



SUPPORTING PEOPLE WITH PRADER-WILLI SYNDROME AND THEIR FAMILIES

Prader-Willi Syndrome Association (NZ) Incorporated

Submission to: Committee Secretariat, Education and Science,
Parliament Buildings, Wellington 6011
Via email: education.science@parliament.govt.nz

Submitted by: Prader-Willi Syndrome Association (NZ) Inc.
PO Box 258, Silverdale 0944, North Auckland
Contact email: jo.davies@pws.org.nz

Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools.

Background

Prader-Willi syndrome is a complex, genetic condition which is characterised by a number of physical, intellectual, learning, behavioural and health issues. As PWS is a spectrum disorder, presentation of individual symptoms can vary in severity. However, most individuals have cognitive skills that fall in the mild intellectual disability range and most will display behaviours typical of autistic spectrum disorders, with research showing that about ¼ of individuals would meet the full criteria for a dual diagnosis of ASD if tested.

We would like the inquiry to consider the following points:

1. The PWSA (NZ) regularly hears from families whose child with PWS is receiving very little or no support at school. We also hear from families who are paying privately for a teacher aide for their child. We know that many families go through the overly complicated ORS application process multiple times and have to appeal decisions in order to get the support needed for their child. Unfortunately, many children with PWS do not receive ORS funding because, despite having global impairments and intellectual disability, their needs do not match those described in the narrow ORS criteria.
Whilst we believe ALL children with PWS will require some additional support at school to achieve their potential, we don't expect a set amount of support to be automatically provided on a diagnosis basis, but would prefer a simplified system to assess individual global needs, with more funding available. In 2014, 1.1% of the school population received ORS funding which is simply not representative of the number of children with high or very high special educational needs.
Many parents are discouraged from applying for ORS funding because an ORS application would be a waste of time. This may be for reasons such as the child being able to decode text at a level which is not far enough below an age appropriate level. 'Islands of competence' do not take into account all the other difficulties the child may be experiencing. All children with PWS experience sensory and processing issues, which

coupled with higher anxiety levels, create specific learning difficulties in addition to their already reduced cognitive abilities. They have impaired executive functioning which means different teaching approaches need to be employed. If tested, many children would also meet the criteria for a diagnosis of dyspraxia and some also have apraxia of speech.

We currently advise families to apply for School High Health Needs funding if their child does not qualify for ORS funding. As children who have PWS have a number of health issues, an application is often successful, particularly in order to prevent life-threatening food related situations caused by hyperphagia. However, the support provided via SHHNF is only to support health needs, is reviewed annually and diminishes with age. Children are expected to be able to overcome or manage their own health needs as they grow older.

Unfortunately, unless a cure for hyperphagia in PWS is found, individuals with PWS are never able to control the food seeking drive and as a result, cannot live fully independent lives as adults. Yet, parents have to fight for this minimal funding on an annual basis.

2. Most children with PWS display behaviours typical of those on the autistic spectrum. They are prone to uncontrollable 'meltdowns' which can be aggressive at times. They thrive on routine, don't adapt well to change and unpredictable situations raise anxiety. Due to executive functioning, language and processing problems, children will also experience much frustration in the school environment which exacerbates behavioural problems. We know that there is very little behavioural support available for these children and their teachers. We are often told that a child is 'not severe enough' to be seen by the overstretched RTLB service or the new Intensive Wraparound Service.
3. During adolescence, it is common for behaviour problems in PWS to deteriorate. It is a time when peer gaps widen and individuals struggle to come to terms with their difference and manage emotions. Due to impaired social skills, it is also common for individuals to be socially isolated. In the past, many pupils with PWS benefitted from a period attending special residential schools such as Halswell and Salisbury. We know that fewer children with PWS are now being enrolled at these schools as the number of places available has decreased and fewer children receive the required ORS funding today. The option of a special school environment is being denied pupils and their families who are in desperate need.
4. Speech and language therapy is extremely beneficial for children who have PWS. Most children have speech delay in early childhood, but speech problems can be ongoing and some also have apraxia of speech. We know that many of our families receive good early intervention services through centres such as WEIT (Wellington Early Intervention Trust), The Champion Centre in Christchurch and via CCS Disability Action, but one area of early intervention that is often lacking is the availability of speech and language therapy. The amount of SLT support provided during early childhood appears to be a postal lottery. In some areas, wait lists are often very long due to a shortage of therapists. We would recommend that the Ministry of Education is more proactive in recruiting and retaining SLTs. Once children reach school age, SLT support is virtually non-existent. Those who are lucky enough to see a therapist usually only benefit from one visit where the SLT provides advice to the teacher. This advice is unlikely to be implemented if there are funding and resourcing

issues. School age one-to-one therapy is unheard of, leaving those who have the financial means to pay for expensive, private speech and language services.

5. The PWSA often visits schools to run training sessions for staff. We understand that PWS is a rare disorder and don't expect that teachers would have extensive knowledge of all rare genetic disorders. However, we feel that teacher education could be improved to increase understanding of specific learning difficulties, impaired executive functioning, sensory and processing disorders. We know that sometimes teachers are inadequately prepared to understand the impact of these disorders on learning and to manage pupil behaviour. We would like to see teachers being more able to identify learning difficulties and use appropriate strategies that aid learning. We would also like to see better trained SENCOs in every school who could provide more support to teaching staff in devising and implementing specific IEP goals. Currently, there are no legal requirements regarding IEPs. Many schools use IEPs because it is good practice to do so, but without specific, appropriate goal setting and adequate resourcing, these are often ineffective. The PWSA has advocated for families in cases where the problems would not have occurred if an appropriate IEP was in place. We would like to see mandatory IEPs in place for all children who have a certain level of special educational need and a requirement that they are reviewed at set intervals. In addition to teachers being able to implement appropriate teaching and learning strategies, there are many intervention programmes that could be utilised by schools for specific learning difficulties such as dyslexia, dyspraxia and ASD. Many of these would be helpful for children who have PWS, for example, programmes that develop social skills. For these programmes to run effectively and for teachers to be able to fully implement appropriate strategies in the classroom, schools and their pupils with special educational needs must be better resourced, as we have already indicated in point 1. However, we feel it would be a mistake to simply fund more teacher aides without supplying the relevant training for teachers and SENCOs to utilise teacher aides more effectively.
6. Finally, we would like to point out that discrimination against pupils with disabilities still occurs, despite the self-review figures that show New Zealand schools have become more inclusive. The PWSA still hears of cases where pupils have been discouraged from enrolling at schools or preschools. We also hear of pupils facing inappropriate behavioural consequences due to insufficient understanding of their disability and support needs. Furthermore, it is common for children to miss out on school activities such as excursions, sport competitions, productions and camps if they cannot be appropriately supported or their parents are unable to fulfil this support role. In cases of discrimination, families find that the Ministry of Education are reluctant to intervene and have no power to do so. Families are left to appeal school and BOT decisions alone. We would like to see legal changes that allow families to appeal discriminatory BOT decisions with the MoE. We also recommend that every Board of Trustees have an experienced representative from the disability / special educational needs sector.