**Department of Social Services**

**Stronger Outcomes for Families Discussion Paper June 2018**

**Children and Young People with Disability Australia**

**Submission – August 2018**

**INTRODUCTION**

# Children and Young People with Disability Australia (CYDA) welcomes and supports the identified outcomes for families and children set out in the *Stronger Outcomes for Families* *Discussion Paper* (the Discussion Paper). The focus of ensuring families and children are: safe and well; strong and resilient; and ready to learn, are fundamental for quality life outcomes for all children and families including those experiencing disadvantage.

# Children and young people with disability experience unique and substantial disadvantage in Australia. Childhood and family life is typically experienced very differently if you are a child with disability. Social, recreational and educational opportunities are often limited or denied due to environmental barriers including deeply embedded discriminatory attitudes and systems.

# Further, children with disability and their families often experience intersectional discrimination based on disability, gender, religion, legal status, ethnic origin, age, sexual orientation or language. People with disability are also more likely to experience economic inequality and disadvantage with 45 percent of people with disability living near or below the poverty line[[1]](#footnote-1). There is also an increased vulnerability to abuse with children with disability known to be three times more vulnerable to abuse than their peers[[2]](#footnote-2). The addressing of this complex interplay of factors necessitates a well-considered and coordinated service system and community response. This should involve addressing immediate and current needs but ideally, in the longer term, it would primarily involve an early intervention approach which addresses and prevents the causes of inequality experienced.

# The National Disability Insurance Scheme (NDIS) is an important aspect of this response but addressing intersectional disadvantage necessitates a much broader approach. The NDIS will essentially provide disability services and supports to some, not all, children and families with disability. It is therefore vital that children and young people with disability and families are a key focus of any newly established family services framework.

# CYDA acknowledges the critical role that families play in providing care, support and developmental opportunities to and for children and young people with disability and works alongside families in this context. Comment and feedback on the Discussion Paper in this submission is thus provided in this frame of reference.

**CHILDREN AND YOUNG PEOPLE WITH DISABILITY AUSTRALIA**

CYDA is the national representative organisation for children and young people with disability, aged 0 to 25 years. The organisation is primarily funded through the Department of Social Services and is a not for profit organisation. CYDA has a national membership of 5300 and a growing social media presence with 22 500 followers across the three major platforms of Facebook, Twitter and LinkedIn.

CYDA provides a link between the direct experiences of children and young people with disability to federal government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences and challenges faced by children and young people with disability.

CYDA’s vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CYDA’s purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

* **Listen and respond** to the voices and experiences of children and young people with disability;
* **Advocate** for children and young people with disability for equal opportunities, participation and inclusion in the Australian community;
* **Educate** national public policy makers and the broader community about the experiences of children and young people with disability;
* **Inform** children and young people with disability, their families and care givers about their citizenship rights and entitlements; and
* **Celebrate** the successes and achievements of children and young people with disability.

**LEGISLATION AND POLICY CONTEXT**

Australia is a signatory to the United Nations *Convention on the Rights of Persons with Disabilities* *2006[[3]](#footnote-3)* (CRPD) and the *Convention on the Rights of the Child 1989[[4]](#footnote-4)* (CRC). These Conventions contain clear standards and obligations regarding the rights of children with disability which are of specific relevance to this consultation regarding provision of family services.

The CRC sets out Australia’s rights obligations towards all children including:

*‘States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.*

*Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child…[[5]](#footnote-5)*

Obligations under the CRPD include:

*‘Children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families’[[6]](#footnote-6)*.

In the domestic context, family services are referred to in the *National Disability Strategy 2010-2020* which affirms that universal personal and community support services are available to meet the needs of people with disability, their families and carers[[7]](#footnote-7).

CYDA acknowledges the particular relevance of the *National Framework for Protecting Australia’s Children 2009-2020[[8]](#footnote-8)* (the National Framework) for the progression of a new family services framework. However, CYDA wishes to note that despite clear evidence demonstrating a higher prevalence and risk of abuse to children and young people with disability, the National Framework contains little specific focus on children and young people with disability. The lack of specific focus on children and young people with disability in the National Framework demonstrates and amplifies the importance of a specific focus on children and young people with disability in the new family services framework as discussed below.

**Relevance of Discussion Paper Outcomes to Children and Young People with Disability and Families**

Children and young people with disability remain one of Australia’s most disadvantaged cohorts. The breadth and consequence of that disadvantage is profound. Across all the outcome areas identified in the Discussion Paper, available statistics and research clearly demonstrate that there is a critical need to focus on children and young people with disability to address the shameful rates of disadvantage experienced.

CYDA strongly supports the proposed outcomes as identified in the Discussion Paper.

**Outcome Area - Safe and Well**

International research states that children and young people with disability are three times more vulnerable to abuse than their peers without disability[[9]](#footnote-9). Children and young people with high communication and behaviour support needs have higher vulnerability again to abuse[[10]](#footnote-10). This aligns with the direct experience of children and young people with disability in Australia. Research also demonstrates that environmental factors commonly experienced by children and young people with disability heighten the risk of abuse[[11]](#footnote-11). This includes spending significant periods in settings that are segregated and emphasise isolation, control and compliance. Further, it is common for abuse to be renamed or excused as ‘behaviour management’ or an ‘incident,’ rather than being seen as abuse and responded to as such[[12]](#footnote-12). Women and children with disability are also at higher risk of experiencing domestic and family violence[[13]](#footnote-13).

**Outcome area - Strong and Resilient**

Disability should be contextualised and experienced as a usual aspect of diversity which strengthens and enriches families and the wider community. The specific needs associated with the functional impact of disability should be met through systems, support and how society is structured. Shamefully this is largely not the experience of many children and young people with disability in Australia. Disability is still often equated with inability and low expectations. These deeply embedded ableist views have a profound impact on how Australian society is structured, including many of its policies, programs and services. The development of strong and resilient families of children with disability involves the establishment of a rights based services system which clearly considers and is inclusive of people with disability in all areas. This service system needs to address ableist attitudes and other systemic barriers which currently exist.

**Outcome Area - Ready to Learn**

Children and young people with disability currently experience profound disadvantage and discrimination in relation to educational experiences and outcomes. Common early childhood education and school experiences for children and young people with disability include discrimination, limited or no resources for supports, inadequately trained staff and bullying. For example, 56 percent of students with disability report experiencing bullying at school[[14]](#footnote-14). The reported experiences of restraint and seclusion are also becoming more common.

In early childhood education and care the representation of children with disability is disproportionately low. Children aged 0-12 years with disability had a lower representation in child care services (3 percent) compared with their representation in the community (6.6 percent)[[15]](#footnote-15). This was also the case for preschool enrolments (3-5 years)[[16]](#footnote-16). Educational disadvantage experienced by children and young people with disability is also clearly demonstrated in educational outcomes. Available statistics show that 45.8 percent of people aged 15-64 with disability, the highest level of education was Year 10 or below, this is compared to 25.7 percent of people without disability[[17]](#footnote-17).

These statistics clearly demonstrate there currently exists for children and young people with disability considerable contextual disadvantage and significant systemic barriers to accessing and participating in education. Significant cross system reform is required to enable and ensure that children and young people with disability are ‘ready to learn’. Therefore, this outcome is clearly of very high relevance to children and young people with disability and their families.

**GENERAL COMMENTS ON THE DISCUSSION PAPER**

 **No Specific Focus on Disability**

Given the demonstrated disadvantage experienced by children and young people with disability, CYDA is concerned that neither the Background or Discussion Papers contain a specific focus on disability. Further, both documents fail to capture the many and complex systemic barriers leading to inequality in participation and outcomes in multiple life areas.

The Background and Discussion Papers also lack adequate discussion or recognition of intersectionality. Intersectionality refers to the overlapping and interdependent nature of discrimination and disadvantage. Children and young people with disability can experience intersectional discrimination and disadvantage based on age, gender, language, culture and sexual orientation. The new family services framework must therefore act to address and reflect the interconnected discrimination and disadvantage experienced by children and young people.

***Recommendation 1: Children and young people with disability are a specific focus of the new family services framework.***

***Recommendation 2: The new family and children services system reflects the intersectional experience of disadvantage.***

**Inadequate Data**

CYDA is concerned about the use of the *Australian Early Development Census* (AEDC) data in the Background and Discussion Papers. Children with “special needs” (defined as children with chronic medical, physical or intellectual disabilities that require special assistance, based on medical diagnosis) are not included in AEDC results measuring early childhood development[[18]](#footnote-18). The significant gains in key early childhood development outcomes discussed in the Background and Discussion Papers therefore exclude a discussion of many children with disability.

The non-collection or inability to disaggregate data by disability in a number of critical areas is a serious and ongoing concern for CYDA. Failing to collect and disaggregate data in this way results in a failure to measure, define and acknowledge the experiences of children and young people with disability. Without this information there exists a lack of incentive and evidence base upon which to act and address existing disadvantage.

Further, as a State Party to the CRPD, Australia has an obligation to collect appropriate information regarding people with disability, including children and young people[[19]](#footnote-19). This obligation encompasses statistical and research data required to enable the formulation and implementation of policies to give effect to the rights set out in the CRPD[[20]](#footnote-20). Data must also be disaggregated appropriately to identify and address the barriers faced by persons with disabilities in exercising their rights[[21]](#footnote-21).

***Recommendation 3: The Department of Social Services reviews and progresses available processes for data collection with the aim of strengthening and increasing the breadth of comprehensive national data which is publically available on children and young people with disability. Key consideration also needs to be given to how existing and future data collection is disaggregated by disability.***

**NDIS Interface**

CYDA is concerned the NDIS and family services system interface is not discussed or addressed in the Background and Discussion Papers.

Under the *National Disability Insurance Scheme (Supports for Participants) Rules 2013* responsibility for the provision of general parenting programs, counselling and other supports for families sits outside the NDIS while supports required as a direct result of a child’s disability, including support that enables families to sustainably manage a caring role, sit within the NDIS[[22]](#footnote-22).

Many children and young people with disability will not be eligible to receive supports under the NDIS. It is critical that children and young people with disability who are not participants of the NDIS still have access to appropriate family services and supports if needed.

As with many other areas, it is critical that the interface between the NDIS and the family services system is well defined with their being no gaps or conflict regarding how necessary services and supports are provided to children and young people with disability and their families.

***Recommendation 4: The interface between the NDIS and the family services system is well defined and ensures no gaps or conflict exist regarding how necessary services and supports are provided to children and young people with disability and families.***

**SPECIFIC COMMENT ON THE DISCUSSION PAPER**

**Funding Streams**

The Discussion Paper proposes a new funding system for family services. The proposal would transition funding from a program based system, where organisations were funded to provide specific programs, to a system where funding was provided under three streams;

* Universal: Information, advice and education available to all families to address issues before they escalate;
* Targeted: More intensive, and where necessary, frequent and sustained support; and
* Place-based: Collaborative responses to address local problems in communities experiencing disadvantage.

It is CYDA’s view that the Background and Discussion Papers do not contain a clear articulation of the intentions in relation to the targeted funding stream. It is unclear whether the intent is to provide funding to support generalist services that provide more intensive support or to provide funding to specialist services that meet the needs of a specific group.

Without this information, and without additional detail regarding how cohorts are identified and the kinds of services proposed, it is not possible to provide comment regarding what is the most effective funding system.

**Targeted Service Delivery – Cohorts**

CYDA is very concerned about the proposed *Access Strategy* which would prioritise access to services based on belonging to a specific cohort. The concern extends to the consultation question asking respondents to identify three cohorts who should be given priority in accessing family services.

CYDA questions the utility of identifying cohorts through this consultation question without an understanding of the reasoning or data upon which these recommendations are made. In addition, CYDA is concerned that the use of cohort identification as the basis for prioritising access to services risks excluding families and children that may have substantial needs. Further, it does not reflect the lived reality of intersectional disadvantage.

**Measuring outcomes**

CYDA strongly supports transparent and effective mechanisms that measure outcomes as a means of ensuring accountability and ensuring continuous and informed service improvements. However, CYDA is concerned about the proposed use of the Data Exchange Partnership Approach set out in the Discussion Paper.

CYDA has previously used the Data Exchange platform for a funded project under the Royal Commission into Institutional Responses to Child Sexual Abuse. It was CYDA’s experience that the platform was difficult to use, that the data collected did not reflect or allow for conclusions to be drawn in relation to systemic outcomes and that the system did not adequately protect people’s privacy. Due to this experience CYDA is concerned about the expanded use of the Data Exchange system to measure outcomes for children and young people with disability in family services.

**Early Intervention and Prevention**

It is CYDA’s view that the family services should ideally be primarily focussed on early intervention and prevention. CYDA also acknowledges that the current reality for many families is the daily lived experience of disadvantage is significant and presents a real, and at times growing need, for assistance to address the immediate circumstances.

***Recommendation 5: Early childhood intervention and prevention services and supports form a key focus of the new family services framework.***

**CONCLUSION**

CYDA welcomes the discussion and consultation on the future of family services. Addressing the disadvantage and systemic barriers faced by children and young people with disability is an ongoing process within which the reform of family services plays a vital role. It is critical that the experience of disability within families form a central focus of these reforms to ensure positive outcomes for children and young people with disability and their families.

**SUMMARY OF RECOMMENDATIONS**

**Recommendation 1:** Children and young people with disability are a specific focus of the new family services framework.

**Recommendation 2:** The new family and children services system reflects the intersectional experience of disadvantage.

**Recommendation 3:** The Department of Social Services reviews and progresses available processes for data collection with the aim of strengthening and increasing the breadth of comprehensive national data which is publically available on children and young people with disability. Key consideration also needs to be given to how existing and future data collection is disaggregated by disability.

**Recommendation 4:** The interface between the NDIS and the family services system is well defined and ensures no gaps or conflict exist regarding how necessary services and supports are provided to children and young people with disability and families.

**Recommendation 5:** Early childhood intervention and prevention services and supports form a key focus of the new family services framework.

CYDA once again thanks the Department for the opportunity to provide feedback on the *Stronger Outcomes for Families* Discussion Paper. CYDA can be contacted for further discussion of any issues raised in this submission.

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