

22/02/2021

To whom it may concern,

Re: Response to the ECEI Reset Recommendations

Thank you for the opportunity to provide feedback on the NDIS ECEI reset plan summarised in the document '*Supporting young children and their families early, to reach their full potential.*'

We are a small private practice, currently comprising two speech pathologists both working part-time. Due to the administrative and financial burden of being an NDIS-registered provider, and time required to communicate with NDIS plan managers, we currently only see NDIS participants who are self-managed, or plan-managed with the capacity to pay on the day and recoup the cost from their plan manager. NDIS participants comprise approximately 75% of our caseload, most of whom are under seven years of age.

We are both doctorally certified: Dr Jessica Boyce has a PhD in speech and language disorders in children with cleft lip and/or palate, and Dr Katherine Sanchez has a PhD in feeding and communication in children who were born very preterm. As a result, we attract a number of highly complex children whose needs have not been met by the level of care provided by therapists with less specialised expertise and qualifications. The concept of 'choice and control' is extremely pertinent to our clients and their families, who often elect to travel long distances to see us, or engage via telehealth to access our services. Similarly, the demand for our services is high, meaning that we need to balance our ability to consult on a greater number of complex clients with our capacity to provide supports in the community.

We were pleased to have the opportunity to review this document after attending a consultation meeting with an NDIS representative on the 10th of February, 2021. Please find our feedback in relation to the recommendations from this document below.

Yours sincerely,

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Positive changes

We are supportive of some of the changes discussed in the consultation papers, such as:

- Recommendation 4: Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported.
- Recommendation 11: Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community
- Recommendation 14: Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age, to help children and families receive family centred support throughout the transition to primary school.
- Recommendation 15: Use the early intervention criteria, under Section 25 of the NDIS Act (2013) to make decisions around access to the NDIS for all young children—**particularly as these criteria include children with conditions such as developmental language disorder, stuttering, and childhood apraxia of speech, who have been frequently excluded from the NDIS.**
- Recommendation 20: Undertake further ongoing research and study on the outcomes of young children after receiving early intervention support, to inform future policy and operational changes.
- Recommendation 23: Offer families of young children a 'transition out' plan for up to 3 months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

Concerns and Queries

We have significant concerns about several of the other recommendations. We have summarised these below.

Recommendation 2: Clearly and consistently, communicate the intent of the new Early Childhood approach and the Agency’s support for best practice, so families understand how the approach informs positive outcomes for young children.

And

Recommendation 6: Consider a range of mechanisms that will enhance compliance of providers with the NDIS Practice Standards on Early Childhood Supports and increase awareness by families of providers that adopt that best practice framework

1. We believe that most of the NDIS practice standards are valid and worthy. Our concern is around the limited application of the term ‘best practice.’ This is discussed further in the project consultation report which says:

“Many children are consistently receiving therapy supports in clinical settings, which is contrary to clear best practice of receiving supports in natural settings like the home or school”

and

“Contemporary best practice early childhood intervention for disability is shaped by the broader transition from the deficit model of disability to the social model. A social model moves away from a focus on diagnosis and deficit and focuses intervention to build capability on the basis of functional impact to support meaningful participation in family and community life.”

These quotations reveal a narrow view of what constitutes best practice that is not supported by current scientific evidence.

The World Health Organisation has long supported a biopsychosocial model of disability, rather than a social model. (World Health Organization, 2002) A social model of disability that does not acknowledge impairment, in addition to activity and participation, is reductionist. Children with childhood apraxia of speech or developmental language disorder or feeding tube dependence certainly benefit from social reform and supports focused on activity and participation; but the **best evidence currently available for changing outcomes supports intensive, clinician-led therapeutic intervention to address the disability at an impairment level.**

(Ebbels et al., 2019; Morgan et al., 2018; Sharp et al., 2020) In fact, early childhood is the best time for these interventions, as greater progress can be anticipated in the context of increased neuroplasticity, decreasing future support needs. While some families might prioritise activity and participation for their children—particularly where little change to functional impairment is anticipated—others will

also wish to access supports that address impairment, and this should not be discouraged or deprioritised. Such supports are not necessarily best delivered in ‘natural’ settings; in some cases, ‘natural’ settings can be a hindrance to progress.

It is our experience that these **exceptions, nuances, and need for individualised care are too often not given adequate consideration by planners and providers** who are used to catering for presentations which benefit more from a transdisciplinary key worker model of care. Thus, we are concerned that in attempting to “enhance compliance” with the NDIS standards, these mechanisms may, when applied in a real-world context, act to **discourage evidence-based clinical decision making** that enables us to deliver a best practice solution that is individualised to the needs of each client.

Recommendation 7: Improve sector wide understanding of how to identify families and young children experiencing disadvantage or vulnerability and tailor culturally appropriate services and resources so they can benefit from early interventions support.

1. While the general principle of this recommendation is laudable, we noted that there is no mention of the omission of funds for interpreters for those clients who wish to be self- or plan-managed NDIS participants. **This raises the concern of giving English speaking participants a higher level of choice and control than non-English speaking participants.** *For example, we were recently unable to provide services for a family who urgently required a therapist for their young child, as the interpreter fees were equivalent to the cost of therapy; neither the family, nor our business could afford this, and so the family were forced to wait for another, less-preferred service. Conversely, we currently see several NDIS participants who bring family members along to interpret. This is problematic for a number of reasons, including but not limited to potentially biased or incorrect interpretation, needing other family members to take time away from work or school, etc.*

Recommendation 9: Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions.

1. At present, there is no plan to consult a child’s existing therapy team to inform their eligibility or funding level. This is a problem because **therapists who have**

existing relationships with families will have a more nuanced and informed perspective of a child's needs than an independent assessor. We wish to

emphasise that equality is everyone receiving the same resources and opportunities; whereas equity is everyone receiving the resources and opportunities that they need. Equity, not equality, is what we should be striving for.

- a. One solution would be to make IAs an 'opt out' scheme, whereby families who wish to use current therapists' reports are permitted to do so, rather than undergoing an IA.
 - b. Another solution would be for IAs to have a clear, protocolised way of integrating assessment and outcome data provided by the child's therapy team.
2. It is currently unclear what qualifications and experience will be required to administer IAs.
- a. Experienced allied health practitioners are best placed to fill this role; yet there are substantial, documented workforce shortages across speech pathology, occupational therapy, and physiotherapy. (Tobler, 2020) Further, assessment-only positions are traditionally very difficult to recruit to. Therefore, implementing IAs in this way would likely **create a significant bottleneck that would delay NDIS access for vulnerable children.** The emphasis on young children in the consultation paper is pertinent. *We have already seen young children wait six months or more for their intake paperwork to be processed by NDIS partners.* This wait is already unacceptable, without adding another, more labour-intensive process before children can access what is intended to be early intervention.
 - b. If professionals without allied health training were recruited to fill these roles, this may create some of the problems we have seen with non-allied health NDIS planners; where they may lack understanding of developmental disorders and disabilities, and the role of allied health in addressing developmental concerns (*for example, we recently had to explain to a planner why dietitians needed to be involved in the care of children with developmental feeding disorders*), and may be less likely to provide an accurate and complete assessment, even with training.
3. There is currently no formal appeal process proposed if families or professionals wish to contest the score from an IA. No developmental assessment or

combination of developmental assessments is 100% valid, nor has 100% sensitivity; certainly not the range of tools proposed in the Independent Assessment Toolkit. **Suggesting that the IA process will be infallible is problematic**, and should be urgently reviewed.

4. We applaud the decision not to apply IAs to children under 12 months. In our opinion, this provision should be applied to children from 0-3. The capacity for developmental screening tests—even domain specific tests—applied early in life to predict later impairment remains extremely limited. (Reilly et al., 2010) **The assessment approach for this age group in particular should be more individualised.**

Recommendation 13: Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision-making. Establish thresholds for key criteria using Independent Assessments. (Specifically, establish clear definitions and thresholds for the criteria ‘substantial delay in functional capacity’ and ‘extended duration’.)

1. Clearer developmental delay criteria are welcome, especially since these criteria are often incorrectly applied to exclude children with eligible developmental concerns such as developmental language disorder, stuttering, and childhood apraxia of speech. However, **the concept of establishing unreviewable thresholds for key criteria** using the Independent Assessment process poses several significant limitations. Even with domain-specific tools (for example a dedicated and detailed language assessment tool), **100% reliable discrimination of children with and without a substantial delay is not currently possible.** (Goday et al., 2018; Murray et al., 2015; Nitido & Plante, 2020) Indeed, many areas that fall within our scope of practice lack consensus as to what comprises a problem, let alone how to quantify that problem. (Goday et al., 2018)
The tools selected for the Independent Assessment toolkit are not domain-specific tools, and lack the sensitivity to establish a reliable threshold, even if such a threshold was possible to define.

Recommendation 17: Introduce a ‘capacity building support in natural settings’ item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.

1. We agree that providing supports in natural settings is best practice for many children, however **we challenge the assumption inherent in this recommendation that it is best practice for all children.** *There is no evidence, for example, that therapy for complex speech sound disorders or fluency disorders is best carried out in the home; rather, our experience has been the opposite. This work requires a high level of focus, which is more easily achieved in a quiet, clinical environment guided by the expertise of appropriately trained professionals.* In pushing more services into 'natural settings' the NDIS may fail to consider those families or children where clinic-based services are more appropriate.
2. One issue we have frequently encountered with 'other natural settings' is that educational and care settings are often **unable to accommodate providers** supporting NDIS participants. *For example, we have one client who is a six-year-old enrolled in a special school. He has a severe paediatric feeding disorder in the context of global developmental delays, and was not eating at all at school. The school did not have the capacity (in terms of time or expertise) to provide mealtime support, however they also had a policy not to allow external therapists to provide services on school grounds.* Other settings may be willing, but do not have the space; or charge rent for providers to use a room on site. If the NDIA wishes to support intervention in natural settings, they can consider:
 - a. Working with the Department of Education to place providers for NDIS participants in schools and early education centres; or
 - b. Liaising with the Department of Education to develop policies and procedures to allow NDIS participants to receive services at schools and early education centres; and/or
 - c. Providing additional funding to offset the cost of the rent charged to providers when they attempt to provide services in schools and early education centres
3. As the NDIA is aware, there are significant workforce shortages across speech pathology, occupational therapy, and physiotherapy. These workforce shortages are likely to worsen due to the impact of the coronavirus pandemic on the higher education sector. *Like many other practices, we currently have a waitlist of 12 months for ongoing therapy, despite the fact that we see clients back-to-back in our clinic. Many other clinics local to us have closed their waiting lists.* Until the

workforce issues are resolved, an increase in community-based supports is likely to mean **longer waitlists**, particularly in regional areas where travel times are longer.

4. Currently, NDIS has a travel cap of 30 minutes for MMM1-3 areas, and 60 minutes for MMM4-5 areas. Fifteen minutes to travel each way (inclusive of considerations such as traffic, parking, public transportation for providers who don't drive) or thirty minutes each way in more remote areas does not allow providers to cover much ground. In our case, we calculated that the travel cap would allow a radius of 2.5 kilometres from our office; meaning that only families within a 2.5 kilometre radius could receive 'capacity building supports in natural settings' via our service. (Frederiksen, 2018) Again, this significantly **restricts choice and control** for families who want to select a provider based on factors other than geographical proximity. Increasing the travel cap would improve choice and control for families and participants, and enable more participants to access supports in natural settings where appropriate.
5. Many participants are concerned that paying for travel from their NDIS funds subtracts from the funding available for direct services. Separating capacity building supports from travel funds may help families feel comfortable accessing supports in natural settings where appropriate.

Recommendation 19: Empower Early Childhood partners to provide families with clear advice about the best providers for their child and situation so families can make more informed choices.

1. 'Best providers', like 'best practice', is a highly subjective term that is susceptible to bias. **The NDIS does not appear to have any reliable or valid way to identify which are the 'best providers'**, as they do not currently collect any data about participant satisfaction or outcomes with specific providers. Even if these outcomes were available, the complexity of individual outcomes and measurement means that these data would be extremely challenging to integrate and analyse. With this in mind, an early childhood partner's recommendations are likely to be influenced by their experiences, personal preferences, and professional philosophy; and not by any objective evidence.
 - a. An improved option could be for early childhood partners talk to parents about the many factors that may influence the appropriateness of a

therapist for their family, using an unbiased discussion framework; to teach the family how to source providers and investigate their suitability; and thus to empower the families to choose based on their priorities rather than on the partner's recommendation.

Recommendation 22: Ensure providers are using the recently introduced 'provider outcomes report', as a mandatory measure to evaluate the effectiveness of their supports and services.

1. Completing this form with a family would require at least one to two sessions, in addition to administrative time outside of sessions. If this is to be made compulsory, all ECEI NDIS plans should provide a **base level of three hours of report funding per provider** in each participant's plan to allow for this report to be completed. This would ensure that the amount of time available for therapy and interdisciplinary collaboration was not affected.
2. The current provider outcomes report is unwieldy as an MS Word document. An online form with an option to print or to submit directly to the NDIS might be more useable.
3. As it stands, the current provider report contains several errors in punctuation and sentence structure.

Responses to Specific Questions

How can we better support families to connect with services that are either funded or available to everyone in the community?

We suggest that the NDIS creates and maintains a central, and easily searchable directory of such services, indexed by location, type of service, and target groups. Such a directory could then be openly accessed by families and providers. NDIS partners could support families to access this directory upon intake.

How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?

It would be beneficial to encourage greater involvement of social workers, nurses, and other appropriate professionals as key workers; and fund an appropriate key worker for more families, particularly those experiencing vulnerability or complex diagnoses.

Currently, our impression is that key workers are rarely allocated to self- or plan-managed participants. In fact, *for one highly vulnerable child on our caseload, the NDIS rejected an initial application for key worker funding, and a review was necessary to obtain the funds to pay a key worker—despite the fact that this child has a team of over 20 professionals involved in his care across the health, disability, and social services sectors. The feedback from the NDIS was that they did not see the value in a dedicated case manager, given that the child already had so many professionals involved.* This poses significant challenges, as a key worker is able to provide essential care-coordination that is often beyond the administrative capacity of a therapist or medical professional.

As discussed above, another key omission in NDIS coverage for families experiencing vulnerability is lack of funding for interpreter services for self- or plan-managed clients. Any family who requires an interpreter should automatically be allocated the same number of hours of interpreter funding as therapy funding in their plan.

It is recommended, from the previous consultation leading to this paper, that a range of mechanisms be considered to enhance providers' compliance with best practice standards and to provide greater transparency on which providers, both registered and unregistered, are following Early Childhood Intervention best practice.

- **What mechanisms do you think could help achieve this?**

Increased availability of key support worker funding could be used to empower parents to:

- Select therapists that are the best fit for their family, based on the complex multitude of factors that determine fit
- Change therapists if the fit is not right
- Interrogate therapeutic supports when they have questions or concerns

The above could empower families to make judgements and decisions, rather than imposing decisions upon them by pushing them towards specific providers and professions.

Making the below changes to registration would also be helpful.

- **Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?**

Existing professional organisations, such as Speech Pathology Australia.

- **What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?**
 - **Provide greater information to families about the benefits of using providers registered by the NDIS Commission.**

As outlined above, it is our belief that pushing families towards registered providers interferes with choice and control, and restricts access to clinicians that may be a better fit for specific families. *We have already heard from families expressing frustration that they were not told that choosing to be agency-managed would substantially restrict their capacity for choice and control, and result in longer waitlists for support that was not suited to their needs.*

- **Establish an industry-led 'best practice accreditation system'.**

Currently, Speech Pathology Australia members must comply with certain requirements to remain members. These requirements are not onerous and provide an additional level of safeguarding.

Unfortunately, unlike many of our colleagues in other health professions, speech pathologists are not eligible for AHPRA registration. The NDIA is well placed to advocate for speech pathology inclusion in AHPRA as a way to mitigate risk to NDIS participants.

These two existing schemes provide a certain amount of industry-led quality control. Rather than establishing a third scheme, we recommend working with professional bodies and AHPRA to ensure that providers meet their requirements.

- **Establish a 'quality feedback / rating system'.**

We would be interested in hearing more about this, and feel it could, if done well, be beneficial. We are unable to provide more definitive feedback in the absence of further details.

- **Make registration with the NDIS Commission mandatory for all providers operating in the EC space.**

The NDIA must be aware of the reasons why many providers choose not to register, or have made an active choice to deregister. The registration process is **expensive and onerous**. The administration required for agency-managed clients is significantly more time-consuming, given their complexity and billing requirements; yet the cap on NDIS rates means that clinicians often have to charge a lower rate than that of other clients. If registered, small businesses like ours would also have to wait longer to receive payments; we are even more cautious given the many months it took to resolve payment issues in 2018 (<https://www.abc.net.au/news/2018-02-21/ndis-tackling-payment-delays-after-providers-left-out-of-pocket/9469926>).

We are a commercially competitive practice, given our level of experience and expertise. Should registration become mandatory, our most likely decision would be to stop accepting NDIS funding, and only see clients who were able to pay out-of-pocket. This would be deeply disappointing, and is not our desired outcome; however it would be much more viable than becoming NDIS registered under the current system.

Rather than forcing practitioners into a position where they must register, the NDIA may be better advised to:

- Improve the registration process so that audits are funded through the NDIA rather than by the provider; and so that complementary assistance and funding is available for practitioners to get 'audit ready.'
- Improve the usability of the MyPlace portal
- Guarantee payment processing within 48 hours of a payment request being made
- Raise the caps on therapy rates to reflect the cost of evidence-based, expert services for complex clients; and to acknowledge the additional time required to participate in NDIS audits and process NDIS payments

If these barriers were addressed, a greater number of practitioners (including us) would be more inclined to register, and this mechanism could be ethically and effectively implemented.

- **Require self and plan-managed participants in the new Early Childhood approach to use only registered providers**

Withdrawing choice and control from participants is not a productive solution. This mechanism also suggests that, as unregistered providers, we provide a lower quality service than registered providers. With current requirements, registered providers are more likely to have the time and financial capabilities to become registered. This does not inherently mean that they provide a better service.

For this solution to be helpful, the registration process needs to be made more viable, by implementing the measures suggested above.

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