

National Disability Insurance Agency GPO Box 700 Canberra ACT 2601

23 February 2021

To whom it may concern

Re: Supporting young children and their families early, to reach their full potential

<u>Exercise & Sports Science Australia</u> (ESSA) is the peak professional association for exercise and sports professionals in Australia, representing over 9,000 members, including university qualified Accredited Exercise Scientists (AESs) and Accredited Exercise Physiologists (AEPs).

AEPs are university qualified allied health professionals who provide clinical exercise interventions aimed at primary and secondary prevention; managing sub-acute and chronic disease or injury; and assist in restoring and maintaining optimal physical function, independence, health, and wellness. AEPs typically register under the 'Exercise Physiology and Personal Well Being Activities' and 'Therapeutic Supports' registration groups and deliver supports in both the 'Improved Health and Wellbeing' and 'Improved Daily Living' categories of participant plans.

AES apply the science of exercise to design and deliver physical activity and exercise-based interventions to improve health, fitness, well-being, performance and assist in the prevention of injury and chronic conditions. They coach and motivate to promote self-management of physical activity, exercise and healthy lifestyles and work in the National Disability Insurance Scheme (NDIS) as personal trainers and allied health assistants (AHAs), in fitness businesses, for sporting bodies, in corporate health and as AHAs for exercise physiologists and other allied health professionals. AESs are three-year trained university professionals.

ESSA's response to the Supporting young children and their families early, to reach their full potential consultation has been prepared in consultation with ESSA members and responds to the topics within the consultation paper most relevant to the experiences of AEPs and AESs engaging with participants under the National Disability Insurance Scheme (NDIS).

Independent Assessments for young children

The National Disability Insurance Agency (NDIA) plan to commission Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce

ESSA members are not supportive of the NDIA's plan to commission Early Childhood partners to administer independent assessments to young children. ESSA notes that Early Childhood partners are appointed by the NDIA and, therefore, are not independent of the NDIA. Additionally, AEPs who have analysed the proposed assessment tools have confirmed that there is a certain level of clinical competency required to complete the assessment forms and accurately assess functional capacity. It is not clear what skills and qualifications are required of Early Childhood partners. ESSA members are confident that the child's existing allied health professional is best placed to administer independent assessments to children, based on the clinical nature of the assessments and history with the child.

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ESSA also notes the importance of establishing trust and confidence when working with children, particularly for some types of disability. An example of this may include a child with autism spectrum disorder (ASD). Diagnosis assessment of ASD typically takes time and collaboration with a clinical psychologist, paediatrician, and a range of allied health professionals, including exercise physiologists, speech pathologists and occupational therapists. This allied health team supports the child, builds rapport with both the child and family, and observes/supports the child at home and in other settings, such as pre-school. When this family seek support from the NDIA, this multidisciplinary team will be able to provide strong insight into the child's needs, current behaviours in different environments and recommendations for ongoing support. Exclusion of this vital information would be to the detriment of the child and his/her family.

Additionally, ESSA members have outlined that participants and their families already have a major burden of attending multiple therapies to demonstrate the impact that the child's condition has on their functional capacity. This process is time consuming and emotional for participants and their families. The use of familiar practitioners who already know the participant and their condition for assessment to access the NDIS, or for ongoing assessment in the case of reviews, would reduce this burden. This is a current process for NDIS reviews and has worked well for participants accessing AEP services. AEPs working with NDIS participants suggest that utilising existing allied health professional working with children will alleviate stress when accessing the scheme so that the participant can focus on addressing their needs, which will likely result in better participant health outcomes and overall service experience within the scheme.

ESSA understands that Early Childhood partners have been selected by the Agency as they are experienced in providing early childhood intervention. However, ESSA suggests that existing service providers, including AEPs, are better placed to conduct independent assessments. This is because they possess the clinical competency required to assess functional capacity, and they have built a relationship and therapy history with the child.

ESSA acknowledges that the NDIA has expressed concern about existing healthcare professionals exhibiting sympathy bias when conducting assessments for their clients to access the NDIS. ESSA reiterates that both AEPs and AES are required to operate under regulated codes of conduct in order to obtain accreditation with ESSA. For example, both the exercise physiology profession and the exercise science profession practice under ESSA's Code of Professional Conduct and Ethical Practice, which outlines that exercise professionals must practice with honesty, integrity and transparency. Therefore, this requirement goes some way to addressing the issue of sympathy bias.

Recommendation 1: That independent assessments for children accessing the Early Childhood Early Intervention (ECEI) program be administered by the child's existing allied health professional.

The NDIA plan to use the following tools (as outlined in an appendix to the previously published Independent Assessment Tools Paper):

- Ages and Stages Questionnaire (ASQ-3) OR Ages and Stages Questionnaire -Talking About Raising Aboriginal Kids (ASQ-TRAK)
- PEDI-CAT (Speedy) OR PEDI-CAT ASD (Speedy)
- Vineland-3 Comprehensive (Interview Form)
- Young Children's Participation and Environment Measure (YC-PEM) for children under 6 vears
- Participation and Environment Measure Children and Youth (PEMCY) for children 5+ years

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ESSA members and other allied health professionals have identified numerous gaps in the proposed assessment tools to be used for independent assessments. If these gaps are not addressed, the independent assessment cannot provide an accurate depiction of a participant's functional capacity. It has been suggested by allied health professionals that the proposed assessment tools do not sufficiently focus on the child's critical environment and family circumstance. Understanding of these factors are vital in determining the child's needs and appropriate supports.

Further, ESSA is concerned that use of assessment tools alone is insufficient in obtaining thorough information relating to functional capacity. AEPs rely on observations and self-reporting of the participant, and those close to them, to be able to form a holistic view of their capacity and subsequent support needs. The independent assessment design does not allow for this and as such, relevant, pertinent information will be missed leading to insufficient funding for early intervention supports.

Recommendation 2: That the NDIA develop more appropriate assessment tools for children accessing the ECEI program in collaboration with relevant stakeholders, including allied health professional associations, to develop more appropriate assessment tools prior to implementation of independent assessments in this cohort.

Early Childhood Intervention best practice mechanisms

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

- Make registration with the NDIS Commission mandatory for all providers operating in the EC space.
- Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.

ESSA does not support the suggestion of mandated registration of ECEI providers or requiring self and plan-managed participants to only use registered providers.

ESSA members report that NDIS registration is a costly and onerous process particularly for small businesses and providers in rural and remote communities. It is difficult for many small businesses to justify the administration time required and the expense, particularly when their business model services a relatively small number of NDIA participants. ESSA is concerned that mandating registration for ECEI providers will result in reduced ECEI workforce and that requiring self and plan-managed participants to only use registered providers will significantly impact on consumer choice and control.

Further, it has been noted by the NDIA and allied health professional organisations that registration with the NDIS Quality and Safeguards Commission does not equate to providers adhering to best practice, as there is no consistent position of what constitutes best practice in the ECEI systemⁱ.

Recommendation 3: That the NDIA do not require ECEI providers to register with the NDIS Quality and Safeguard Commission, nor require self and plan-managed participants to use only registered providers. Rather that the NDIA focus on developing ECEI best practice Standards in collaboration with relevant stakeholders, including allied health professional associations.

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Consumer guidance material

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.

AND

NDIA 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.

Allied health organisations, including ESSA, have identified the need to educate ECEI participants' families on the range of services available to them and suggest that the NDIA develop a consumer guide to provide such information. A guide would be a useful tool for families to review prior to planning meetings.

ESSA members also suggest that guidance material should be provided to families to explain how to write goals and determine which services are best placed to help them meet their goals. This is especially important given AEPs have reported that there are discrepancies in the funding allocated for therapy based purely on the terminology used in the development and justification of goals.

Such guidance material may empower families to exercise informed choice and control in the pursuit of their goals and the planning and delivery of their supports.

Recommendation 4: That the NDIA develop a consumer resource, in consultation with organisations that provide services under the NDIS, including AEPs, to provide to all ECEI participants' families to review prior to their planning meetings.

Ensuring appropriate planning and budgeting for effective Early Intervention

NDIA Recommendation 3: Develop and publish new Early Childhood-specific Operating Guidelines – so our decision-making processes and best practice evidence are transparent and implemented consistently by partners and NDIS planners.

AND

NDIA Recommendation 16: Increase Early Childhood partner capacity and flexibility to tailor the level of support provided to families to implement a child's plan and more quickly connect to the right supports and services.

ESSA members have described situations where children have not had adequate funding allocated to exercise physiology interventions. An AEP gave an example of a client with autism spectrum disorder (ASD) aged 6 who was allocated only \$2000 for exercise physiology, which was grossly insufficient for consistent service delivery. As a result, the child only received a finite number of sessions which ceased when funds were exhausted, and the child was not able to resume exercise physiology intervention until after their next planning meeting. Exercise physiology is known to have positive outcomes for children with ASD, including improving fine and gross motor skills, social behaviour, communication, and sensory skills ii-vii. However, When the AEP was able to resume working with the

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child, it was as if they were starting the program over again, despite the positive outcomes seen after the previous round of exercise intervention.

ESSA members have observed that, for the greatest outcomes, children require consistent support service delivery. This is likely due to the provider's ability to maintain rapport with the child and establish and maintain routine. Consistency in ECEI participant support is heavily dependent on allocation of funding and planning prior to accessing supports, including exercise physiology.

ESSA notes there are advances in disability related research every year and ECEI planners should be subject to ongoing professional development to ensure they stay up to date with best practice and innovative evidence-based interventions for children with a disability.

ESSA strongly recommends that all planners be educated about the role and value of allied health professions available under the ECEI program. ESSA would welcome the opportunity to provide the NDIA with education and resources on the role and value of exercise physiology.

Recommendation 5: The NDIA consider the importance of support service consistency for young children when developing the new Early Childhood-specific Operating Guidelines and the impact that inadequate funding for supports will have on participant outcomes.

Recommendation 6: Ensure NDIA Planners receive ongoing education about the role and value of allied health professions, including AEPs.

Thank you for considering our feedback on the *Supporting young children and their families early, to reach their full potential* consultation. Should you have questions about the contents of this letter please contact Policy and Advocacy Officer.

Yours sincerely

Policy & Advocacy Manager

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¹ National Disability Insurance Agency (NDIA), Early Childhood Early Intervention (ECEI) Implementation Reset – Project Consultation Report November 2020 [Internet]. [place unknown]: National Disability Insurance Agency; 2019 [cited 3 Sep 19]. Available from https://www.ndis.gov.au/media/2892/download

ii Bass, M.M., Duchowny, C.A., & Llabre, M.M. (2009). The effect of therapeutic horseback riding on social functioning in children with autism. *Journal of Autism and Developmental Disorders*, 39(9), 1261-1267. https://doi.org/10.1007/s10803-009-0734-3

Emck, C., Bosscher, R., Wieringen, P.C.V., Doreleijers, T., & Beek, P.J. (2010). Gross motor performance and physical fitness in children with psychiatric disorders. *Developmental Medicine & Child Neurology, 53*(2), 150-155. https://doi.org/10.1111/j.1469-8749.2010.03806.x

Hameury, L., Delavous, P., Teste, B., Leroy, C., Gaboriau, C., & Berthier, A. (2010). Équithérapie et autismeEquine-assisted therapy and autism. *Annales Médico-psychologiques, revue psychiatrique, 168*(9), 655-659. https://doi.org/10.1016/j.amp.2009.12.019

^v Nicholson, H., Kehle, T.J., Bray, M.A., & Heest, J.V. (2010). The effects of antecedent physical activity on the academic engagement of children with autism spectrum disorder. *Psychology in the Schools, 48*(2), 198-213. https://doi.org/10.1002/pits.20537

vi Pan, C.Y., Tsai, C.L., & Chu, C.H. (2009). Fundamental movement skills in children diagnosed with autism spectrum disorders and attention deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders, 39,* 1694. https://doi.org/10.1007/s10803-009-0813-5

vii Pan, C.Y. (2010). Effects of water exercise swimming program on aquatic skills and social behaviours in children with autism spectrum disorders. *Autism*, 14(1), 9-28. https://doi.org/10.1177/1362361309339496