INSiGHT Research Ltd

Independent Network of Specialists in Guidelines & Health Technology

Consultation Survey

Feedback on draft paper on physical activity and young people on the autism spectrum

We are grateful for your time and contribution to this important update to the New Zealand Autism Spectrum Disorder Guideline on physical activity.

Please enter your responses below (add more space if required). The deadline for participating in this sectoral consultation is **Monday March 24, 2020**.

1. How **clear** and **readable** is the Supplementary Paper?

The paper is clear and readable however there are a couple of instances where person first language has not been used e.g. describing autistic people rather than people with autism on page 2 of introduction. Most of the language is person first but can we be consistent?
There was clear inclusion criteria, the strengths and limitations were clearly discussed. This appears to be a robust process.

The supplementary paper is clear, readable and very thorough and has very promising recommendations for young people with ASD. The outcome of the systematic review is a positive step towards enhancing physical well-being of young people with ASD and will be welcomed in schools as a guideline to follow. Based on the findings of this research the new Recommendations and Good Practice points are valid.
This review and the subsequent recommendations provides adequate evidence to be used to try to implement changes at an organisational level.

Barriers need to mention sensory processing and regulation difficulties – page 2.

2. Is the systematic review **well conducted**?

Yes – I was impressed with the consideration of the limitations of the review and the studies that were included.

Yes the recommendations and good practice points are valid and are clearly based on the reviewed research.

Very clear inclusion/ exclusion criteria.
Sound use of the Levels of evidence to grade the research
The systematic review was conducted using strong guidelines and the processes used when analysing the collated articles was outlined in depth
Critical appraisal followed robust Checklist, with clear Evidence Tables to support ease of understanding results
The limitations of the research were identified well and we agree with the recommendations for future research - these fit well with the ICF and F-word frameworks (i.e. considering environment and personal factors and trying to identify physical activities that children find fun in order to promote compliance and long term adherence).

3. Are the new Recommendations and Good Practice Points **valid** (based on the reviewed research)?

Yes I think they reflect the research reviewed.

Yes these are relevant across a number of areas including schools and the community.

4. Are the proposed Recommendations and Good Practice Points **relevant** and **applicable** to sectors of the community you engage with? (e.g; people on the spectrum/whānau, clinicians, service providers, educators)

Essentially they are relevant – although many whānau, schools, service providers might feel this is further down their list of priorities as they are more focused on managing day to day behaviour.

Physiotherapists completing this feedback include:
Special School
MoE Physiotherapist – all schools
MoH Physiotherapist – primarily working with children under 5 yrs, but also older children in Mainstream school (post surgery)

MoH Physiotherapist – working with children as inpatients in a hospital setting

Generally the focus is to increase the amount of physical activity the children with special needs engage in every day.
Focus has been on supporting the health benefits that physical activity has for everyone. These guidelines provide evidence of the broader effect physical activity has for people with ASD across social, cognitive and behavioural domains. This evidence makes it even more appropriate as physiotherapists working with these children and will hopefully increase the likelihood of changes to current procedures and daily classroom plans.
It is realistic for regular physical activity to be scheduled by teachers as part of a daily school routine for children with ASD.

5. Are the proposed Recommendations and Good Practice Points **able to be implemented** (are there realistic expectations for them being applied)?

Given the limitations of services in the disability sector these recommendations may be hard to implement especially when organisations who provide access to physical activity do not have specific ASD understanding.
Also issues of equity and environmental factors e.g. transport, housing, income often can be a large barrier to accessing services. The document does not appear to acknowledge this, unless I have missed it somewhere.
The recommendations are appropriate, further research is needed to provide more specific guidelines in relation to evaluating interventions in naturalistic settings. This is identified in the paper and would be very beneficial.

Whilst it is ideal to state that physical activity is important for young people with ASD we acknowledge that the how is really important.
Whilst the Guideline is useful, we know that engaging with these young people can be very challenging especially if its not an area of interest to them.
We believe it would be really helpful if there was more detail in the Recommendations and Good Practice Points sections (such as some strategies/ comments/ideas/ behavioural courses or videos/ podcasts etc) for people working with children/students with ASD for them to use to increase engagement and support behaviours that may be challenging.

6. Do you have any **other comments** or suggestions about how we can improve this Supplementary Paper?

The document acknowledges the importance of the Treaty of Waitangi on page viii. However, this is not then addressed in the rest of the document. Either in the process for review, potential stakeholders or even acknowledging a lack of research in this area for Māori.

Furthermore, The Waitangi Tribunal Hauora report described the "3 P's as reductionistic and we should be referring directly to the articles of the Treaty.

If the document (and process) acknowledges the importance of the Treaty of Waitangi I would like to see the evidence of how they met the obligations under the Treaty.

As noted above additional strategies in relation to how this can be implemented would be beneficial.

7. Can you suggest any **other topics/areas** that need to be **updated** in the NZ ASD Guideline and why? (e.g., new research, current Recommendations no longer apply, gap in the current guideline)

In my view, this summary of research evidence of the effect of physical activity for children with Autism and a related practice guideline is well written and follow best practice procedures for clinical guidelines (AGREEII tool). It is has a very clear audit trail with links back to the specific research evidence and the grading system used is made explicit. Helpfully, a link is also made between this guideline and prior NZ guidance on physical activity and ASD- namely that it was previously omitted. The scant research that was found does (appropriately) place the decision making about PA for people with ASD in 'negotiate what is right for you' category of evidence-based practice. But it does importantly bring it to peoples attention- PA is just as important and likely to have the same health benefits for people with ASD as it does for other people. Often PA levels/ enjoyment/ participation can be overlooked in the health systems preoccupation with problems. There are rights-based arguments to ensure opportunities for PA for people with ASD as well as health based arguments-as presented here.

Authors could consider bringing in these arguments, drawing on literature about the experience of exclusion from PA opportunities (alongside other

ways of participating in society) and limited opportunities to participate in some communities. They may also decide that this is outside of their scope but it in effect may by a restriction on meeting the health guideline targets for PA.
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Summary: New recommendation and good practice points
Summary Table I: New recommendation relevant to physical activity and autism

Reference	Revised recommendation	Grade
2.3.9a	Physical activities provide benefits across social, cognitive and behavioural domains in addition to general well-being and should be considered for children and young people on the autism spectrum	**B**

Note: Grades indicate the strength of the supporting evidence rather than the importance of the evidence. Grade A indicates good evidence, B is fair evidence, C is international expert consensus, and I is insufficient, poor quality, or conflicting evidence. See **Table A1.2** in **Appendix 1** for details.
Summary Table II: New good practice points relevant to physical activity and autism

Reference	New Good Practice Points	Grade
2.3.9b	When supporting individuals participating in a physical activity or programme, their preferences should be respected and needs accommodated	Ü
2.3.9c	Further research that targets meaningful outcomes for the autistic community is essential	Ü
also 4.1.6	Further research that targets meaningful outcomes for the autistic community is essential	Ü

Note: Where a consensus-based recommendation is based on the experience of members of the Living Guideline Group, it is referred to as a good practice point.

We believe it would be appropriate to consider adapted sport programs that could be run by organisations and communities - using well established and researched strategies with young people with ASD eg: alternative communication, TEACCH structure, to ensure the physical activity opportunity is successful and fun, making it more motivating and engaging for young people to participate in

We feel more could be added to this Guideline in relation to Developmental Coordination Disorder.
Research has identified that many children with a diagnosis of DCD often have a dual diagnosis of ASD. If this occurs, then we believe that children

with ASD may benefit from interventions that have been shown to be valid and reliable for DCD e.g. Neuromotor Task Training and Cognitive Orientation to Occupational Performance (CO-OP).
These interventions may have an effect on motor skill acquisition issues that were found not to improve in the research articles that were reviewed. One contributor noted that she has seen this anecdotally with children she has worked with a dual diagnosis of DCD/ASD - improved motor skill acquisition has led to increased participation in the school curriculum resulting in improved social and behavioural skills i.e. treating the DCD aspects has improved their ASD symptoms.
From a Service perspective, (specially The Physical Disabilities Service), children with ASD are excluded. However, we know based on the ICF, that the health condition does not fully describe an individual's experience or situation. We do not believe that a diagnosis alone should exclude a child from a service. Instead, an identified need should determine access to intervention/ support.

- It is a well structured document which provides relevant research and information related to physical activity for children with ASD.

- It was good to see that a broad range of positive outcomes to physical activity were considered, that is sensory, behavioural, cognitive, social as well as the physical aspects of fitness, co-ordiantion, weight control etc.

- It is not an easy area to research given the variables that need to be considered - age of child, degree of disorder, cognitive function, type of physical activity provided, level of motivation etc. Therefore, the importance of
ongoing research.

- Developmental Coordination Disorder is a common co-morbidity with Autism and certainly does need to be considered when formulating physical activity programmes for children with ASD.

- The call for further research in a naturalistic setting is important. Targeting the child's area's of interest in necessary in order to establish their "buy-in" and to maintain their level of motivation.

- In my clinical experience "movement breaks" (physical activity) are a commonly used strategy to assist children with ASD to self-regulate their behaviour. Vestibular and proprioceptive input provided by physical activity does appear to have a calming influence.

Overall, the document appears to provide a valid recommendation and relevant "good practice points".

Thankyou

Please return this completed questionnaire to Marita Broadstock
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or **post** to INSIGHT Research Ltd, 181 Blighs Rd Strowan 8052.

Responses are due by 5pm **Monday March 24, 2020**