



Education Act Update
Ministry of Education
PO Box 1666

Thursday 10th December 2015

Wellington 6140

education.update@education.govt.nz

Submission on Review of the Education Act 1989

Introduction:

Albinism Trust is a voluntary not for profit organisation which is committed to emphasising positives and achievements by people with Albinism. The Trust was established at Palmerston North on Saturday 6th October 2007. On 1st April 2008 we were Registered with the Charities Commission [Reg No CC22352]

Our Trustees are Allen Little – Levin; Richard Baines – Hutt; Dr Don McLaren – Rotorua; Rod Buick – Geraldine; Jan Crews – Auckland. All Trustees are Albinos.

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We aim to share ideas and information which enables people with Albinism to live, learn, work and play. Further to be a resource hub for parents and families of children with Albinism. The Trust strives to foster and promoting understanding along with positive attitudes about Albinism. When necessary we act as an objective advocate for persons with Albinism. The Trust is aligned with the Blindness Sector Forum (NZ) and collaborate with various organisations seeking to advance the interests of Blind and Sight Impaired persons.

There are estimated to be about 109 children known to have Albinism in New Zealand. Explaining “Albinism” to children can be difficult. It’s hoped our publications will help parents to have realistic expectations about children with Albinism.

In New Zealand we are fortunate to have a dedicated team of highly trained professional educators involved with “BLENNZ” who are available to support Children in their learning.

Albinism Trust NZ
7 Earl Street, Levin 5510

www.albinism.nz
Ph (06) 367-5900



The Ministry will be aware of the BLENNZ mission and purpose. We hope there would be realistic advocacy for funding and service provision to assure children, young person's and their support networks are resourced to enable successful learning. Albinism Trust supports the BLENNZ model and hopes the present review will enable the organisations longevity.

Principal Concerns:

- **Special needs children and young people in New Zealand struggle because the 1989 Act has failed to deliver.**
- **Learning is a whole of life process carried on in a developed economy. People with Albinism can excel with assistance and due consideration.**
- **Parents and whanau of children or young persons with Albinism need reassurance that students will not be disadvantaged in their education.**
- **Sun safety and commitment to both class room and playground design are important.**
- **We strongly advocate for provision of all learning media in accessible formats and peer appropriate styles which encourage ownership.**

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Response to document:

Regardless of age, gender or cognitive capacity we believe the law around education needs to reflect the basic right of every child and young person to have an education which equips them for success in life. The **goals for education** should be around enabling all children to develop as well balanced, energised and engaging citizens who thrive whilst making a positive contribution to our shared society. When a child lives with Albinism we assert that they are entitled to benefit from education and learning which should be enabled through un obstructed access to such aides, appliances, devices or technologies as are needed to ensure success.



Provision of such aides, appliances, devices or technologies should be facilitated with assured Government funding which is not a charge against local school or college budgets.

The process used for setting a national priorities statement for early learning and schooling needs to begin around engaging with whanau in the domestic situation. There needs to be a developmental continuum from earliest infancy through to Tertiary level. This should begin with data capture around health and milestone attainment. Setting national priorities is not about defining some 'one size and style for all' but about understanding the breadth of individual differences represented across the paediatric demographic. Priorities should accommodate the real needs of all students from point of entry. From the early childhood sector children should progress into schooling furnished with a profile which confirms their Sensory and Developmental maturity or capacity. The Ministry of Education would then be able to gather data on potential students and support local or nominated schools as they prepare for a student to enrol. This whole preparedness strategy would enhance potential success and equipping to meet educational needs.

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Albinism Trust believe any new provisions need to make clear in law that children and young people have a right to learn and raising individual achievement, is of uttermost importance. We believe law makers must use unambiguous precepts to make clear to schools, kura and early learning services what is expected of them. Standards are one thing attaining them is another. There needs to be more clarity around direction which says who is responsible for what, and how schools or kura should plan their priorities and report on progress. **The roles and responsibilities of a school or a kura board** will be around Governance whilst the Principal teacher would be responsible for operational matters such as Individual Learning Plans and Curriculum compliance.



Its important for everyone who engages with the education sector to be clear about expectations and reassured that individual pupils or learners will not be disadvantaged by systemic inefficiencies. The Board will receive its funding and needs to make sure it is not misappropriated in the face of other more demanding priorities. The Board will keenly monitor expenditure and assure money intended for Blind and Sight impaired students is spent for purpose. In its Planning and Accountability reporting The Board will confidently assure there has been no diversion of funding toward local in-house priorities.

The law should enable schools, kura, Communities of Learning and child support learning services to work collaboratively delivering the best education for every child and young person.

To ensure **simplifying of planning and reporting** we need to begin planning and enablement early in a child's education and cluster needs to be met with resources in a timely manner. Every School could be connected on-line and furnish reports according to demand. Analysts could then gather the data and formulate quality reports for Policy Planners and Administrators. Key to success is capacity to access and extrapolate data. It is important to minimise 'black-hole-bureaucracy' which does not give added value to the school or enhance the pupil experience. Stream lining systems administration **will enable groups of schools and kura to work together in their planning and reporting.**

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Albinism Trust wants to support and encourage increasing cultivation of public engagement with schools and kura. Reporting should happen openly and honestly so as to celebrate the diversity of learning which has been experienced within the curriculum. The community will appreciate unambiguous sharing of actual results and achievements.

Parents who are informed participate.



Reporting on school performance is about outcomes for children and young people. These are reflected in achievement to when communicated to parents, family, whānau and communities?

We believe a review of the Education Act needs to anticipate evolution of modern innovative learning environments. Historic methodology is not a sound basis for progressive learning. Modern children need to be enabled to learn and achieve. Albinism Trust are of the opinion that learning is a whole of life issue founded on infrastructure which inspires discovery and acquisition of the building blocks of knowledge.

A reflection of the indicators and measures for school performance plus student achievement and wellbeing are:-

1. Self respect, personal dignity and liberty
2. Energised Engagement for common good
3. Capacity extension and sharing
4. Pursuit of Unit Standards
5. Ethical and social concern
6. Community well being
7. Mental and Physical fitness
8. Tolerance and inclusiveness
9. Innovation and inventiveness
10. Respect for other persons and property

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One of the challenges New Zealand faces is underachievement. We turn young people out from tertiary education with little or no hope of them securing employment in a field which satisfies. When you present with a disability there are obstacle's to overcome. Schools should be equipped to identify potential vocational challenges and respond with innovation's such as providing increased vocational support. Boards and Executive **teachers should be free with decision-making authority** to modify and adapt the learning environment to enable community responsive education.



School, Kura, College, Tertiary and such like Boards should be encouraged to collaborate and share resources whenever it is desirable to do so. **Boards could work more closely together** around Professional Development; Safety Management; Security; Innovation and resource sharing.

We believe schools and kura should have whatsoever flexibility and empowerment is desirable or necessary, including **capacity to operate with flexibility to introduce cohort or group entry** where the need is justified or in the interest of student.

We strongly advocate for provision of all learning media in peer appropriate styles which encourages ownership. Generally the parents of children and young people throughout the country seem to encounter a lack of transparency when it comes to accessing education and associated learning resources. Our colleagues at PVI have found from their research that Blind and Sight impaired children often have a variety of disabilities requiring different teaching and education techniques extending beyond the school and classroom to our families and homes. There have been some 79 amendments to the Education Act since 1989 and the wider world has changed with the passage of time. **Albinism Trust** believes attendance should be **compulsory for children once they have started school or kura before they turn six years old** and there needs to be a clear continuum from Early childhood / preschool learning. A significant number of young Albinos are amongst the 3500 or so children with Blindness and Vision impairment educated under the 1989 Act. Since 2000 the reshaping of education services for blind and vision impaired children seems to be more constrained than educators would like. Collaboration with the Ministry of Education, Blind Foundation, teachers and staff at Homai College, plus the Visual Resource Centres and parents evolved into the world class model for the delivery of education services we have today. Today many students with Albinism are mainstreamed.

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There are any number of situations where proposals have been made either to establish and open new facilities or close, amalgamate or administer sites. Full frank and timely **consultation are important with communities** on concepts and strategies. A comprehensive Social Analysis needs to be commissioned in order to reassure interested parties. To answer a hypothetical question concerning **what should be taken into account when making decisions about opening, merging or closing schools** is not something to which a simple answer can be given. **Albinism Trust** would hope promulgator's of such proposals would have genuinely engage with communities of interest on any proposal. We don't have an opinion about the **proposed changes to improve how enrolment schemes are managed** except to say critical to ultimate success is to formulate a firm proposal and openly consult those interested.

We believe every pupil in the education system has an inalienable right to receive an education which equips them for advancement and success in life. For most children learning happens naturally as a consequence of exposure to age appropriate curricula. Learning involves the acquisition of knowledge or skills through study, experience or teaching. All education involves a mix of media and instruction.

For a person with sight impairment adaptive technologies and reading assistance are important.

Albinism Trust is aware that many people with Albinism become adept at extracting information through what might be seen as alternative strategies. When they can't see an object an albino will often revert to a supplementary way of gathering clues, remembering descriptions, to be checked out later. The affect of this 'delay' can potentially be misinterpreted in assessments or otherwise reported as behavioural inattentiveness.



The Education Act review needs to provide for more reliable assessment and reporting which takes account of individual capability and learning differences. It is noted that approximately 65% of Blind and Low Vision students present a variety of complex needs. For a person with Albinism this will include a need for playground Sun safety. The review must somehow assure parents and families of a commitment to sun safe playground design.

One of the issues for young families of Albino children is around how they meet the added costs of education. The Ministry Of Education does not keep data on the numbers of students with Albinism funded by the ORS scheme. As at 7 December 2015 the number of students with ORS funding was 8759 with a total funding of some \$152 million.

	Enrolled at School	Not Enrolled at a school	TOTAL
High	6529	175	6704
Very High	2047	83	2130
ORS Extension	183	0	183
Total	8759	258	9017

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Over several years our constituency has asked questions about the criteria for and levels of ORS funding. There seems to be some perceived mystique around process and expectations. The Ministry Of Education do provide full information about ORS funding on line at:-

www.education.govt.nz/school/student-support/special-education/ors/

We are unclear as to how this might be improved except to say the issue has been brought to our attention. It's possible that there might be a degree of localised confusion arising when people do not understand funding mechanism's. From earliest contact we believe clear, logical and unambiguous information about funding should be discussed with and provided to Parents and Whanau. In reviewing the Education Act 1989 policy makers need to reflect on the ways information is communicated.

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Our primary concerns are around the education, training and equipping of children and young persons with Albinism who are currently on the BLENNZ Roll and number 109 persons.

<u>Age Bands</u>	5 & under: 24
	6 – 15yrs: 67
	16 – 21yrs: 18

Regional Vision Resource Centres

Northland	4
Auckland	30
Hamilton	10
Tauranga	6
Gisborne	2
Napier	3
Taranaki	7
Palmerston North	4
Wellington	15
Nelson	2
Christchurch	19
Otago	3
Southland	4

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There is also an additional smaller fringe grouping who's visual acuity places them in the Low Vision category and they are still likely to struggle at school.

Albinism Trust support's early connection with BLENNZ. All children require opportunities to mix with others of a similar age in order to develop social skills, be able to form friendships, solving problems or sharing experiences. Of course this is developed from an early age when children first start school. A child with Albinism will want to be with his or her peers but often other children in their exuberance can be less than accepting of the inability to catch ball, skip or move fast in games. So the child with Albinism can be left out or seldom chosen for games.



Light, reflection and glare from it are problematic for all people with Albinism and will affect a Childs playground experience. It is really important that the school environment is sun-safe with attractive options which keep children comfortable and engaged.

Social and emotional well-being are perhaps the most significant part of a child's development. Without love, friendship or security children can struggle to learn and progress in other areas. Children need to feel happy and secure in order to remain motivated and successful individuals. Its usual at school for children to connect and make friends amongst their play mates. It is essential from for a Child with Albinism to have a range of opportunities from an early age to mix with other children and learn key social skills. Children need to interact with others their own age, in different settings and environments. Both the class room and playground are places where spontaneous relationships form in spite of someone's impaired eyesight or ability to interact visually. Beyond the standard curriculum, there needs to be fostering of a child's social and emotional wellbeing. When children spend time with others of their own age or interact with children from a range of different backgrounds they learn how to get on with others as they share experiences and learn to empathise.

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When Reviewing the Education Act **Albinism Trust** appeals to those with influence to ensure they are aware of the synergies in a child's school world. Education is more than the Class Room for a child with Albinism. Learning, Growth and Development take place over the entire campus and on the way to or from school.

Albinism Trust is committed to working with any parties it might concern, to ensure young people with Albinism thrive as citizens of Aotearoa New Zealand.

Allen Little

Allen Little QSM,JP

National Organiser

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