



SUPPORTING PEOPLE WITH PRADER-WILLI SYNDROME AND THEIR FAMILIES

## **Prader-Willi Syndrome Association (NZ) Incorporated**

Submission to: **Committee Secretariat, Education and Science**  
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### **Education (Update) Amendment Bill**

#### Introduction

This PWSA(NZ) submission advocates for our family members who have a child with Prader-Willi syndrome. In this submission we focus on sections of the Education (Update) Amendment Bill that are relevant to the issues and concerns raised in surveys and communications with our members.

PWS is a genetic disorder caused by an abnormality of chromosome 15, affecting approximately 1 in 16,000 New Zealanders. PWS causes a variety of health issues, behavioural challenges, physical and cognitive disabilities.

Most children are diagnosed as having a mild intellectual disability, some have moderate intellectual disability and a few have cognitive abilities in the borderline to low average range. Currently within the NZ education system, nearly all children with PWS attend mainstream schools and approximately just under 40% of children with PWS do not meet the criteria for any learning support via the ORS fund.

#### General Position

The PWSA(NZ) would like to see the government use the opportunity of an Education Act update to incorporate legislation to ensure that the rights of pupils to an inclusive education are upheld.

Within the current model there is no mechanism in place to ensure pupils with disabilities are not discriminated against and are given equal opportunities. There needs to be provision within the Education Act to ensure schools meet their obligation of providing an inclusive education. Currently schools can self-review their inclusive practice and deem it to be satisfactory whilst this opinion may be at odds to the views of parents who have no input to the review process. The PWSA has heard stories from members of being discouraged from enrolling children with PWS at early childhood centres and schools, suggestions to parents that they provide financial support for a teacher aide, children only being allowed to attend school part-time, behaviour and bullying being inappropriately managed and children being unable to participate fully in school activities, such as trips and camps. Sometimes a BOT may be unaware of failures in inclusive practice due to insufficient internal reporting, and because many parents do not take complaints to the Board of Trustees as they do not want to jeopardise any support a school offers or may offer when there is so little available in the underfunded special education sector. Our children are vulnerable and their rights need protecting.

The PWSA appreciates that whilst many schools do their best to provide an inclusive education, inclusion can be difficult to achieve in the current climate whilst a lack of understanding, training, funding and resourcing exists.

We believe a fundamental shift in inclusive attitudes, greater accountability and a change in government priorities are required.

### Detailed Comments

We wish to make the following comments on sections of this Bill:

#### **Schedule 2 (schedule 6 replaced), Part 2: Powers and Functions of Boards**

##### **4 Board is governing body of school**

(1) A board is the governing body of its school.

(2) A board is responsible for the governance of the school, including setting the policies by which the school is to be controlled and managed.

##### **5 Board's objectives in governing school**

(1) A board's primary objective in governing the school is to ensure that every student at the school is able to attain his or her highest possible standard in educational achievement.

(2) To meet the primary objective, the board must—

(a) ensure that the school—

(i) is a physically and emotionally safe place for all students and staff; and

(ii) is inclusive of and caters for students with differing needs;

##### **13 Board has complete discretion**

A board has complete discretion to perform its functions and exercise its powers as it thinks fit, subject to this and any other enactment and the general law of New Zealand.

We are pleased to see the responsibility for inclusion outlined above but are disappointed that these changes are not supported by due processes for when a Board fails to fulfil its obligations. Will parents be aware of the obligation of BOTS to ensure a school is inclusive and know of a procedure to follow if the BOT does not meet this obligation?

Boards of Trustees consist of community members who may have no experience of disability and may have a poor understanding of inclusion. The BOT will rely on information from the Principal (CEO) – how will inclusive practice be monitored within a school? What checks will be in place to ensure a Principal or Board do not exercise discretionary powers in a discriminatory manner?

One recommendation to ensure inclusive attitudes exist within a BOT is to structure Boards to include representative members from the disability sector. We would also like to see greater accountability for inclusion, the Ministry of Education provide advocacy for families when needed and an independent complaints body which would be able to resolve issues promptly.

#### **Clause 30, Section 25 amended: Students required to enrol must attend school**

(3A) Despite subsections (1) to (3), if a child is aged 4 or 5 and is enrolled at a registered school,—

(a) the child's parents, the principal, and the Secretary may agree a plan to help the transition of the child to school, depending on the particular needs of the child; and

(b) the child is required to attend school in accordance with the plan.

We have concerns that this enables a principal to limit the attendance of a child with additional needs against the wishes of the parents. It is not clear how much weight is given to the views of the parents in the transition plan agreement.

Parents often transition their children to school with initial part-time attendance, which is appropriate for some children with PWS, and the flexibility for transition to school must remain. However, sometimes part-time attendance is encouraged because the school feel more support is needed and they only feel able to offer part-time support. Parents should not feel pressured into a part-time attendance option because it appears to be the only option available for their child.

We recommend resourcing should be available so that all children can be supported as needed when transitioning to school and following discussion with the school and special education advisors, parents should have the right to choose an appropriate transition plan for their child.

### **Clause 43, Section 61 replacement: Teaching and Learning Programmes**

The board of a school must ensure that the school's principal and staff develop and implement teaching and learning programmes that—

- (a) give effect to any foundation curriculum policy statements and national curriculum statements in force under section 60A; and
- (b) give effect to any national standards in force under section 60A; and
- (c) give the school's students access to a nationally and internationally recognised qualifications system.

### **Clause 43, Section 62 replacement: Monitoring of and Reporting on Student Performance**

- (1) The board of a school must ensure that the school's principal and staff monitor and evaluate the performance of the school's students.
- (2) Monitoring and evaluating must include, but is not limited to, monitoring and evaluating the performance of the students in relation to—
  - (a) any national standards in force under section 60A; and
  - (b) any qualification systems referred to in **section 61(c)** that are offered at the school.
- (3) The board must ensure that information about a student's performance is given to the student's parents in a timely manner and in a form that is readily understandable.
- (4) The board must report to the Secretary, to its school community, and to parents on the performance of the school's students in accordance with any regulations made under **section 118A**.

It is concerning that there is no direction for teaching and learning programmes to be individualised when aspects of the national curriculum are inappropriate and / or when learning support interventions are required. There is also no requirement to monitor and evaluate the performance of students in relation to individualised learning programmes. At present, there is only a requirement for those who qualify for ORS funding to have an Individual Education Plan (IEP), but we believe these are essential for all children who have learning support needs.

We recommend IEPs or Learning Support Plans become compulsory for pupils who need them.

There is a clear focus on student academic performance and qualifications but schools also need to ensure teaching, learning and evaluation relates to the general development of pupils for whom working towards a national standard is unreasonable, or for whom other goals need to be prioritised. Schools need to be able to measure the progress of some pupils toward meaningful goals in alternative ways and therefore build a more accurate picture of their school performance.

### **Clause 96, new section 118A inserted: Regulations about planning, implementation, monitoring and reporting**

The required publication of four yearly strategic plans and annual implementation plans on school websites is good for transparency but we question what monitoring will take place to ensure these are followed, especially in regard to vulnerable groups such as pupils with special educational needs.

There is no mention in this section that annual reports, strategic and implementation plans or performance reports need to include any data on provision for pupils with special educational needs and their progress. Improvements are needed in the collection of statistics and data in this area. Information should also be gathered on the inclusion of pupils and any complaints received and resolved. The ERO school review system relies on Self-Review Audits and Board Assurance Statements and does not allow opportunities for parental input. The opinions of those who understand our very individual children best are not valued. Parent complaints are not recorded and are handled at the discretion of the Principal and Board. Therefore, the needs and concerns of minority groups can be quietly ignored and this Bill does not rectify this issue.

### **Clause 38, New Part 3A inserted: Communities of Online Learning**

#### **35ZF Enrolment at full communities of online learning**

A person must not be enrolled at a full community of online learning unless the person's enrolment is in accordance with any conditions set by the Minister on accreditation of the community of online learning.

#### **35ZG Fees for enrolment or tuition at communities of online learning**

A community of online learning may charge fees to the categories of students specified in regulations made under **section 35ZO**.

### **35ZO Regulations relating to communities of online learning**

The Governor-General may, by Order in Council, make regulations for communities of online learning, and the regulations may prescribe any or all of the following matters:

- (b) the criteria for enrolment at a full community of online learning, and different criteria may be fixed for all or any of the following:
  - (i) different communities of online learning;
  - (ii) communities of online learning of different classes or descriptions;
  - (iii) early childhood, primary, and secondary classes at communities of online learning;
- (c) the categories of communities of online learning that may charge, and the students that may be charged, fees for enrolment and tuition at a community of online learning;
- (d) the requirements for attendance in sections 20 and 25:

The PWSA(NZ) cannot speak for members regarding their approval or disapproval of the establishment of Communities of Online Learning, but we wish to raise concerns regarding potential risks to children with special educational needs. We feel this Bill needs more clarification around the following issues:

Will there be regulations to ensure the availability of a variety of online learning programmes to suit individual learning needs?

What training and expertise requirements will COOLs be required to have to cater for specific needs?

Will there be equitable access to COOLs?

What assurance can be provided that COOLs will not be used as a tool to coerce children with special educational needs from the state school environment, informally excluding them?

More information is required about how COOLs will provide for pupils with additional needs, how provision will be monitored, and what Ministry of Education supports and interventions will be in place.

### **Clause 47, New Section 71A inserted: Off-site locations for schools**

- (1) This section applies to the use of off-site locations by schools to provide education to 1 or more students on a long-term or full-time basis.
- (2) The Minister may, by written notice to the board of a school, approve the use of an off-site location by the school.
- (3) The Minister may issue a notice under **subsection (2)** only if he or she is satisfied that the board and the owner or occupier of the off-site location have both agreed to that use and the terms of that use.
- (5) In any case, following notice of approval being given and before any use is made of the off-site location, the board must enter into a written agreement with the Secretary that sets out—
  - (a) who is responsible for the education provided at the off-site location;
  - (b) who is responsible for the welfare and safety of the students at that location;
  - (c) the terms agreed on any other matter the Secretary considers relevant in the particular case.

This section raises similar concerns to those made above regarding Communities of Online Learning - parents of pupils with additional needs may feel pressured into their child being educated at home or at an off-site location and clarification on the purpose of off-site locations is needed.

The Bill does not include detail of what will happen when a parent does not agree to their child being educated at an off-site location.

### **Clause 48, Sections 75A-75E: Communities of Learning**

#### **75A Community of learning approved by Minister**

- (3) The Minister may approve a community of learning only if the Minister is satisfied that—
  - (a) the purpose of the group is to come together for the purpose of raising achievement for children and young people; and
  - (b) the membership of the group that will form the community of learning is appropriate having regard to that purpose.

#### **75B Secretary may enter agreement with community of learning**

- (1) The Secretary and the members of a community of learning may enter a community of learning agreement.
- (2) The matters that a community of learning agreement may provide for include (without limitation) any or all of the following:
  - (a) the activities that the community of learning will undertake;
  - (b) the commitments of individual members of the group in carrying out the activities;
  - (c) any resources that may be provided to carry out the activities;
  - (d) any data collection requirements related to the activities;

(e) the format and content of the plans and annual reports required under **sections 73C and 73D**.

(3) Each member is jointly and severally liable for the obligations and responsibilities of the community of learning set out in the agreement.

#### **75C Community of learning that has agreement with Secretary must also prepare plan**

(1) A community of learning that has a community of learning agreement with the Secretary must —

(a) prepare and maintain a plan to cover a period agreed to by the Secretary; and

(2) The plan must have regard to the statement of National Education and Learning Priorities (if any).

#### **75D Report to Secretary by community of learning**

A community of learning that has a community of learning agreement with the Secretary must report annually to the Secretary regarding—

(a) its performance and progress in relation to the activities it has agreed to undertake; and

(b) the use of any resources provided to or by the community of learning in accordance with the agreement to carry out the activities.

The PWSA welcomes opportunities for schools to share expertise and Communities of Learning have the potential to benefit pupils by supporting inclusion and providing additional or new learning opportunities. However, with each COL member being jointly and severally liable for the obligations and responsibilities of the COL, there is a risk that pupils with very individual needs will not have their needs met due to the joint focus of the COL agreement and / or a breakdown in accountability. Whilst being able to benefit from a COL agreement, there also needs to be separate, additional planning and monitoring systems in place for children with learning support needs.

The sharing of knowledge, expertise and resources has the potential to be of great benefit to pupils, but in an already over-stretched system with limited learning support for pupils, there is also a risk that the sharing of staff and resources may cause resources to be stretched further with negative consequences for pupils. The Bill needs to stipulate that a COL agreement shall not result in a reduction of services or funding.

### **Clauses 55 - 64: Risk Management Schemes**

#### **56 Section 78I amended (Application of interventions)**

(1) After section 78I(1)(c), insert:

(ca) a requirement by the Secretary that the board attend a case conference to enable a particular issue or issues to be discussed and actions to be agreed;

(cb) a requirement by the Secretary that the board engage an appropriately qualified person to undertake a specialist audit of any aspect of the school's affairs;

(cc) the issuing by the Secretary to the board of a performance notice requiring the board to carry out a specified action by a specified date;

(cd) the appointment by the Minister of a trustee (who may be the chairperson) to the board for a specified period of time;

(2) After section 78I(1), insert:

(1A) The Secretary may apply any of the interventions described in subsection (1)(a) to (cc) to a school if he or she has reasonable grounds for concern about the operation of the school, or the welfare, or educational performance of its students.

#### **57 Section 78J amended (Requirement to provide information)**

After section 78J(1), insert:

(1A) The Secretary may also require, in the notice, that an analysis of the specified information be provided.

Replace section 78J(3) with:

(3) A board that receives a notice under subsection (1) must provide the Secretary with the information required and an analysis of the information (if this has been sought) — and

(b) in the form (if any) required by the Secretary.

#### **58 Section 78K amended (Specialist help)**

(1) After section 78K(2), insert:

(2A) The Secretary may also require, in the notice, that the board provide to him or her a report or reports (for example, a progress report and a final report) on the specialist help —

#### **60 New sections 78LA to 78LE inserted**

After section 78L, insert:

##### **78LA Case conference**

(1) The Secretary may, by written notice to the board of a school, require the board to attend a case conference on a specified date.

(2) The notice must particularise the issue or issues to be discussed.

(4) The Secretary may invite any person to attend the case conference, if the Secretary considers that the person's presence at the conference is desirable.

(5) If the case conference results in the parties reaching agreement on any action or actions to address any issue or issues, the agreement—

(a) must be recorded in writing; and

(b) is binding on the parties.

(6) If the Secretary and the board are not able to agree on an action or actions to address any issue or issues, the Secretary may, by written notice to the board,—

(a) require it to take a particular action or actions; and

(b) require it to provide to him or her a report or reports (for example, a progress report and a final report) on the action or actions taken—

#### **78LB Specialist audit**

(1) The Secretary may, by written notice to the board of a school, require the board to engage an appropriately qualified person to undertake a specialist audit of any aspect of the school's affairs.

#### **78LC Performance notice**

(1) The Secretary may, by written notice to the board of a school, issue a performance notice requiring the board to carry out a specified action by a specified date.

(2) The Secretary may also require, in the notice, that the board provide to him or her a report or reports (for example, a progress report and a final report) on the action taken—

#### **78LD Appointment of additional trustee by Minister**

(1) The Minister may, by written notice to the board of a school, appoint an additional trustee of the board, and the Minister may also appoint that trustee as the chairperson.

#### **78LE Amendment and revocation of notices**

(1) The Secretary may at any time, by giving written notice to a board, amend or revoke a notice given by him or her under this Part.

Clarification of the complaint process to the Secretary is required. Will parents be aware that they are entitled to take complaints to the Secretary when performance issues cannot be resolved with the Board? Accessible guidelines for parents are needed.

In the above clauses, the interventions designed to help schools experiencing difficulties in ensuring the achievement of all pupils are all dependent on the Secretary or Minister. What independent investigative systems will be in place to ensure the accuracy of information supplied to the Secretary by the Board? There is also no allowance for feedback from parents or complainants regarding the success of interventions. Our members tell us that having a child with a disability means a lifetime of advocating for them - it can feel like an ongoing battle and they are so relieved when their child's needs are understood and provided for without the need to advocate for them. Our members state that they do not want to be the parent that has to complain and it takes great strength to do so when you are a minority group. It is therefore very disheartening to see parents are voiceless in this process and their opinions not valued.

#### **Clause 107, Section 154 amended: Closure of Schools**

(2) After section 154(2A), insert:

(2B) A decision to close a school under subsection (2) is in the Minister's absolute discretion.

#### **Clause 113, Section 157 amended: Consultations**

(1) In section 157(3), replace "without first consulting" with "unless **subsection (3A)** applies, without first consulting".

(2) After section 157(3), insert:

(3A) Subsection (3)(f) and (g) does not apply if the relevant board or boards have already been consulted on a closure or merger option as part of a review of the provision of schooling in a particular area.

These amendments in the Bill are very concerning to the PWSA and our members. Whilst we strongly believe in creating an inclusive education system, we have also long been a supporter of Salisbury School which the Ministry is trying to close. We believe that there are fundamental flaws in the inclusive nature of our education system which means that special residential schools like Salisbury are needed. We are also aware of the positive

impact residential schools have on pupils with PWS and support parental choice in being able to choose the most appropriate schooling option for their child, especially when their needs are not being met elsewhere.

Clause 113 limits the requirement for the Minister to consult about the possibility of closing a school or merging schools. We understand that the consultation process is prolonging the length of time it may take for the Minister to achieve her aim of closing Salisbury School (and indeed pupils with PWS currently attending are also left in limbo as to whether they will return to school in the next term), but the consultation process is entirely necessary and in this case, has highlighted the depth of feeling towards maintaining this school by a large group of supporters. Salisbury School provides a unique educational experience that cannot be fully understood without an essential, in-depth consultation process. The absolute discretion to close a school given to the Education Minister in clause 107 is extremely worrying as these decisions cannot be made lightly with so much at stake. We recommend that this section be removed from the Bill.

### **Clauses 140-143: Competence Authority**

#### **141 Section 410 amended (Complaints about competence)**

After section 410(3), insert:

(3A) The Education Council may, after any investigation it decides to make, refer to the Competence Authority a complaint or other matter that relates to competence for a decision as to whether the required level of competence has been attained.

We appreciate that a Competence Authority has been established to speed up the competence complaint resolution process, but the process for making a complaint needs to be simplified for families too. It also needs to be clear to families how complaints can be made and the correct steps to follow to reach a satisfactory resolution.

Families who have a child with PWS who are experiencing disappointment or difficulties with their school may feel isolated within their school community due to their child's rare and unique needs. They need reassurance that there is a clearly advertised procedure to follow if obligations are not being met. They need to know that their concerns will be listened to and acted upon.

We do not know of any cases where our members have had complaints investigated by The Education Council and can assume most complaints made are managed by teachers, Principals or Special Education offices. We know of rare instances where complaints have been referred to the Board and know that families have been let down by this process when the Board has failed to act on parental concerns.

We recommend the introduction of a well advertised, clear and fair complaints procedure where steps can be escalated until resolution is reached. Complaints should be positively managed with confidence. Positive and fair experiences of making a complaint will lead to a more positive view of the education system for pupils with additional needs and their families. Effective management and monitoring of complaints made at school level should reduce the need for further escalation.

### **Clause 144, New Part 33 inserted: State Integrated Schools**

#### **442 Preference of enrolment**

(1) The children of parents who have a particular or general philosophical or religious connection with a State integrated school must be preferred to other children for enrolment at the school.

(2) Subject to **subsection (1)**, no prospective student may be refused enrolment at a State integrated school on the grounds of —

(a) religion, race, or socio-economic background; or

(b) lack of willingness of the parent to make financial contributions to the school.

Enrolment rights in this section do not specify that a student cannot be refused enrolment on the grounds of disability. We would hope that this is an error and expect this to be rectified because to refuse enrolment on the grounds of disability is contrary to other sections of the Education Act and would not be in alignment with the Human Rights Act.