

Neurodevelopmental Psychiatry Clinic
Child and Adolescent Mental Health Service

Thursday 13th of May 2021

Submission in response to the NDIS Consultation paper: Interventions for children on the autism spectrum.

The Neurodevelopmental Psychiatry Clinic (NPC) is a tertiary level specialty clinic within the Child and Adolescent Mental Health Service (CAMHS) at GV Health. The team coordinates and undertakes multidisciplinary team Autism Spectrum Disorder (ASD) assessments of young people and adolescents who have complex experiences, and who have been referred by their paediatrician or their CAMHS team.

GV Health's primary catchment includes the local government areas of Greater Shepparton (70% of primary catchment population) and Strathbogie. Our total catchment stretches into Southern New South Wales and the overall catchment population is approximately 120,00 people. Greater Shepparton has a higher percentage of children under 14 years (20.9%) and a slightly higher rate of people aged 15- 24 years (13.4%) compared to the rates for rural Victoria (19.1% aged under 14 and 12.6% aged 15-24).

Young people with autism and their families within the GV Health catchment experience additional challenges in accessing assessment and support compared to residents of metropolitan areas. As a specialist tertiary service providing assessment and recommendations for young people on the autism spectrum and their families, we offer our feedback related to the *Consultation paper: Interventions for children on the autism spectrum*.

We applaud the ongoing commitment towards clarity and welcome the focus on the reduction of the current issues and challenges listed on page 6 of the consultation paper. We endorse the core principles outlined within the consultation paper; holistic assessment, individual and family-centred, lifespan perspective and evidence based.

Within our clinical practice, we also support the acknowledgement that "no 'one size' fits all" (p. 9) and that interventions should be individually selected within a framework of evidence and child and family context.

We support the seven key principals provided within the consultation paper at Item 6.1.

In relation to Item 6.2: 3 *The intervention provides significant benefits.* The example provided discusses the use of weighted blankets and the study that found weighted blankets were not associated with faster sleep onset or duration for children on the autism spectrum. This example states that weighted blankets would then be considered an everyday expense rather than an NDIS funded support. However, the example also acknowledges that the study had not investigated calming and other potential factors that families have found beneficial. There is moderate level evidence that suggested weighted blankets can be calming. A support that assists a child to calm and regulate may be the support that then helps them function in other areas, such as have a greater tolerance for other stressors like change, transitions, mealtimes or therapy. In this circumstance, a weighted blanket should indeed be a NDIS stated support if it is recommended and monitored by a qualified provider and the item addresses the specific goal of the family.

In relation to Item 6.2: 4 *The intervention is carefully monitored and reviewed on a regular basis.* We support this statement in principal and acknowledge that this then requires the funding for monitoring and review. We do caution the statement about a lack of clear benefits, which ties in with the later note;

“[situations where we will not fund] there is weak or no evidence that the intervention will support an increase in developmental or functional skills, independence or social participation. For example an intervention has been in place for 12 months and there has been no capacity building gains”

For young people on the autism spectrum, some supports may be in place to maintain certain levels of functioning. When reviewing the outcome of these supports, we must be mindful that the expectations and demands on young people increase as they age. A *capacity building gain* may indeed present as a maintained ability to participate at the same level, or at times may even present as someone appearing to have less functional capacity – however, without said support their capacity would significantly decline further. Therefore, we caution the assessment of gain and how this will be measured. This points to the need for ongoing plans to be informed by therapists involved in the care of the young person.

In relation to Item 7.4: 3 Outcomes focused – as capacity is built, professional supports reduce and 7.5 Proposed levels of funded support for autism early intervention. A significant concern within this Consultation Paper is that the *Lifespan approach* noted does not appear to be embedded within the proposed levels of funding and the outcomes monitoring. As a specialty tertiary clinic, we often receive referrals for young people when the demands upon them have exceeded their capacity to cope and mask – typically through schooling. As mentioned earlier, demands and expectations change and increase for all young people as they move through developmental stages. For young autistic people, schooling can present a significant challenge, particularly when transitioning into high school where independence, executive functioning and social communication becomes of heightened importance.

It is not appropriate to suggest that goals met early in life mean that young people with autism will not need or benefit from professional support in high school. A true lifespan and holistic approach would recognise this. The suggestion that capacity building plans will reduce when a child enters the educational system overlooks the lifespan approach and the new demands upon the young person and the family. Without adequate support during schooling and into early adulthood, young autistic people and their families have greater difficulties with maintaining employment and social participation. As an insurance scheme, the reduction of appropriate intervention then appears to be short-sighted, as the long-term economic costs are likely to be more significant.

Thank you for considering our feedback for the Consultation Paper. We look forward to reviewing changes made through the community consultation.



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