Australian Physiotherapy Association **Submission**



National Disability Insurance Scheme Autism Consultation

Submission by the
Australian Physiotherapy Association

May 2021

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Executive Summary

The Australian Physiotherapy Association (APA) welcomes the opportunity to provide policy input to the National Disability Insurance Agency's (NDIA) guidance for reasonable and necessary funding of early interventions for children on the autism spectrum.

The APA supports the core principles as outlined in the 'Interventions for children on the autism spectrum' paper to support a framework to guide evidence-based practice with emphasis on capacity building and inclusion towards a whole-of-life approach to autism.

Physiotherapists are trusted allied health professionals who use a family and person-centred, goal directed model of care across the lifespan. Providing intervention to individuals diagnosed with autism spectrum disorder (ASD) requires the physiotherapist to develop rapport and trust with the child and family/carers.

Physiotherapists provide specialised early intervention services and supports fostering best practice and inclusive interventions to best target the child's (developmental) delays. Children with ASD, particularly levels 2 and 3, typically require multiple visits with an allied health member before they will trust and work with the physiotherapist. Consequently, it typically takes more than one visit to complete an assessment in order to guide an intervention. Notably, we highlight that the proposed *Independent Assessment Model* is inconsistent with this principle, where a young person on the autism spectrum will have to undergo periodic assessment by a complete stranger.

The APA supports the NDIA's core aim to enable supports to build the child and family capacity in daily activities and everyday settings. However, we are concerned that the funding levels for autism early intervention, as proposed in the consultation draft, place unrealistic expectations on families to implement therapy at home.

Having levels of funding that do not align with the levels of ASD diagnosis is confusing to participants, their families, carers and providers. Using a different terminology, such as band of funding, or altering the levels to match with ASD levels, would make it clearer and easier to understand.

In ensuring the intervention is adapted to need, a focus on targeted responses through a multidisciplinary approach enabling different therapies, or therapy combinations at different stages of development, is required. Enabling flexibility in policy design to apply the required treatment factors – type, duration and intensity – is also essential.

Evidence for physiotherapy interventions for children with autism spectrum disorders is based on programs of higher intensity and duration than the NDIS is proposing (Steinbrenner et al, 2020). Underfunding interventions is similar to taking half a course of antibiotics, expecting a full cure and then being surprised when it costs more overall to treat the consequent complications.

Further, in realising the NDIA's core policy aim, a clear risk lies in the omission to gross motor skills or mobility within these examples. While we note physical development is captured, this is too narrow in approach. Mobility needs to be highlighted and prioritised in earlier responses, as movement difficulties are highly prevalent in ASD and impact significantly their ability to participate in their community with both peers and their families. In determining funding levels, we offer further advice at Q9 of our submission and in Appendix 1, and would welcome an opportunity to brief the Agency further on these requirements.

The APA supports the need to promote evidence-based practice within the NDIS and support families to be in a position to make informed decisions on the interventions they engage in, however the level of funding must be reflective of the needs of the child and the family and must have a level of flexibility to change at times of need through the lifespan.



Introduction

Physiotherapy is a highly regulated discipline with specialist knowledge, skills and training in understanding how people move and learn to move, and the development of movement, specifically, as these relate to the health, well-being and quality of life of people of all ages. Physiotherapists are trained in the biomechanics of movement, combining knowledge of physics, physiology and anatomy to analyse movement and determine movement difficulties (Young & Muller, 2014). Physiotherapists analyse an individual's quality of movement, identify motor impairment, and investigate the interrelationship between movement and other neurological and physiological factors such as sensory perception and pain.

Sub speciality focus

Paediatric physiotherapy, as a sub specialty of physiotherapy, focuses on the development of children and the relationship of movement to long term quality of life outcomes (Baque, Jones, & Bialocerkowski, 2020). Physiotherapists working with children assess challenges in movement and development of movement in the areas of gross motor skills, fine motor skills, motor planning, movement awareness (vestibular function), movement perception (proprioception), and sensory perception, to determine the relationship between dysfunction and performance of movement activities performed as part of daily life such as sitting, standing, dressing, walking, running, and playing (Baque, Jones, & Bialocerkowski, 2020).

While autism spectrum disorder (ASD) is defined by core deficits in social communication, and the presence of restricted and repetitive behaviours, in the Diagnostic Manual of Mental Disorders Fifth Edition (DSM-5) some motor deficits are acknowledged, for example, odd gait and clumsiness. (American Psychiatric Association, 2013). However, over the last 20 years, evidence increasingly shows a heterogeneous range of atypical motor function, including motor delays, deficits, and motor planning challenges, in many children and adolescents with ASD (Hudry, Chetcuti, & Hocking, 2020).

In a recent American study, 87% of children with ASD, aged between five and 15 years, were found to be at risk of movement difficulties, with these difficulties persisting into adolescence (Bhat, 2020). Relative to typically developing peers, the risk of movement difficulties is reportedly 22% greater in children with autism (Bhat, 2020). A recent West Australian study examining motor difficulties of children with ASD, assessed at time of diagnosis (from 2.8 to 6 years), found that clinically significant motor difficulties were as prevalent (35.4%) as intellectual impairment (37.7%) (Licari, et al., 2020).

Despite this prevalence, this research identified that motor difficulties were poorly recognised, that is, in only 1.34% of children, by diagnosticians including paediatricians, psychiatrists, psychologists and speech language pathologists (Licari, et al., 2020).

By contrast, physiotherapists working with young children identify movement difficulties, often before children are diagnosed or identified at risk of ASD (Lim, et al., 2021). A survey of Queensland physiotherapists in 2011 (prior to NDIS and other funding arrangements enabling physiotherapy intervention for children with ASD) found that considerable physiotherapy services were provided to children with ASD, with a range of movement difficulties identified in children with ASD aged from one to 18-years (Eskelinen, et al., 2011).

With limited clinical understanding of motor difficulties in children with ASD, it is difficult to determine the impact of these and implications for interventions (Hudry, Chetcuti, & Hocking, 2020). Movement difficulties are likely to interact with the social, cognitive, restricted, repetitive and sensory behaviours characteristic of autism. For example, movement difficulties may exacerbate these behaviours, may impact on the clinical assessment of core autism characteristics, and may impact on the effectiveness of interventions, although this is as yet unclear (LeBarton & Landa, 2019). Movement difficulties may impact on a child's academic and physical performance, social relationships, independence with self-



care, and community participation, further highlighting the need to fully understand the extent of movement difficulties in children with autism (Case & Yun, 2019).

The recent Autism Cooperative Research Centre (CRC) report provides a scientific review of non-pharmacological interventions for children with ASD (Whitehouse, et al., 2020). This review excluded studies which focused solely on exercise, however, it included studies of interventions with a positive effect on motor outcomes, including a systematic review which included 20 movement interventions from 18 studies, including 11 with fundamental movement skills, three with physical activity, and two with equine therapy (Case & Yun, 2019). Of note, these included interventions, often prescribed by physiotherapists, were found to be effective. Another recent systematic review of 13 studies found that motor-based interventions likely led to an increase in language skills (Odeh, Martell, Griffin, Johnson, & Gladfelter, 2020).

Other interventions found to be effective in the Autism CRC report, such as: naturalistic developmental and behavioural interventions (cueing, prompting, modelling, shaping and reinforcing required movement behaviours, child led interactions and imitation), parent mediated interventions and sensory intervention strategies (combined with motor outcomes) are often strategies utilised by physiotherapists to develop gross and fine motor skills in children with ASD (Whitehouse, et al., 2020).

While parent mediated strategies are effective, this requires access to specialist knowledge and experience of physiotherapists, as part of a multidisciplinary team, to enable families to understand the most effective approaches to be used with their child's motor skills and to support the ability to implement interventions to build capacity and increase participation. Further, the access to therapy in short blocks as suggested reduces the ability to build a routine, rapport and therapeutic alliance with a young person with ASD and their families, to enable goal directed therapy to be implemented.

With the complexity and heterogeneity of ASD, parents seek the support of many disciplines to understand and develop the most effective strategies for their child with ASD. Instead of a single discipline providing support to a child with ASD and their family, each member of a multidisciplinary team supports families to have a greater understanding of the child from their specialised knowledge and skills, for example, occupational therapist's knowledge of sensory regulation, emotional regulation, and the development of play skills; the speech language pathologist's knowledge of language, communication, and social skills, and the physiotherapist's knowledge of movement, motor planning, movement awareness and motor development.

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Submission questions

Part 1 | Promoting best practice

- Q1. Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?
 - √ NDIS website
 - √ NDIS Operational guidelines
 - ✓ Participant decision making guides
 - √ My usual NDIS or NDIS partner contact
 - ✓ Autism organisations or peak bodies

In addition to information sources outlined above, there are a number of additional source locations at the discipline level.

Physiotherapists

Currently physiotherapists choose best practice for children with ASD through a combination of:

- Undergraduate professional degree
- Post graduate masters' courses
- International courses
- Professional Development (PD) from our professional body and private PD providers
- Best research evidence from academic journals, databases and texts
- Their own clinical expertise
- The clinical expertise of others, accessed via supervision and mentoring with others, multidisciplinary collaboration and key publications
- The values and preferences of each child, their family, and caregivers

In the future, physiotherapists may use NDIS operational guidelines if they are updated to be directly relevant to interventions for children with ASD.

Physiotherapists working with children with ASD

Physiotherapists working with children with ASD note these children's families and caregivers access information through:

- Their NDIS partners
- ASD organisations and peak bodies such as Aspect, Autism CRC
- Autism consumer groups
- Online forums with other families and caregivers
- Their service providers

In the future families and caregivers may use the NDIS website and participant decision making guides if they are directly relevant to interventions for children with ASD.

Q2. Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?

In addition to the sources already outlined in Q1 above, guides on best practice interventions can also be located on the following websites:

- 1. Information on the NDIS website, printed participant decision making guides, with:
 - 4 core principles from the CRC narrative review



- 7 principles from question 4 of this submission
- 7 standards from question 5 of this submission
- Questions to ask service providers and what to do next
- 2. Australian Physiotherapy Association website:

Has information on subjects relevant to Autism such as Toe Walking, Gross Motor Development and Gait Assessment.

Reference: https://choose.physio

- 3. International organisations with information on evidence-based physiotherapy/physical therapy interventions for children with ASD:
 - "Physical therapy guide to autism spectrum disorder".
 - ChoosePT by the American Physical Therapy Association. Reference: https://www.choosept.com/symptomsconditionsdetail/physical-therapy- guide-to-autism-spectrum-disorder
- 4. International organisations with information on other evidence-based interventions for children with ASD:
 - "Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health" National Health Service, UK

Reference: https://apcp.csp.org.uk/system/files/service-model-2015.pdf

- 5. Australian state health websites:
 - "Referral guidelines for autism spectrum disorder" Reference (QLD example):https://www.childrens.health.gld.gov.au/referral-guidelineautism-spectrum-disorder/
- 6. Australian disability advocacy services, for general information on evidence-based principles and advocacy for best practice such as:
 - Resources, Australian Federation of Disability Organisations Reference: https://www.afdo.org.au/resource-disability-advocacy-organisations/
- Q3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. How can we help families to find and connect with other supports outside of NDIS?

The APA suggests that the following resources would be useful to connect families to broader supports.

NDIS website

Develop a directory or an information resource page across the spectrum of supports. Include names of services, service types, and primary contact details. This would be used by participants, families, caregivers, planners, local area coordinators, support coordinators, and service providers including physiotherapists. It would need to be updated regularly.

Smart device app

Develop a directory across the spectrum of supports. Include names of services, service types, and primary contact details. This would be used by participants, families, caregivers, planners, local area coordinators, support



coordinators, and service providers including physiotherapists. It would need to be updated regularly.

Information supports

Train NDIS call centre staff in how to navigate a directory across the spectrum of supports (website and/or app).

Make information about other supports available to NDIS Support Coordinators.

Develop and pilot a peer-to-peer participant/family/caregiver information exchange program or online forum.

Apps

Jooay app: "Jooay is a free app that helps children with disabilities and their families to locate leisure opportunities that are: close to where they are, accessible, suit their needs and abilities, match their preferences, can help them develop and participate in society. Jooay is also a community, to help parents, rehabilitation professionals, educators and community to connect, exchange, and learn from each other". Jooay is available in Australia (website: https://jooay.com/).

Part 2 | Reasonable and necessary

Q4. 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?

While these principles appear fair and have the potential to promote evidence-based, effective treatments that meet the needs of young children on the autism spectrum, we are concerned that they may be difficult to assess against, monitor and/or regulate. We would like to see more detail on how the NDIS plans to identify interventions that do (and do not) adhere to these seven key principles, and how it will act on this information.

Understanding the process and criteria for evaluation is particularly important for the principles that may be more subjective than others. For example, in principle 2, "The people who deliver the intervention know the person well and respect their feelings and views" could be harder to evaluate than "Research evidence shows the intervention can work for people on the autism spectrum" (principle 5) which can be addressed with a literature search.

Physiotherapy interventions for children on the autism spectrum adhere to the seven key early intervention best practice principles identified by the NDIS. How the profession meets these expectations is outlined further below against each of the seven principles.

1. The intervention is based on a good understanding of autism:

Paediatric curriculum within universities in Australia embrace the topic of ASD and equip students with graduate capacity to support clients with ASD. Physiotherapists have provided intervention to children with ASD for some time now. Through mentoring, professional development and post-graduate opportunities, physiotherapists working in Australia extend their skills and understanding of autism and provide safe and effective intervention to children with ASD.



- 2. The people who deliver the intervention know the person well and respect their feelings and views, and,
- 3. The intervention is adapted to the needs of the person receiving it:

Physiotherapists are trusted allied health professionals who use a family and person-centred, goal directed model of care across the lifespan. As a core feature of family-centred practice, physiotherapists respect the views and feelings of children on the autism spectrum and their families, and incorporate their individual needs and preferences when collaborating with families on treatment decisions.

Providing intervention to individuals diagnosed with ASD requires the physiotherapist to develop rapport and trust with the child and family/carers. Children with ASD, particularly levels 2 and 3, typically require multiple visits with an allied health member before they will trust and work with the physiotherapist. Consequently, it typically takes more than one visit to complete an assessment in order to guide intervention. Notably, we highlight that the proposed *Independent Assessment Model* is inconsistent with this principle, where a young person on the autism spectrum will have to undergo periodic assessment by a complete stranger.

4. The intervention is based on a theory that is logical and scientifically plausible:

Evidence-based interventions aiming to improve the movement functions of children on the autism spectrum are the core domain of physiotherapists and physiotherapy. World Physiotherapy, the peak international advocacy and professional organisation representing the Physiotherapy Profession, defines Physiotherapy as: "...services provided by physiotherapists to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan. The service is provided in circumstances where movement and function are threatened by ageing, injury, pain, diseases, disorders, conditions and/or environmental factors and with the understanding that functional movement is central to what it means to be healthy" (World Physiotherapy, 2019).

The prevalence of motor difficulty (as defined by a standard score of <70 on the motor domain of the Vineland Adaptive Behavior Scales) is at least 35% in Australian children on the autism spectrum, almost as common as intellectual disability in this population (Licari et al., 2020). In very-large population-based cohort study (n=11,814) of children on the autism spectrum in the United States, almost 90% of participants met criteria for definite motor impairment or suspect Developmental Coordination Disorder using a validated parent-report questionnaire (Bhat, 2020).

A systematic review of 25 studies examining motor function in children with neurodevelopmental disability aged 0-24months identified that impairments in gross motor function are already evident before 2 years of age in children later diagnosed with autism (Lim et al., 2021). Motor impairment has also been postulated to be part of the set of 'core features' of autism (Rinehart & McGinley, 2010).

Therefore, physiotherapy interventions have a logical and scientifically plausible basis to address highly prevalent motor impairment causing activity limitations and participation restrictions.

5. Research evidence shows the intervention can work for people on the autism spectrum:

One exemplar of effective, evidence-based physiotherapy intervention for people on the autism spectrum is promotion of physical activity. Children and youth on the autism spectrum are at risk of low levels of physical activity and high levels of sedentary behaviours, putting them at risk of developing non-communicable diseases associated with inactivity (Cynthia et al., 2019). There are a number of barriers to the physical activity participation of individuals on the autism spectrum, including pragmatic communication differences, sensorimotor impairments, and lack of accessible and inclusive programs (Cynthia et al., 2019).



A large, recent systematic review and meta-analysis of 29 studies including n=1009 youth on the autism spectrum 2-22 years of age found moderate to large effect sizes of physical activity interventions on muscular strength/endurance, locomotor skills, manipulative skills, skill related fitness, and social functioning of participants (Healy, Nacario, Braithwaite, & Hopper, 2018). The majority of these interventions were delivered outside of a clinic in school and community environments (Healy et al., 2018).

As one key purpose of physiotherapy is to "promote the health and wellbeing of individuals and the general public/society, emphasising the importance of physical activity and exercise and the facilitation of such activities" (World Physiotherapy, 2019), physiotherapists are uniquely qualified and positioned to provide movement and physical activity interventions to children on the autism spectrum. Based on their own clinical practice experiences and best available research evidence, physiotherapists have suggested that incorporation of physiotherapy in routine care of children on the autism spectrum has the potential to improve their health and wellbeing through promotion of physical activity and improved motor development (Cynthia et al., 2019).

6. The intervention works in the real world, not just in a research laboratory:

Within the 'real world', this has been evidenced by the success in the number of programs that children with ASD can now access and engage in. For example, within Queensland, a physiotherapist working with children with profound and complex disability, including children with ASD, has not only made gains within the clinical setting, but also within the community. Within the clinic, children with ASD have improved their core strength, balance and motor skill capacity, as evidenced by achieving short-term goals. In addition, physiotherapists have successfully taken their knowledge of human movement and motor skill attainment to develop sporting programs for children with disability.

Within different cohorts of children, practitioner-led, peer-group sports intervention has shown to result in "improved sports participation and activity goals" (Clutterbuck, Auld & Johnston, 2020). Considering this research, 'Over the Net' is a tennis program that was developed by a physiotherapist and aligned with Tennis Australia's School Curriculum, but capable of meeting the needs of children with mild-profound disability by embracing evidence-based physiotherapy intervention. Within this program, children with ASD have improved their physical activity capacity, while at times have improved their individual tennis skills. This program has a waitlist and is now extending its partnership with various stakeholders, further evidencing the success of this intervention.

7. The intervention supports mainstream and community participation:

Physiotherapy interventions in children with disability are guided by the World Health Organization International Classification of Functioning Disability and Health Framework which centres a person's participation in life situations, including home, social, community and economic participation (World Health Organization, 2007). Physiotherapists set participation goals and provide participation-focused therapy that promotes mainstream and community participation in children with neurodevelopmental disability, including in sports and physical activities (Reedman, Boyd, Trost, Elliott, & Sakzewski, 2019).

The physiotherapy profession embraces inclusion and supports children with ASD to link with mainstream services where available and when suitable. In addition, physiotherapists often undertake intervention within these locations to both upskill staff and support access to mainstream supports. Overall, the physiotherapy profession supports patients, including children with ASD, to enhance their motor skills and consequently independence in order to participate within their natural settings and community. Physiotherapists working in paediatrics follow the 'National Guidelines: Best Practice in Early Childhood Intervention'.



Q5. 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?

Physiotherapy interventions for children on the autism spectrum adhere to the seven key early intervention best practice standards identified by the NDIS.

- 1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals; and
- 2. The people delivering the intervention follow established guidance.

Physiotherapists are appropriately qualified allied health professionals who are accountable to professional standards to deliver evidence-based therapy. Physiotherapists are also obligated to practice within the limits of their competence, expertise and scope of practice (Physiotherapy Board of Australia, 2014).

We agree that physiotherapists working with children on the autism spectrum should have adequate clinical experience in this area of practice. Graduates and physiotherapists new to working with children on the autism spectrum should have access to adequate levels of professional development, professional supervision and mentorship to develop their knowledge and skills. We agree that interventions should be delivered according to any established guidance (when available and/or appropriate) in order to increase the likelihood of success.

3. The intervention provides significant and lasting benefits.

We agree that interventions delivered by physiotherapists to children on the autism spectrum should provide significant and lasting benefits. The exemplar provided in the consultation paper on this standard (a research study on the effect of weighted blankets, and subsequent decision that weighted blankets are not 'reasonable and necessary' supports) highlights one potential problem, however, with equating existence (or absence) of research evidence with the real-world effectiveness of an intervention. As highlighted in a qualitative study of physiotherapists providing interventions to children on the autism spectrum, there is a paucity of high quality studies demonstrating efficacy of physiotherapy interventions in this population (Cynthia et al., 2019).

Physiotherapy to address limitations in gross motor development, for example, in children on the autism spectrum is, however, scientifically plausible and likely to be beneficial (Bhat, 2020; Cynthia et al., 2019; Healy et al., 2018).

Physiotherapists working with children with ASD are making gains and this is evidenced in plan review reports and stakeholder feedback, for example, parent and teacher feedback. Within paediatrics, it is not always easy to obtain ethical clearance for research on paediatric cohorts. A lack of research within this area does not equate to a lack of effectiveness, but instead simply a lack of research.

- 4. The intervention is carefully monitored and reviewed on a regular basis;
- 5. The intervention does not cause significant physical or emotional harm; and
- 6. The benefits outweigh any costs (including risks).

Physiotherapy is a profession that is goal-oriented and consequently monitors and review intervention on a regular basis. As a reflective profession, monitoring allows for intervention to be adjusted and targeted, hence client- and family-centred to optimise outcomes.

Without physiotherapy intervention, children with ASD are at risk of ongoing motor delay which with increasing age will place a child with ASD further and further behind their peers. In addition, a lack of motor skill and confidence has been shown in the literature to result in reduced physical



activity. Furthermore, it is common knowledge that a lack of physical activity has significant negative costly consequences which would further impact an individual's ability to participate and engage in community life.

7. The intervention is good value for money and time invested:

The Australian Physiotherapy Association recently commissioned a report on the value of physiotherapy as demonstrated through exemplar health conditions ('The Economic Value of Physiotherapy', APA and Nous Group, 2020). The net economic benefit of physiotherapy for each episode of care delivered to children with cerebral palsy (another neurodevelopmental disorder characterised by impairments in posture and movement) was estimated to be \$1,502 (Nous Group, 2020).

As for the seven key principles, more detail is required on how the NDIS plans to identify interventions that do (and do not) adhere to the standards, and how it will act on this information as this has important implications for the advocacy for the funding and conduct of scientific research into physiotherapy interventions.

Q6. "Reasonable and necessary" is a term from our legislation. <u>Appendix one</u> of the consultation paper includes case studies which might be used to explain reasonable and necessary. Do these case studies help you to understand what we mean by "reasonable and necessary"?

No. We believe stronger emphasis is required in the areas of gross motor skills, mobility, and access to the physical environment. The case studies referred to are limited to fine motor skills and need to be expanded to capture wider examples of what can be understood by 'reasonable and necessary'.

The examples provided (as capacity is built, professional supports are reduced) do not present a realistic picture of how capacity is built across the breadth of presentations. Instead, they present a very idealistic progression of capacity building. Unfortunately, progression does not often occur in the idealistic manner. Progression can be very slow and changes in circumstances, environments, development can even present in temporary regressions.

The idea of short intermittent therapy blocks to build on specific skills does have its advantages but often there is a rolling need of capacity building such that therapy may continue for some time but the goals of therapy change throughout the year.

Q7. Do you have any other feedback about how we explain "reasonable and necessary?"

Whilst the explanations for reasonable and necessary are clear, the consideration of whether a support fits within this category should be an individual consideration that takes into consideration a person's environment. This includes their physical environment, the capacity of informal supports such as socio-economic position and education of informal supports. Some families are more equipped to be able to support a child with autism at home.

In enabling choice, the role of the NDIS is to listen to what families perceive as reasonable and necessary. They are the people living in this situation every day and have the best knowledge of how and why something is reasonable and necessary to them.

It must also be considered that the socio-economic position of families varies greatly and that disability is more prevalent in lower socio-economic bands and what may be an everyday



expense for some families is not financially achievable for others. For example, having a trampoline or play gym/monkey bars in the back yard, or having balls to play ball sports with, or to be able to fund participation in mainstream activities such as swimming lessons, sports activities or social activities at recreation centers.

Q8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain indicative level of funded support for children on the autism spectrum (Section 7.5.). Do these table/s clearly explain the indicative levels of funded supports?

The tables do not clearly explain what the funding looks like in terms of intervention in regards to the number of hours funded and how this might be dispersed across the time of a plan and across the various disciplines a child may require funding from. When this is done it becomes more apparent how grossly underfunded some participants may be.

Q9. Do you have any other feedback about how we explain the indicative levels of funded supports?

Having levels of funding that do not align with the levels of ASD diagnosis is confusing to participants, their families, carers and providers. Using a different terminology, such as band of funding, or altering the levels to match with ASD levels, would make it clearer and easier to understand.

Whilst physical development is mentioned there is no reference to gross motor skills or mobility within these examples. It would be good to have these mentioned as highlighted in earlier responses movement difficulties are highly prevalent in ASD and impacts significantly their ability to participate in their community with both peers and their families.

In Appendix 1, we have endeavored to provide a clearer picture of what the funding levels would look like from an intervention perspective as well as provided feedback on these levels of funding.

Q10. 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?

This fluctuating level of support required is a serious consideration and families need to have assurance of an ability to access top up funding in a timely manner when situation arise without the need for a full plan review. Having an ability to top up extra funding in situation of unforeseen change, such as a change of teacher, school, therapist family situation, stress or mental health decline, regression of skills with a simple method to demonstrate such change would be a good option and give families assurance of supports.



Part 3 | Supporting parents and carers to exercise choice and control

Q11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. In <u>Section 8.2</u> there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention. Are these questions helpful for parents and carers when selecting providers?

The APA supports the consumer having the ability for informed decision making. As an Allied Health Practitioners Regulation Agency (Ahpra) registered profession, physiotherapists are bound to provide information in regards to interventions so that participants can make informed choices. Building the capacity of families to ask the above questions is important and we support the Agency to do this. These types of questions are commonly asked and answered in physiotherapy practice. A thorough initial consultation with families along with the development of service agreements in partnership with families provides a good platform for these discussions and assists with the development of therapeutic alliance with families.

Q12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

A resource to explain the interventions included and a breakdown of professionals who may implement these types of therapy, including physiotherapists. This must be in simple language without medical or health terminology. Clear explanations of those that do not have evidence is just as important.

Part 4 | Conflicts of interest

Q13. 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?

Conflicts of interest

We understand that managing and addressing conflicts of interest can be challenging within the disability sector. However, physiotherapists are registered professionals with the Allied Health Practitioners Regulation Agency (Ahpra) which means they are held to Ahpra's Regulations related to conflicts of interest. These include, but are not limited to, regulations on professional code of conduct, recency of practice, continuing professional development, advertising, and mandatory reporting.

In line with these Regulations, physiotherapists should not use interventions without a sound evidence-based, physiotherapists should not over use therapy interventions, physiotherapists should not incentivise therapy, and physiotherapists should not advertise in ways contradictory to the previous points. Further, physiotherapists are bound to report other physiotherapists who do not adhere to any of Ahpra's regulations related to conflicts of interest. Reference: <u>AHPRA---Procedures---CST-Conflict-of-Interest-Procedures---RM007---April-2015 (1).PDF</u>

All NDIA registered providers must hold and use policies and procedures for managing conflicts of interest. Also, it is common for non-NDIA registered physiotherapy *organisations* and sole traders to hold and use policies and procedures for managing conflicts of interest. Finally, a significant proportion of registered physiotherapists are members of the Australian Physiotherapy



Association (APA) and must abide by the APA Code of Conduct including items relevant to conflicts of interest. Reference: <u>APA_Code_of_Conduct.pdf</u> (australian.physio)

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About the Australian Physiotherapy Association

The APA's vision is that all Australians will have access to quality physiotherapy, when and where required, to optimise health and wellbeing. The APA is the peak body representing the interests of Australian physiotherapists and their patients. It is a national organisation with state and territory branches and specialty subgroups. The APA represents more than 29,000 members who conduct more than 23 million consultations each year. The APA corporate structure is one of a company limited by guarantee. The APA is governed by a Board of Directors elected by representatives of all stakeholder groups within the Association.

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Appendix 1: Indicative funding supports table

Under 7s (table 2)

Indicative level	Functional impact	This may look like a child with	Supports
Level 1 equates to 20-41hrs at the current price guide rates. 20hrs minus [6hrs 'higher intensity'] minus [4hrs preschool/childcare visits] = 10hrs remaining for 'fortnightly' interventions of one therapy type only. This is a wasted opportunity to build children's skills as quickly as possible and will promote 'rationing' of one therapy over another, losing precious time until the next NDIS plan to add a second therapy. 41hrs minus [12hrs 'higher intensity'] minus [4hrs preschool/childcare	Children with the lowest needs are the ones that are most likely to have the greatest capacity when older (Roberts, Williams, Smith, & Campbell, 2016) yet underemployment remains a huge problem for adults with ASD (NDIA, 2018). It follows that everything possible should be invested in these children to help ensure the longevity of the Scheme for future generations, as these are the children most likely to contribute taxpayer dollars as employed adults. The influence of the family's capacity to support the child's development is vastly overestimated in this model. E.g. the Australian Bureau of Statistics puts our clinic in the 9th percentile for socioeconomic disadvantage in Australia and during the COVID	One area of high need and one medium-low does not mean that other areas wouldn't benefit from intervention. E.g. a variety of motor skills programs for young children have resulted in improved gross motor, physical activity and social skills (Ketcheson, Hauck, & Ulrich, 2017).	Supporting children at this age to engage in gross motor skill development increases their participation long-term because, for example, they are more likely to be included in games with neurotypical children, which will give them greater opportunities to practice their social skills. Further, the stronger social connections that result from increased participation at this young age logically lead to more opportunities as adults, which may lead to improved employment rates in the current cohort of children receiving Early Childhood Early Intervention (ECEI). Evidence for physiotherapy interventions for children with autism spectrum disorders is based on programs of higher intensity and duration than the NDIS is proposing (Steinbrenner et al., 2020). Underfunding interventions is similar to taking half a course of antibiotics, expecting a full cure and then being surprised when it costs more overall to treat the complications.

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Indicative level	Functional impact	This may look like a child with	Supports
visits] = 25hrs remaining for 'fortnightly' interventions, which could alternatively be used as [12hrs 'higher intensity' of a second discipline], i.e. 41hrs minus [12hrs discipline 1 plus 12hrs discipline 2 plus 4hrs preschool visits between the 2 disciplines] equals 13hrs for 'fortnightly' interventions.	sessions. Although these would be 'everyday expenses' for most families, it must be remembered that there is a higher prevalence of disability in poorer, less educated and predominantly CALD communities		



Indicative level	Functional impact	This may look like a child with	Supports
Level 2 equates to 41-61hrs of capacity building support at the current Price Guide rates.	baseline level of funding provided to	Our clinical and lived experience from the examples given in this table is that physiotherapy can help children with this level of need with toilet training and physical development.	At the lower end of this funding band, supports would still need to be "rationed" between the multiple therapies required to achieve best outcomes for the individual.
Assuming speech, OT and physio are required in combination to address the one area of high need and 2-3 areas of medium-low need: 41hrs minus [12hrs 'higher intensity' and 4hrs 'school visits' for 3 disciplines] equals a shortfall of 7hrs (because 16 x 3 = 48), as well as no ongoing 'lower intensity' therapies.		Using toilet training as an example, the successful use of pelvic health physiotherapy as an intervention can result in significant cost savings in continence products throughout the person's lifespan as well as environmental savings from reduced landfill of single-use continence products.	



Indicative level	Functional impact	This may look like a child with	Supports
Level 3 equates to 61- 154hrs	This level of functional impact will be adequately supported by the proposed level of funding.	The inclusion of physiotherapy in this type of child's supports will give them the best possible chance of success when starting school, as exercise and movement based interventions have been shown to be effective for 3-5 year-olds in the following outcome areas: Communication Social Play Cognitive School readiness Academic/pre-academic Challenging/interfering behaviour Motor skills (Steinbrenner et al., 2020)	This level of funding will allow therapists to work as responsive teams to adjust service delivery based on the child's changing needs (e.g. if new challenging behaviours occur or if the child changes preschool/primary school).



Indicative level	Functional impact	This may look like a child with	Supports
Level 4 equates to 154- 180hrs	This level of funding will allow the described number of areas of need to be addressed by a team of therapists using a specialised behaviour support plan to support the family in all environments.	(as per Level 3)	Physiotherapy may also assist with behaviour, night waking and play skills for children who present in this way (Wong et al., 2015).



Table 3 – 7 to 12 years

The same feedback applies overall to table 3 as to table 2. Specifically, though:

Indicative level	Functional impact	This may look like a child with	Supports
Level 1 equates to 12 to 24hrs of capacity building therapies at the current Price Guide rates.	For this level of funding to be successful, the child will have already had previous NDIS plans.	diagnosed at the age of 7 with level 2 ASD. Struggles with social communication, but also with joining	professional intervention" however, 24 hours (maximum) of funding minus 4 school visits does not leave 24 hours remaining for professional



Indicative level	Functional impact	This may look like a child with	Supports
Level 2 equates to 24 to 37hrs of capacity building therapies at the current Price Guide rates.	This is still an unrealistic baseline level of funding provided to children with an ASD diagnosis severe enough to make them eligible to become NDIS participants. Between the ages of 7 and 12, children are expected to work more independently and think more abstractly, however cognitive load has been shown to interfere in gross motor task performance in children with developmental disabilities (Schott, El-Rajab, & Klotzbier, 2016). Sufficient funding to include physiotherapy in a child's supports is necessary to give the child the best chance of a successful transition to high school.	diagnosed with level 2 ASD who began high school. His insistence on sameness and inflexible adherence to routines made it difficult for him to cope with moving between classrooms throughout the school day. With physiotherapy, he was able to increase his exercise tolerance and the variety of community participation that he was able to engage in, making it easier for him to transition between classrooms during the school day, as	As per level 1 (above) the maths is incorrect: 37 hours (maximum) of funding minus 4 school visits cannot possibly leave 36 hours remaining for professional intervention.



Indicative level	Functional impact	This may look like a child with	Supports
Level 3 equates to 37 to 92hrs of capacity building therapies at the current Price Guide rates.	purposes, physiotherapy to increase exercise tolerance and competence at a	Case example: 9-year-old boy who was unable to engage in physiotherapy at a younger age due to the need to prioritise speech therapy and behaviour support to reduce behaviours of concern. Now that his functional communication has improved to the point that he can participate in physiotherapy without resorting to challenging behaviours, he has begun to show pleasing improvements with his running, ball skills and has also recently learnt to ride a bike.	As per levels 1 and 2 (above) the maths is wrong: 4 school visits from a maximum of 92 hours of funding does not leave up to 90 hours for professional intervention. Releasing a table with incorrect maths sets practitioners up to be labelled "greedy" because families will expect that the NDIS has allowed sufficient funds for the suggested supports.



Indicative level	Functional impact	This may look like a child with	Supports
Level 4 equates to 92 to 108hrs of capacity building therapies at the current Price Guide rates.	described number of areas of need to be	The inclusion of physiotherapy in this type of child's supports will give them the best possible chance of success when starting school, as exercise and movement based interventions have been shown to be effective for elementary and middle school students (approx. 6-14 years-old) in the following outcome areas: Communication Social Cognitive School readiness (transition to high school) Academic Challenging/interfering behaviour Motor skills (Steinbrenner et al., 2020)	Again, the maths is lower than required: 108 hours minus 4 hours of school visits will not leave 105 hours. Again, this will set practitioners up for conflict with families who expect more than what can be provided with the funds allocated.