



VISION



"VISION" is the Official Publication of Parents of Vision Impaired (NZ) Inc.

PVI's Whakatauaki/Proverb:

*Kia hora te marino, Kia whakapapa pounamu te moana, Kia tere te karohirohi,
I mua I to haerenga, Kia tau te rangimarie.*

*May the calm be wide spread, May the sea glisten like greenstone,
May the shimmer of summer dance across your pathways, May you always find peace.*

Issue 91

May 2012



Hayley Craig seen here on the
"Spirit of Adventure"
see page 7 for her
review of her amazing trip

- Congratulations Hayley, you are proving that BLINDNESS is no barrier
- Congratulations to Hayley's parents for the strength shown to allow Hayley to blossom!
- To other PVI parents, look and read this story and see what positive attitudes can achieve. This young woman is inspirational!

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Parents of Vision Impaired (NZ) Inc is on facebook



From Your National Office...

Dear Parents,

The following must be shared and used to empower us in our respective journeys.....

“Equals in Partnership” published by National Association of Parents of Vision Impaired—USA

Many parents of children with disabilities discover very quickly that there is plenty within them and within their families. Through their own resolve, their love, and their networking with other parents and professionals, these parents begin on going search for the resources that will help their child realise the highest of potentials.

In their journey, parents need not be experts in anything other than being the one person who knows their child best. We need no degrees, no special education knowledge; we don't even know anyone of influence.

We, as parents, need only two things. First, we need confidence in our own persistence: and second we need to remind ourselves of our confidence in our child. As parents, we will be our child's life long advocates. No one will ever know our child as we do. Many will help, some will be life savers, others will be great teachers, but none will be mother and father.

The great Viennese psychiatrist, Alfred Alder, remarked almost 100 years ago, that if he could give a child one personality trait over all the years, he would give her or him courage. Because with courage, Adler continued, each of us can overcome life's greatest problem, which is fear.

Regardless of our children's disabilities, our real job is to harness all the confidence and courage we can for us and model that for our children. On this journey together, we all need plenty of it. And in modelling it early on, we help our children prepare for the day we won't be with them except for that which we taught them.

In doing so, we will find many wonderful people who will make all the difference in our world. We will encounter many difficult people and institutions and policies. When life becomes difficult, advocacy begins in a new way. The word advocate comes from the Latin “advocatus” which literally means “to call, or to answer, to call to help another”. This is the parents task. This is the task that requires confidence and courage....All that we can muster. Someone once said, ‘In life, trouble is to be expected. Misery, though is optional’.

As parents, we need to be able to find those who can help in their best way and to establish our place of equality with them.

PVI new Staff Member:

PVI has a new staff member, introducing MAXINE JEFFERY. Maxine is employed as a PVI Parent Support Worker. Maxine is based in the National Office where she is working her way through the Waikato parent list. She has rung many parents who in return have received her call in a very positive fashion. Parents are reporting they are delighted to have been contacted by PVI; and it is neat hearing from another mother on a similar journey.

Maxine is currently employed for 5 hours per week to have direct parent contact. This is a special pilot project until the end of June, when subject to available funding, we shall review the project with a view of extending the concept to other areas should it be successful.

PVI National Office Move & Return:

Since late January, we have been in temporary accommodation based with the RNZFB in Caro St, Hamilton. We moved from 15 Liverpool Street because the building had to be renovated to accommodate all the RNZFB staff and build a new office for PVI...

Now, we are back and I must say we are very happy with our accommodation and the support shown to us from the RNZFB...THANK YOU.

Our physical address in Hamilton is RNZFB Building, 15 Liverpool Street, Hamilton, not far from where the CHIEFS play!!

PVI—RNZFB Board/Management Support re Parents as voting/governing members of the RNZFB Board of Directors elections. Many PVI parents may not understand that they are able to vote in the RNZFB Board of Directors elections held annually. As a result of conversations with the RNZFB Board and management, we are looking at how we can improve the understanding from parents on this important matter. Read more from the Chair of the RNZFB Board on page 3.

While on the matter of the RNZFB Board elections, our very own David Heather who stood in the last election has been appointed to take the place of a Board member who has resigned. Our job is to support David to add value to the RNZFB Board!

“PVI Facebook” Parents of Vision Impaired (NZ) Inc is on ‘facebook’, We invite you to join - to access we have to confirm you are a member of PVI, as it is a closed ‘facebook’. Join the club and find support from other parents.

Parents, this is your chance to be a part of decisions on behalf of your child

Dear Parent

We want you to take part in the decisions the Royal New Zealand Foundation of the Blind (RNZFB) makes when providing services for your child. So if you're not sure if you're a Guardian Member on behalf of your child, we'd like to encourage you to become one. There is a registration form attached to this letter which you can use to sign up as Guardian member, or to update your details if you already are one.

There are a number of good reasons for getting involved as a Guardian Member, whether its services the RNZFB has now to assist your child now or in the future.

As a Guardian member you can:

- vote for Board members that have a special interest in children's blindness services,
- be part of the discussion about how best RNZFB services are delivered participate in surveys to help us measure our quality of services delivered,
- access the Homai Special Formats Library, which is located at the Blind and Low Vision Education Network of New Zealand (BLENNZ) campus in Auckland. This library for children and young people, allows borrowers to get material that supports the school curriculum or just to enjoy some leisure reading,
- access our collage service which enables young children to learn from tactile representations of shapes and objects,
- make requests for personal material (such as unpublished documents, personal correspondence or small extracts from published works) to be turned into accessible formats, like braille, audio, large print or electronic text,
- access **technology, and training, designed to assist blind and partially sighted children to participate more fully** in a range of communications,
- take part in our Parents and Child Enrichment (PACE) programme, which works to emphasise the family model that forms the basis of our services.

- receive adaptive living skills and orientation and mobility to help your child adjust to vision impairment
- plan for and receive active input from counselling and employment staff as the transition between school and employment approaches,
- benefit from the wide knowledge the RNZFB gains by being an active participant in the disability sector at home and the international blindness community around the world, and,
- benefit from the relationships the RNZFB has with important agencies such as Ministry of Health, Ministry of Education and Ministry of Social Development.



ROYAL NEW ZEALAND
FOUNDATION OF
THE BLIND
TE TUĀPĀPĀ O TE HUNGA KĀPŌ O AOTEAROA

I hope that I've given you a number of good reasons why becoming a Guardian member will help you to make a difference in your child's life.

If you would like any more information, please contact the RNZFB or Parents of Vision Impaired using the contact details below. As always, we would like to hear your feedback and we appreciate your input.

Remember, if in doubt as to your ability to vote then please phone the 0800 numbers listed below.

Yours sincerely

Rick Hoskin
RNZFB Chair

Riripeti Paine
PVI Chair

Royal NZ Foundation of the Blind

Tel: 0800 24 33 33 or 09 355 6951

Email: general@rnzfb.org.nz www.rnzfb.org.nz

Parents of Vision Impaired New Zealand

Tel: 0800 312 019 or 07 839 4205

Email: paul@pvi.org.nz www.pvi.org.nz



Information for Very High & High Needs School Leavers

Ministry of Social Development Ministry of Education

Very High Needs School Leavers:

Students who have been assessed while at school as having very high needs under the Ministry of Education's Ongoing Reviewable Resourcing Schemes (ORRS) are eligible for individualized funding to provide a post-school service.

Students who have been identified as having very high needs, have been described as being non-verbal, non-mobile and requiring assistance with eating and toileting.

This funding can now be used from the legal school leaving age of 16, although students may stay at school until age 21 to achieve the maximum value from the education system. The funding for very high needs school leavers is contracted for services through the National Contracts team of the Ministry of Social Development. Contact details of the National Contracts advisor for your area are listed in the right hand column.

High Needs School Leavers:

While high needs school leavers are not eligible for the same funding as very high needs school leavers, they can access other vocational services funded by the Ministry of Social Development. Parents/guardians of high needs school leavers can contact their closest National Contracts Advisor to find out what services are available in their area.

Transition from School Services

Both very high needs and high needs school leavers can make use of transition from school services funded by the Ministry of Social Development.

Transition services are designed to provide the student concerned with a smooth and seamless move from school to a future activity. This service is based upon developing and implementing an "individual transition plan" for each student and ensuring that the goals and aspirations of the disabled person are at the centre of the service.

The disabled student should experience a variety of services during his or her last year at school so that the decision as to which provider will deliver the post-school service is based upon the informed choice of the student and his or her family/whanau.

Your school should already have been contacted by a Ministry of Social Development transition provider. If this has not happened, please ask your local National Contracts Advisor to give you a list of transition providers in your area.

National Contracts Advisors:

Northland: Lynne McRae, Phone (09) 983 9118
Email lynne.mcrae001@msd.govt.nz PO Box 947 Whangarei

Auckland

Anna MacNicol, Phone (09) 916 1827
Email anna.macnicol004@msd.govt.nz
Private Bag 68—911, Newton, Auckland

Waikato and Bay of Plenty

Lyall Wilson Phone (07) 902 7098
Email lyall.wilson 014@msd.govt.nz
PO Box 117, Paeroa

East Coast

Jason Leach Phone (06) 974 8232
Email Jason.leach004@msd.govt.nz
Private Bag 6015, Napier

Taranaki, Wanganui, Manawatu, Wairarapa, Horowhenua and Kapiti

Joe Riley Phone (06) 902 2790
Email joe.riley001@msd.govt.nz
PO Box 442 Hawera

Wellington, Nelson and West Coast

Karen Vause Phone (04) 918 9561
Email karen.vause001@msd.govt.nz
Phone 04 918 9561 PO Box 1556 Wellington

Canterbury, Otago and Southland

Lisa Sacksen
Phone (03) 914 2485
Email lisa.sacksen001@msd.govt.nz
PO Box 1556
Wellington 6140

An Apology from Paul: -

Due to PVI changing its telecom provider we experienced delays in getting the 0800 number Redirected. If you phoned and no-one answered then I apologise, however the

PVI 0800 312 019 number is now working, and we will welcome your call.

PVI Website, www.pvi.org.nz is now live after some re development. We have tried to create a website that is easy to read and clutter free. We have yet to put some pictures up and a video, so it will improve. Please have a browse, tell me what you think and please send me some wonderful family pictures....Paul.



CHOICE IN EDUCATION FOR DISABLED CHILDREN NOT A REALITY

CCS Disability Action - Media Release

No Real Choice for Disabled Children

3 April 2012

CHOICE IN EDUCATION FOR DISABLED CHILDREN NOT A REALITY

Finding suitable schooling for disabled children in New Zealand is not a level playing field for parents, according to new research from CCS Disability Action.

The Families Choices:

Choosing Schools for Disabled Children research suggests that the choice of education for disabled children may in fact be an "illusion" for some parents.

The research reveals that for the majority, the process is emotionally stressful (60%), time-consuming (33%), financially draining (29%) and negatively impacts siblings (35%). Very often parents also have to enrol their children in distant schools (32%).

"In theory, a wide range of educational choices are available to parents of disabled children," says CCS Disability Action Chief Executive David Matthews.

"However, based on this research we can't ignore the fact that for many parents, there is limited choice for their children's education and indeed, choice in education is nothing more than an illusion."

The research explores education choices available to families who have applied for the Ongoing Resourcing Scheme, which provides support for students who have the highest need for support during their education.

The study found nearly half of the 217 respondents felt they have "not always had real choice" between schools. Almost a quarter of those who had not been able to enrol their children in the school of their choice reported an "unwelcoming" atmosphere, lack of special services and poor equipment and physical access.

The research revealed that when choosing a school, the most important factors are availability of necessary facilities to support the child's learning needs (51%), school reputation (46%) and attitudes of principals (45%) and teachers (44%).

"A crucial factor in schooling decisions for many families is the attitude of the school principal and staff," said Mr Matthews. "Yet we have many stories of families feeling unwelcome, even discriminated against due to lack of understanding and knowledge of disability and special needs."

This issue also forces many families to choose to move children to different schools for reasons such as lack of teacher awareness of a child's needs (27%), parents feeling disrespected (24%), poor attitudes of the principal (22%) and the teacher (21%).

The research also highlighted the significant barriers children with disabilities face including having a delayed start at school (38%) and being unable to realise their potential (36%).

Parents and caregivers have indicated that in order to improve the process of choosing schools for their children, they want better information and advice, more support and for the legal and funding issues to be addressed, said Mr. Matthews.

IHC claims that the education system is failing disabled pupils. With the support of the Human Rights Commission, IHC has bought a Human Rights Tribunal case against the Ministry of Education.

"This research adds further support to their case," says Mr. Matthews.

"We are continually told that New Zealand has been committed for many years to inclusive education for disabled children. This research brings into question the strength of this commitment."

For further information contact:

David Matthews

Chief Executive Officer

CCS Disability Action

TEL 0274 984262

david.matthews@ccsdisabilityaction.org.nz

RNZFB new children's services programme for 2012

PACE Update:

Following the brief overview of the PACE programme in December in this newsletter, we have presented the children's service improvements to the PVI Board. Through the Board, we have circulated the first section of a three tier skills mastery programme and are looking forward to feedback and suggestions shortly from parents for formatting ideas and ease of understanding

Our Children's Services team have attended a three day workshop on how the service improvements will be implemented and were presented with the latest techniques for working with children with cortical vision impairment. They have also shared some very valuable learnings from the International Mobility Conference, held recently in Palmerston North.

Some excellent questions were raised following the previous newsletter and it may be helpful to take this opportunity to address some of these concerns.

1: What happens to service delivery once my child turns 5 and goes blind after that age? Who does the needs assessment and more importantly who provides the services....

Response: If your child has never been registered with the RNZFB, a referral can be made through the RTV, an eye care or health professional or parents can contact us directly on 0800 243333 and a RNZFB Child and Family Social Worker (CFSW) will assist with the registration process and carry out the needs assessment.

The CFSW will refer to a developmental instructor or other members of the RNZFB team as appropriate. If an orientation and mobility need is identified for your 6-16 year-old, they will be referred to BLENNZ, if it is determined they are the service provider.

If your child is already a member of the RNZFB, parents can contact the CFSW or developmental staff member known to them, the regional RNZFB office or on 0800 243333, or alternatively, the RTV can complete a referral which is sent to the regional office and you will be contacted by one of our children's team.

2: Where does BLENNZ and its services fit into this service. Is there a collaborative approach to services from the two providers? As parents we do not wish to have any gaps....

Response: The RNZFB will continue to work with BLENNZ both at a national and regional level.

3: As parents might well choose to become purchasers of services in the future, is this service meeting Blind and Deafblind and Vision Impaired Children's and their Whānau's needs?

Response: Individualised funding is a potential for the future. The RNZFB believe that with the introduction of the PACE programme of service we will be well placed to offer services that parents, government agencies and others would consider purchasing, as PACE clearly state's what the programme, if selected, is aiming to deliver.

4: Orientation and Mobility for children aged 6-16 is provided by contract from the Ministry of Education. The Review of Orientation and Mobility on pages 8-11 looks at this in more detail, how will O&M be delivered by BLENNZ in the future, if BLENNZ is the service provider?

Response: This question is for BLENNZ and or the Ministry of Education to address.

If you have any questions or would like further information on the RNZFB PACE programme, or to access this service, please contact our **Children's Services team** on **0800 24 33 33**.

Alternatively, you can email Karen Connolly, Service Development Manager, at kconnolly@rnzfb.org.nz

Kind regards,

Teresa Bradfield

RNZFB Executive Director, Client Services

PVI Response:

The PVI Board has received a presentation from the RNZFB PACE implementation team. We found the presentation and following documentation on the programme quite technical. PACE has many levels and is very comprehensive. Providing there are no gaps between what BLENNZ offer and what PACE is offering, we and our children should be well served.

PVI is wishing to bring PACE to you with a series of PACE focus meetings around the country. We understand the RNZFB and PACE staff will be assisting PVI in this **consultation**.

During this consultation, it is PVI's wish to also ensure other consumer groups like Ngati Kapo, Association of Blind Citizens NZ, DeafBlind NZ, and Retina NZ also have opportunity to attend these **consultation** meetings.....

Nothing about us without us!

Orientation and Mobility for children aged 6 -16 - a service in transition...	Extracts of The Natural Authority of Families By Micheal Kendrick
<p>Over the last 12 months, there has been a national review of Orientation and Mobility (O&M) Service.. How O&M was previously delivered and how could this change to better meet the needs of our children today. One of the outcomes of the review is that future delivery of the Ministry of Education's O&M contract for school aged children is now to be delivered by BLENNZ not the RNZFB.</p> <p>The RNZFB has a focus of delivering O&M to the preschool aged children under the new children's service named PACE. We are advised that school aged children will be prioritised by the BLENNZ/ RNZFB to ensure urgent O&M is delivered. We ask for your patience while the Ministry of Education and BLENNZ consult with us over how we can deliver a service that better meets the needs of our children.</p> <p>The Ministry of Education is looking at ways of better funding the service and in this tough fiscal climate, this will be a challenge. To put it more bluntly, this is the Ministry's/Minister of Education's problem - not ours. Naturally, we will work with them encouraging more funding to be allocated to this much needed discipline of O&M. On the matter of the value of good O&M skills, I can assure you that the adult blind community will advise that O&M is as important as literacy skills. The Ministry now understands the importance of well resourced and taught O&M skills. Now we will work with them to be part of an exciting new service.</p> <p>One might ask why the RNZFB no longer delivers an O&M service as they use to. Simply put, the Ministry of Education contract was so poorly funded the RNZFB could no longer afford to provide the service. Hence the O&M Review and the current situation.</p>	<p>With great regularity, people with disabilities and their families will find themselves having to deal with professionals, bureaucrats and others in roles of authority. Not uncommonly the authority figure tends to overshadow the authority of "small people". It helps sometimes to remember that families have a natural authority of their own which can go a long way to reducing this imbalance of power. Families need to appreciate this natural authority and be willing to act on it. What follows is a brief description of some of the common sources of authority that families can call on when they are acting in the interests of a family member.</p> <ul style="list-style-type: none">• The general public recognizes that families have the authority to be fully involved because they have greater responsibility for the well-being of their family members.• Families know their family member the most fully and over the longest period of time. Therefore they have the authority that arises from long term observation, insight and personal relationships.• Families typically care about or love their relatives more than would be true of others, however committed the others may be. Not only do families usually care more but they are also expected to care more.• Families have to live with the long term consequences of service failures to a greater extent than any other party, except the person themselves.• Families are granted considerable presence in the decision-making processes affecting their family members.• The family is an authoritative witness to the performance of professionals and systems and may have special insight into events that take place.• Family members bring to their role a wide range of talents and experiences which can give them additional authority on many matters. For example, a parent might also be an educator. <p>Parents: - Take strength from these, use them and above all value your knowledge of your child.</p>
 <p>Levi is seen here being encouraged to run by his RTV. While O&M is in transition, devoted RTVs' will no doubt support our children as this one is doing.</p> <p>Think about how brave Levi is. Try running blind-folded and you only get a smidgen of what he has to cope with.</p>	

THE SPIRIT OF ADVENTURE – TRIP OF A LIFE TIME! By Haley Craig



For those of us who went, in February, the Spirit of Adventure was 5 days of fun and adventure in and around the Hauraki Gulf – apparently! I say apparently because I had no idea where we were at any given time – I CAN'T SEE!

The Spirit of Adventure is a big old-fashioned sail boat that kind of looks like the boat on the movie “Voyage of the Dawn Treader”, except without the dragon. It has lots of masts and lots of square sails. I went on what is called the Inspiration Voyage, which is especially for teenagers who have a disability. Each teenager onboard is given a buddy (also in their teens) to help them with whatever they need.

The week I climbed aboard the Spirit of Adventure, I was waiting for an operation on my knee, which was giving me a lot of pain. I had also sprained my toe that morning. The voyage was always going to be a challenge for me; these things just increased the challenge!

On the Saturday afternoon I had just competed in a blind sailing NZ race on the Auckland harbour, (our boat came 2nd), then headed straight for the Spirit and went aboard, but the ship didn't leave until Sunday. The boat is berthed by The Viaduct in Auckland, which, on a Saturday, is INCREDIBLY noisy! On top of that, the sleeping quarters were really cramped – the beds were narrow bunks, 3 high; and movement was impossible without banging into something – seriously, I couldn't even roll over in bed!

Over the five days, the highlight for me was climbing the tallest mast. It was the best activity; the most challenging activity; and the worst activity all at the same time! “What”? I here you say.....”How confusing”! Let me explain:

Monday was the day we climbed the tallest mast. We had to be all harnessed up. They tied our cameras to our harness so that we could take photos from the top. It was so awesome being able

to conquer the challenge – going up wasn't so bad – but it was SO hard on my knee coming down! I had to rest up for quite a while afterwards and stoked up on painkillers! BUT, having said all that, I have no regrets whatsoever, because I would have missed out if I hadn't done it because of the pain, and I would have regretted NOT doing it for the rest of my life! These opportunities don't come around too often.



One day we went sailing on smaller yachts that they keep onboard. We had to take turns as there were only 2 yachts and lots of us. I found it really fun, as I go sailing on a regular basis with Sailability, so it was great to be in a smaller boat again; although they were still bigger than what I'm used to. That same day we rowed on rafts to Lady's Bay on Kawau Island. We had another swim in the sea and a BBQ for dinner before rowing back to the Spirit.

I say 'another' swim because every morning we had to wake up at 6.30am and go for a swim in the sea, instead of showering, to conserve water. We would jump off the side of the boat (some would climb down the ladder) and swim around the boat. The water was always *freezing* at that time of day, even though it was still summer!

**“THE SPIRIT OF ADVENTURE”
A TRIP OF A LIFE TIME! (Cont.)**

Every day, we had to clean the boat, thoroughly! It is an old boat and if it doesn't get cleaned every day, it will go to ruin quite quickly with all the sea salt water and spray to rust it out. Every day we would scrub the deck, clean the rooms, wipe the windows, mop the downstairs areas, wash the stairs and polish the brass on the tiller (steering wheel) and the bell. We also had to prepare veges for dinner every day, do the dishes and clean the toilets.

If anyone ever felt sea sick, they would have to put on a harness and be clipped to the edge of the boat on the deck. That way no-one would fall overboard while throwing up and the fish would get fed rather than the deck!!

The crew on the boat were all really helpful, understanding and kind. The food was awesome and the atmosphere was fun – just a really great place to be! I would LOVE to be able to do it again sometime.

Overall, the five days went really quickly and before we knew it, we were back in Auckland and it was time to say our goodbyes. The Spirit of Adventure – trip of a life time – if I can do it, with all my extra challenges, anyone can! I would totally recommend it!



FAMILY TIME



David Heather, current PVI and RNZFB Board Member seen here with son, Richard. Richard is DeafBlind seen here looking very fresh. Dad looking very proud. Dad and Richard cycled the Otago Rail Trail, on a tandem. I hear David was checked re drugs, but was allowed to continue due to the minor level of pinot gris..... Mum, Rhonda, provided the much needed moral support via the support vehicle, a wise woman!

NZ VIEW / PVI collaboration to support P.V.I. parents: -

In the previous “Vision”, we advertised the opportunity for some PVI mothers to adopt a support person from NZ VIEW. Members of NZ View are vision impaired or blind women who are coping and getting on with their lives. They have skills that might prove useful, insights that will empower parentsto make contact with NZ View contact Ailsa from NZ View at aislabie@clear.net.nz or Paul either phone 0800 312 019 or email me at paul@pvi.org.nz

CHILDREN'S SPECTACLE SUBSIDY SURVEY—a Joint PVI & Ministry of Health Review

PURPOSE:

To understand how the children's spectacle subsidy is working from a parent's perspective.

Your feedback is important to us. We would like to ask you some questions so that we understand how the children's spectacle subsidy is working from a parent's perspective.

Anything you tell us is strictly confidential. All the results will be shared with members of PVI in our Vision magazine (with all identifying information being removed) and will be shared with the Ministry of Health who manages the children's spectacle subsidy.

How old is/are your child/children with a vision impairment?

Do you know about the Children's Spectacle Subsidy? ☐ Yes ☐ No

If yes, how did you hear about it?

- ☐ Advertisement in the newspaper
- ☐ Vision and hearing Technician (e.g. Well-child check)
- ☐ GP
- ☐ Ministry of Health Children's Spectacle Subsidy brochure
- ☐ Optometrist e.g. sent an appointment for a check up
- ☐ Ophthalmologist
- ☐ PVI
- ☐ Other

When did you use the children's spectacle subsidy last?

If no, is it because

- ☐ You don't think you need to
- ☐ You would have if you had known about it
- ☐ You don't have a community services card
- ☐ Any other reason?

The last time you took your child to the optometrist, was this because you were:

- ☐ Worried about their vision
- ☐ A teacher or other professional (such as a Vision Hearing Technician, Resource Teacher Vision and learning) worried about their vision
- ☐ Broken/repairs
- ☐ Eye patches

What was the result of your assessment?

- ☐ New children's frames
- ☐ New adult size frames
- ☐ New lenses
- ☐ Other products such as lens cleaner
- ☐ Appointment in mail for a check-up reminder
- ☐ No replacement glasses/frames

Did you have to pay for replacement glasses over and above the subsidy?

- ☐ Yes ☐ No

If no

- ☐ Did the subsidy cover the costs
- ☐ Could not afford to pay any difference in costs

If yes, approximately how much did you pay?

\$.....

If you did pay the difference, how did you pay?

- ☐ Privately
- ☐ With help from Work and Income
- ☐ With help from the District Health Board
- ☐ With help from a family member
- ☐ With help from your bank (bank loan)

Have the new frames/spectacles made a difference to your child and if so in what way?

- ☐ Yes ☐ No

If yes,

- ☐ Improved learning such as –reading, writing
- ☐ Improved Self esteem
- ☐ Improved behaviour
- ☐ Participating more at home

If no,

- ☐ My child does not wear the new glasses (e.g. does not like the look of them)
- ☐ Deliberately damaged the glasses so that he/she does not have to wear them

How many times has your child/children replaced the glasses in a one year period i.e. since May 2011?

Thank you for taking the time to complete this survey

Please post to: P Manning PO Box 366 Waikato Mail Centre Hamilton 3240 or

Scan and email to: paul@pvi.org.nz

PARENTS: - WE REALLY NEED YOU TO SUPPORT THIS SURVEY



Transition Checklist Post school

Describing the required components of the transition plan. During your child's high school years, it is essential that the IEP team adhere to these requirements.

- The student should/must be invited to participate in IEP meetings to discuss his/her goals for life after high school.
- You may request several IEP/Transition Planning meetings during the school year.
- You may invite representatives of local agencies to these IEP meetings to discuss transition goals and services to support those goals.
- The IEP, including the transition plan, should be based on person-centered planning, and reflect the student's interests and skills.
- The work experiences or "community based work assessments" (CBWAs) chosen should be based on the student's interests and abilities. Students should NOT be placed in a community based work assessment simply because it is available.
- Any placement should help the student develop skills in a setting that is of personal interest to him/ her and where his/her unique abilities can be successfully utilized and improved with job coaching.
- Annual transition goals in the IEP should lead to successful post- high school outcomes
- Progress should be documented and measurable.
- Ask for progress reports about your child's community based work experience. Discuss with the IEP team how your child will meet the goal of being employed after graduation, without a lapse in supports and services.
- Maintain a portfolio and resume of your child's experiences, progress reports, and favourable reviews from your child's supervisors.

Permission by Wrightslaw.com

An Australian perspective: -

Getting young people with disabilities ready for study & work: A guide for parents

This new Guide aims to support parents and carers of young people with disability through the process of transition from high school into post-secondary education , training and work. This resource was developed by the National Disability Coordination Officer (NDCO) program hosted by the University of Western Sydney, through a Strategic Project Grant funded by the Australian Government.

The new resource includes a guidebook and a range of supplementary factsheets including comprehensive content on topics such as:

- ☐ Top ten tips for parents and carers;
- ☐ Explanation of the transition process and elements of good transition planning;
- ☐ Advice on the positive roles parents can play during transition, navigating their changing parental roles during the process, overcoming common transition barriers; and working constructively with professionals involved;
- ☐ Overall description of post-school pathways and detailed facts on each specific option, including entry processes, how to access disability support and where to find more information; and
- ☐ Facts on disability and privacy rights and responsibilities of young people with disability.

For more information see:
<http://pubsites.uws.edu.au/ndco/get-ready%20ndco/index.htm>

The Guide accompanies an existing workbook for young people with disability called *Get ready for study and work: Top ten tips for young people with disability* which is also available online at the same website. The two resources can be used together or independently.

If you rely on the government to meet the needs of your child, expect to be disappointed..... Our children need us to be involved to think outside the square and apply common-sense!
Paul



From and For Parents.....

Schools refusing access to our children: -

Absolutely. I can clearly think of several PVI parents who can attest to the "we don't want your child" attitude. And how many of us have children who cannot do certain things at school that we would wish or have identified in IEPs as being important, due to insufficient Teacher Aide (T/A) time? I know Katelyn cannot go to swimming as she has to share T/A time with other kids. As for school camps, (amongst other school activities) well, not happening. And even when they did happen, we had to pay for the T/A time out of our own pockets. Yes our kids face discrimination every single day, in the one environment the Government has pretty much full control over,..... so if they are not willing to face Yes indeed, I plan to support this move whole-heartedly.

Pat Fox

PVI Response: Naturally we support any move to ensure our schools actually practice "inclusive behaviour". This so called selective inclusion that some schools do practice (20%), needs to be high-lighted and challenged by society most firmly. If we as a society let this selective inclusion continue to occur, then how do we expect the Minister of Education to act.....OR perhaps we expect the Minister of Education to act reflecting societies views!.... **INCLUSION is NOT SELECTIVE, not on any level!** Paul.

Dear RNZFB

I was just reading the Consumer updates from the RNZFB in the PVI Vision Magazine. The last article was entitled Paralympic Dreams which mentioned one of your members who is a cyclist. I just wanted to let you know that you have three other RNZFB members who are participating in Paralympic Trials.

Áine Kelly-Costello, Daniel Holt and Daniel Sharp are all travelling to Sheffield, England to compete in the British Disability Swimming Championships (which are the Paralympic Trials for the swimmers) between the 6-8th April. They depart on the 27th March for a training camp in Swansea first.

Just thought you would like to know.

Kind regards

Katherine Kelly (Áine's Mum)

For Parents:

How often has it happened -- an acquaintance hears your story or sees your child and says, "I'm not as strong as you. I could never deal with all the things you deal with." And you shake your head modestly, and brush it off, and maybe even feel a little condescended to. But you know what? They're right. You're strong. You're facing things that the average parent doesn't even wa...nt to imagine, an...d you're handling them. Whether you were strong to begin with or had strength thrust upon you by necessity, you're one strong parent, one strong person. Your family needs that strength, your children thrive on it. You may wish you never had to be so strong. But appreciate that strength now. It makes you special. Capable. A force to be reckoned with.



PARENT BURN OUT only a matter of time.....

- Do make attempts to write on your calendar, dairy whatever, time for yourself and stick to it
- Do remember to laugh otherwise the reality at times is just too much
- Talk, talk to other parents always the best tonic....



From Dennis Prager, Principal at a high school in Toronto, on the first day of classes in 2011

"Students and faculty of our high school. I am your new principal, and honoured to be so. There is no greater calling than to teach young people.

I would like to inform you of some important changes coming to our school. I am making these changes because I am convinced that most of the ideas that have dominated public education in Canada have worked against you, against your teachers, against your parents, and against our country.

First, this school will no longer honour race or ethnicity. I could not care less if your racial makeup is black, brown, red, yellow, or white. I could not care less if your origins are African, Latin American, Asian or European, or if your ancestors arrived here on the Mayflower, leaky SE Asian refugee ships or on slave ships. The only identity I care about, the only one this school will recognize, is your individual identity -- your character, your scholarship, your humanity. And the only national identity this school will care about is Canadian. This is a Canadian public school, and Canadian public schools were created to make better Canadians.

If you wish to affirm an ethnic, racial, religious identity through your school, you will have to go to another one. We will end all ethnicity - race - and non-Canadian-nationality-based celebrations. They undermine the motto of Canada. Everyone is equal, coast to coast.

This school will be guided by Canadian values. That includes all after-school clubs. I will not authorize clubs that divide students based on any identities. This includes gender, race, language, religion, sexual orientation, or whatever else may become into vogue in a society divided by political correctness. Your clubs will be based on interests and passions -- not blood, ethnic, tribal, racial or other physically defined ties. Those clubs just cultivate narcissism -- an unhealthy preoccupation with the self -- while the purpose of education is to get you to think beyond yourself. So, we will have clubs that transport you to the wonders and glories of art, music, sport, debating, astronomy, languages you do not already speak, maths, carpentry, and many many more. If the only extracurricular activities you can imagine being interested in are those based on ethnic or racial or sexual identity, that means that little outside of yourself really interests you - and that means you don't belong in this school.

Secondly, I am not interested in whether or not English is your native language. My only interest in terms of language is that you leave this school speaking and writing English as fluently as possible. The English language has united Canadian citizens for more than 200 years, and it will unite us at this school. It is one of the indispensable reasons this country of immigrants has always come to be one country. And if you leave this school without excellent English language skills,

your teachers and I will have been remiss in our duty to ensure that you are prepared to compete successfully in the Canadian employment market. You will learn other languages here -- it is deplorable that most Canadians only speak English. But if you want classes taught in your native language rather than in English, this is not the school for you.

Third, because I regard learning as a sacred endeavour, everything in this school will reflect learning's elevated status. This means, among other things, that you and your teachers will dress accordingly. Many people in our society dress more formally for a meal at a nice restaurant than they do for church or school. Those people have their priorities backwards. Therefore, there will be a dress code at this school.

Fourth, no obscene language will be tolerated anywhere on this school's property -- whether in class, in the hallways or at athletic events. If you can't speak without using the "F-word," you can't speak. By obscene language I mean the words banned by the Federal Communications Commission plus epithets such as the "N- word," even when used by one black student to address another, or "bitch," even when addressed by a girl to a girlfriend. It is my intent that by the time you leave this school, you will be among the few of your age to distinguish instinctively between the elevated and the degraded, the holy and the obscene, the educated and the non-educated.

Fifth, we will end all self-esteem programmes. In this school, self-esteem will be attained in only one way -- the way people attain it will be by earning it from their fellow students and teachers. One immediate consequence of this is that there will be only one class valedictorian, not eight.

Sixth, and last, I am reorienting the school programme toward academics, scholarship, and away from politics and propaganda. No more time will be devoted to scaring you about smoking and caffeine, or terrifying you about sexual harassment or global warming. No more semesters will be devoted to condom-wearing and teaching you to regard sexual relations as only, or primarily a health issue. There will be no more attempts to convince you that you are a victim because you are not white, or not male, or not heterosexual, or not Christian. We will have failed, if any one of you graduates from this school does not consider himself or herself inordinately lucky -- lucky to be alive, lucky to be well educated, and lucky to be a Canadian.

Now, please stand and join me in singing, OH CANADA to the only flag in Canada. As many of you may not know the words, your teachers will gladly hand them out to you."



Technology update

PHONE SIMPLE AG.PHONE available from
Auckland Disability Resource Centre phone
Ph: 0800 625 100

The Simple Phone is designed to be so simple anyone can use it.

This is especially important for people who cannot use modern smaller mobile phones. The phone gives people a sense of security and independence.

The Simple Phone is designed to be so simple anyone can use it.

This is especially important for people who cant use modern smaller mobile phones. The phone gives people a sense of security and independence.



\$190.00 Incl GST

FEATURES

- Large keys (10mm x 10mm)
- Easy to read screen with adjustable contrast levels
- Loud adjustable ringtones
- Can be set up to dial up to 11 different numbers simply by holding down the button that corresponds to the contact
- SOS emergency button that can be programmed to call up to 4 numbers
- Easy to read screen
- FM Radio
- LED Flash Light
- Great for security and independence
- The phone operates on the Gsm 900/ 1800 Mhz frequency band
- In New Zealand the phone will work on the Vodafone and 2Degrees network

Transition Expo 2012

The progression from school to community life. Hosted by Parent & Family Resource Centre (PFRC) and Ministry of Social Development (MSD).

When: Tuesday, 15 May, 2012

Where: AMI Netball Centre

7 Allison Ferguson Drive, St. Johns, Auckland

Time: 9am – 2.30pm

This Expo is suitable for all students aged between 14-21 years who are ORS funded, parents, family members, caregivers, education experts, careers advisors, school transition coordinators, teachers and all those involved in the care of a young adult with a disability. Transition Providers and 'leisure' providers will each have a stall providing information, pamphlets, booklets, DVD's and promotional material. Representatives from each organisation will be available for advice, including WINZ and Ministry of Education. Please contact PFRC for further info or if your organisation would like to hold a stall, on (09) 636-0351 or pfradmin@pfrc.org.nz

Websites and Info

www.pvi.org.nz This is our website under reconstruction

www.blennz.school.nz The new BLENNZ website, take a look, well worth the effort!

www.kapomaori.com The official website of Ngati Kapo Aotearoa Inc

www.abcnz.org.nz The largest Blind Consumer group in N.Z. An excellent website.

www.humanware.com Excellent products available for both Low Vision and Blind users.

www.pacificvision.org.nz This website has links to many international providers of Low Vision aids.

www.biopticdriving.org This website explains how some low vision people can gain extra vision by using bioptic lens that in some cases enables them to drive legally!

www.aniridia.net: Anidria Foundation International.

www.aniridia.org: Anidria support

www.albinism.org.nz New Zealand's website for those wishing to know more about Albinism.

www.nzord.org.nz This website has links to many international sites containing information concerning rare disorders. This site is the New Zealand link.

www.rnzfb.org.nz The website of the Royal New Zealand Foundation of the Blind.

www.quantech.com.au This website has good info new Mountbatten training resources. Worth visiting if your child uses braille.

www.tsbvi.edu The Texas School for the Blind and Vision is a leading educational facility. Excellent information and links to other places.

www.minedu.govt.nz The official Ministry of Education website. Good information, easy to use.

www.varietyclub.org.nz The Variety Club may be able to provide financial assistance for children with special needs. I have found them most supportive and helpful in the past **09 522 3743**.

www.parent2parent.org.nz Parent 2 Parent is a nationwide support group of parents who have children with special needs.

www.carers.net.nz This is the official website of Carers NZ. This website has excellent information on a range of carers needs. They produce an excellent magazine called "Family Care". This magazine is free to all carers, just ring Sara at 09 406 0412 or email: info@carers.net.nz

www.napvi.org The National Association of Parents of Vision Impaired USA. Good website, note the section re parent matching.

www.cpsociety.org.nz NZ's Cerebral Palsy site an excellent website, very informative and easy to use.

www.wrightslaw.com An excellent website for tips on IEP's, it is USA based where laws are different, the tips and ideas are very similar though.

www.zabonne.com Zabonne's website hosted by Ivan Pivac, much information regarding blind and low vision aids, plus technology aids for children with additional disabilities.

www.maparentsupport.com: - a web site for parents to find support from others who have children with Microphthalmia Anophthalmia.

www.atmac.org for assistive technology for Mac OS X, iPod, iPhone and Apple Users

www.parentsvoice.org.nz and/ or 'like' Parents Voice on Facebook .

<http://www.health.govt.nz/publications/subsidy-glasses-and-vision-tests-spectacles-subsidy>

Needs Assessment and Coordination:

www.disabilityinfo.co.nz

RNZFB Holiday Home: The RNZFB have one Holiday Home available to rent for members. Located in Tauranga at \$50.00 per night. For further information contact Karen at the Tauranga RNZFB Office between 9.00am and 12.00noon on **07 578 2376**.

The Koru Care: This charity is linked to Air N Z. They specialise in taking children with Special Needs to Disneyland/Gold Coast Australia. Contact **09 523 2456** to see if your child qualifies. There are also contacts at Wellington and Christchurch offices of Air New Zealand.

www.yesdisability.org.nz: Yes Disability Resource Centre in Albany. Note the Mothers support group known as Mum's @ Yes" Information Swap Network Group Meetings.

A CD called "A Family Affair", available from **BLENNZ** Homai Campus, **09 2667109** it gives good information re the National Assessment Services available at BLENNZ.

PacificVision: email Barry at barryb@pvi.co excellent low vision equipment.

Parents: - Feel free to write to the following Members of Parliament **the good news (Positive Advocacy) or bad news concerning either your child's needs or yours as a parent!**

Prime Minister: pm@ministers.govt.nz

Minister of Education: hparata@ministers.govt.nz

Minister of Disability Issues and Lead Minister of the Carers Strategy: tturia@ministers.govt.nz

Minister Maori & Assoc Min Education: psharples@ministers.govt.nz

PVI Regional Support Vacancies:

We need more parents to volunteer as Regional Representatives in the following areas: -

- Northland
- Sth Auckland
- Waikato
- Taranaki

We need more parents acting as signposts to support other parents in your community. We wish to create teams within your own community hence sharing the workload. Training is provided FREE normally in a community near you. If you have a little time to give and wish to further support us please contact

Paul: 0800 312 019



Your PVI Board

Northern N. I. Representatives:

Mrs. Kim Lewin: 094221012 lewinfamily@xtra.co.nz
Mr. Grant Davies: 09 473 4713 dandgdavies@xtra.co.nz

Central N.I. Representative & PVI Treasurer:

Mr. D Fairgray: 027 286 7798

Southern N. I. Representative: PVI Vice Chair

Mr David Heather: heatherdavid1945@gmail.com

Northern S.I. Representative:

Mr Tim Marshall tim4jenny@paradise.net.nz

Southern S. I. Representative:

Ms. Judith Hyslop: 03 476 6666 judithhyslop@xtra.co.nz

Anywhere in N.Z. Representative:

Mrs. Dionne Gilligan: 06 344 7755 dionnesg@gmail.com

Tangata Whenua Representatives: PVI Chair

Ms. Riripeti Paine: 06 838 3949

1 Position Vacant please contact Riripeti

Return Address:
Parents of Vision Impaired NZ Inc
PO Box 366
Waikato Mail Centre
Hamilton 3240



Regional Support Parent Contacts

Dargaville:	Gaynor Edgar	09 439 4439	Taranaki:	Vacancy please Apply
Wellsford:	Kim Lewin	09 422 1012	Wanganui:	Amanda & Rex Van Elswijk 06 345 0327
North Harbour:	Linda Moore Carter	09 442 1330	Manawatu:	Jane Hoani jane.hoani@gmail.com
Auck. Central:	Vacancy please apply		Wellington:	Christine Pask 04 527 7585 Joanne Beaver 04 589 3719
Auck. South:	Kawaljeet Singh	09 299 8028	Kapiti	David & Rhonda Heather 04 203 6539
Auck. West:	Paulette & Rodney Francis	09 835 1232	Nelson:	Adrian Secker 027 201 1028 Trudy Perrett 03 544 6641
Auck. East:	Kawaljeet Singh	09 299 8028	Christchurch:	Andrea Lamont 03 980 1566
	Tirzah Shepherd	09 530 9539	Oamaru:	Pat Fox 03 434 3499
Hamilton:	Maxine Jeffery	07 853 7006	Alexandra:	Sarah Hinton 03 449 2414
Tauranga:	Linda & Don Fairgray	027 286 7798	Dunedin:	Alaina Gillies 03 484 7433
Rotorua:	Lex & Helen Craig	07 349 3191	Invercargill:	Kim Hartley 03 217 1906
Wairoa:	Riripeti Paine	06 838 3949		
Napier:	Lou Halbert	06 845 4706		