

Exercise & Sports Science Australia Submission

Interventions for children on the autism spectrum

National Disability Insurance Agency

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1.0 About Exercise & Sports Science Australia

Exercise & Sports Science Australia (ESSA) is the peak professional association for exercise and sports professionals in Australia, representing over 8,000 members, including university qualified Accredited Exercise Physiologists (AEPs), Accredited Sports Scientists (ASpSs), Accredited High-Performance Managers (AHPMs) and Accredited Exercise Scientists (AESs).

AEPs are recognised allied health professionals (AHPs), with 4 years of university training and provide clinical exercise interventions aimed at primary and secondary prevention; managing acute, sub-acute and chronic disease or injury; and assist in restoring optimal physical function, health and wellness to people living with disability. Exercise physiology is a recognised and funded profession under compensable schemes such as Medicare Benefit Services (MBS), Department of Veteran Affairs (DVA), the National Disability Insurance Scheme (NDIS), private health insurance, and state and territory-based workers' compensation schemes. AEPs typically register with the NDIS Quality and Safeguards Commission 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.

AESs 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 *Interventions for children on the Autism Spectrum* consultation has been prepared in consultation with ESSA members and responds to the topics most relevant to the experiences of AEPs and AESs engaging with participants under the NDIS. ESSA welcomes the opportunity to respond to this consultation and appear before the National Disability Insurance Agency (NDIA) if invited.

2.0 Summary of Recommendations

Recommendation 1: That the NDIA recognise the evidenced benefits of exercise physiology for children with ASD and support better outcomes by enabling funding for AEP services.

Recommendation 2: That the NDIA ensure Planners receive ongoing education about the role and value of allied health professions in supporting people with disability, including AEPs, and ongoing education about the emerging evidence of therapeutic supports for children with ASD.

Recommendation 3: That the NDIA employ exercise physiology advisors that can educate and provide guidance to NDIS planners.

Recommendation 4: That the NDIA require planners to have qualifications and/or experience in health, human services and support planners to develop a strong understanding of the complex needs associated with particular disabilities, including ASD.

Recommendation 5: That the NDIA does not allow planners to delegate therapeutic supports to support workers, as support workers are not appropriately qualified and experienced; supports delivered in this way cannot be carefully monitored by the allied health professional; and the intervention has heightened risk of causing physical and emotional harm to participants. Any delegation of therapeutic supports to support workers or allied health assistants should only be conducted at the discretion of allied health professionals' clinical judgement.

Recommendation 6: That the NDIA agree to fund multiple supports that help children with ASD progress toward the same goal if requested by participant families, to promote a best practice multidisciplinary approach, and to enable families to determine the most appropriate supports for their child's needs, enhancing choice and control.

Recommendation 7: That the NDIA encourages a multidisciplinary approach to supporting children with ASD by addressing that therapies may overlap when clinically relevant, as directed by allied health reports, in any relevant decision making policy documents, including operational guidelines.

Recommendation 8: That allied health provider recommendations for supports required by children be considered with a greater weighting than independent assessment results, or the indicative funding tables provided in the consultation paper.

Recommendation 9: That the NDIA create a policy document for public publication, indicating how funding will be determined for children with ASD, with a particular emphasis on how allied health professionals' recommendations will be integrated into decision making.

Recommendation 10: That the NDIA develop a consumer resource, in consultation with organisations that provide services under the NDIS, including AEP services, to provide to all participants to review prior to their planning meetings.

Recommendation 11: That, to promote informed participant decision making/choice and control, the NDIA provides education to participants about conflict of interest within support coordination providers that also offer therapeutic/allied health supports. Education should be provided directly to participants that use support coordination services within their plans, and should also be accessible online for participants to review at any time.

3.0 Introduction and Summary of Issues

ESSA would like to highlight the critical role that AEPs can play in supporting children with Autism Spectrum Disorder (ASD). While NDIS planners have typically only allowed exercise physiology supports to be funded for physical conditions, evidence demonstrates that the benefits of exercise therapy are widespread, especially in relation to supporting people living with a disability, including ASD.

ESSA's response to this consultation addresses the following topics:

- AEPs and autism
- reasonable and necessary
- supporting parents and carers to exercise choice and control, and
- conflicts of interest.

4.0 Evidencing how AEP services support someone with ASD

AEPs can support children with ASD to achieve improvements in the areas of:

- motor, manipulative and locomotor skills
- cognitive functioning
- behavioural stereotypy
- aggressive behaviours
- socioemotional functioning
- physical condition and skill related fitness.

A global screening of the relevant literature suggests that clinical exercise is a sensible approach to addressing a variety of problems associated with ASD ¹.

People with ASD typically experience challenges in the domain of motor skills. Limited motor coordination, deficiencies in fine and gross motor functioning ^{2,3}, and repetitive, stereotypical movements, are common in people with ASD. Examples include hand waving when excited or extraordinary [postures](#) in stressful situations ⁴. Additional challenges include maintaining balance and motion planning ⁵.

Physical activity programs have provided evidence as an effective means to prevent problems in the general population, as well as in the ASD population ⁶, such as by reducing BMI in people with severe autism, and improving balance and flexibility ⁷. Further to this, there is evidence of the positive effects that physical activity has on ASD specific behaviours. For example, research has shown that exercise therapy in children with ASD has:

- improved stereotypical behavioural issues ^{7,8,9}
- allowed effective development of manipulative skills, locomotor skills, fitness, muscular strength and endurance ¹⁰
- improved social interaction and communication skills ^{10,11,12,13}
- improved academic engagement ¹⁴, on-task behaviour and performance on simple learning tasks¹⁵
- enhanced sensory skills¹⁶

A caveat to the evidence is that the relationship between exercise and cognition is complex and is moderated by multiple factors such as individual differences ^{15,17}. One such factor that may contribute to reductions in stereotypy is the possibility that the physical stimulation obtained via exercise may be similar to that obtained via stereotypy for some children ¹⁸.

ESSA is concerned that exercise therapy, or supports delivered by AEPs to children with ASD, was excluded from the Autism CRC study commissioned by the NDIA. This is particularly concerning, given the evidence highlighting the multitude of benefits that exercise therapy has on children with ASD, as outlined above. Further, ESSA members from all over Australia have reported that NDIS planners have denied participants funding for exercise physiology supports for children with ASD, with NDIS planners claiming that ASD is not a physical condition and that AEPs can only provide supports for physical conditions. The above information indicates that the advice NDIS planners have provided to participants is not supported by evidence. Furthermore, such erroneous advice is resulting in families' lack of choice and control in relation to the services they have been able to access to assist children in managing their ASD.

Recommendation 1: That the NDIA recognise the evidenced benefits of exercise physiology for children with ASD and support better outcomes by enabling funding for AEP services.

5.0 Reasonable and necessary

4. Building from the Autism CRC research the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1.) Is there anything you would like to add?

5.1 Planner education on allied health supports

ESSA notes that AEP supports align closely with the principles prescribed in the consultation paper. As outlined above, exercise therapy delivered by an AEP has a range of capacity building benefits for children with ASD that are based on a good understanding of ASD, scientifically plausible, and supported by research evidence. AEPs design individualised exercise programs for NDIS participants to support them in achieving their goals. In many cases, AEPs deliver supports in the community, to support participants with ASD to build capacity in real life settings. Additionally, AEP sessions are typically 45-60 minutes, allowing AEPs the opportunity to build rapport and gain a sound understanding of each participant that they work with.

While AEP supports align with the suggested principles for ASD intervention, ESSA is concerned that planning decisions may negatively impact AEP interventions for children with ASD, as planners have previously not been educated on the relevance of AEP for this participant cohort. ESSA members have previously reported claims from planners that AEP supports are only relevant for people with a physical disability, and that ASD is not a physical condition; therefore AEP should not be funded for participants with ASD. As stated above, people with ASD often experience fine and gross motor skill challenges, which indicates that ASD often has physical implications on participants. In addition, various forms of exercise therapy have been proven to provide behavioural, emotional and social benefits for people with ASD, as indicated above.

Given the research around ASD is constantly evolving, NDIA decision makers should be subject to ongoing professional development to ensure they stay up to date with best practice and innovative evidence-based interventions for people with ASD. ESSA would welcome the opportunity to provide the NDIA with education and resources on the role and value of exercise physiology for participants with ASD.

Recommendation 2: That the NDIA ensure Planners receive ongoing education about the role and value of allied health professions in supporting people with disability, including AEPs, and ongoing education about the emerging evidence of therapeutic supports for children with ASD.

Recommendation 3: That the NDIA employ exercise physiology advisors that can educate and provide guidance to NDIS planners.

Recommendation 4: That the NDIA require planners to have qualifications and/or experience in health, human services and support planners to develop a strong understanding of the complex needs associated with particular disabilities, including ASD.

5. Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2.) Is there anything you would like to add?

5.2 Delegation to support workers

ESSA notes that AEP services align closely with the standards prescribed in the consultation paper. AEPs are university qualified allied health professionals that require accreditation with ESSA, and subsequently compliance with ESSA practice standards and Code of Conduct, in order to provide services to NDIS participants. AEP supports can provide significant and lasting benefits to participants in the areas of mobility^{2,3}, cognition, emotional regulation¹⁹ and social participation^{10,11,12,13}. Interventions delivered by AEPs are carefully monitored and known to be safe due to sufficient clinical oversight, i.e. do not cause physical or emotional harm.

ESSA has concerns that when clinical exercise supports are not delivered by an appropriately trained and qualified individual, such as an AEP or AES, exercise physiology supports no longer align with the NDIA proposed standards. This concern is highlighted by NDIS planners delegating AEP/AES therapy to support workers. Delegation of AEP/AES therapy to support workers contradicts at least four of the seven proposed standards for providing supports to children with ASD. These are:

1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals.
4. The intervention is carefully monitored and reviewed on a regular basis.
5. The intervention does not cause significant physical or emotional harm.
7. The intervention is good value for money and time invested.

ESSA acknowledges that in some circumstances, there may be a role for unqualified workers to engage participants in physical activity, but note that there is a significant difference between providing support to engage in physical activity and delivering clinically prescribed exercise programs.

Support workers do not require any qualifications or experience to become employed as a NDIS support worker. As a result, support workers are not able to conduct risk stratification during the execution of the exercise intervention, or adjust the prescription of exercise based on the physical, mental and emotional presentation that is so highly varied day to day in many disability presentations. ESSA members have reported that, in cases where planners have instructed AEP supports to be delegated, only between one hour per quarter and one hour per month has been allocated to an AEP to develop an exercise plan, assess and report on participant progress, as well as provide training on the exercise program to support workers. This raises a number of participant safety and service quality issues that have been observed by AEPs.

1. It is not possible for a support worker to obtain four years of AEP knowledge and training in just one hour of training. Therefore the person delivering the support is not appropriately qualified, experienced, *or* trained. This is further exacerbated when unqualified support workers are expected to be trained in multiple allied health therapies.

2. Even if a support worker *could* rapidly acquire sufficient knowledge to conduct an AEP exercise therapy program safely and effectively, participants do not always receive supports from the same support worker, making it difficult to train a consistent team of support workers to deliver therapy support. When AEPs have been directed to train support workers in exercise therapy, funds allocated have been insufficient to train multiple support workers.
3. Support workers who are trained by AEPs often do not follow through on actively supporting participants to engage in prescribed activities, resulting in participants not achieving or progressing toward their goals, and creating further inconsistencies in support delivery and risk to NDIA investment.
4. Consistency in service delivery is critical for achieving participant outcomes and goals, especially when providing supports to children with ASD, i.e. consistent weekly or fortnightly supports. With constantly changing support workers who may or may not have received AEP training, as alluded to in point 2 above, and the lack of commitment from support workers to follow through on therapy, as in point 3 above, children with ASD lose the consistency in exercise therapy supports that they would otherwise have received with regular AEP supports (or AHA, if clinically appropriate).
5. To enhance adherence and promote engagement in exercise therapy, AEPs must regularly review and change the program. This is not possible with only one AEP session per month or quarter and directly contradicts standard 4, requiring regular review of therapy.
6. If AEPs are not present during the delivery of the exercise program, they are not able to carefully monitor the child's response to the intervention, as required by standard 4, and will not be able to adjust therapy when clinically appropriate. AEP's inability to supervise and amend therapy during the delivery of the intervention poses risks to participants' physical and emotional wellbeing, also conflicting with standard 5, requiring interventions to not cause significant harm.

ESSA has also been made aware that some of the disability organisations employing support workers share these concerns with AEPs, reporting that some have been known to restrict their employees from engaging in the delivery of therapy supports, citing duty of care concerns.

Recommendation 5: That the NDIA does not allow planners to delegate therapeutic supports to support workers, as support workers are not appropriately qualified and experienced; supports delivered in this way cannot be carefully monitored by the allied health professional; and the intervention has heightened risk of causing physical and emotional harm to participants. Any delegation of therapeutic supports to support workers or allied health assistants should only be conducted at the discretion of allied health professionals' clinical judgement.

7. Do you have any other feedback about how we explain "reasonable and necessary?"

ESSA is concerned about the NDIA's list of "situations where we will not fund an early intervention support or require further evidence." ESSA suggests that prescribing a list of situations where supports will not be funded, contradicts the NDIA's acknowledgement that different supports will be reasonable and necessary for different people; limits participant choice and control; and ignores evidence based approaches to care.

5.3 Engaging multiple providers for overlapping supports

ESSA would like to highlight to the NDIA that, in most cases, a multidisciplinary approach to care is considered best practice. In the case of allied health supports engaged for the purpose of achieving the same participant goals, allied health professionals aim to provide services that complement each other, as seen in Case study A, below.

Case Study A

A 19 year old female with ASD has been working with an AEP, an occupational therapist and a dietitian for over 3 years. She sees each service monthly to work towards predominantly achieving the same goal of improving her ability to climb stairs. All three therapies have contributed to her progress toward this goal by using their different clinical techniques.

1. Exercise therapy has improved cardiovascular fitness and endurance, increased coordination with proprioceptive and specific training for stair climbing
2. Diet intervention has reduced sensory stimulation from eating protein dense foods
3. Occupational therapy has assisted with grip and sensation of holding on to stair rails when required.

Further, the example given in the consultation paper is, arguably, necessary to help the family determine what approach will best suit their child to achieve their goals, as an individual speech pathologist is likely to utilise a different strategy to an early intervention team to increase the range of foods in a child's diet.

Case study B, below, describes an example seen by one of our members where a participant was denied access to multiple supports, as the NDIA was concerned that these supports were overlapping. This case study highlights the effects of not having access to overlapping supports (e.g. AEP, OT and physiotherapy). While the child was able to progress toward a number of their goals, she saw a decline in fine motor control that could have been addressed if overlapping supports were considered. All therapies are equally important to ensure different areas of a child's development are covered and should be considered together, when appropriate.

Case Study B

An 8 year old female with ASD level ½, engaged in 1 x 60 minute weekly sessions with Exercise Physiologist. Her goals were surrounding strength, balance, coordination and ball skills.

This child did not have access to Occupational Therapy sessions through NDIS funding as NDIA denied funding due to 'overlapping support' between AEP & OT.

This child made great improvements in their 'aiming & catching' and balance assessment scores. However, the child's manual dexterity skills (which is a focus of OT therapy supports) declined at subsequent assessment, resulting in the child falling further behind their peers in certain activities.

Recommendation 6: That the NDIA agree to fund multiple supports that help children with ASD progress toward the same goal if requested by participant families, to promote a best practice multidisciplinary approach, and to enable families to determine the most appropriate supports for their child's needs, enhancing choice and control.

Recommendation 7: That the NDIA encourages a multidisciplinary approach to supporting children with ASD by addressing that therapies may overlap when clinically relevant, as directed by allied health reports, in any relevant decision making policy documents, including operational guidelines.

5.4 NDIA disagreeing with parental requests or provider recommendations

ESSA is concerned that the NDIA have stated that there will be instances where it will decline parental request and/or provider recommendations for intensive capacity building supports (page 19 of consultation paper). This approach limits participant choice and control and ignores the clinical judgement of university trained and qualified allied health professionals. The consultation paper also claims that this may occur where recommendations do not consider the principle relating to plans, or the reasonable and necessary criteria.

However, ESSA has been advised of multiple planners across the nation refusing to allocate funding for supports recommended by AEPs and requested by participants' families, even after the provision of extensive evidence and progress reports outlining the positive impact that therapy is providing to the participant.

Case study C

A 9 year old male with ASD presented with communication shut-down, emotional regulation issues, lack of motivation and below average fine and gross motor skills. Short term goals include developing communication and social skills so he can build and maintain friendships and relationships with others, and to recognise and understand emotions, learn strategies to self-regulate his emotions. Medium to long term goals include improve fine and gross motor skills. During the 12-month plan period, as a result of weekly AEP intervention the client had improved confidence in gym environment; increased engagement and communication with AEP with little to no signs of communication shut down; increased exercise tolerance; increased time engaging within a community environment; improved gross motor skills through use of interactive fitness technology; required little to no parental support and supervision during therapy compared to last plan period; and improved movement milestone developed. The participant's AEP recommended in progress report to continue to receive ongoing support to progress further towards his goals and recommended that a future goal be to increase his exercise tolerance from 45 minutes to 1 hour per week.

However, at plan review, all AEP funding was removed and only funding for Occupational Therapy and psychology was provided (costed out for specific number of sessions with each therapy), despite the family's preference for him to continue seeing his AEP. The planner indicated that funding for AEP was removed, as the child would now be able to get the physical activity they needed from school. After a few months of engaging with the new plan, the clients' parents contacted his AEP to provide feedback that the client is disengaging from school due to reduced confidence to participate in social and sporting activities as he did not have the coordination or social skills to participate. He is also not responding to Occupational Therapy or psychology therapy and does not have the rapport with new therapists as he did with his AEP.

Further, by refusing to accept a participant request for support, if reasonable and necessary, the NDIA are directly convening the principle relating to plans prescribed in section 31(g), which states that the participant's plan *"be underpinned by the right of the participant to exercise choice and control over his or her life."*

9. Do you have any other feedback about how we explain the indicative levels of funded supports?

AND

10. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?

5.4 Funding during transition periods

The consultation paper indicates that NDIS funded supports will decrease when a child enters the education system, as schooling will support capacity building and encourage social inclusion for children with ASD. However, ESSA members have observed that, typically, children with ASD require additional funding to support this significant life transition. There are many challenges which make the transition to school much harder than typically developing children. Often children with ASD already struggle with changes to routine, new environments, new teachers and new peers. It is generally made even more difficult when these kids are already typically behind their peers in most areas of development, including social, mental and physical areas of development. Without continued therapy support, children often fall further behind their peers, which can also result in further disengagement with the education system due to reduced self-confidence, as seen in case study C.

One of our members described an example of a participant they had been working with. The participant was an 8 year old male with ASD (level 2) who had changed schools twice and swapped classes multiple times due to many difficulties at school (e.g. troubles with other children, limited skills of teachers or support staff, unsuitable school environments etc.). Due to continuity in therapeutic support from his AEP during this transitional period, the child has settled at home; is no longer constantly anxious in attending school; and engages well with other therapy each week. ESSA members advocate that simply attending school will not provide children with ASD the support they need.

As outlined in Case Study C, a change or reduction in supports during this time may negatively impact the participant, even after a reasonable period of time post transition into school. This highlights the importance of considering provider recommendations prior to determining funding reduction. Providers, in particular allied health providers, have a far better understanding of a child's needs, due to the consistent engagement with the child and their family, than an NDIS planner, who does not necessarily engage with the child at all.

Recommendation 8: That allied health provider recommendations for supports required by children be considered with a greater weighting than independent assessment results, or the indicative funding tables provided in the consultation paper.

Recommendation 9: That the NDIA create a policy document for public publication, indicating how funding will be determined for children with ASD, with a particular emphasis on how allied health professionals' recommendations will be integrated into decision making.

6.0 Supporting parents and carers to exercise choice and control

12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

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

ESSA members have also suggested that guidance material should be provided to the participant 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 participants to exercise informed choice and control in the pursuit of their goals and the planning and delivery of their supports.

Recommendation 10: That the NDIA develop a consumer resource, in consultation with organisations that provide services under the NDIS, including AEP services, to provide to all participants to review prior to their planning meetings.

Further to education for consumers, planners also require ongoing education and training on the supports available, and when they are appropriate to recommend to participants and their families for consideration, to better support participant decision making, as indicated in [section 5.1](#) of this submission.

ESSA members have reported regular instances of conflict of interest in relation to support coordination, where support coordination service providers also offer inhouse allied health and other therapeutic supports. Inhouse referring of support coordinators to their own therapeutic and allied health services reduces capacity for participants to exercise choice and control, as they have not been made aware of alternative options for supports. See [section 7.0](#) for further details on this issue.

7.0 Conflicts of interest

13. This question relates to Section 8.3 of this paper: “Addressing conflicts of interest.” How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

ESSA members have reported cases where support coordinators arrange inhouse services and prioritise referral to these internal supports, which results in limiting participant choice and control when selecting their support providers. The NDIS commission’s [Code of Conduct](#) requires providers to declare to a participant when a conflict of interest exists (e.g. a support coordinator must tell the participant that they are referring them to an inhouse service), but it does not encourage the support coordinator or participant to search for additional options for their supports.

ESSA suggests that the NDIA provide participants with additional accessible education to ensure they can optimise their choice and control when they use support coordination services. Education should include advice to participants that support coordinators should provide multiple quotes when seeking appropriate services; educate participants on the potential for conflict of interest when using support coordinators, including “Questions to ask your support coordinator”; and information on how a conflict of interest from support coordination providers can limit the supports received by the participant.

Recommendation 11: That, to promote informed participant decision making/choice and control, the NDIA provide education to participants about conflict of interest within support coordination providers that also

offer therapeutic/allied health supports. Education should be provided directly to participants that use support coordination services within their plans, and should also be accessible online for participants to review at any time.

8.0 Contact

Thank you for the opportunity to provide feedback to the *Interventions for Children on the Autism Spectrum* consultation. Please contact our Policy and Advocacy Team on 07 3171 3335 for further detail or any questions regarding the content of this submission.

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