



Invitation to engage on the Review of Interventions for Students with the Highest Level of Learning Support Needs

Thank you for the opportunity to participate in this first engagement phase of the review, to help determine the scope and terms of reference. The following response is on behalf of the Developmental Special Interest Group (SIG) of the Paediatric Society of New Zealand, Te Kaahui Maatai Arotamariki o Aotearoa.

The purpose, objectives, and desired outcomes of the review were clearly described in the Min. of Education document attached to the invitation to engage.

Aotearoa New Zealand in 2021 is a different place, with a much more diverse and much larger population, than at the time of the last significant review for students with highest leaning needs (Review of Special Education 2010)

Both as a nation, and within communities themselves there is a change in the kaupapa of how we want to support all children but for the purposes of this review how we want to support children and young people with the highest level of need. This is reflected in both Health and Education.

Q1: who are the tamariki and rangatahi we are looking to better support or support differently

Firstly we recognise the significantly increasing complexity of children presenting with highest learning needs and wish to highlight the following tamariki who we would like to see better supported or supported differently

a/We have much greater understanding and recognition of the **impact of social adversity and trauma (in utero, in the first years of life and ongoing) on children's physical, cognitive, and emotional wellbeing. There is a well recognised group of children and young people presenting at all ages in the education system with very significant behavioural challenges both externalising (disruptive) and internalising, mental health difficulties, and learning difficulties, who are not supported or inadequately supported under current highest need support provisions.** At times there is or has been an interface with Oranga Tamariki Care and Protection and Youth Justice, but in many cases this is not so, and there are very limited resources and access to intervention available.

Schools are often the only safe haven and keeping children and young people engaged and attending school is essential. With the current very limited supports available stand downs, suspensions, expulsions, and exclusions become the only action available to schools. Increasing appropriate resourcing – both the appropriate specialist assessment and interventions (including a trauma informed approach when appropriate) and resourcing staff in the school and classroom is required urgently. More flexible joined up approaches between health, education and care and protection are recommended, and frequently discussed but siloed funding makes change difficult. Current boundaries with education working primarily only in schools and other services only in homes can be confusing, duplicating and at times counter productive for children and their whanau. This group of children requires specific consideration but also a co design with other agencies and services around funding.

b/There is also internationally a well recognised real increase in the prevalence of children and **young people with neurodiversity, fitting within the wide autism spectrum**. (Autism is common with a prevalence 1:100 and increasing – internationally the Centers for Disease Control and Prevention (CDC) prevalence in 2016 was 1:54 and limited local data from the recent NZ Health Survey (NZHS) found families and whanau self reporting having received an ASD diagnosis for their child was 1.6 % for 2-14 year olds (Min. of Health(MOH) 2019)). Not all children with autism meet the highest level of learning support needs, but there are a very significant group who need additional support and are unable to access this. Because of social and communication differences, sensory needs and difficulties with theory of mind, neuro diverse children are frequently seen in paediatric services for review with very challenging behaviour in ECC settings and the school environment.

There have frequently been difficulties accessing specialist support services – firstly in the preschool period difficulties accessing appropriate communication support especially in the < 2 – 3 year olds, where children aren't always eligible for Min. of Education (MOE) EI in some regions; MOH Disability Support Services (DSS) funded parent education and support programmes eg ASD Plus accessed through Explore have long (average of 9 month) wait lists, and most MOH Child Development Services (CDS) around the country do not accept referrals for this group of children for intervention. A large body of international literature supports the earlier the input for children with autism the better the long term outcome, capitalising on the neuroplasticity of the developing brain. Developing nationally consistent funded pathways for intervention for very young and preschool children with neurodiversity including the wider autism spectrum is required between MOE, MOH and other providers.

In the school environment there are significant numbers of children and young people with autism not meeting ORS or other funding streams, and schools describing challenges providing the level of support in the classroom, both to access the curriculum and behaviour support. There are a significant number of children not attending school or only for several hours or 1/2 day each day as schools report children are unable to be maintained in the class room due to their behaviour (putting the child and other children at risk), and lack of specialist support and teacher aides to implement programmes.

c/We understand around 1.2% of children and young people are **ORS funded** and there has been an increase in ORS funding since 2020, over 4 years, with an increase in TA hours based on individual need. Generally those with the highest level of support in the education system including ORS have access to a range of appropriate supports, but schools and families do also report funding is inadequate and schools report having to “top up” funding to enable adequate TA support. There also continue to be a significant number of children with high needs, who don't meet criteria or applications are declined and for whom again schools struggle to support. ORS applications are long, complex and time consuming for those involved and there is at times a perceived reluctance to apply unless success is almost guaranteed- delaying until after children commence school and they have to “fail” first.

This review needs to ensure the ongoing understanding and support of children and young people with the highest learning support needs who are not eligible for ORS funding, but will have life long significant cognitive and learning difficulties, eg functioning just above level one of the curriculum towards the end of their schooling . How they will be supported in the education system and ensure they do reach their maximum potential, avoiding the current stand downs, bullying, mental health problems and whanau distress, needs to be addressed as part of this review.

d/ The **Communication service** that supports students with speech, language and communication needs **is currently not available beyond 8 years of age**. A number of children have ongoing or in particular previously unrecognised challenges beyond 8 years of age. This group of young people is increasingly recognised in juvenile and adult Courts and

justice system, with communication support made available during the judicial process to add understanding and outcomes. The lack of a Communication service in upper primary school and the secondary school system undermines the ability of many young people to access the curriculum, and ultimately experience some success at school.

e/ There has been **an increase in the survival and life expectancy of children born prematurely (resuscitation of 23 weekers now offered routinely in NZ) and children born with underlying chromosomal and congenital anomalies ,and other acute and chronic medical conditions receive life preserving complex medical and surgical care** , the majority of whom do extremely well . There will be a small but significant number who will have high and very high levels of learning support needs, including bio-medical and technological support. The increase in cochlear implants in NZ has brought huge benefit to a small but important group of children but also meant a change in teaching practise and specialist support to this group of children. And there will be other new and innovative practises in the future requiring support in the education system. This review needs to be cognisant of this group of children and have flexibility to meet children with new needs and challenges.

f/ **The current support for mobility / physical disability (PT/OT)** in the students with the Highest Level of Learning Support Needs in the school system is variable around NZ. In some areas it is provided by MOE or special school therapists through ORS or the MOE Physical Disability contract for “moderate needs”. There are however overlaps eg when there is a surgical intervention requiring post op therapy eg botox – this may be picked up by MOE therapists or CDS. At times there can be two services involved – confusing and potentially counterproductive for the child and whanau. Services over the school holidays for MOE supported students can be challenging.

The division of equipment provision between education “to access the curriculum” and home is similarly counterintuitive. There are not always specialist equipment assessors available in MOE/ education setting and despite school staff knowing the child and their needs best – CDS staff may be requested to do the specialist assessment.

There are well recognised windows for children with Cerebral Palsy (CP), when the provision of “boosts” of therapy significantly improves long term outcome. The first is up to 4 years of age usually provided by MOH funded CDS’s but the second is for 7-10 years of age. The provision of this therapy under MOE funded services can be problematic as the limited PT services are generally consultative and rely on TA implementation (again frequently not available).

g/ There are similarly reported difficulties with **“feeding assessments” by SLT’s** in school aged children usually with ORS funded children with at times 2 SLT’s involved - one from Health and the other from Education both assessing the same child.

Q2: to better support the tamariki and rangatahi you have identified in Q1, what are the non negotiable things that should be considered within the scope of the review?

It has been identified services are fragmented and siloed, not only within education but also health and social support – all working with the same group of children with the highest level of learning needs, with duplication and at times confusion and frustration for children and whanau. A joined up approach with one plan is frequently discussed, but seldom been successfully actioned.

This review would be ideal opportunity for the Ministry of Education to revisit this with Ministry of Health – not only DSS funded services (CDS , NASC, Explore and BSS) but also the interface with the wider Paediatric and Child Health services in NZ . There is good evidence

40-50 % of all paediatric outpatient consultations are for developmental and behavioural concerns and a great many of these are for children and young people with the Highest Level of Learning Support Needs in the education system. Although there are successful local relationships in some areas there needs to be negotiation and development of a national systemic way of moving forward and developing one plan.

Q:3 is there anything else that should be considered as the scope and terms of reference are developed

1/The attached material clearly identifies the first phase of engagement will include treaty partners, and the education sector including akonga, Pacific communities, parents, disabled people and disability organisations . We would also ask that engagement include people in our community who are perceived as “unable to be reached”– and that is real effort to engage those whanau who don't self identify.

2/Clearly the review will uphold Ti Tiriti O Waitangi, the UN Convention on Rights of people with disabilities, and United Nations Convention on the Rights of the Child - Article 23 recognising the rights of the disabled child. **We would strongly support engagement with the Office of Children's Commissioner.**

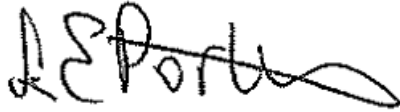
3/Engagement with Health sector as highlighted above – Min of Health, DHB's and allied health and paediatric specialist organisations eg Paediatric Society NZ / PSNZ Developmental SIG/ Child Development Clinical Network, should occur.

4/Inclusion is a fundamental human right which recognises that schools provide equal opportunities for all children, and be valued and have their needs and interests met, including meeting the learning needs of all students. However even when there is a strong desire for inclusion within a school, for children and young people requiring the highest level of learning support there needs to be adequate resourcing including environmental modification. The current case brought by IHC before the HRC highlights the complexity in this area. There is no doubt there are magnet schools that are more accepting of children with neurodevelopmental and neurobehavioural differences. But there are also schools that provide physical environments that are better suited to children with neuro diverse needs. The Modern (Innovative) open plan Learning Environment is not generally conducive to children with sensory needs, or difficulties with attention and self regulation. Many parents express concerns about their local school not meeting the needs of their child. Unless there is a very significant increase in funding and ability for all schools to meet all childrens needs (true inclusion) there needs to be some ability for families to choose the school best suited to their child and whanaus needs.

Although there is a stated difficulty in balancing a rights base view for inclusion with the provision of special schools – specialist day schools, sensory specialist schools and residential specialist schools; it is very clear special schools support a very significant number of children with the Highest Level of Learning support needs. There is a clear preference for attending a special schools by some parents as demonstrated by the current wait list for a significant number of children in South Auckland to attend their local special schools and a number of children not attending any school as a result. Special schools are also supported by parents, local schools and Ministry of Education staff when ORS funded children who commence at their local primary school at 5 years are unable to be maintained there as they become older , physically bigger and the gap with their peers widens. The ability to pool resources, specialist staff and knowledge and expertise in Special Schools clearly has benefits to reach a greater number of children. The continued support and funding of special schools and units has to be addressed particularly in regions of high population growth.

Thank you again for this opportunity to respond and we would be very happy to be contacted for further korero and input in the future stages of this review.

Naa maatou noa, naa



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