



30 April 2023

Dear Early Years Strategy Team,

## **RE: Department of Social Services - Early Years Strategy**

Inclusion Australia is the national Disability Representative Organisation representing the rights and interests of Australians with an intellectual disability and their families. Founded in 1954, our mission is to work to make sure people with an intellectual disability have the same opportunities as people without disability. We have teams in Victoria, Western Australia, and the Northern Territory, and we have member organisations in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia.

We thank the Department of Social Services for the opportunity to provide feedback on the Early Years Strategy (the Strategy) Discussion Paper. We hope our response is valuable in ensuring the Strategy can actualise its vision to create a future in which all Australian children will thrive.

### **Context of this letter**

Intellectual disability is the most common grouping of disabilities among children aged 0-14 in Australia.<sup>1</sup> Within this age cohort, it is estimated that around 190,000 children, or 4.3%, have an intellectual disability.<sup>2</sup>

In addition, there is an under—but increasingly—reported cohort of parents with an intellectual disability. Available data suggests that among people with an intellectual disability in Australia, 8% are parents.<sup>3</sup> Parents with an intellectual disability are conservatively estimated to be 0.4% of the Australian parent population, equating to about 17,000 parents.<sup>4</sup>

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<sup>1</sup> While this age group extends beyond the Early Years Strategy target of 0-5 years, a broader age range of 0-14 is used for data collection by the Australian Bureau of Statistics (ABS). It is also important to consider an age range of 0-14 in this context given that most children are diagnosed with ID between 5 and 9 years.

<sup>2</sup> Australian Institute of Health and Welfare. (2022). *Australia's children*. Retrieved from <https://www.aihw.gov.au/reports/children-youth/australias-children>

<sup>3</sup> Man, N. W., Wade, C., & Llewellyn, G. (2017). Prevalence of parents with intellectual disability in Australia. *Journal of Intellectual & Developmental Disability*, 42(2), 173-179. doi: 10.3109/13668250.2016.1218448

<sup>4</sup> According to University of Sydney academics, the figure is likely to be higher: Collings, S. et al. (2022). Parents with intellectual disability need more support. Retrieved from: <https://www.sydney.edu.au/news-opinion/news/2022/08/19/parents-with-intellectual-disability-need-more-support.html>

Australian Bureau of Statistics. (2011b). Information paper: Disability, Ageing and Carers, Australia: User Guide, 2009. Canberra: ABS cat. no. 4431.0.55.001. Australian Bureau of Statistics. Retrieved from

This letter is informed by the collective expertise that guides our work in advocacy for greater inclusion of people with an intellectual disability, including young children, in all levels of Australian society. In particular, we wish to highlight evidence contained in two key submissions we made to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission):

- [Submission to the Disability Royal Commission – the Omnibus](#)
- [The Experience of Children and Young People with Disability in Different Education Settings – Position Paper for the Disability Royal Commission](#)

These submissions form the background to the issues raised in this letter.

### **A note on accessibility and inclusion**

We believe it is vital that the ongoing consultation processes towards the design of the Strategy **include and value the experiences of children with an intellectual disability, their families, and parents with an intellectual disability.**

To this end, we ask that all future engagements or consultations that aim to capture community voices, ideas and intentions for the Strategy be accessible to children with an intellectual disability, their families, and parents with an intellectual disability by:

- Continuing to provide Easy Read translations of all consultation materials; and
- Actively seeking out, engaging with, and including the voices of families of children with an intellectual disability, as well as parents with an intellectual disability, in the design of the Strategy and its related policy priority areas.

Doing so will help to actualise the intentions of the Strategy to be child and family centred, as well as inclusive.

### **Key issues**

There are three points we wish to emphasise to the Strategy team in the hope they will inform the outcomes and priority policy areas of the Strategy as they are developed.

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[www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/E01AA04B925A1E0DCA2578B100186453/\\$File/4431055001\\_2009.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/E01AA04B925A1E0DCA2578B100186453/$File/4431055001_2009.pdf) ;  
Healthy Start. (July 2014). Estimated prevalence and living circumstances of parents with intellectual disability in Australia from National Surveys. Retrieved from [https://ses.library.usyd.edu.au/bitstream/handle/2123/13551/HealthyStart\\_PrevalenceStudy\\_Technical%20Report\\_1\\_Aug2014.pdf?sequence=1&isAllowed=y](https://ses.library.usyd.edu.au/bitstream/handle/2123/13551/HealthyStart_PrevalenceStudy_Technical%20Report_1_Aug2014.pdf?sequence=1&isAllowed=y)

## 1. Support evidence-based and accessible antenatal education for parents who may have a child with an intellectual disability, as well as parents with an intellectual disability.

While intellectual disability is commonly diagnosed in early childhood, prenatal screening is now a routine part of antenatal care for many pregnant people.

All parents need access to material, social and emotional resources to ensure their children thrive, as these are factors that influence child outcomes.<sup>5</sup> Yet there is a significant lack of information and support available to parents when they are presented the option to screen for a number of conditions in pregnancy, many of which are associated with intellectual disability.<sup>6</sup>

Many families report not receiving adequate—if any—information about the conditions they are being tested for. For those considered as being likely to have a child with a disability post-screening, the information provided is often lacking, out-dated, unsupportive, or negative.<sup>7</sup> Often, it's a combination of each.

For example, in a 2017 survey run by Down Syndrome Australia, nearly three out of four women surveyed reported not receiving any information about Down syndrome. For those who did receive information, it was often framed in a highly medicalised, negative way.<sup>8</sup>

Negative community attitudes and outdated information about intellectual disability means that many families and health professionals are unaware of what raising a child with an intellectual disability is actually like.

Similarly, there is a lack of accessible information and support for parents with an intellectual disability during the antenatal period and beyond.<sup>9</sup>

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<sup>5</sup> Hindmarsh, G., Llewellyn, G., & Emerson, E. (2017). The social-emotional well-being of children of mothers with intellectual impairment: A population-based analysis. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 469–481.

<sup>6</sup> Proctor, S. N., & Azar, S. T. (2013). The effect of parental intellectual disability status on child protection service worker decision making. *Journal of Intellectual Disability Research*, 57(12), 1104–1116;  
Retzer, A., Kaye, J., & Gray, R. (2020). A factorial survey investigating the effect of disclosing parental intellectual disability on risk assessments by children's social workers in child safeguarding scenarios. *The British Journal of Social Work*, 50(4), 1185–1200.

<sup>7</sup> Down Syndrome Australia. (no date). Position Statement on Prenatal Screening. Retrieved from: [https://www.downsyndrome.org.au/wp-content/uploads/2019/12/Position\\_Statement\\_on\\_Prenatal\\_Screening\\_PDF.pdf](https://www.downsyndrome.org.au/wp-content/uploads/2019/12/Position_Statement_on_Prenatal_Screening_PDF.pdf)

<sup>8</sup> Seror, V., Ville, Y. (2009). Prenatal screening for Down syndrome: women's involvement in decision-making and their attitudes to screening. 29(2):120-128.

<sup>9</sup> Collings, S., Grace, R., & Llewellyn, G. (2017). The role of formal support in the lives of children of mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 492–500;  
Collings, S. and Spencer, M. (2000). Practices that support parenting by parents with intellectual disability. *Australian Institute of Family Studies*. Retrieved from: <https://aifs.gov.au/resources/short-articles/practices-support-parenting-parents-intellectual-disability#footnote-0010>

Parents with an intellectual disability also experience poor early engagement by services and a lack of cross-agency collaboration. This, coupled with negative community attitudes and a lack of training among maternity staff and other professionals means parents with an intellectual disability tend to receive a lower standard of care; have their parenting capacity questioned or negatively judged; and resources are not invested in keeping families together.<sup>10</sup>

All parents deserve to be empowered in their journey to parenthood, so their children have the best chance at thriving.

The Early Years Strategy should acknowledge the gaps in the provision of accessible, up-to-date information and support for pregnant people who themselves have an intellectual disability or may be having a child with an intellectual disability. It should design an outcome that aims to promote the provision of accessible, evidence-based information and social and emotional support that is human rights based.

## **2. Acknowledge and design a specific outcome addressing the increased risk of child removal among parents with an intellectual disability.**

During the Disability Royal Commission, advocates in almost every jurisdiction reported multiple cases of child protection taking the children of people with disabilities without cause. Advocates said there was an urgent need for legal reform, including of guardianship laws.<sup>11</sup>

Despite being a very small percentage of the parental population in Australia at about 0.4%, parents with an intellectual disability experience alarming rates of child removal and are significantly overrepresented in the child protection and legal proceedings.

This is not new.

In Victorian child protection cases first investigated in 1996-97, cases in which a parent had an intellectual disability were almost twice as likely than cases where parents did not have an intellectual disability.<sup>12</sup>

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<sup>10</sup> Collings., S. and Spencer., M. (2000). Practices that support parenting by parents with intellectual disability. *Australian Institute of Family Studies*. Retrieved from: <https://aifs.gov.au/resources/short-articles/practices-support-parenting-parents-intellectual-disability#footnote-0010>

<sup>11</sup> Inclusion Australia. (October 2020). Submission to the DRC – the Omnibus. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

<sup>12</sup> Allen Consulting Group. (2003). Protecting children: The Child Protection Outcomes Project. Melbourne: Victorian Department of Human Services. Retrieved from <http://www.allenconsult.com.au/publications/download.php?id=301&type=pdf&file=1>

In reviewing 285 court files in two children’s courts in New South Wales in 2000, researchers found that 8.8% of cases featured a parent with an intellectual disability.<sup>13</sup>

Research suggests that factors contributing to this over-representation include discrimination and a lack of accessible information and support services in the antenatal period and beyond.

Academics from the University of Sydney have noted that the NDIS does not fund general family support, despite inclusion as a priority group in the latest National Framework for Protecting Australia’s Children. As they put it:

“If a mother with intellectual disability is assessed as requiring support with living skills, an NDIS funded support worker may [support] her to buy and prepare meals and do the laundry. But the same worker is often not permitted to teach her how to sterilise her baby’s bottles or wash nappies”.<sup>14</sup>

There is an increasing body of evidence that demonstrates people with an intellectual disability can and do parent successfully when they receive timely and appropriately-delivered supports, combined with informal assistance from family, friends and allies.<sup>15</sup> Research demonstrates time and again that parents do well when they are given “genuine chances to practice new skills in their own home, have training matched to individual need, and receive support from workers who understand them and offer help with things they consider a priority”.<sup>16</sup>

We strongly recommend the Strategy acknowledge the over-representation of parents with an intellectual disability in the child protection system and make this a priority policy area to address the need for accessible support for parents with an intellectual disability during the antenatal period and beyond.

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<sup>13</sup> McConnell, D., Llewellyn, G., & Ferronato, L. (2000). Parents with a disability and the NSW Children’s Court. Sydney: University of Sydney. Retrieved from: [https://aifs.gov.au/sites/default/files/publication-documents/issues31\\_0.pdf](https://aifs.gov.au/sites/default/files/publication-documents/issues31_0.pdf)

<sup>14</sup> Collings, S., Hindmarsh, G., Spencer M., and Wedgwood, N. (August 2022). Parents with intellectual disability need more support. Retrieved from: <https://www.sydney.edu.au/news-opinion/news/2022/08/19/parents-with-intellectual-disability-need-more-support.html>

<sup>15</sup> Collings, S., Grace & Llewellyn. (2017). Home and the social worlds beyond: Exploring influences in the lives of children of mothers with intellectual disability. *Child: Care, Health & Development*, 43(5), 697-708. doi:10.1111/cch.12456;

Collings, S., Strnadová, I., Loblinzk, J., & Danker, J. (2020). The benefits and limits of peer support for mothers with intellectual disability affected by domestic violence and child protection. *Disability & Society*, 35 (3), 413-434. doi:10.1080/09687599.2019.164715;

Tarleton, B., & Turney, D. (2020). Understanding ‘successful practice/s’ with parents with learning difficulties when there are concerns about child neglect: The contribution of social practice theory. *Child Indicators Research*, 13, 387-409. <https://doi.org/10.1007/s12187-019-09682-y>

<sup>16</sup> Collings, S., Spencer, M., Wedgwood, N., & Hindmarsh, G. (2022). Supporting the Woman, Supporting the Mother: Final Report. Research Centre for Children and Families, University of Sydney. p. 20.

### **3. Acknowledge and, over time, work to end the over-reliance on early-intervention, segregated settings and special programs for children with an intellectual disability.**

When students with an intellectual disability go into a segregated school or learning unit, they are put on a pathway to a lifetime of exclusion from the community. We often refer to this as the 'polished pathway' to describe the way people with an intellectual disability face significantly fewer barriers to segregated environments in areas like education, housing and employment.

The barriers to inclusive education experienced by families and children with an intellectual disability must be removed. The Strategy should include this as a priority policy area.

Although many children with an intellectual disability experience mostly inclusive early-learning environments, many children with an intellectual disability are diverted to special schools when they begin primary school at age 4 or 5.<sup>17</sup>

Children with an intellectual disability who start special school in primary school do not go on to mainstream high school or post-secondary education.

This is the beginning of the polished pathway, where children and young people face barriers to mainstream education opportunities, and as adults, are only offered work in Australian Disability Enterprises (ADEs) as opposed to the mainstream workforce and will live at home or in a group home for the rest of their lives. This is the beginning of a life of segregation.

In our recent Position Paper to the Disability Royal Commission, we detailed the following policy asks:

- By 2024, no child to enter special school, or special units in mainstream school, in pre-primary or Grade 1. State and territory governments commit to progressive closure of special schools at primary level in the following five years.
- As each year of primary special schools close, those resources are to be transferred over to mainstream schools.
- Specific teacher professional development in how students with an intellectual disability learn in primary school is to be developed and implemented for all primary teachers in mainstream schools.
- Accessible and appropriate learning materials are made available in mainstream schools.

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<sup>17</sup> Inclusion Australia. (2023). The experience of children and young people with disability in different education settings. Retrieved from: <https://www.inclusionaustralia.org.au/submission/the-experience-of-children-and-young-people-with-disability-in-different-education-settings/>

- Peer resources for families about mainstream education and the polished pathway are developed.<sup>18</sup>

We strongly suggest that the Strategy acknowledge the barriers to inclusion faced by children with an intellectual disability and their families in educational settings, and work to resolve these as a priority policy area.

## **Conclusion**

When children with an intellectual disability, their families, and parents with an intellectual disability are included and empowered, the whole of society benefits. Including the policy areas detailed in this letter will enhance the overall Strategy and lead to better outcomes for all children and their families.

We thank the Department of Social Services for the opportunity to provide feedback on the Strategy on behalf of the people with an intellectual disability and family members we represent. We share the same vision for an inclusive Australia in which all children can thrive.

We warmly welcome any further opportunities to discuss the issues raised in this letter.

Kind regards,



**Catherine McAlpine**  
**Chief Executive Officer**

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<sup>18</sup> Inclusion Australia. (2023). The experience of children and young people with disability in different education settings. Retrieved from: <https://www.inclusionaustralia.org.au/submission/the-experience-of-children-and-young-people-with-disability-in-different-education-settings/>