



SUPPORTING PEOPLE WITH PRADER-WILLI SYNDROME AND THEIR FAMILIES

Prader-Willi Syndrome Association (NZ) Incorporated

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Submission to: Ministry of Education, PO Box 1666, Wellington 6140
Via email: education.update@education.govt.nz

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Updating the Education Act 1989

Introduction

This is a brief submission as we have already indicated our main concerns regarding the support of pupils with special educational needs to the recent Parliamentary inquiry by the Education and Science Subcommittee. We also feel that this update is not addressing the key issues affecting pupils who have special educational needs, which in turn would have a positive impact on the learning experiences of all children if acted upon.

Making sure everyone knows the goals for education

The goals for education should ensure that ALL children are able to learn to their full potential and for some children, this means more support is essential. For some children, an adaptation of curriculum content may be required so that a pupil can be learning important life skills and working towards independence – currently only those who receive ORS funding are exempt from working towards and being assessed against National Standards. Preparing for a meaningful adult life and enabling a smooth transition is of high priority to many parents of children who have PWS.

Supporting boards to focus on what's important

We would like Boards to have a clear responsibility for ensuring inclusion in their schools. Children who have special education needs are often unable to participate in school events, camps, productions, sports activities, excursions etc. Children should not be discriminated against due to behaviours that are typical of their diagnosis. When parents have concerns about inclusion practices and discrimination, they need a point of contact on the Board of Trustees if difficulties cannot be resolved with their school. Boards need to be accountable to the Ministry of Education for ensuring inclusion takes place.

Parents often have to 'battle' for their child's rights – they deserve the reassurance that their concerns will be heard and their children will be treated fairly.

Enabling collaboration, flexibility and innovation

We would like to see schools collaborate and share expertise, particularly in the field of special educational needs. Some schools are very successful in managing the needs of pupils with special educational needs and as a result, become a 'magnet school' for parents who hear of its good reputation. We would like to see these schools being able to share their approaches, methods and resources. We also support any changes that create opportunities for more equitable access to specialist support services or resources.

We would like to see the flexibility remain for the school starting age. Whilst many parents believe their children who have PWS have every right to attend school with support systems in place from age 5, other parents prefer to wait until their child is more 'ready'. As all children with PWS are unique, their developmental delay in the early years varies, and so does the age at which they will be ready for school.

Making every school and kura a great one

We strongly believe that an inclusive ethos is essential in the making of a great school. Central to this is having a great SENCO as facilitator. If a great SENCO is leading the way and promoting inclusive and innovative teaching approaches, we feel that less problems would arise in schools. We would like to see better training for SENCOs and the sharing of expertise.

Making best use of local education provision

Area strategies could include the improved sharing of specialist support services, resources and expertise. Where there are special units or special schools in an area, their knowledge, experience and approach could be shared with others.

We support any changes that allow more enrolment choice for children who have special educational needs.

Summary

We feel that an updated Education Act needs to reflect and celebrate the diversity of learners and their needs. It needs to make clear that all children have a right to a fully inclusive education and that measures must be put in place to ensure this happens. Inclusion is not simply allowing a child to enrol in a mainstream school; it is putting the supports in place that allow equal opportunities.

We would like to see the focus move away from all children working towards achieving standard curriculum levels and a recognition that a more individual approach is required for many. We agree that progress and achievement needs to be measured, but for many this can be done through the IEP process. We would like to see schools welcoming pupils with special educational needs without concern that their standard achievement results will be affected.

However, we believe that a real rise in the achievement of pupils with special educational needs will not take place whilst the sector remains so grossly underfunded.