



SUPPORTING PEOPLE WITH PRADER-WILLI SYNDROME AND THEIR FAMILIES

Prader-Willi Syndrome Association (NZ) Incorporated

Dear **(National MP / Minister)**

We are writing to you on behalf of our members with some concerns and questions regarding the proposed Learning Support Update. We feel it is important to make MPs aware of some of the educational issues affecting children with Prader-Willi syndrome and we would welcome your comment on the following six issues with some clarification about the planned changes. We would appreciate our concerns being addressed with some urgency owing to the proposed changes being phased in early next year.

First of all we would like to say that we are pleased to see the Learning Support Update is attempting to address some of the issues families face, such as the inadequacies in speech and language provision and the overly complicated application processes to access learning support and behaviour services. An overhaul of the learning support system is long overdue and we can see that this update is a step in the right direction. However, there are issues which have not been addressed, a lack of in depth understanding about some of the problems and with no promise of an increase in funding, the proposals are just words on a page as we cannot see much individual benefit to be gained by merely adopting a new approach.

1. LACK OF FUNDING: Although the complex application processes for funded learning support are due to be streamlined, individual needs should be identified and targeted earlier under the new early triage model and the Ministry intends to maximise efficiency with an interagency team approach, it is still obvious to parents, teachers, Principals and learning support specialists that learning support will remain appallingly underfunded. We understand that a funding review needs to take place to examine the cost implications of the proposed changes and investment analysis will be undertaken to inform future funding decisions, but it is clearly evident that an immediate increase in funding is also urgently required. Many pupils have attended school long enough already with insufficient support due to funding limitations – how much longer will they have to wait whilst the Ministry of Education experiments with reshuffling funds, trials new approaches and analyses investment?

The MOE acknowledges that demand for services will exceed their forecasts, but it is also stated in the July cabinet paper that the Ministry will examine how the new approach to learning support may free up resources – we find this an incredulous statement when so many deserving children already receive very little or no support at all which means a very large amount of resources will need to be ‘freed up’ to support their needs. It has been confirmed that pupils will continue to receive the same level of support they currently receive and it is good to hear that support will not be withdrawn, but this also adds to our speculation of how a large amount of resources can be ‘freed up’ to provide enough funding for all who need additional learning support? We would like to question what mechanism will signal to the government that increasing the learning support budget is necessary?

An example of underfunding The majority of pupils with PWS present with mild intellectual disability in cognitive testing, with around 25% presenting with moderate intellectual disability, but up to 25% score in the borderline to normal, low IQ ranges of 70-85 with a few scoring higher. Whatever their intellectual abilities, pupils with PWS all present with multiple learning disabilities which often include difficulties in areas such as auditory processing, sequential processing, expressive speech, attention, short term and working memory. However, only approximately 60% of pupils meet the criteria for any learning support

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funding via ORS and many families find that the level of support provided is insufficient. Those who do not qualify for ORS may receive High Health Needs funding, but this is mainly due to concerns with safety around food and may provide a teacher aide to supervise during morning tea and lunch – it is not learning support. From our affiliation to other PWS Associations, we know that in countries like the USA all children with PWS will receive learning support and at a greater level of provision.

Funding for School-age Pupils We also have concerns that the reshuffle of more learning support funding to early intervention may affect the availability of funds for current school age pupils with PWS who are often being poorly supported. Pupils with PWS face life-long educational and behavioural challenges and their needs may increase. Whilst the Learning Support Update accepts that some pupils will have enduring needs which cannot be 'fixed' by early intervention, there will effectively be even less funding available to these pupils. Will the experiment to reshuffle more funding to early intervention result in a freeze on extra investment in learning support for school-age pupils?

Regional Funding The funding for learning support is currently population based, not needs based, and is divided into regional funds which are capped. If there happens to be many high needs pupils in one region, there is less funding per pupil. We often hear of regional discrepancies in support - is the MOE collecting data on whether a child with a certain rating scale in one region is receiving the same support as a child in another region? What data is the Ministry using to set regional learning support budgets?

Discrimination triggered by Funding Inadequacies Currently not all children can attend ECE or school on a full time basis due to a funding cap on their teacher aides making this unsafe. Currently many children miss out on school activities due to a lack of teacher aide support. This is discriminatory and immediate action needs to be taken to ensure pupils are given equal opportunities. The Minister states that strengthening inclusion is a priority so what action will the MOE take?

2. ORS and OPTIONS FOR OVER 18s: The suggestion in the November cabinet paper that there may be better options for some pupils than remaining at school is regional dependent and ideal local opportunities will not exist for all, particularly for those living in small centres with limited availability of specialised supported learning programmes, specialised courses or vocational training. Will the option to remain at school still be available for these pupils even if it is deemed that better options exist elsewhere? We are pleased to see the government recognising that people with disabilities want more choice and control over their lives, but developmental delay also needs to be considered when enabling pupils to exercise choice in how they remain in education until they are 21. Pupils with PWS experience developmental delay in many areas, including social and emotional development. Careful consideration of both their needs, wants and the wishes of their parents should take place when planning their educational future. Our concern is that these proposed changes have originated in an effort to cut costs without due consideration of what may be best for some pupils, their wellbeing and of the needs of their families. An equally wide range of opportunities do not currently exist for people with disabilities as do for their neuro-typical peers transitioning from school, therefore the government should not be considering cutting the educational budget for the 18-21 age group until further transformation of the disability sector has taken place along with thorough research into any benefits and detrimental effects of leaving school earlier. What assurances can the MOE provide in this area?

3. MONITORING PROGRESS: The July cabinet paper refers to the Government wanting to ensure they get a "return on investment" for learning support funding and suggest this links in to progress in National Standards. This is not an appropriate way to assess the value of learning support for all children with disabilities. What data does the MOE collect on the progress, achievement and well being of disabled children? How do we know how well their needs are being catered for? The IEP process of individual goal setting and reviewing progress is good educational practice but it is only mandatory for pupils receiving ORS to have an IEP. Those who narrowly miss out on ORS funding and who will often also have high learning support needs may not have an IEP and their progress is only measured

against National Standards, which they are likely to be achieving well below. Reporting to parents that their child is consistently achieving well below standard is not helpful and only has a negative impact on pupil self-esteem. A recently published NZCER survey revealed a common theme that National Standards offered little to students with additional learning needs and clear concerns about the negative effects of labelling student performance as 'below' or 'well below' over the long term.

We are pleased to see the planned implementation of individualised learning support plans and hope these will be available for all pupils with significant learning support needs. We are also pleased to see a note in the November cabinet paper that the Ministry will collect and manage pupil learning support data from schools to inform decision-making for learning support needs and improve accountability, but we would like to know what measures or format will be used for this data collection? We know there is a gap in knowledge about the progress of pupils who consistently achieve below the standards and are encouraged to see this being addressed, but it is unclear whether this will still involve reporting to parents about their child's progress towards inappropriate national standards rather than their all round progress and development towards meaningful goals. We would also like reassurance as to whether learning support data collection will continue following completion of the pilot scheme and any subsequent investment decisions?

4. EDUCATION AND TRAINING FOR TEACHERS: Following the December 2015 release of the findings of the Government's consultation with stakeholders, six areas were targeted for improvement in the "Update Action Plan". Number one was "Better guidance and training for teachers – from early childhood education onwards". We are pleased that the Government plans to work with the Education Council in developing initial teacher training, but what compulsory professional development for teachers, teacher aides and SENCOs will the MOE providing next year to make some progress on this key objective in their update plan?

The Role of SENCO The November cabinet paper discusses the roles of local Learning Support Teams and Lead Practitioners within the new model, but there is no mention of the role of school based Special Educational Needs Coordinators (SENCOs). The role of SENCO within a primary school is often fulfilled on a part-time basis by a Deputy or Assistant Principal who may have no formal training in this area or a particular desire to pursue learning support as a career path. If teachers and SENCOs are not effectively trained, they may not consistently identify pupil needs which need to be referred to the triage access line or provide the triage access line with appropriate information (as exemplified in appendices 2 and 3 of Next Steps Nov 21). We would like to see more status given to the position of 'Learning Support Coordinator' (SENCO) as a specialised role within schools as this is the person teachers can seek immediate guidance from to inform their planning, teaching and assessments; the person that may regularly liaise with parents / whanau and the person who may coordinate school-wide support programmes. According to the YouthLaw report 'Challenging the Barriers', the role of SENCO is not formalised and receives no additional staffing entitlement, there are no qualification requirements and the quality of SENCOs varies greatly. SENCOs often receive very limited specific release time from other duties and a NZEI survey revealed that just under half of SENCOs receive no specific release time at all. The lack of provision for a qualified SENCO is a major barrier to schools ability to provide supportive and inclusive education. We would like to see the profile of SENCO / Learning Support Coordinator raised and would like to know if the MOE intend to target dedicated funds to this?

The Role of Teacher Aides We would also like to see the availability of appropriate training for Teacher Aides and their profile raised to Learning Support Assistants / Facilitators.

Training in Behaviour Management for Pupils with Behavioural Challenges Given the recent changes to policy regarding seclusion and restraint, we understand guidelines are being provided to schools to update their behaviour management practices. Access to specialist behaviour support services such as RTLB and the Intensive Wraparound Service are already extremely limited, so in what form will the MOE be extending training in this urgent area of need?

5. COMMUNICATON SERVICES: In the November cabinet paper, the MOE admits there is a rising demand for services, that gaps in services exist due to funding caps and there is a proposal to explore different ways of providing communication services, particularly in the early years. A possible increase in the number of therapists is welcome news and desperately needed. However, the focus appears to be only on creating change for service delivery in the early years and the demand for communication services amongst older children is expected to decrease in time. The MOE states "Older children will continue to receive services based on their needs" but this contradicts an earlier summary of current provision in section 47 which affirms that some children with communication difficulties do not meet the criteria to access services, there is limited support available during the first three years at school and no support after the first three years at school (unless a pupil is ORS funded). Many parents of children with PWS find it extremely difficult to access any speech and language support, the support available is often regional dependent and support during school years can be non-existent, yet many children with PWS have ongoing communication difficulties and parents sometimes self-fund ongoing private therapy. Children with developmental delay or Autism may not even begin speaking until school age, and children who will always be non-verbal will need assisted communication device support throughout school.

Rather than older children 'continuing' to receive services, we would like to see older children 'start' to receive services based on their needs. Can the MOE be clearer about what provision will be available for school age pupils?

6. RIGHTS TO INCLUSIVE EDUCATION The Learning Support Update makes references to the NZ Bill of Rights 1990, The Human Rights Act 1993, Article 24 of the UN Convention on the Rights of the Disabled Person and the UN Convention on the Rights of the Child, yet despite declaring a commitment to strengthening inclusion, we were very disappointed to see no provision for legally ensuring the right to an inclusive education within the proposed amendment to the Education Act 1989. Boards of Trustees will have an obligation to ensure inclusion but there will be no safeguards to ensure this obligation is upheld. Under the self-governing schools model accompanied by the inadequate review process by ERO, many pupils are quietly excluded from school activities, a lack of resourcing can be too easily excused and parental complaints can be ignored. The ineffectiveness of this system has been recently highlighted by the continued inappropriate use of seclusion rooms for so long, apparently unnoticed.

Currently there is a lack of internal complaint reporting within schools. Boards of Trustees are not required to have a system for recording the management of complaints. When unresolved issues are brought to the attention of MOE, they are often referred back to the BOT. It is far too easy for parent concerns to be ignored. In their recently published "Challenging the Barriers" research, YouthLaw have called for an independent body to deal with complaints and have asked for the creation of an Education Tribunal with broad jurisdiction and the power to make binding decisions and directions to schools and the MOE. Does the MOE support this idea? Also, how can the complaints process be made easier for parents without the need for escalation to tribunals? Does the MOE consider the structure of BOTS which may contain volunteers who have no experience of disability to be conducive to ensuring inclusion within schools?

We are pleased to see parental voices will be listened to as increased parent / whanau satisfaction with the access to and quality of services will be counted as a measure of success of the new model, but if the MOE is truly committed to building an inclusive education system, the rights of pupils to an inclusive education need to be formally protected. How will the MOE achieve this?

Kind regards



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on behalf of PWSA(NZ) Inc.

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