**DSA Submission**

**ECEI Reset**

February 2021

**About Down Syndrome Australia**

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down Syndrome Australia is making this submission on behalf of its members. Down Syndrome Australia and its members work together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome.  We work in partnership to maximise the opportunities and support for people with Down syndrome and their families and support networks.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.[[1]](#footnote-1)

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# Submission: Early Childhood Early Intervention (ECEI) Reset

Down Syndrome Australia (DSA) welcomes the opportunity to provide a submission to the National Disability Insurance Agency on the ECEI reset. DSA is providing a separate submission on Independent Assessments.

As outlined by the discussion paper, the NDIA is working to improve the ECEI approach so that it ensures children and families can identify and receive best practice supports and that young children can benefit early from intervention supports. We welcome the focus on evidenced based best practice including the central role of the family, the importance of transdisciplinary teams in supporting families, and the availability of therapies in natural settings.

DSA recognises that the NDIA has consulted widely in the development of this new approach and we appreciate our involvement to date in this process. While we are broadly supportive of the recommendations which are included in the consultation paper, we do have concerns that some of the initiatives may lead to unintended consequences and require additional consideration. We are also concerned about the lack of information about how the Independent Assessments will be utilised to inform the package amount for children. DSA strongly urges the NDIA to provide further detail about how Independent Assessments will inform planning and packages in ECEI and provide adequate opportunity for the sector to provide feedback on the proposed approach once this detail is available.

## Removal of Lists

DSA is concerned that the removal of lists as part of the access process may have unintended consequences. List-D has been used to assist in determining whether a child’s condition met the early intervention requirement and provided a pathway for automatic eligibility. For children with Down syndrome, List D has been essential to facilitate an easy and early entry into NDIS.

The evidence clearly shows that children with Down syndrome benefit from early access to early intervention supports. All children with Down syndrome will have some developmental delays and will be eventually found eligible for NDIS Early Intervention. List D has meant that families are not required to prove that a delay already exists to access the Scheme. It has also streamlined the process and reduced resourcing for the NDIA. DSA has a number of cases where families with babies with Down syndrome were initially told that they would have to wait to access the scheme until their baby showed a 6-month delay in milestones. After contacting DSA, we supported them to advocate for their child’s right to access the Scheme under List D.

Data from the NDIA on the number of participants by age group suggests that less than 50% of children under one year of age with Down syndrome are accessing NDIS. If List D is removed, we would anticipate that this will fall dramatically to perhaps only 5 -10% of children under one years old. This delay in access to the scheme (and therefore delay in access to supports) has the potential to have negative impacts on both participants and future costs to the Scheme.

The consultation paper is silent on the process for access for children under one years old (while it notes that IA will only be conducted for children one year and older). It is sensible for there to be a process to facilitate access for children who have a disability which is known to benefit from Early Intervention supports (such as Down syndrome).

If List D is not working in its current form, a different list could be created which focused on disabilities which are diagnosed early and are permanent for the purpose of informing access for children under one who will not be completing the Independent Assessments. It is essential that there is some type of transparent approach so that families have certainty about access and a clear process.

**DSA strongly recommends that List D is continued as an approach to ensuring early access to the Scheme for children with diagnosed disabilities that will clearly benefit from the ECEI approach.**

## Mechanisms to support providers to comply with best practice standards (Recommendation 6)

Down Syndrome Australia supports the NDIA’s aim to improve the quality of support and services delivered to the child. There are a range of initiatives and strategies which need to be employed including:

* Upskilling families on the role of early intervention and best practice approaches. Families will be better able to identify providers who will support best practice and will have a better understanding of what type of supports will lead to better outcomes for their family. The NDIA should invest in quality independent research to continue to develop the evidence base and support families to make good decisions about supports (Recommendation 20). The NDIA has an important role in translating existing resources into information that is accessible to families.
* DSA agrees that ECEI providers should be regulated, have appropriate training, and commit to ongoing professional development.
* A consumer led quality feedback/rating system would also support families in making informed choices about providers.
* The focus of these changes should be around upskilling families to make informed choices. It is essential that family’s choices are not limited to providers who have the resources to undertake onerous NDIS audits. Any limitations to self-managed participants about the providers they use should be implemented carefully to avoid losing opportunities for creative solutions/supports.

## Use of Independent Assessments (Recommendation 9)

The introduction of Independent Assessments (IA) in the ECEI space is consistent with the current practice. ECEI partners already conduct a range of assessments as part of the planning meeting. They have experience utilising these assessments, alongside information from participants’ formal and informal supports to identify the needs of a child. ECEI Partners are staffed by skilled professionals whose area of expertise is child development and have the appropriate skills to conduct these assessments.

The novel part of IA is how they will be utilised to inform funding and plans. The current consultation paper provides little information about how the IA will be linked to funding and what if any level of judgement the ECEI partner will have in developing a plan. Based on the other consultation papers, it can be assumed that the IA will be linked to a funding algorithm which will provide a set level of funding for each participant based on the outcome of the IA.

There are potential benefits to an introduction of a more standardised approach to setting budgets for this cohort. The current model which links funding to goals can be problematic for some families who may be uncertain about their child’s needs in the early years. For example, we often see plans with minimal funding equivalent to that set with one to two goals (when realistically, children with Down syndrome would generally have anticipated needs across the six key developmental areas). The IA may determine a greater level of need than parents (particularly in the early days) may anticipate, which could lead to increased funding for some children.

Without further information about how the IA will link to funding packages, it is impossible to comment on whether this is an appropriate approach. It is concerning that the methodology around linking IA to package size has not yet been tested, nor as far as we are aware is there a plan to test this approach before implementation. For ECEI, it is essential that the ECEI partner is allowed to utilise their expertise to inform this budget if they believe the algorithm has not provided an appropriate level of funding. Given the benefits of early intervention to both participants and to the resourcing of the Scheme, it is essential that children have access to an appropriate level of supports. This level of flexibility and judgement will be particularly important in the early phases of implementation given the lack of testing of the approach.

Provided there is confidence that the right IA tools are identified and implemented meaningfully, and the planners are supported to utilise their expertise to inform the plan budgets, there is every opportunity for these assessments to provide solid guidance around access and funding, without this having to financially disadvantage a family nor be dependent upon their geographic location.

**DSA recommends that the sector is consulted further on the use of IA in ECEI once information is available about how the assessments will be tied to funding and planning. ECEI Partners should be allowed to utilise their expertise in informing the plan budget and not be constrained by a fixed algorithm.**

## Increase Partner capacity to connect families to local support networks and services (Recommendation 11).

To date there has been variable engagement between the ECEI partners and the local Down Syndrome organisations, despite efforts to engage with these organisations. Our State and Territory members provide a range of information and support to families. A warm referral to a local Down syndrome organisation should be part of the role of the ECEI Partner when they are providing support to a family with a child with Down syndrome. Our organisations can provide peer-support, information, and support in accessing main-stream services including education. Our organisations can also provide assistance and training to the ECEI partners about the specific needs of children with Down syndrome.

**DSA recommends that the ECEI partners provide direct referral to the relevant organisations for children (e.g., families with a child with Down syndrome should be connected to the local Down Syndrome organisation).**

## Short Term Early Intervention Support (Recommendation 12)

Short Term Early Intervention (STEI) is designed as a short-term intervention to meet the needs of children with less significant delays. The recommendation to increase Partner capacity to provide STEI supports is sensible. There has been limited information about how this recommendation relates to children with permanent disabilities such as Down syndrome. In our communications with the NDIA, our current understanding is that this approach will only apply to children with developmental delay that is not linked to a diagnosed disability. Our understanding is that children with Down syndrome will not be required to access STEI and will instead have timely access to evidence-based supports.

**DSA recommends that children with permanent disabilities such as Down syndrome have timely access to evidenced-based support, and that this access is not delayed due to the new approach of STEI.**

## Raising the age for early child supports from 7-9 (Recommendation 14)

DSA welcomes the recommendation to extend the early child supports from 7-9. Often children can face additional difficulties when transitioning to primary school. These challenges can include:

* ‘gatekeeping’ by schools
* accessibility needs not being met (i.e., ‘reduced hours’ being offered; not having the curriculum modified to an accessible standard; parents being asked to attend school multiple times daily to cater to personal care needs).
* not providing adjustments/ support within school until child is old enough to have a formal cognitive assessment
* lengthy process to be assessed for supports (SSO).

The continuation of the ECEI approach until a child is 9 will enable the child’s early intervention team to work alongside families and schools to best support the child during transition to primary school. This approach should include supporting families to access NDIS supports in the first year of school when educational supports may not be immediately available. The disability and education systems need to ensure a more coordinated and collaborative approach to meeting a child’s holistic needs once they enter formal schooling, rather than expecting NDIS supports to stop at the school’s front door immediately upon the first day of primary school.

**DSA strongly supports raising the age for early child supports from 7 to 9.**

## Increase Early Childhood Partner Capacity to support plan Implementation and Connection to Supports (Recommendation 16)

There is clearly a need for increased support for plan implementation and connections to support for many families. Families are often having to acquire vast amounts of knowledge regarding their child’s disability, daily care needs and NDIS all within a short time. Families struggle to understand the NDIS and how to utilise funding to support the needs of the child. The Down syndrome organisations are regularly approached by families for support in understanding the child’s plan and how to implement it.

It is unclear as to whether focusing on the Partners’ capacity in this space is the best solution to this problem. To date ECEI partners have not provided adequate support to families regarding plan implementation. In some cases, implementation meetings have taken the form of an email sent to families, or a very brief phone call checking-in with a family. Currently there is a high turnover of ECEI Partner staff, which makes it difficult for them to be the central coordination point. If the Partners take on this responsibility it means that families have little recourse if they are not getting the support they required. A preferred approach would be to provide families with the option of inclusion of Support Coordination funding for children so that families can choose who is best able to support them in navigating the complexities of NDIS and identifying appropriate supports. Perhaps the Partners could be included as an option for Support Coordination, but not be mandated as the only choice.

**DSA recommends an increase in access to Support Coordination for ECEI families instead of expecting the ECEI partner to cover this requirement.**

## Capacity Building Supports in Natural Settings (Recommendation 17).

DSA welcomes the approach of encouraging the provision of therapies within natural settings, which is supported by the evidence. This change will be particularly beneficial for families in regional or rural areas where there can be significant travel to be able to access therapies. As part of this reset, it will be important for the NDIA to engage with the Department of Education regarding access to early intervention within school settings. Increasingly schools are prohibiting access to therapies during school hours. This can create difficulties for families to access therapies due to limited time outside of school or being forced to pull a student outside of school to attend therapies. Increased access to NDIS-funded therapy within the school day would also allow for greater communication about essential therapeutic strategies across all who support the child daily, which is more aligned with a holistic approach which is supported by the evidence. Case studies should be developed to support families in how they can use their NDIS supports in interacting with the education system (e.g. meetings between therapists and teachers to discuss classroom strategies etc).

**DSA recommends that the NDIA work with the Department of Education to ensure access to capacity building supports within schools as part of the work to provide therapies within natural settings.**

## New Guidance on what is considered ‘reasonable and necessary’ for children on the autism spectrum (Recommendation 18)

DSA welcomes an evidenced-based approach to making decisions about supports for children with specific disabilities. This approach for Autism brings into question whether similar guidance should be developed for other specific disabilities (such as Down syndrome). There is also a question of how this guidance will be utilised when children present with a dual diagnosis. For example, up to 10% of children with Down syndrome also have a diagnosis of Autism Spectrum Disorder. There needs to be greater clarification about the appropriate supports for children with multiple disabilities taking into account the complex cumulative functional impact for children with multiple diagnoses.

**DSA recommends that NDIA consider and consult with the sector about how the new Autism guidelines will relate to children with multiple disabilities.**

1. Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from <https://www.downsyndrome.org.au/about-down-syndrome/statistics/> [↑](#footnote-ref-1)