until six years. This is a critical period in the development of persons with disabilities.

Research indicates that the impact of interventions in the early years can have a significant impact on a person's long-term development.

The experience of families and their young children during the early years establishes precedents which influenced the choices they make in their engagement with services and the community into the future.

The early years is a highly productive time in which to engage with other children and families about the nature of disabilities and the importance of inclusion.

It is therefore critical for the success of any Disability Strategy that it focuses on positive outcomes during this period.

In our view, previous Disability Plans in Australia have been adult centric in their focus. They have addressed issues predominantly relevant to adults with disabilities. The inadequacy of such an approach is now evident in nearly half the participants in the National Disability Insurance Scheme being children aged 0 – 14 years.

Critical to addressing the situation faced by children is the recognition of role of families in their development. Young and dependent children with disabilities cannot be considered in isolation from those who support them. The role families play evolves over time. Also, families bring different skills and resources to the task of raising a child with a disability. It is necessary to recognise the complex demands families face in supporting the development of a child with a disability. These include emotional, informational, and financial demands. If they are not addressed, then they can directly impact on a family's capacity to support their child's development.

The pressures faced by families is further compounded by the current organisation of services, which is chaotic. In the period from birth to six years, children's families will have to negotiate access to disability support (NDIS), childcare, preschool and school. This includes accessing different types of 'inclusion' funding. These services are provided by different levels of

government, use different language, and have different eligibility criteria for their inclusion programs. There is not a joined-up approach. The focus appears to be on program demarcation rather than ensuring families can easily access the support they need.

Other interfaces with services, for example health, are also complicated. These are important policy issues that have not been either acknowledged or addressed in Disability Plans. The practical outcome is greater stressors for families. The wellbeing of children is directly related to the wellbeing of their family.

Guiding Principle, No 8

In relation to Guiding Principle No 8 we propose that:

- The Convention on the Rights of the Child is formally endorsed as guiding this principle
- The role of families is explicitly acknowledged.

We welcome that the guiding principles of the ADP are based in the Convention on the Rights of Persons with Disabilities (CRPD).

We note that under the CRPD, children have the rights of all persons with disabilities.

In addition, State signatories to the CRPD are expected to:

- ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children
- act in the best interest of the child
- ensure that children with disabilities have the right to express their views freely on all matters affecting them on an equal basis with other children
- ensure children access an inclusive education system, so they are not excluded from the general education system, and
- provide the support required, within the general education system, to facilitate an effective education for children with disabilities.

The Convention on the Rights of the Child (CRC) adds significantly to the recognition of the rights of children with disabilities. Under the CRC children with disabilities have the same rights as all children and additional rights because of their disabilities.

Crucially, the CRC recognises: *the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children* (Preamble).

The CRC also has specific provisions for children with a disability (Article 23) which include that:

- A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community

- A disabled child should receive special care and assistance to the eligible child and those responsible for his or her care
- A disabled child should be supported to achieve the fullest possible social integration and individual development, including his or her cultural and spiritual development.

The recognition that children with disabilities have the same rights as other children under the CRC is foundational to their full recognition as a member of society. It should be formally included in the Guiding Principle. The CRC is recognised in the NDIS legislation.

Recommendation: That the Convention on the Rights of the Child be formally included under Guiding Principle No 8 and acknowledged throughout the principles.

The role of the family needs to be explicitly acknowledged in Guiding Principle No 8. The current wording of the principle does contextualise that the evolving capacities of children with disabilities occurs within a family context. The lack of recognition of the importance of the role of family, and community, in supporting the development of the child has serious ramifications for policy and services. If the child is portrayed in isolation, then policies and services also treat the child in isolation. This is counter to current research and practice across early childhood. Current research and practice focus on building the capacities of the adults supporting the child. An ecological framework makes clear connections between the child and the people who support that child, their community and broader cultural context. Services need to acknowledge the role of parents and caregivers in supporting children, and the need to provide services using evidence-based practises which are family centred, strengths based and culturally responsive.

Recommendation: Guiding Principle No 8 needs to explicitly acknowledge the role of families.

The 8 Principles

In relation to the 8 Principles in general we propose that:

- They be reviewed to specifically look at the implications for children and families
- A panel of parents and professionals be convened to assist this review and to represent the interests of the child in their further development.

All the guiding principles need to be considered from a life stage perspective to identify their relevance to children. In this process the principles must explicitly recognise children with disabilities and developmental delay AND their families. This can be done through relevant examples, noting the risk of 'individualising' the principle when the only case studies portray the experiences of adults with a disability. The terminology needs to be made explicit to children's experience, for example the importance of community and educational settings in their lives.

For example, Principle 1 needs to include an understanding of the environmental enablers and barriers that people with disability experience that promote (or not) respect for their dignity and autonomy.

For example: in Principle 3 children's *full and effective participation* needs to acknowledge family life, as well as community life. Prompting questions need to include issues of inclusion and participation for children.

Recommendation: That all the principles be specifically reviewed to consider their implications for children and families.

Children's interests have been poorly represented in the development of Disability Plans to date. This may reflect the complexity of getting good representation for children, which is not as straightforward as participation disability advocacy groups representing adults. Nonetheless this needs to be actively addressed. A lack of representation is discriminatory.

Recommendation: A panel of parents and professionals be convened to represent the interests of the child in the further development of the principles.

General comments

There are two general comments. These are:

- The need to develop a more complex understanding of early intervention
- The importance of equity in responding to disability

Early Childhood Intervention for children needs to recognise that child development is complex and there are not clear distinctions between significant developmental delays and 'disability' in young children. Significant developmental delays may be a precursor to the identification of a disability, or they may have a different cause. In either case there is a need to take early action to address the issues. This means it is important not to wait until a disability is identified before acting. This has been a feature of recent responses. There needs to be a coordinated and more holistic approach with the disability and health sectors working together to identify and respond to children with developmental issues early. Supporting parents with strategies that support their role in their child's development is also essential.

Recommendation: That the principles enable a coordinated and holistic approach to early childhood intervention across the disability and health sectors.

The final issue that we wish to raise is that the terminology used in the principles is equality, not equity. The meaning of the term equality needs to be clarified. Equality can be interpreted to mean that each individual or group of people is given the same resources or opportunities. Equity recognizes that each person has different circumstances and needs different resources and opportunities to reach a similar outcome. The recognition of intersectionality is important in this context. Families and individuals can experience multiple factors that compound

their access to resources and their opportunities in general. In the context of child development, a focus on equity is important.

Recommendation: The term equity be used.