



VISION



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

PVI's Whakatauki/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.*

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RNZFB Taupo Camp — January 2012



**"Children with disabilities are like butterflies with a broken wing.
They are just as beautiful as all other children but they just need a little help to spread their wings."**

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From Your National Office...

Greetings fellow Parents,

It is the time of year we long for/loath all in one breath..... They have **returned to school** and we as parents have survived another lengthy break. With their return you are probably busy working with new teaching staff, how is it going?

- Are you able to engage in a manner that takes the teacher with you?
- Are you delivering your message in a manner that is non confrontational?

When I look back at the work Marie put into the new teachers at the beginning of each year, I think wow she really did some amazing “**relationship building**” ensuring the teaching staff best understood how to get the best out of Jessica.... In the early days of primary years we would struggle with this concept. We still believed the teachers knew best and did not need to know our knowledge of Jessica...actually, we were wrong!

We embarked on working closer with Jessica's teachers. This actually meant I had to become involved to best support Marie and the school. Being on the BoTs helped! Plates of scones/muffins, nice comments on how they look, the odd rose from my garden...all helped to create a feeling of “**working together**”. Whether we liked the teacher did not come into it. This was purely a charm offensive. Discussions followed that were often far more honest and as a result Jessica started to get a better deal....

Now-days teaching staff are far more enlightened about working with parents of disabled children. Your efforts to engage and support your teachers should be greeted with an improved sense of inclusion....

One of the big messages I have learned over the years is not to show my displeasure, but to use supportive language and smile and to be positive about Jessica's abilities, focusing on what she can do....What I was doing was trying to get the teaching staff to concentrate on Jessica, rather than her disabilities....**See my child first**. This sadly is easier said than done. It is though very rewarding if you persevere...

When you act in the above manner, you are modelling behaviour that will be respected and you will be seen in a more positive light and SO WILL YOUR CHILD....

2012 = 78.95 Full Time Equivalent positions of Resource Teachers Vision now work with us and our children. In 2008 only 35 FTE RTVs were employed... Smart advocacy works aye!

Direct Parent Contact/Support Staff

For far too long, I have been frustrated by my inability to have the **direct parent contact** I believe you all deserve. Quite simply I cannot do it by myself. Hence the PVI Board has approved a pilot whereby we will hire a staff member to concentrate on direct parent contact. Should this concept work and I believe it will, we will introduce more staff as funding permits.

What are we hoping to achieve by these positions?

- To better support parents and whanau so you are better empowered to support your child
- Provide advocacy if required
- That PVI is effective at local levels
- Acquire more accurate information as to your needs

“All grand ideas” I hear some cynics saying... well I wonder what this service might look like when it is By Parents For Parents...hopefully, this will be better appreciated by our parent community.

Government Funding and PVI's Independence:

As a result of decreasing budgets from the RNZFB, PVI has had to look elsewhere to grow its funding base so we are not reliant on one funder.....As a result of this, we have had to consider applying for government funding and what this might do to our perceived independence. Quite simply I believe we will still remain loyal to our core parent group needs. By applying and hopefully getting Government funding, this might just work in a manner whereby we can better inform Government of our needs...

On a **personnel level**, I recently had to advocate for my adult daughter's rights concerning her residential care. I was so worried and upset that I needed to take a support person with me. It worked a treat and I was very well behaved. (I practiced what I preached for a change!) The outcome was that my daughter and I and our family received an apology. Their policies and service delivery methods have changed to better include families...

I am fast approaching 60 and I still have to watch & support my daughter to ensure her rights are upheld. I need to prepare others around us to take over....Circles of Support spring to mind! - Pa

Farewell from a man that did make a difference....

I have valued working with you Paul, especially on our trips down the Whanganui awa. You play such a valuable role advocating for the needs of children and their families.

It has been a privilege working with the blind and vision impaired community over the last 8 years. I came into this work through my daughter Julia, who was blind before she died. I have been inspired by the courage and attitude with which so many people face personal challenges and embrace the recreational opportunities and challenges which we have provided. It has been a joy to be part of the sense of community and mutual support so evident in the residential programmes, and to see people grow through these opportunities.

I have been reflecting on the special qualities of so many of the children and teenagers I have worked with. I have found them to be so accepting of one another's differences. While many young people are locked into conforming, I have found most of our young members to be wonderfully supportive and accepting of others, and respectful of us older staff. I have been impressed and inspired by the calibre and character of the young leaders who are such wonderful role models helping at the annual Taupo Summer Camp. I think that the training of these young leaders and giving them opportunities to serve has been a real highlight of what the Recreation staff do.



Richard seen here with Elsa

Working with people of all ages has been enriching. I have valued the opportunities as a Recreation Advisor to network with others and to develop new initiatives. It has been a privilege working alongside dedicated field staff, volunteers and other professionals who thrive in working directly with members. Keep up the good work.

Regards, Richard West

NZ View to support PVI Parents

PVI Response: Having worked alongside Richard for some considerable time I can only attest to the wonderful work he did with our children. Parents from around the country have always commented on Richard's sincerity and willingness to work with families.....

Richard, thank you for all that you did and we wish you well for the future.

Paul.

Parent Support offered from NZ VIEW

NZ VIEW (Vision Impaired Empowering Women) a Consumer Group from the Royal New Zealand Foundation of the Blind is offering to provide support to primarily mothers enrolled with Parents of Vision Impaired NZ Inc.

I have met with NZ VIEW on behalf of PVI and can attest to the good natured offer of help/support. This offer comes from a different perspective. These women from VIEW are all members of the Royal New Zealand Foundation of the Blind. Hence as a mother raising a blind or vision impaired child you are invited to receive support, ideas etc from someone with a sight loss condition.

The relationship between PVI parents and NZ VIEW members will be a private one. That is two adults sharing information and taking the relationship from there as both feel comfortable.

The process is simple, PVI parents contact Paul at paul@pvi.org.nz and I shall pass on your **name and contact details** to NZ VIEW who in turn will find the appropriate support person.

Remember this is an offer of support that some of you might well appreciate, hearing and learning from a person who has been there and done that is often what we as parents value most.

To NZ VIEW we say thank you, your offer of support is appreciated.



From your PVI Board



Is this your PVI Board in training for the Otago Rail Trail bike ride?

Greetings Parents,

Below are brief biographies from your Board and E O. We feel it is important that you know your Board and understand, that above all else, we are parents just like you. All at different stages of this journey with our children...

Riripeti Paine Tangata Whenua Representative & PVI Chair

Ko Maungapohatu te Maunga
Ko Hinemateroa te awa
Ko Tauarau te marae
Ko Ngati rongo te hapu
Ko Tuhoe te Tangata
Ko Riripeti taku ingoa

Greetings

My name is Riripeti, I sit on the Board as a Tangata Whenua representative

I have four children, six grandchildren and a great grandson.

I live in Wairoa Hawkes Bay and have 16 years of experience in the field of disability

David Heather Lower North Island Representative and Vice Chair.

Hi, I am married to Rhonda and we have two children Kirsty and Richard. Richard was born with congenital rubella syndrome and as a result has complex needs. Richard is visually, hearing and intellectually impaired, but leads an amazing life.

Don Fairgray Central North Island Representative and PVI Treasurer.

Father to Laura (13) who is Vision impaired. She is in the mainstream school system and at her first year in high school. I am a farmer and work part time for Farmlands.

Dionne Gilligan Anywhere in NZ Representative

Hi, I have a 9 yr old son who has Cortical Visual Impairment plus other needs.

I work in the early childhood sector and would love to hear from other parents who have young children.

Tim Marshall Upper South Island Representative

Hi, I am new to the board, having just recently been appointed. I am married to Jenny and together have 3 children, Elliot (16), Lewis (12) and Olivia (12). Lewis has a Visual Impairment and will begin his transition to high school at the end of the year. I work as a social worker with the mental health trust in Christchurch.

Kim Lewin Upper North Island Representative

Hello, I am Kim and I am from Tapanui and I am one of your Upper North Island Board Reps. I am married to Cliff, I have 3 children, my youngest who is 16 years old is Alyson who has Ocular Albinism.

Grant Davies Upper North Island Representative

I am a Travel Consultant with United Travel married to Dianne who is a Plunket Nurse. Our son Joshua (11yrs) is vision impaired due to Albinism. We have been PVI members since 2003 and gained immensely as a result.

Judith Hyslop Lower South Island Representative

As a mum of two young ladies aged 20 and 23, I bring a slightly different perspective to the Board. Krystal has multiple disabilities including visual impairment. It is an honour and privilege to be part of the team on the PVI Board.

Paul Manning Executive Officer PVI

Greetings fellow parents, I am husband to Marie of 38 years, proud father of 6 children and 6 grandchildren. My daughter Jessica is living in a supported flatting environment here in Hamilton. She is now 25 and is enjoying life with her friends.



Above, Your PVI Board and E O: Back Row from L—R, Tim Marshall, Kim Lewin, Riripeti Paine, PVI Chair, Grant Davies, Don Fairgray PVI Treasurer, and Judith Hyslop. Front Row: - Dionne Gilligan, Paul Manning EO PVI and David Heather PVI Vice Chair.

Message from Tariana Turia, Minister for Disability Issues

Suggested Constitutional Changes to the PVI Constitution

Tena koutou katoa.

I am delighted to be Minister for Disability Issues again.

I want to build on last year's employment summit, to ensure that we develop a vigorous disability employment plan. I am particularly keen to see that transitions from school to employment are improved for disabled young people.

I am watching closely the impacts of the Ministry of Health's demonstration in Tauranga of a new model for providing disability supports. In my mind, the most important challenge that faces us in creating an enabling society is to ensure that we support disabled people and their families to have more choice and control in their lives.

Last year I commissioned an independent working group to report on **"Enabling Good Lives"**. This report takes a 'first principles' look at the types of supports government should provide so disabled people can have the life they aspire to like other New Zealanders. It proposes that the 'day and community participation service' model be incrementally changed to enable disabled people to do 'everyday things in everyday places' in their communities.

I would encourage you to read the **"Enabling Good Lives"** report. It is now available on the Office for Disability Issues website, at <http://www.odi.govt.nz/what-we-do/improving-disability-supports/index.html>.

Mauriora!

Na Tariana

PVI Response re **"Enabling Good Lives"**

Having read the report titled **"Enabling Good Lives"**, I can only endorse what the report is saying. It is a refreshing step forward that is trying to enable **People With Disabilities and their families** to have a greater say in how services are purchased. It is trying to un-clutter the myriad of funding agencies we currently have to deal with. Admittedly it appears to be aimed at the post school era, it is still very relevant as it will affect all of our children whether in our care or not..... Paul.

"Life is either a daring adventure or nothing."
- Helen Keller

Your Board has been discussing the need to update our Constitution. The following are suggested changes which the Board wishes to consult/discuss with you. In the **June Issue of "Vision"**, we will be publishing the suggested changes that will be presented to the parent membership at this year's AGM to be held in Auckland on the 27th of October 2012 at the Bella Vista Express Hotel, 14 Airpark Drive, Auckland Oaks, Auckland.

The Board's suggested Changes to the PVI Constitution dated May 2009:

2.1: Change registered office address from 6 Vialou Street to: **"15 Liverpool Street, Hamilton"** or as determined by the Board of PVI".

2.2 Change Postal address to: **"PO Box 366 Waikato Mail Centre, Hamilton"** or as determined by the Board of PVI".

Add new clause:

6.0 A: PVI may choose to appoint a PATRON. Nominations for the position must be have a signed acceptance by the nominee and be proposed and seconded and be in the hands of the Board to enable the membership to be advised 3 months prior to the AGM.

6.0 B: The passing of the resolution to appoint a Patron will require three quarters of those eligible to vote at the AGM.

6.1A: Add "Royal" before "New Zealand Foundation of the Blind".

ADD new clause:

6.5: That the award of "Life" membership maybe recommended by the Board and presented at the AGM.

8.1: Delete the word "postal"

9.5: Delete the clause and renumber the remaining sub-clauses accordingly.

9.9: Change the word "co-opt" to "appoint".

9.10: Delete this clause.

10: Delete words "for a further 2 years". To read, "The term of office for all representatives shall be 2 years with the right to be re-elected".

15.1: Delete words "at a location within New Zealand", To read:-The Board shall meet a minimum of 3 times annually.

15.2: Change to: "The quorum of the Board shall be a majority of the filled voting positions".

A copy of our current constitution will be available to read on our website.... The Board welcomes your comments: email: paul@pvi.org.nz



Success for all, every school, every child—The aggregation of sensory ORS 2012

In 2010 the then Minister of Education, Rodney Hyde, announced Success for All, Every School, Every Child, the Government's four-year plan of action to achieve a fully inclusive education system. This introduced significant changes to the resourcing for learners who had been verified for vision and/or hearing. For the first time the resourcing for these learners, generated by verification, would automatically go to one of the three sensory schools, Blind and Low vision Education Network NZ (BLENNZ), Kelston Deaf Education Centre (KDEC), or Van Asch Deaf Education Centre (VADec). The intention was that this would enable them to provide appropriate services to meet the needs of learners who are blind, deaf, deafblind, hearing impaired or have low vision.

Throughout 2011 the Ministry of Education worked closely with the three sensory schools to work through the process of implementing this government plan. In 2012, *Success for all*, means that the resource generated by the Ongoing Resourcing Scheme (ORS) for learners verified for vision and /or hearing is now being aggregated and the collective resource will now go to the appropriate sensory school to enable them to provide relevant specialist services.

If a learner is verified for vision only their ORS resourcing now goes automatically to BLENNZ, who can then provide BLENNZ services, including the Resource Teacher Vision.

For BLENNZ this applies to those learners who have been verified for vision only, with the exception of learners with a dual verification of vision and hearing. Learners with the dual verification will have their resources aggregated to BLENNZ, who then work with the Deaf Education Centres to ensure the needs of the learner, identified in the IP process, are aligned with the appropriate provider, sometimes this is Van Asch or Kelston, sometimes BLENNZ and sometimes a mixture of the two.

Many of BLENNZ learners are verified for vision as well as their other needs, for these learners the decision to transfer resourcing to BLENNZ remains with the IP team and the enrolling school so decisions for transferring the resourcing for these learners continues to be made on a case by case basis.

For Visual Resource Centres across the network the immediate impact of this change has been varied. For some centres, such as Gisborne, Wellington and Christchurch, the change is minimal as the majority of schools with learners who were verified for vision only, in these regions, were already transferring the ORS allocation to BLENNZ, whereas the change for Auckland has been significant.

An example of how aggregation is making a difference can be demonstrated by what is happening in Auckland. The aggregation of ORS for Auckland attracted 9 fulltime specialist teaching positions. The certainty that aggregation brings meant that BLENNZ has been able to appoint 6 new permanent Resource Teachers Vision to the Auckland team. Even better news, of the 6 people appointed 2 already hold the specialist teacher

qualification, 3 are currently undertaking training through Massey University and the other team member is keen to take up training next year. This has got to be great for learners and Whānau.

A part time permanent position was also able to be made fulltime in the Palmerston North team. The decision to make other positions permanent will be considered this year and will be largely dependent on the predicted continuity of the resourcing.

What is really positive for all of BLENNZ Resource Centres is that the staffing of these centres is now more certain, and therefore we are more confident that we can provide staff with the appropriate training and qualifications to support BLENNZ learners.

We have gone from a situation where in 2009 BLENNZ was allocated 15 RTV positions bringing the total to 50 fulltime teacher positions. In 2011 BLENNZ Managers of Visual Resource Centres had organised the transfer of 16.7 additional fulltime teacher positions through the voluntary transfer of ORS specialist teacher time by some schools and now in 2012 there are 28.95 additional fulltime teacher positions being transferred automatically to BLENNZ.

Success for all has meant that the resource that is being generated by a learner's verification is now provided automatically to the sensory school best placed to meet the learners need. For those learners verified on the basis of their vision only this means BLENNZ.

Aggregation has brought about a significant change to BLENNZ resourcing and there are bound to be some initial challenges in either resourcing processes or service provision which we will work through one at a time with ministry, sensory schools and our BLENNZ team and community.

Our thanks go to the parent community and other blindness sector groups who have advocated long and hard for this change. A big thank you also to the BLENNZ Managers of the Visual Resource Centres and their respective teams, they have done a wonderful job in their regions to support a smooth transition for the introduction of this government plan. It is a credit to each of them that the aggregation of resourcing to sensory schools, is progressing so well.



Lindsay Voice, a new Full Time Equivalent Resource Teacher Vision based in BLENNZ Auckland



Preparing for vision loss: enter the information void

For too long sight loss services in Aoteroa/New Zealand have focused on the 'legal blind' criteria set by the Royal New Zealand Foundation of the Blind (RNZFB) in collaboration with the medical profession of course. We are aware of the variations of blindness just as we are aware of the variations of the sight loss conditions, it is all very complex. However what supports are available for the ever increasing numbers of our population who have a sight loss condition that is not of the RNZFB entry level, but never-the-less there life is affected in a negative capacity as a result of their sight loss.

PVI for many years has tried to provide information and advocate for families who have children with a sight loss condition whose children are not entitled for RNZFB membership. The following article I read in the Retina NZ magazine and have sought permission from the author to reprint in our magazine, this has been given...enjoy the read and please give me feedback on how we might improve this situation.....

At a Disabilities Studies Conference at the University of Otago in Nov. 2011, Dr Lynley Hood and Assoc. Prof. Gordon Sanderson gave a joint paper entitled: "An Absence of Vision: the case for comprehensive, publicly-funded, low-vision rehabilitation services in New Zealand." This is an abridged version of Lynley Hood's contribution:

In December 2009 I lost the central vision in my left eye, suddenly and permanently. Then the vision in my right eye began to deteriorate. Fear of blindness kicked in. Throughout history people have feared blindness more than any other disability.

My greatest concern was that if I lost the central vision in my right eye as suddenly as I had lost it in my left, I would be in big trouble. What would I do? How would I cope? If I need a new microwave, or a new phone, what should I look for to ensure it will be easy to use if my sight deteriorates further? But I could find no information on preparing for possible vision loss. In view of the number of older people losing their sight gradually, this seemed an oversight.

I phoned the 0800 number for the Royal New Zealand Foundation of the Blind. I assumed that, as with the Arthritis Foundation or the Cancer Society, if you call a charity in search of advice and information, the person on the other end of the line will do their best to help. But the Foundation helps only it's own members, and the Foundation bar for membership is set very high.

For the 2001 post-census disability survey, Statistics New Zealand defined a visual impairment as a difficulty, or an inability, to read ordinary newspaper print and/or see a face across the room. If the difficulty or inability to see was corrected, e.g. by glasses or contact lenses, the person was not defined as having a disability. The survey found that only 12 percent of New Zealanders with long-term uncorrectable vision loss were members of the Foundation.

The survey also found that 71 percent of visually impaired adults living in households, and 97 percent of those living in residential facilities, require magnifiers, large print books, audio books and other special equipment. But for all but the most severely visually impaired, information and support is scant or non-existent. Since vision loss trebles for each decade over the age of 40, with our ageing population the problem is bound to get worse.

How did this situation arise? Why are there services, support groups and advocacy groups nationwide for people coping with other disabilities, but next to nothing for those facing vision loss? Part of the answer lies in the poorly understood consequences of even minor levels of visual impairment.

The Statistics NZ survey found that of all types of disabilities - mobility, agility, hearing, seeing, speaking, psychiatric/psychological, learning, remembering and "other" - vision-impaired people ranked with mobility and agility impaired people as the second most likely to need help with everyday activities like personal grooming, meal preparation, shopping, housework and personal finance. Only the intellectually handicapped were in more need of help. The survey also found that of all people with disabilities aged between 15 and 64, people with visual impairments were the least likely to be in paid work. People with intellectual disabilities had the lowest levels of educational attainment and needed the most help with everyday tasks, but they were more likely to be in paid work than better educated people with visual impairments.

As these findings demonstrate, the consequences of low vision can be devastating. If you have trouble reading the newspaper, you have trouble reading your mail and you have trouble paying your bills. You have trouble cooking because you can't see the controls on your oven or water level in your saucepan. You have trouble looking smart because you can't see the food stains on your clothes or the cat hairs on your coat. You have trouble with housework because you can't see the dust and spills. You have trouble shopping because you can't read the price tags. You have trouble getting around because you're not allowed to drive, or you're too scared to drive.

Preparing for vision loss: enter the information void (cont...)

So you either struggle on, or you curl up in the foetal position, pull the duvet over your head, and give up. There are numerous studies showing that the emotional impact - the fear, the depression, the anxiety and the risk of suicide—of gradual sight loss is far greater than that of sudden blindness. So it's not surprising that the most common sensory impairment among people in long term residential care is vision loss.

If people who lose their sight later in life could get themselves organised they could do what other disability groups do. They could send out newsletters and press releases. They could lobby politicians. They could do everything in their power to make their voices heard. But this has not happened for the cruellest of reasons: visual impairment makes you illiterate. If you can't see the words on the page of the daily paper, the books on your bookshelves, and the magazines and newsletters that keep you connected with the world, your relationship with the world is over.

Another reason why nothing has been done to meet this unmet need is that most people think the Royal New Zealand Foundation of the Blind provides that service. After all, the principle objective of the Foundation is "to promote and provide for the independence, integration, enablement and well-being of blind and vision impaired people in New Zealand society." On government bodies, on inter-agency committees, in news releases and submissions to parliament, the Foundation presents itself as the primary provider of services to the blind and vision impaired. But, as visually impaired people and their families soon discover, The Royal New Zealand Foundation of the Blind claims to represent people it won't even allow to join its organisation.

I'm not suggesting that the Foundation should throw open its doors to people with low vision. They're not equipped to do that. It would put an impossible burden on their resources. The Foundation's expertise is in providing services to the blind and almost blind and they deserve our support to do the best job they can. All I'm asking is that they stop pretending to be all things to all people. The huge unmet need for low vision rehabilitation services has to be acknowledged so it can take its rightful place on the public agenda.

It won't be easy for social service agencies and the public at large to meet this need - partly because visual impairment is so confusing. It comes in many different forms and is defined in many different ways. Visually impaired people aren't blind. Everyone knows what blindness means. But what does visual impairment mean? Some visually impaired people see only what's straight ahead of them. Others see only what's on the periphery. Some struggle with focus, or contrast, or depth perception, or colour. Some are blinded by too much light, or by not enough light, or both.

That's one of the reasons people with low vision don't like talking about their disability - it's so complicated to explain. Another reason is that hardly anybody takes them seriously. After all, they're not blind. So most people with low vision struggle on unobtrusively. But sometimes - like when a friend stops them from stepping in front of oncoming traffic - the impairment may be discussed. "You should get a white cane. Then drivers would see you." But you have to be a member of the Foundation before you can be trained in the use of a white cane. And what would the public think of a person who is obviously not blind using a white cane? Is it okay to use a white cane and look in shop windows? Worries of this sort make it hard for visually impaired people to accept help without feeling like frauds, or being seen as frauds. And yet, as the statistics show, if people with low vision do not get the help they need when they need it, there's a high risk they'll end up as burdens on the community for the rest of their lives.

What about the eye care specialists, haven't they noticed there's a problem? Of course they have. Thanks to high-profile campaigns over the past decade, public awareness of the principal causes of irreversible vision loss in New Zealand - glaucoma and macular degeneration - has risen dramatically. These campaigns focus, quite properly, on prevention and early detection.

The glaucoma message is: "Glaucoma is the number one preventable cause of blindness in New Zealand. Blindness from glaucoma can be prevented by early detection and appropriate treatment." The macular degeneration message is: "Macular degeneration is the leading cause of blindness and severe vision loss in New Zealand. Untreated, the majority of people with wet macular degeneration become functionally blind within two years."

If you take nothing else from this paper, take this message: Have a comprehensive eye examination every two years. Early detection is the best way to save sight. It's important to note that the glaucoma and macular degeneration messages do not promise more than current, state of the art, medical science can deliver. Early detection and appropriate treatment can prevent blindness. The corollary, that early detection and appropriate treatment cannot prevent vision loss, is not a message that doctors want to deliver or patients want to hear. But the full to overflowing eye clinic waiting rooms nationwide attest to this unpalatable truth.

There are already far too many New Zealanders struggling to cope with vision loss unaided. Their numbers are escalating daily. This is a public health crisis. It needs to be acknowledged and addressed. Now.

Lynley Hood

Anything a school system does that undermines parents' trust creates a climate that is costly in dollars, time, peace of mind, and the quality and success of services given to the child.

Here are the most significant school system mistakes, according to persons at every level of the system:

1. Refusing to let parents or parents' experts see programs, either within or outside of the school system. When school systems tightly restrict the parents' access to their own programs, the parents wonder what they are hiding and assume the worst; when they refuse to clear the way for parents to see an outside program, the parents will assume that the grass is greener over there;
2. Failing or refusing to communicate and actively coordinate with outside experts working with the child, such as the child's therapist or a tutor;
3. Ignoring reports from independent evaluators; failing to speak to those evaluators to clarify ambiguous information or recommendations; failing to add the evaluator's recommendations to the IEP when reasonable;



4. Failing to respond to parents in writing or at a meeting when a problem arises;
5. Taking a patronizing and/or antagonistic and/or insulting attitude toward parents; personalizing issues between school and parents; attempting to blame parents for their children's educational failures rather than looking for solutions (school system professionals need to treat parents with respect even if those parents are insulting and belligerent themselves);
6. Sweating the small stuff (e.g., spending twenty minutes at a team meeting arguing about whether the meeting can be tape-recorded);
7. Failing to observe procedural timelines and notice requirements (e.g., scheduling timely meetings, getting evaluations to the parents before the team meeting, notifying the parents who will attend the meeting, providing clear written explanations of parent rights);

8. Writing careless and sloppy IEPs. Parents, evaluators, and hearing officers all look first at the extent to which the written IEP reflects a thorough and logically coherent view of the child, the goals and objectives for that child's program, and a clear and understandable description of what will be provided, how, by whom, and when; and how the child's program will be evaluated;

9. Failing to implement an IEP and, worse, trying to cover up that failure;

10. Failing to modify an IEP that is not working and waiting, instead, for the program - and the child - to collapse;

11. Failing to provide additional or different services as a way to avoid having to make more restrictive (and expensive) outside placements;

12. Failing to call in expert consultants from outside the school system with good reputations among both school and parent communities who can help develop or monitor a program for a child with unusual needs;

13. Losing contact with families who have placed their child unilaterally. Some school systems forget or ignore their continuing responsibility to evaluate, review, and propose IEPs for children when they are attending outside placements at their parents' expense;



14. Botching the required procedures around suspension or expulsion of students with identified or suspected special education needs (e.g., failing to convene the team, failing to make a manifestation determination, failing to re-examine the IEP to see if services are appropriate and have actually been provided, failure to provide FAPE to suspended or expelled students with special education needs);

15. Failing to ensure that non-special education administrators - particularly building principals - are fully informed about and are following the required special education policies and procedures.

Mistakes Parents make....www.wrightslaw.com

Because the stakes are so high, it is difficult for parents of children with special educational needs to advocate calmly and objectively for the educational and related services their children need.

Here are some common mistakes that undermine parents' ability to obtain appropriate services:

1. Viewing the special education process as the moral equivalent of war, fighting that war with a "scorched earth" approach, and letting personal animosity toward administrators and/or teachers distort one's judgment about what is best for the child and what is realistic to accept;
2. The opposite mistake: trusting administrators and teachers too uncritically; assuming that if they are "nice" they are also competent and interested in serving the child's best interest; not questioning slow, or nonexistent progress as long as the child, parent and teacher have a cordial relationship;
3. Taking an "all or nothing" approach: waiting too long before getting good independent advice, then insisting on instant delivery of needed services rather than steady progress toward the right program;
4. Failing to understand that the special education process sometimes requires that the parent educate the child's special education team about the child's disabilities and needs (the school system may not be wilfully refusing to meet the child's needs; they may simply not understand those needs);
5. Not trying a program or added services, even on a temporary basis, when they are offered by the school system -- holding out for an alternative program only to have a hearing officer decide the untried program might have worked;
6. Attempting to "micro-manage" the details of a child's life in school; even if parents don't feel things are going well, their efforts to control the child's day usually backfire when the hearing officer concludes that the parents were over-protective and didn't let the school professionals do their job;
7. Focusing on minor, nonprejudicial procedural missteps by the school (e.g., the parent who already knows her rights who says, "Aha! Gotcha! School district forgot to give me the rights brochure!") instead of focusing on the substantial issues in the case;
8. Not consenting to school evaluations;
9. Choosing the wrong independent evaluators: e.g., "hired guns" who only say what the parents want them to say, and have a reputation for doing so; those who will not follow through by observing programs, attending team meetings, etc.; those who do not have training or experience to evaluate a child like yours;
10. Not providing copies of independent evaluations to the school, or not providing them in a timely way;
11. Not responding in a timely way to proposed IEPs;
12. Not documenting issues with the school; not sending letters to confirm agreements with the school or to record important conversations with school personnel.
13. Seeing the school system as a monolith ("All those teachers are incompetent [or wonderful!]); failing to look carefully at alternatives within the system for this year and at next year's teacher possibilities.



Experienced Advocacy: What I Rely on Most and a NZ perspective by an Advocate in Vermont USA (Special Ed Advocate wrightslaw@wrightslaw.com)

Recently, we heard from an experienced advocate in Vermont who shared some insight about his years as an advocate and what has served him well. We thought we would share, and also say "thank you" for the recommendation for Wrightslaw.

"In my advocacy experience the things that I rely on most often are:

- Letting people save face - sometimes accompanied by blackmail/extortion/intimidation.
- Writing decent goals and transition plans in the body of a letter. That way I know at the very least, they will end up in the file even if they are not used.
- Documenting everything in writing.
- Making sure something *doesn't get documented* in writing.
- Having an outside expert or an expert source of information (US Department of Education / National Reading Panel, State Department of Education / EdPubs.org, etc.)
- Knowing state academic content standards.
- Understanding what test scores mean.
- Having a growing collection of manuals for Wilson, Slingerland, OG, all the Lindamood programs, etc. and on the dark side, Reading Recovery, DRA's, Everyday Math, etc.
- Making sure everyone stays focused on problem solving, *including me*.
- Having the ability to keep talking when I need to throw up. I also have magic underwear, magic jewellery, and magic pencils for meetings where I am not sure what will blow up first.

And, the thing that school personnel seldom understand. The last 3 meetings I went to...the parents never would have called me if the case manager had just been honest with them. In special education this sometimes means the same as apologizing on a fairly regular basis."

A PVI perspective: -

The above is from WRIGHTSLAW, a company in the United States of America that specialises in advocating for parents who have children with special needs. In America there is the D.E.A. Act, this stands for Disability Empowerment Act. It is federal law which means all State Governments must abide. What this law does is guarantee funding and supports for students with special needs. Problem sorted for parents in America one would think. Judging by the above tips etc there still is much to work on around attitude; why indeed, is there a need for WRIGHTSLAW?

In New Zealand, we do not have a law such as the D.E.A....sadly. What we do well is we have strong social and education policy that works in a collaborative manner with parents and schools, communities and the nation as a whole.

By changing attitudes and encouraging society to be more inclusive of difference, our children might grow into a more enabling society. It is societies attitudes that are disabling. This is the root of why we have to have such strong policy drivers like the N Z Disability Strategy doc, the Convention of the Rights of Disabled Persons and an enormous amount of reports commissioned by Government sitting in various ministries....We have so much information on how bad it has been for families raising children with disabilities, yet, very little appears to have changed or has it?

The latest attempt from the Ministry of Education, "Success for All" could almost be seen as a last ditched attempt to fashion change in attitudes of our school systems and society in general. Perhaps the real question is why do we need these social policies? I suggest they are there to protect the vulnerable, to protect those who cannot speak for themselves..... Sadly this all appears to be done in isolation of the family/whanau.

We keep on introducing and applying new policy independent of the family/whanau. If we continue to treat our children in isolation of parents and our families then little wonder we are struggling to affect a more inclusive society.

I want you to have conversations about what this article raises, ask yourself and others why we are not more inclusive....Then and perhaps when we as a nation start having these conversations we might well become more inclusive.... Paul.



Carers NZ and the Carers Alliance need your expert help!

Dear friends at the Carers Research Network,

We are retaining the economist Suzanne Snively to evaluate the cost/benefits to the state should it pay carers supporting someone with high 24/7 needs.

As many of you have undertaken literature reviews and research projects relating to family caregiving ... encompassing the economic aspects of caring e.g. leaving paid employment to care, reduced productivity due to caring, working below experience/qualifications while caring, impacts on household income and related poverty etc ... anything with an economic tinge ... we need to compile this information for review by Suzanne and her graduate student.

We expect this to be a three phase project beginning in February. Phase I will look at scenarios for paying 24/7 carers; the economic value of their work; and their ability or not to participate in other paid work. The paper will include recommendations for social and political debate.

Phase II will look at the wider economic and productivity issues relating to family caring, with a solutions-focused lens e.g. Australia's new disability insurance 'no blame' scheme.

Phase III will review and make further recommendations.

We seek the Network's assistance to identify the key New Zealand and overseas research/papers to inform Suzanne's Phase I work. Would someone be willing to help us put this together or is there an existing review or work to use as a foundation?

Thank you for your help and suggestions. Currently the Government's appeal of the payment for carers case is being heard in the Court of Appeal in Wellington. We expect the families to win again. But after this we want to be in a position to recommend credible solutions to government, lest it feel it's only option is to legislate against any kind of payment to carers for cost reasons.

Please phone me if you have suggestions or perhaps this email will catalyse comments about how best to proceed from an evidence point of view.

All the best to you this year ...

Laurie Hilsen
CEO
Carers NZ

Carers New Zealand
Sara Rogers
National Coordinator
Phone: 09 406 0412
Fax: 0832 67540
Email: sara@carers.net.nz
www.carers.net.nz
PO Box 133
Mangonui, Far North 0442

***"Adversity is another way to measure
the greatness of individuals. I never had a crisis that
didn't make me stronger."
- Lou Holtz***

Humorous!

A man and his ever-nagging wife went on vacation in Jerusalem . While they were there, the wife passed away. The undertaker told the husband, "You can have her buried here in the Holy Land for \$150 or we can have her shipped back home for \$5,000. The husband thought about it and told the undertaker he would have her shipped back home. The undertaker asked him, "why would you spend \$5,000 to have her shipped home when you could have a beautiful burial here, and it would only cost \$150?????"

The husband replied, "Long ago, a man died here, was buried here, and three days later, rose from the dead. I just can't take that chance!"

Consumer updates from the RNZFB....

Netball

The Supporter Relationships team is really pleased to announce that the RNZFB is the charity of choice of Netball NZ. The relationship has only just been established and we'll have more news soon on what the full extent of opportunities are for the RNZFB.

Blind Week Results

Thank you to everyone involved in raising a significant sum of money for the RNZFB during Blind Week 2011. We have had nearly 10,000 postal donations and over 1,400 volunteers who baked a difference, shook online 'virtual' buckets and ran many community events. Blind Week has raised almost \$600,000 and donations are still coming in every day. Last year's target was an ambitious \$700,000 and we intend to take all the things we have learnt to raise even more money this year. One of the most significant things we have learnt is that our supporters do like to engage in different ways, such as the online appeals and bake a difference, but that the more traditional street collections remain very important to our communities too. We look forward to taking what we have learnt and applying it to the Red Puppy Appeal next month...

Red Puppy Appeal

Red Puppy Appeal is running from Friday 30 March to Sunday 1 April. This year we are really encouraging staff and volunteers, including community committees, to get involved in the Appeal by coordinating street collections and other fundraising events in their communities. We will also be appealing to our fantastic supporters via a direct mail and email appeal, as well as inserts in a variety of magazines. Building on the success of last year's Red Puppy Bikkie Day, we are inviting businesses, day care centres, primary schools and a number of volunteers to bake a difference on Friday 30 March. We will also ask our Facebook fans and other online friends to shake a virtual bucket through MyBucket.

Parent and Child Enrichment Programme (PACE)

The PACE brochure is in its final stages of design. We expect to have the final print production underway within the next month. We are also looking at the possibility of having a Te Reo version of the brochure printed.

Recent media releases 20 February - RNZFB and Macular Degeneration NZ (MDNZ) issued a joint media advisory in response to Dame Judi Dench's announcement that she has age-related macular degeneration (AMD). In New Zealand one in seven people over 50 years old is affected by AMD and almost 40% of the members of the RNZFB have AMD. MDNZ is hosting a free seminar on Saturday 21 April 2012, starting at 10am, at the Waipuna Lodge, Auckland, to share information on new advances in research, treatment and management of age-related macular degeneration.

15 February – RNZFB issued a media advisory in support of the public debate on workplace barriers experienced by people with disabilities, prompted by the call from Deaf Aotearoa and MP Mojo Mathers that more needs to be done to facilitate access.

Embryonic stem cell treatment gives new hope.

A case report recently published in the Lancet medical journal outlines a procedure carried out on two blind registered American patients, both suffering from degenerative eye conditions, which partially restored their vision. Both volunteers were injected with retinal pigment epithelium made from human embryonic stem cells and crucial for nourishing the light sensitive rod and cone photoreceptors in the eye. A follow up examination four months later, showed that both patients had objective improvements in their vision and improved pigmentation visible in their retina.

Touchscreen technology made accessible

In the last month, touchscreen technology has inspired the creation of revolutionary braille writers. A prototype iPhone app called BrailleTouch has been unveiled by researchers from the Georgia Institute of Technology and a group of students at Stanford University have created a tablet-based braille writer. In each case, when a user places their fingertips on the touchscreen, virtual keys align underneath each fingertip. These developments mean that in time these apps should soon be available on all smartphone and tablet platforms.

Paralympic Dreams

RNZFB member and cyclist, Phillipa Gray, is currently competing in her final tests with the hope of qualifying for the London 2012 Paralympics. Phillipa and her tandem partner Laura are currently in Los Angeles racing at the Track World Championships, the final international event which counts towards qualifying for the games. We wish the pair success in their coming races and await the final selection for the games to be announced in late April.

For further information on any of the above, please contact the Communications Team at comms@rnzfb.org.nz

12 years, 12 percent, come join the celebrations!

The BrailleNote family is celebrating 12 years of excellence assisting blind users maximise their digital productivity. If you have an older generation BrailleNote or a competitor notetaker, we wish to let you know about our generous trade in offer that is available until the end of April this year.



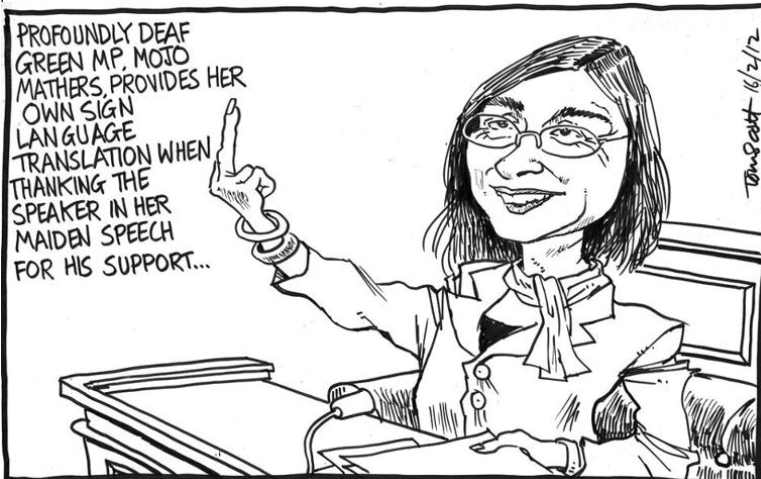
There are three models of Apex: a BrailleNote with speech output and a built-in refreshable Braille display of either 32 or 18 cells, and a VoiceNote that has speech output alone. In each model, there is a choice of a Braille, Perkins-style keyboard or QWERTY, computer-style keyboard.

You can trade your BrailleNote Classic, mPower or BNPK for a brand new BrailleNote Apex and enjoy 12% off the full price. If you have another platform such as a BrailleSense, PAC mate or BrailleLite, trade it in to receive 10% off.

HERE ARE THE PRICES WITH THE 12% OFF

- Buy a BrailleNote Apex 32: regular price \$8,750, trade in price \$7,700, **saving \$1,050**
- Buy a BrailleNote Apex 18: regular price \$5,850, trade in price \$5,150, **saving \$700**
- Buy a VoiceNote Apex: regular price \$2,850, trade in price \$2,500, **saving \$350**
- In 2000, HumanWare introduced the first BrailleNote. In 2005, the BrailleNote mPower was launched bringing USB connectivity and increased speed and efficiency to this range of productivity tools. Launched in December of 2009, the BrailleNote Apex, with a completely redesigned look, while maintaining the successful ergonomic design of past BrailleNotes, saw HumanWare pack the most powerful BrailleNote into the thinnest package available.
- Why would you want to trade in for an Apex? The BrailleNote Apex's added processing power, memory and connectivity allow users to achieve more than they could with their prior notetakers. In addition to providing dozens of benefits as a stand alone Braille digital assistant, the BrailleNote Apex can also interface with many mainstream technologies, providing familiar braille access and productivity in situations where Braille may have been previously absent.
- For more information or to arrange your trade in, please contact your nearest HumanWare representative or phone our head office on 02 9686 2600. We can also be reached by email at au.sales@humanware.com.
- **12 years, 12 percent, come join the celebrations!** HumanWare (www.humanware.com)

Oh Dear Oh Dear



The Mojo Mathers' debacle in Parliament only goes to show our children need vigilant support and protection...When the "Speaker of the House" cannot and it appears will not provide for one of its Parliamentary members to access an inclusive/fully accessible Parliament..... Oh Dear Oh Dear this could have been handled much better.



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: Aniridia Foundation International.

www.aniridia.org: Aniridia 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.familytimes.co.nz a newspaper produced quarterly, ChCh and Auck based, well worth a read.

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

Taranaki:	Vacancy please Apply	
Wanganui:	Amanda & Rex Van Elswijk	06 345 0327
Manawatu:	Jane Hoani	jane.hoani@gmail.com
Wellington:	Christine Pask	04 527 7585
	Joanne Beaver	04 589 3719
Kapiti	David & Rhonda Heather	04 203 6539
Nelson:	Adrian Secker	027 201 1028
	Trudy Perrett	03 544 6641
Christchurch:	Andrea Lamont	03 980 1566
Oamaru:	Pat Fox	03 434 3499
Alexandra:	Sarah Hinton	03 449 2414
Dunedin:	Alaina Gillies	03 484 7433
Invercargill:	Kim Hartley	03 217 1906