Dear Sir/Madam

Submission to the 2021 NDIS consultation on supporting young children and their families early, to reach their full potential

The Australian Psychological Society (APS) welcomes the opportunity to provide a submission to the 2021 NDIS consultation on supporting young children and their families early, to reach their full potential.

The APS is the peak professional body for psychology in Australia, representing over 25,000 members nationally, many of whom work in the disability sector. For the past 76 years, the APS has played a central role in establishing standards to ensure the quality and safety of mental health care in Australia.

In this role, the APS is responsible for promoting excellence and ethical practice in the science, education and practise of psychology as the key discipline for the reducing the burden of mental ill-health and increasing the wellbeing of all Australians. It sees the importance of ensuring people with a disability receive high quality and effective psychological services to support their mental health and enable them to live active and fulfilling lives as valued members of the community.

The submission that follows is based on feedback sought from those members. It addresses the consultation questions where relevant to psychology and member feedback.

If the NDIS requires further APS input, I may be contacted through my office on (03) 8662 3300 or by email at z.burgess@psychology.org.au.

Yours sincerely

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Chief Executive Officer
Australian Psychological Society Submission to the 2021 National Disability Insurance Scheme Consultation on the Early Childhood Intervention Reset

Preliminary comment

The APS strongly holds the view that Early Childhood and ECEI are specialised fields that require specialised planning, workforce development and training. Early childhood development, disability and family systems are not all taught in adequate depth in university degrees. There are as yet no specialised early childhood intervention post graduate degrees in Australia.

Consequently, as identified by the NDIA, there are opportunities for practitioners, including psychologists, to learn about the evidence and best practice rely on in-service professional development and experience (Recommendation 4, p70). These need to be taken up.

The APS agrees with the NDIA in that there is a substantial need for further research in the field in all facets of Early Childhood Intervention (ECEI) access, delivery and outcomes. In addition, however, it believes that all facets of the NDIS should be reviewed by strategic research (Recommendation 20, pp. 81). The APS is of the view that significant investment in research is urgently needed, particularly around the need to develop and refine suitable resources.

The APS emphasises, as it typically does with its submissions to the NDIA, that it is imperative to all get Scheme amendments 'right', rather than to make precipitate alterations to the Scheme. This necessitates appropriate tracking of effects on children, consultation with families, industry and peak professional bodies, provider organisations and workers (hereafter referred to as key stakeholders) and the APS.

The APS offers the following responses to the consultations questions and other considerations.

Do you have any specific feedback in relation to:

1. The increased focus on STEI outside of access to the Scheme

The APS is of the view that Short Term Early Intervention (STEI) should not be a function of the NDIS partners. This is because those parties are not well placed to provide it either in training, experience or position within systems of support.

Rather, the APS believes the NDIS needs to work to actively promote integrated systems of support for all children between the Commonwealth, NDIS and states and territories (as well as across state and territory boundaries). An inclusive service system is built by strengthening the services available for all (state), enabling supports to be accessed by those needing a little more (e.g., Community Health Services), and then adding in supports for those with greatest need (Commonwealth and NDIS).

As it stands, the proposal is inherently un-inclusive and segregationist. The APS believes it does not assist the effort to build state service systems so they are well placed to support children with short term needs to be included into their generic services. It further believes that the arrangements as described have unintended consequences for NDIS participants by not strengthening local service skills in support of participation. With respect to the proposed
Recommendation 12 (p 76)], the APS is concerned the STEI supports will act as a further stop-gap for children who need support and would mean their families would need to explain their situation to additional people prior to meeting their best practice key worker support. Best practice ECEI is built around family’s building a relationship with one principal worker. The APS does not believe the proposed STEI supports fit within this concept.

2. The proposed increase in age range for the EC Approach from under 7 to under 9 years of age
The APS considers proposed age range extension to 0-8 years for ECEI is sound and will support consistency in services’ coverage between commonwealth, states, and territories.

3. The desire to see more successful transitions from the Scheme to the next state of life
The APS views the desire for more successful transitions out of the scheme is a worthy goal which requires systemic support. As with consideration one, it can be facilitated by the Commonwealth NDIS taking on the complex task of really studying to understand the services available in each state/territory and then working with them individually and collectively to consider the developmental implications of each, and to promote their respective inclusive capacities and awareness. It cannot be achieved by simple "Band-Aid" solutions. There are currently no incentives for parents/carers to move children off the scheme. The community inclusion and lower intensity supports need to be enhanced to provide attractive, inclusive alternatives to NDIS support. Without these alternatives, the NDIS unintentionally acts to make participant children exceptional, labelling and potentially stigmatising them in their families and communities, rather than promoting their inclusion, as intended.

Strengthening mainstream services is an excellent goal, necessitating appropriate opportunities for collaboration between mainstream and NDIS services. This requires extensive relationship building between mainstream services and NDIS providers. For example, system wide processes for collaborating with kindergartens or preschools/schools under the relevant state and federal education departments are required (Recommendation 5, p70)

4. How can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use such as:
   - best practice
   - capacity building
   - natural settings, and/or
   - evidence.

These terms and their implications for service delivery need to be the foundation of all aspects of engagement with families under the NDIS. Plain English versions of the terms, as determined by a Fog Index or similar, should be developed in consultation with parents/carers. Video material should demonstrate these practices in action. In addition, these terms should be so familiar to planners that they are assumed as first preference modes of ECEI delivery. Providers need to be trained to understand what best practice is, evidence based, capacity building and how professionals might provide it under the NDIS. The NDIA also needs to address the price guide disincentives to providers offering best practice.

While beyond the specific ambit of this question, the APS wishes to state its view that the intention to adopt a best practice approach is worthwhile (Recommendation 1, p69). As part of this, there needs to be clearer planning and support for education, training and supervision of
ECEI clinicians to achieve best practice. There is a huge skills shortage in allied health. The APS recommends that the NDIS track job advertisement for practitioners and actively gather data about this. Senior practitioners report observing many new graduate therapists (of all disciplines) going to work in (sometimes solo) private work without adequate support and guidance where they can earn the same as an experienced clinician. There is insufficient recognition within NDIS of the value of senior, experienced clinicians. An ECEI key worker requires a broad knowledge base often built over years of team experience. Best practice cannot be achieved without having well trained and supervised therapists from all areas of allied health including psychologists across ECEI teams. There has not been any effort from NDIS to address the significant investment in workforce required. Lock funding for organisations to train their workforce including principal/key workers and senior practitioners in ECEI is required.

The APS also agrees that working in natural environments is best practice (Recommendation 17, p 80). However, it is concerned that a lone specific item has the potential to limit flexibility with plans. For example, if funding is divided between “natural settings” and “regular” then families and therapists will feel they have to use some resourcing on clinic time, but only the allocated amount on natural settings. A better arrangement would be to place all funding under “natural settings” - as is best practice. The APS proposes that further clarity is needed there.

5. What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?

The APS believes the NDIS should develop a reporting system which provides a framework for measuring outcomes in relation to function, participation and adaptive skills. It also strongly suggests the NDIS should commission research projects from academic teams to develop suitable measures and reporting systems.

6. Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?

Yes, the APS strongly believes in the worth of such a tracking report. It also believes such an accountability measures for providers would be beneficial and should be introduced.

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

See response to question three.

8. How can we make the process of transitioning out of the NDIS something to celebrate?

See response to question three.

9. If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?

Most obviously this could occur via telehealth and online peer groups. Less obvious, but nevertheless important, is the change that could occur thought the use of incentives (via not only remuneration and allowances, but also professional support like supervision and resources).
10. How can our Early Childhood partners and mainstream services best support peer-to-peer connections?
The APS strongly believes Parent/carer peer-to-peer connections should be supported through online networks, playgroups, and programs like “Now and next” being rolled out nationally.

Peer-to-peer groups for children need to be developed gradually, starting with older children, so that in the instances that children/families express a need to locate a similarly-diagnosed peer, they have opportunities to find such connections.

11. Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?
The APS would be pleased to work with the NDIS and field leading experts to develop peer networks.

12. 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?
The APS believes this can be done by adopting more inclusive approaches that encourage the involvement of participants in decisions about their care and mobilising professional groups via incentives.

Importantly, different approaches are needed for different groups. Separate and distinctly different targeted approaches are needed to each of the following groups - children who experience socio-economic/AEDI disadvantage, children who have multi-cultural/linguistic issues, children from rural/remote areas, children who have experienced abuse/neglect/trauma and children who are in out of home care.

These “equity of access goals” [Recommendations 7 (p 71) and 10 (p 74)] are very important. However, they do not go far enough to address systematic barriers to achieve access and equity in ECEI supports.

The reality is that vulnerable families need a strong outreach approach that allows for services to actively work to engage a family and have time to build a relationship before families need to independently complete forms and manage a complex budget. This aspect of NDIS provision needs much greater focus. Basic current barriers (e.g., having to complete paperwork, thoroughly describe their child’s delays (when parents have no background in understanding child development or what is typical or delayed), attend appointments, apply well before age 6) are not proposed to be addressed. Some other recommendations (e.g., for IAs) have the potential to increase the barriers (cultural, ESL, logistical & engagement) to access an ECEI Plan. There is no clear plan for how potential inequalities in these areas will be addressed for disadvantaged and vulnerable families.

It is recommended that the Agency implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions. Specifically, we are planning to:

- Commission Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce
- Use IAs for young children above 1 years of age
• Use the following tools (as outlined in an appendix to the previously published Independent Assessment Tools Paper):
  a. Ages and Stages Questionnaire (ASQ-3) OR Ages and Stages Questionnaire - Talking About Raising Aboriginal Kids (ASQ-TRAK)
  b. PEDI-CAT (Speedy) OR PEDI-CAT ASD (Speedy)
  c. Vineland-3 Comprehensive (Interview Form)
  d. Young Children's Participation and Environment Measure (YC-PEM) for children under 6 years
  e. Participation and Environment Measure - Children and Youth (PEM-CY) for children 5+ years

Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?

The APS strongly disagrees with the proposed use of independent assessments and of partners as independent assessors (Recommendation 9, p73). It has numerous concerns about such a proposition; viz., that

i. Assessment in early childhood is a sensitive matter for parents who are still learning about their child’s condition and prognosis. Feedback needs to be provided in a timely and sensitive manner by those who have a longer term relationship with the child and parent. An include/exclude assessment process, such as proposed, would be both distressing and fraught. The APS believes the proposed IA process serves the needs of the NDIS, not the children and families. It would not be suitable for families to learn of and elaborate on their understanding about their own or professional concerns. The process of reaching mutual understanding often takes many sessions to reach sufficient depth of information sharing.

ii. The IA process, as proposed, means that families would need to share sensitive and personal information with additional professionals, thus placing extra stress on them and potentially interfering with their privacy and more appropriate relationship building with their ongoing key worker.

iii. Assessments are best completed by therapists who know the child and family well already or who are initiating an ongoing relationship. The children’s therapists can support the families in assessment and skills development ongoing and when appropriate in exiting the scheme.

iv. Determining the type, focus and intensity of his/her for child participants involves much more than assessing the children’s developmental level, functional skills and independence - and needs to take in a range of other factors; for example, family capacity, family education and background, local supports, skills and experience of mainstream services, such as the kindergarten teacher etc.).

v. Access criteria should be as broad as possible to ensure no child in potential need of supports misses out. Assessment needs to be as close to local service provision as possible to enable this to be achieved.

vi. Parent report measures may be influenced by parents understanding of the purpose of the assessment and its impact on funding (e.g., educated parents will know score low=high funding).

vii. The detail is lacking in how the test scores will be used to ascertain funding budgets.

viii. Not mentioned in the consultation is the ongoing issue that NDIS use ASD diagnosis “levels” from DSM as a mechanism for determining access to funding, which is explicitly warned against in DSM-V (Recommendation 13, p 77).
ix. Questions of diagnostic assessments have not been addressed in the consultation. The APS is eager to know these processes will link with traditional diagnostic assessments. Although diagnoses are implied by the NDIS to be problematic, their strength is to have provided families and therapists with information about the type, focus, intensity, rate of learning and pace of intervention needed. How will this gap be addressed and replacement processes facilitated? Currently, families are struggling to access assessment for ASD for their children. Also measures used, such as the Vineland may point to need for further assessment (e.g., cognitive assessment for ID).

x. The NDIS does not appear to understand the difference between a screening instrument and an assessment tool. The IA proposes the use of an assessment framework without an adequate rationale for and defined framework for the assessment overall.

Using IAs for young children above 1 years of age
The proposal to use IAs for young children above 1 years of age is inadequate. The proposed age of 1 year for List D access is also inadequate and too limiting. The APS proposes that children should have automatic access to the NDIS if they are under 3 years of age and have a diagnosed condition. Also, infants without diagnoses should also have access to the NDIS at whatever age their needs are identified including under one year of age. How is this proposed?

Using the specified tools
The APS offers the following responses:

a. Ages and Stages Questionnaire (ASQ-3) OR Ages and Stages Questionnaire - Talking About Raising Aboriginal Kids (ASQ-TRAK). This is the best tool available to measure developmental level but is far from a perfect instrument.

b. PEDI-CAT (Speedy) OR PEDI-CAT ASD (Speedy). The proposal to use this tool ignores the very substantial problems professionals have repeatedly outlined to the NDIS about the tool.

c. Vineland-3 Comprehensive (Interview Form). A good instrument, but designed to suggest the skills the child does not have, rather than to address the important issue of describing all the adaptive skills the child has learned and how these might be used in future, later life.

d. Young Children's Participation and Environment Measure (YC-PEM) for children under 6 years. A good early instrument addressing this area but completely inadequate for describing participation, opportunities, experiences and environments sufficiently to be comprehensive and suitable for the purpose proposed.

e. Participation and Environment Measure - Children and Youth (PEM-CY) for children 5+ years. See response to d immediately above.

There are research projects needed to address these questions. The whole assessment process should be planned to commence at a suitable future time when appropriate structures and instruments have been developed. This might possibly be as long as 5-10 years hence.

13. What mechanisms do you think could help achieve this?
Publicly available data on services compliance with best practice standards, accountability and reporting mandatory.
14. Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?
An authority specifically created for this purpose, such as a National Quality Standards Authority. If the NDIA wishes to keep this in house”, the APS believes that the NDIA Quality and Safeguards Commission is the logical gatekeeper of this responsibility. It also believes it would be apt for a reference group of peak bodies, including the APS, to be appointed to support the Commission in this task.

15. What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?

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<th>Ideas</th>
<th>Benefits</th>
<th>Concerns</th>
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<td>Provide greater information to families about the benefits of using providers registered by the NDIS Commission.</td>
<td>This only works if registration comes with practice standards. Registration is so expensive of service time at present that it is out of the reach of many small services and those who deliver few NDIS services.</td>
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<td>Establish an industry-led 'best practice accreditation system'.</td>
<td>Greatly needed to ensure families understand when they are likely to be accessing better standard services.</td>
<td>Needs to be accompanied by accreditation system and accountability requirements. Industry-led has been inadequate in the past. What would make this different?</td>
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<td>Establish a 'quality feedback / rating system'.</td>
<td>Would be valued by some families.</td>
<td>Unlikely to adequately reflect all the key elements of ECEI service delivery.</td>
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<td>Make registration with the NDIS Commission mandatory for all providers operating in the EC space.</td>
<td>Really important.</td>
<td>Needs to be simpler and cheaper for services. Could reduce the number of providers, if not cheaper and simpler to achieve.</td>
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<td>Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.</td>
<td>Quality assurance. Potentially increases the children’s exposure to better quality services. Reduces exposure to predatory practices.</td>
<td>Potentially reduces the flexibility of services available for provision. Reduces families’ choice and control.</td>
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The APS again expresses its appreciation of the opportunity to submit to this consultation. It remains concerned that various changes outlined in this consultation exist as a fait accompli (e.g., removal of access lists). It perceives that there is much work to do on the IA process before the best model is able to be implemented.

As per previous submissions to NDIA consultations and various inquiries into the NDIS, the APS actively seeks the opportunity to engage in meaningful (i.e., not faux consultation where
information is placed the website or in a consumer newsletter and post hoc discussion is sought), top-down and bottom-up ongoing consultation processes.

Also, as in the past, the APS emphasises its willingness to partner with the NDIS/NDIS around education, training and research for providers and other stakeholders requiring information around psychological matters pertinent to the NDIS. That research would do well to focus on everyday needs such as a need for monitoring of outcomes, as well as service guidelines, standards and accountability and ongoing higher level research questions; for example around implementing and translating EBP, guideline development and workforce identification and development.