

VISION

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

PVI's Whakatauaki/Proverb:

*Kia hora te marino, Kia whakapapa pouamu 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 98

June, 2013



"The Thorndon Project—Stories to Tell", a PVI disability awareness campaign. Pictured left is Mark Lockett who was the driving force behind the Jazz concert and CD. Below is Wgtn identity George Taggart seen here sharing "his story". "Stories to tell" booklet can be downloaded: www.pvi.org.nz

CDs can be purchased from PVI, paul@pvi.org.nz, \$30.00 includes packaging and post.



Have you tried the PVI closed facebook ? It might be well worth a visit as many PVI parents, mainly mothers are using it. Enter/to join: Parents of Vision Impaired (NZ) Incorporated (Note: only registered parents of PVI are allowed to join). A great avenue for sharing and learning.

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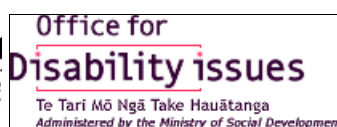
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Parents of Vision Impaired (NZ) Inc is on facebook



FUNDS FOR YOUR COMMUNITY



From Your National Office

PVI Conference and AGM 2013 why should I attend?

Greeting fellow parents,

Well winter is here with vengeance. I often think as one gets older the winters get colder...Probably much to do with less activity!

PVI has been in Wellington recently promoting the voice of "parents" through a publication we have produced called "Stories to Tell". A copy of stories to tell can be accessed from www.pvi.org.nz on the Home page.

Thursday 20 June shall live in the hearts and minds of those who attended the Jazz concert at "Old St Pauls Church", Wellington. The weather threw everything at us, yet it added to the atmosphere and quality of the performance of the musicians. Vocals from Caitlin Smith were fantastic. This woman is very special. Mark Lockett a virtuoso on drums. A CD has been compiled called, "Caitlin Smith—Stories to Tell—The Thorndon Project." Available from PVI \$30.00 inclusive of post and packaging.

Our opening of the campaign took place 10th June in the Grand Hall of Parliament. Minister Turia spoke very well. A copy of her speech is on page 4...It is a delight to read. This Minister really understood our perspective.

On understanding our perspective, it is a shame that the Minister of Health, Tony Ryall, has seen fit to introduce legislation that affects the democratic rights of the unpaid carer — more on pages 8 and 9. (I spoke with Ruth Dyson recently in Wellington, she advised that Labour would repeal this act should they become government.)

PVI Conference is coming up. This year to be held in Auckland at the Bella Vista Express Hotel, Auckland Oaks, Auckland. The one near the airport. We have secured the same rate as last year in that it will cost \$112 for a room per night. Hence if you share then it is \$56 per night. Includes a continental breakfast.

Cut off date especially for those requiring airfares is the 19th July, so please be quick with your registration forms. If air travel is required then please ring us on 0800 312 019.

Many parents choose to arrive on the Friday night, this is often around airline schedules and also the opportunity to catch-up with other parents; Friday night is often valued as catch-up time.

Please think seriously about attending.

**PVI parents are urged to attend our AGM and to be held at the
Bella Vista Express Hotel
14 Airpark Drive, Auckland Oaks,
Auckland on Saturday, 21st and
Sunday, 22nd September, 2013 at 11.15am
The Conference follows our AGM**

- **By attending you will be part of a supportive parent culture**
- **Be able to hear from/speak to and learn from other parents**
- **PVI will pay for reasonable travel expenses to and from Conference, however be warned, registrations close 19th July, 2013.**
- **PVI will provide food at the conference venue including the Saturday evening meal with a t/shirt theme.... "a PVI Parent is..."**
- **Registration form is on page 3. If you have not been before, then we urge you to attend. There is nothing as supportive as a PVI Conference; become part of the PVI whanau.**

There is no registration fee, but we ask that you pay for your accommodation.

Accommodation is your Responsibility to book 0800 235 528 ask for Bella Vista Auckland Airport or reservations @bvexpress.co.nz

PARENTS, PLEASE FILL IN THE REGISTRATION FORM, and we will see you there...

**Proxy Voting forms will be available on the PVI website, should you wish to vote in the AGM but cannot attend. Please download and fill in, then either fax, scan or post to, Parents of Vision Impaired NZ Inc, PO Box 366, Waikato Mail Centre
Hamilton by 19 September 2013**



21st and 22nd September, 2013 PVI Conference Registration form

Attending Parent-Caregiver/s details:

Please print:

Parent 1: [Last name]

[First name]

Parent 2: [Last name]

[First name]

Telephone Day:

Evening:

Mobile:

Email:

Postal Address:

Travel arrangements: By Car: ☐ **Air** ☐ (Please talk to Lyn or Paul re booking preference on 0800 312 019)

Friday evening meals are at your own cost as is your accommodation.

Accommodation Requirements: Friday night (at own cost): ☐ Saturday night (at own cost) ☐

PVI has negotiated a very good accommodation rate inclusive of a continental breakfast at \$56 per person twin share or \$112 per room for couples

Please Note: Accommodation bookings are your responsibility, mention you are part of the PVI Conference. Payments can be done upon check-in please/or provide credit card details

Special requests: Diet:

Mobility Issues:

Parent Confirmation of Membership:

I confirm my child:(name of child needed to confirm membership) has a serious sight loss condition and that I am a registered parent/caregiver of Parents of Vision Impaired NZ Inc

Signed:

Registrations close Friday, 19th July. 2013

**Please send this form to Parents of Vision Impaired PO Box 366
Waikato Mail Centre Hamilton 3240 or scan and email to paul@pvi.org.nz
or Fax to 07 839 5588**

PVI will pay for reasonable travel, and food at the Hotel.

PVI will not pay for any alcohol or private food purchases or communication technology costs.

Remember numbers are limited and preference is given to first time attendees,
so if you have not been before, now is the time!

Disability Awareness Campaign – “Stories to Tell”

Parents of Vision Impaired N.Z., Thorndon Project Official Opening Address by The Right Hon Tariana Turia, Co-leader of the Māori Party, Monday 10 June 2013; 5pm; Grand Hall, Parliament Buildings

My parliamentary colleagues; **Paul Gibson** our Disability Commissioner; **Riripeti Paine**, the Chair of Parents of Vision Impaired; **Paul Manning**, your Executive Officer; family, friends and tamariki/mokopuna.

Once upon a time...those magical words have captivated our children and given joy to both storyteller and listener for ever and a day.

Stories transport us to another time and place, on foreign shores or just around the corner. These stories grow in our heart and sit deep inside, waiting for the right moment, when like a little mouse peeking out from the corner, they are ready to face the world.

Today we are here to celebrate the stories that have been coaxed from the mouths of parents.

This project, **Stories to Tell**, represents the experiences from an organisation which encompasses over two thousand parents of blind or vision impaired children.

The project received support under the *Think Differently* campaign – one of the initiatives I am really proud of – an initiative which is driven by the challenge to promote positive perceptions of, and greater social awareness towards, disabled people.

In the 2013 Budget it was pleasing to be able to announce a further six million dollars invested into the *Think Differently* campaign.

And tonight, this event, represents all the promise and the possibility of that campaign. It reminds us of all the reasons why we need to tackle negative attitudes head on, to confront behaviours that limit opportunities.

One of the authors, Lee Rutene, gives voice to the aspiration that so many stories share, *“In the future I want to own my house and control my own life. My advice for people like me is to be strong and do the best that you can, with what you have got, and don’t let anyone tell you different”*.

This collection of stories starts, then, from that basis, and shares memories, and experiences that have shaped journeys both as parents and children.

The book provide glimpses into the lives of the everyday heroes who, in their own words, *“try to face the reality of their child’s disability with determination and courage”*.

Today marks the release of these stories into the world. Over the next fortnight, Parents of Vision Impaired intend to tell their stories to the Thorndon community as part of their campaign of awareness for and of their blind and visually impaired children.

The fabulous High Tea that forms the concept in this event is so fitting for the nature of the Thorndon Project. And this is where a sense of history is captured between the pages of this resource.

For over half a century the New Zealand Foundation of the Blind operated an office in Tinakori Road. Many a lifelong friendship was formed at the children’s Christmas Party held in the rose garden.

And it was in this part of town, that the Mayor of Thorndon was first elected in 1941 – a tradition which was carried on with annual contests for the mayoralty right up until 1985.



“The Thorndon Project — Stories to tell” (Cont.)

Apparently the crowning of the Mayor of Thorndon was a prestigious ceremony – complete with clowns, parades and a variety of bands. A modest fee was charged – just a penny to vote – and before long a sizeable fund was established. That fund – the Mayor of Thorndon Blind Kiddies Appeal – lives on today in funds and grants made to children right across Wellington.

In the opening page of the book, the rationale, then for the Thorndon Project is laid out. We are told, *“parent support networks....survive on stories”*.

The word, survive, is profound in its application.

For some – like Amanda –her story began in tragedy with the loss of her twin sister. Both girls were born with inherited retinoblastoma. Her story is entitled, *‘it’s not a fairytale – it’s our tale’*.

The struggle for survival, in fact, resonates through many of the pages.

Joshua arrived in the world twelve weeks earlier than expected, fighting for his life from his first breath. His little feet were not much bigger than the wedding ring his proud parents wear. At one stage Christine and Nigel were told to prepare for his funeral. Hospital was the home away from home: appointments with orthopaedics, neurosurgery, ENT, hearing tests, eye tests, paediatricians.

But through it all Josh has continued to battle to stay here – and likewise his parents battle to give him the best that life can provide. He thrives in their cuddles, he bursts into laughter at a drop of a hat.

They say that laughter is the best medicine. And that is surely a common theme woven throughout all the tales.

Nico’s tale is a particular ripper. He’s enraptured with all the little things that any ten year old boy shares – the sound of a good fart, rolling a ball into the washing machine just to hear the hollow bang. And it’s in the uncanny ability that a blind child has to spot a McDonalds sign from two miles away. As his parents say, *“McDonaldshelping the blind see since 1940”* should become their corporate logo.

One of the most effective messages in the book, is that relayed to us by our proud MC for the night David, and his wife Rhonda Heather. Their story contrasts what they were told, and what has instead been the lesson of their life.

They were told *‘this kid has no hope, you don’t have to take him home he won’t live past thirty years’*.

The purpose of a storyteller is not to tell you how to think, but to give you questions to think upon. And so we ponder, what might have happened if parents chose to believe the predictions of those with supposed authority. What might have happened to their child, to their family?

David and Rhonda chose, instead, to live by the **Yes We Can** philosophy of life – and 44 years later their son learned to ride a bike at 23; he has completed the Otago Rail Trail twice on a tandem and has attended Outward Bound three times.

In other words, their family has done everything possible to turn the impossible into the everyday; and to fully embrace the challenges, successes and failures and important lessons in life.

When it comes down to it, perhaps that’s one of the greatest impacts of this project, **Stories to Tell**. Of course, throughout the stories are written many moments of frustration and confusion; days of despair and nights of anguish.

Mark Lockett, a wonderful example of “Yes I Can”.



“The Thorndon Project — Stories to tell” (Cont.)

But as Kirsty Ferguson says in her memories, there is so much more.

There are plenty of giggles to share; and in every case the children exceed the expectations that all others have put upon them – that is except those closest and dearest to them who want nothing more for their children than the entire world.

And so it is in the words of the children, that I want to leave us tonight. Who better to honour the courage, the faith, the trust and the all enduring spirit of optimism that tell the stories of the parents of Vision Impaired?

The parents in this booklet – like so many parents of disabled children – are fiercely focused on what people can do, rather than what they can't. They are indeed the champions of the philosophy our Government is advancing in the *Enabling Good Lives* approach.

And so, the last word goes to Kirsty, who sums up a message which could be and should be heard by every parent in this book:-

“So to you, our mum and dad, we say thanks for the gift, the love and the journey. And whilst the journey wasn't as you'd probably hoped and dreamed for, you have climbed Mt Everest and further, not only for Richard, but through your drive and determination for the disability world.

Not an easy road, but one we wouldn't have any other way; we have your fighting spirit and we thank you for your strength and role models.

Here here to fighting spirits and interesting journeys”.

I want to thank you all for the privilege of being able to say, “I now declare “Stories to Tell” officially launched”.

To: Minister Turia, our sincere thanks for the sensitivity shown in your speech.

From: P.V.I. Board and Members

Email feedback in italics:

David, Paul

Hi you two, well you pulled it off – and boy did you pull it off. It was a wonderful occasion, professional without being pompous, meaningful without being 'worthy'. You did a grand job. I thought your lady President???? Was the piece de resistance. The poem was a killer. And what about the Minister. The project couldn't have fitted more perfectly into her idea of Enabling Good Lives.

So half job well done guys – looking forward to next week.

Please, please flick me some photos from last night that we can put them on our website and let everyone know about the project, CD etc.. I am also trying to get the Minister's speech because it was so good, it deserves sharing. Talk to you soon. Regards Trish.



Trish Green | Team Manager | Social Campaigns Family and Community Services |
Ministry of Social Development

“The Thorndon Project — Stories to tell” (Cont.)

Dear Paul and David

Just to say a big thank you for a great concert last night. I am totally confident that all those who attended will remember the evening for always!! It was a most dramatic evening in terms of weather but the quality of the presentation in a stunning venue was really memorable. I'm sure Caitlin will always shiver when she thinks of Wellington in the future — I think we also had goosebumps but not only from the weather — her voice was amazing! Loved the quality of the musicians — so talented. A really lovely evening — thanks for putting it on and for your hospitality.

Keep warm and dry!

Best wishes

Sally Jackson—Senior Executive, Special Education, Ministry of Education, National Office, Wellington.



Hi David, I quite liked the drama of it all. That beautiful woman with hardly any clothes on — with that beautiful voice — in that gothic chamber — on a wild and wonderful Wellington night. It is a night we will never forget it. It was great.

Please thank Rhonda for the tea towel!

Talk soon
Trish.

A great evening... Despite six months planning which included a prayer to the rain gods, we succeeded in embracing the worst storm in Wellington since 1967. For those that braved the elements and are now at home recovering we had the most fabulous concert you could imagine.

PVINZ thanks Caitlin Smith, Mark Lockett, James Illingworth, and Nick Tipping for a wonderful evening. **Caitlin Smith** was interviewed today (21/06/13) on **Radio New Zealand Concert Programme** and you can access that podcast on their web site now for a great interview. My goodness have we had fun these last two weeks in Thorndon! The Mayors would be so proud of us!

Cheers David Heather and all at PVINZ Inc



- We had 750 “Stories to Tell” books printed; only 50 left!
- CD sales available, contact paul@pvi.org.nz
- Stories to Tell available on PVI website homepage PDF copy and a word copy
- Caitlin Smith and Mark Lockett absolutely fantastic to work with. They have captured the PVI spirit perfectly. Mark was the driving force re CD and Jazz concert, asking Caitlin to sing was a master stroke.
- Old St Pauls Church — a venue beyond reproach
- To the punters that turned out in the worst of storms....Thank-you, a huge thank-you

And yes we want to do it all again!

Editorial: Disability bill demonstrates contempt for due process

On any number of counts, the New Zealand Public Health and Disability Amendment Bill represents a particularly sorry piece of law-making.

Both its content and the manner in which it made its way through Parliament warrant the strongest criticism. The bill, which allots \$23 million annually to people who care for disabled adult family members, was passed under urgency, denying public input through select committee hearings. To add insult, official advice from the Health Ministry on the legislation was heavily censored, with whole sections of the 28-page document blacked out.

The legislation's contents see the Government again exercising its impulse to clear the decks when it comes across a situation that is out of the ordinary. In the process, constitutional niceties are dispensed with. The courts can be over-ridden and the checks and balances that should circumscribe Parliament are removed.

In this instance, the Government is responding to a Court of Appeal decision that its policy of not paying family carers to provide support services to disabled family members constituted unjustifiable discrimination on the basis of family status.

The legislation limits the liability of the Government. Payments of the minimum wage are limited to adults assessed as having high or very high needs. It is estimated that the cost would jump to \$65 million a year if payments were extended to all carers and all disabled adults.

In the normal course of events, those rendered ineligible by the legislation would surely mount a legal challenge to see if the Government's policy complied with the verdict of the Court of Appeal. But under the legislation people can no longer bring unlawful discrimination complaints about the new law or any family care policy to the Human Rights Commission or take court proceedings. In the words of the Chief Human Rights Commissioner, David Rutherford, "This sends a chilling message to anyone seeing litigation as a road to solving issues relating to the protection of their economic and social rights."

Unsurprisingly, the Attorney-General, Chris Finlayson, found that the clause in the legislation which prevents carers from making a legal challenge breached the Bill of Rights Act because it limited the right to seek a judicial review. Not extending payments to all family carers could also be a breach of the Bill of Rights Act, he said. The Government, intent on limiting future claims, ploughed on regardless.

Constitutional law expert [Professor Andrew Geddis has labelled](#) the Government's actions as "trampling all over a basic foundational principle of our constitutional order".

This is not the first time that it has nullified the role of the judiciary, both in interpreting and applying the law and as an avenue of public recourse. Legislation governing the response to the Canterbury earthquakes dictated that the decisions of individual government ministers could not be challenged in court. Similarly, the decisions of an authority set up to fast-track applications for facilities for the Rugby World Cup could not be reviewed by the High Court, except on points of law. In the latter case, at least, the legislation went through a select committee. In this instance, even that has been deemed superfluous.

It could be argued the World Cup and the Canterbury earthquakes were events out of the ordinary that demanded such an urgent response setting aside constitutional nuance. But that can hardly be said to be the case in terms of improving the support of disabled people and their families. The Government's unseemly focus on reducing litigation risk has triggered a shabby piece of legislation and a deplorable flouting of parliamentary process.

BLENNZ BoT's update

Congratulations to all BLENNZ Board of Trustees returned in the recent BoT elections.

Clive Lanksink as Chair and Don Fairgray as Vice Chair, both very experienced and passionate about our children's education.

Govt slammed over censored caregiver legislation

(By [Isaac Davison](#) @Isaac Davison Email [Isaac](#) from the NZ Herald 20 may 2013)

Labour Party disability issues spokeswoman Ruth Dyson said she had never seen such a heavily redacted statement: "It is unprecedented."

She said the refusal to publish some official advice was highly inappropriate given the controversial nature of the legislation.

A report by Attorney-General Chris Finlayson found that the clause which prevented carers from making a legal challenge breached the Bill of Rights Act because it limited the right to seek a judicial review.

Legal expert Andrew Geddis said that the implications of the law change were highly significant.

In a blog on the website Pundit, he wrote: "The judiciary's primary function - to declare the meaning of law and its application in particular cases - has been nullified.

"Furthermore, the judiciary's role as protector of individual citizens in terms of ensuring that they are being treated in accordance with the laws of the land has been removed. "While the stakes may be small in the immediate case, this is about as big a deal as it gets in terms of our constitution."

In introducing the bill in Thursday's Budget, Mr Ryall confirmed that \$23 million would be allocated to pay people who cared for a disabled adult family member.

It was a response to a legal case which found that the Government was discriminating by not paying family carers.

The bill was supported by National, Act, United Future and the Maori Party, and opposed by Labour, Greens, New Zealand First, Mana and Brendan Horan.

The new policy did not extend payments to spouses of disabled adults or parents of disabled children.

Mr Finlayson's report on the bill said that not extending payments to all family carers could also be a breach of the Bill of Rights Act.

Officials reported that if all carers for adults with high or very high needs were paid - including spouses and parents of disabled children - the cost to Government would increase to \$40 million.

Payments were also limited to adults who were assessed as having high or very high needs.

There were estimated to be around 5600 disabled adults being cared for by family members, 1600 of these who were assessed as having high needs.

If payments were extended to all carers and all disabled adults - not just high needs - the cost to Government would jump to \$65 million.

Really!

Are you aware that residential providers choose their own audit agency and give them a contract for ? years which in the case of the big providers like IHC, NZ Care etc the contracts are worth a serious amount of money so all audit agencies want to keep in favour with the provider. In one of my cases the senior auditor and I made a few critical comments re the audit with lack of recordings of consumers programmes etc. The provider complained to our audit CEO so it was done again and all was sweet as !!

I think that the MOH should be in charge here and appoint the audit agencies to do the audit. I also think the audits should be "spot" audits all the time. The MOH are trialling this in some areas, BUT not all are done this way.

Gillard brought to tears while introducing disability legislation

By chief political correspondent [Emma Griffiths](#)

Prime Minister Julia Gillard has been brought to tears in Parliament while introducing legislation to help fund the national disability insurance scheme.

In an emotional speech, Ms Gillard spoke of some people with disabilities she has recently met, including a 17-year-old boy from Brisbane, called Sandy.

"Sandy has big dreams for his future, like any teenager, but his future also has some big needs: mobility aids that cost tens of thousands of dollars, personal care to maintain his hygiene, physical therapy to maintain his muscles and his health," the Prime Minister told the House of Representatives.

"When I met this young man he handed me a card signed by him and his mates to say thanks for what we are doing for people with disability."

The Prime Minister said Sandy and others with a disability would finally have "security and dignity" with the introduction of the DisabilityCare scheme.

"This, above all, is why Australians so overwhelmingly support DisabilityCare," she said.

"Over the past six years, the idea of a national disability insurance scheme has found a place in our nation's heart.

"In March, we gave it a place in our nation's laws. Today we inscribe it in our nation's finances.

"DisabilityCare Australia starts in seven weeks - and there will be no turning back."

When she finished, the Prime Minister was embraced by Disability Reform Minister Jenny Macklin.

"This is a reform whose time has come, a reform that will deliver significant benefits to people with disabilities, to their carers and to their families and to the wider Australian community," she said.

Opposition spokesman on families Kevin Andrews was the only Opposition MP in the House to hear the PM speak.

The legislation will increase the Medicare levy by 0.5 of a percentage point, raising \$3.2 billion a year.

The money will be put in a special fund and will help roll out the scheme, which is estimated to need \$8 billion a year in federal funding when it is fully operational in 2018-19.

The Opposition has said it will support the measure, but wants to see the details of how the scheme will work and who will be covered in the legislation.

What is the NDIS?

- The scheme will support more than 400,000 Australians with a disability, their families and carers
- It will help pay for **carers**, to give parents of children with a disability a break
- It will help pay for **new wheelchairs** tailored to individual needs
- It will fund **home modifications** to help people with a disability move around easier
- It will fund early intervention services children, like **physiotherapy** and **speech pathology**
- The increase to the Medicare levy equates to an extra dollar a day for an average income earner
- The change would collect \$20 billion in its first five years

<http://www.abc.net.au/news/2013-05-15/gillard-cries-while-introducing-disability-legislation/4690692>

PVI Response:

A stark contrast exists in Australia where the nation is prepared to pay an extra tax to ensure all are covered by the above scheme...Could the same happen here? Not likely, as we are too willing to accept crumbs from this National Government.

VICTA

VICTA (Visual Impairment Charitable Trust Aotearoa NZ) now has Charities Commission registration, so are up and running. Dame Cath Tizard is the Patron, Assoc Prof Gordon Sanderson is the Chair. Their website is <http://www.visualimpairment.org.nz/>.

VICTA have launched a petition to Parliament for a Select Committee inquiry into the need to comprehensive, accessible low vision rehabilitation services in NZ.

The beauty of a Select Committee inquiry (unlike a ministerial inquiry) is that Select Committee inquiries are held in public, in front of the media, and anyone can make a submission. So this will be a great chance to get the issue on the public agenda.

Check out the website where you can download a pdf of the petition form, and a pdf of an information sheet about the reason for the petition.

If you'd like to support the petition, please print off copies of the form and information sheet, collect a few signatures and return the form(s) to VICTA, PO Box 5862, Moray Place, Dunedin 9058, by the end of May.

For further information about VICTA and /or the petition please contact :

Dr Lynley J Hood, Trustee VICTA, PO Box 5862, Moray Place, Dunedin 9058

phone: 0800 206 620 enquiries@visualimpairment.org.nz www.visualimpairment.org.nz

More children getting help to see

Hon Tony Ryall
Minister of Health
23 May 2013

More young New Zealanders in need of glasses to correct their vision have received free spectacles through a Government-funded subsidy.

"More than 28,000 children aged 15 years or under had their eyes tested and were given glasses if required last financial year – over 10,000 more than in 2008," says Health Minister Tony Ryall.

"Over three quarters of the children who had their eyes tested required new frames, new lenses or repairs to their current glasses.

"Funding for the Children's Spectacle Subsidy has nearly tripled under this government – from \$2 million in 2007/08 to nearly \$6 million last financial year.

"This extra funding has meant the number of children from low income families receiving the subsidy has grown considerably over the last four years.

"The Spectacles Subsidy is up to \$287.50 a year and can help with the costs of a vision test and glasses.

"Anyone 15 or under with a vision problem whose parents have a current community services card or a high use health card is eligible for the subsidy."

To find out more about the Children's Spectacle Subsidy visit the Ministry of Health website www.health.govt.nz/your-health/conditions-and-treatments/disabilities/vision-loss/subsidy-glasses-and-vision-tests

PVI Response:

PVI Chair, Riripeti Paine, and PVI Executive Officer, Paul Manning, have been working with the MoH reference group with a view to protecting this very much needed and appreciated subsidy.

The government needs to take credit for continuing to provide this subsidy despite budget over-run as a result of increased usage by parents. Credit also needs to go to the J R McKenzie Trust's sponsored "See Here" project which produced thousands of brochures and distributed out to schools and through PVI to parents alike.

Technology update — Proloquo2Go — By AssistiveWare.com

Open iTunes to buy and download apps.

Description:

Proloquo2Go® provides a “voice” to over 50,000 individuals around the world, who are unable to speak or have difficulty speaking. Proloquo2Go enables people to talk using symbols or typed text in a natural-sounding voice that suits their age and character.

“Users can open Proloquo2Go and begin to use it for effective communication immediately.” - Susan Berkowitz, MS-SLP, AAC Consultant.

Proloquo2Go, an award-winning Augmentative and Alternative Communication (AAC) solution from AssistiveWare®, is for anyone who cannot afford to spend thousands of dollars on a dedicated AAC device and yet wants a solution that is just as good if not better. SLPs, teachers, and parents recommend Proloquo2Go for children and adults with autism, cerebral palsy, Down syndrome, developmental disabilities, apraxia, ALS, stroke, or traumatic brain injury.

Introduced in 2009, Proloquo2Go was the first AAC app for iOS devices and the first to include genuine children voices. Features include:

- √ American, British, Australian and Indian English natural sounding Text to Speech voices, including several fun character voices. All voices are free!
- √ Genuine American English (Josh and Ella), British English (Harry and Rosie) and Australian (Liam and Olivia) children voices co-developed by AssistiveWare and Acapela Group.
- √ Two researched-based vocabularies, Core Word and Basic Communication, provide a solid communication platform that can be quickly tailored to individuals needs, skills, environment, personality and language level using Proloquo2Go's innovative VocaPriority™ system.
- √ ExpressivePower™ for adding prerecorded expressions and sounds to individual buttons. Coupled with the many free specialty voices, users have a wide range of voice versatility to help get their point across and spice up conversations. (New in 3.0)
- √ Adaptive switch access via standard external switches or by tapping anywhere on the screen, for those with physical access challenges. (New in 3.0)
- √ Select on Release option for those with difficulty keeping just one finger on the screen. (New in 3.0)
- √ Intuitive, powerful and easy to use editing interface for customizing pages, folders and buttons.
- √ Symbols and images – choose from 14,000 high-resolution SymbolStix™ symbols, your photo library, or take a photo right inside Proloquo2Go.
- √ Social sharing - use email, Facebook, SMS, or Twitter to share your words, from right inside Proloquo2Go. (New in 3.0)
- √ Automatic grammar conjugation support for language learning and efficient production of grammatically correct sentences using Ultralingua technology.
- √ Self-learning, multi-word prediction in the typing view for literate users and developing spellers.
- √ Support for multiple Proloquo2Go users on one device, each with their own customized vocabulary and settings.
- √ Easy backup and restore via iTunes File Sharing, WiFi, and Dropbox.

(continued p 13)

Some Gems to live by

- ✓ Purchase once - customers do not have to buy Proloquo2Go twice to run on iPhone and iPad.
- ✓ No active internet connection required for operation.

Additional Notes:

- Educational institutions can get a 50% discount on Proloquo2Go if they purchase 20 or more licenses through Apple's Volume Licensing Program for Education (available in Australia, Canada, France, Germany, Italy, Japan, New Zealand, Spain, the United Kingdom and the US.).
- Proloquo2Go includes American English Ryan (adult, male) and Tracy (adult, female) voices. Additional American, British, Australian and Indian English adult and children's voices can be downloaded over WiFi free of charge.
- Educational tutorials, support videos, webinars and frequently asked questions can be viewed at:
<http://www.assistiveware.com/support>

7 Rules Of Life

1. Make peace with your past so it won't screw up the present.
2. What others think of you is none of your business.
3. Time heals almost everything, give it time.
4. Don't compare your life to others and don't judge them. You have no idea what their journey is all about.
5. Stop thinking too much, it's alright not to know the answers. They will come to you when you least expect it.
6. No one is in charge of your happiness, except you.
7. Smile. You don't own all the problems in the world

Whisper of the heart

Don't Forget To Share This

A friend is one of the nicest things you can have, and one of the best things you can be.



Downgrading arguments to disagreements

Teenagers need someone to set a great example when it comes to handling topics where opinions differ. Remember that it takes two people to keep an argument going. If this is a recurring problem in your house, look for ways to change the old patterns before the next dispute is in full swing. Encourage turn-taking and model genuine listening to the other's point of view. When an issue comes up, sit down together and write down precisely what the problem is that needs to be solved. This will help keep things focused and to the point. List several possible solutions, and ask your teen to provide some as well. This gets you both out of the rut of, 'My way vs. your way', a place where no one is willing to look at other options or even consider changing their viewpoint. Disagreements are normal - but they don't have to be disastrous.

Responsible Inclusion

Dr Phil Hatlen visited NZ before BLENNZ was born and reckoned if we pulled off implementing the model it would be world class. The rest is history....

Classroom

written by: Cheryl Gabbert • edited by: Lamar Stonecypher • updated: 7/12/2012

When the topic is special needs education, it seems to be all about inclusion. Visually impaired students are sometimes placed in the regular ed classroom, but is that the best choice? This article may help in making the decision of whether or not full inclusion is the right placement.

What's the Best Placement?

If you're a teacher faced with helping to make the decision for or against placing a [visually impaired](#) student in a regular education classroom, it goes without saying that your goal is to place the child in the best possible learning environment. The question is, where exactly is that? Many argue the case for inclusion. Visually impaired students have many challenges. Those challenges should be considered before making this important decision.

Support in the Regular Ed Classroom

The first question teachers ask is what sort of support will be in place for the visually impaired student? Most regular ed teachers have no idea how to deal with a student who uses braille. Therefore, a teacher skilled in teaching braille should be available to directly teach the visually impaired student, as well as assist the regular ed teacher. This means both teachers must work closely together in order to make this situation work well. This can happen, but it requires a lot of hard work. Most school systems do not allow for a VI teacher to be available all day, so the schedule should be worked out in a way that meets the student's needs within the limits of the VI teacher.

Challenges of Learning in a Regular Ed Classroom

[Visually impaired students](#) may or may not exhibit cognitive delays, but there are some learning considerations that may not be obvious. Young blind or low vision children are functioning in a limited world, where the sense of sight is either severely limited or totally removed. Learning challenges exist simply because the visually impaired child is not able to learn from what he sees. This carries over to the classroom. If placed in a regular ed classroom, will the child be able to make academic and environmental gains as well as he would in a school where teachers are trained to bridge these gaps? This should be considered when making the decision of best placement.

Social Integration

Does a regular ed placement help the visually impaired child to adapt better on a social level? Many children with visual impairments have significant problems adapting socially in the regular classroom. Children may not easily accept a blind or low vision child without some direct support from teachers. Even then, social adaptation is unfortunately not easily accomplished. The ability of a child to socially adapt depends on the individual. Some children may make the adjustment easier than others. In other cases, a school for the blind may be the best place for a visually impaired child to feel accepted.

In this day and age, we hear a lot about the importance of inclusion. Visually impaired students can be served well in a regular education classroom setting, but the best placement for these children cannot be determined across the board. Each child's needs must be carefully considered in order to determine the placement that will best benefit the child and provide a stimulating learning environment for that particular student.

Resource

Responsible Inclusion Belongs in an Array of Placement Options, by Phil Hatlen, Superintendent of Texas School for the Blind and Visually Impaired: <http://www.tsbvi.edu/Education/inclusion.htm>

Websites and Info Bites

www.pvi.org.nz This is our website, please use it.... **Free-phone 0800 312 019 Email: paul@pvi.org.nz**

www.blennz.school.nz The new BLENNZ website, take a look, well worth the effort! Word-class, a global leader!

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 Products for both Vision Impaired and Blind users.

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

www.biopicdriving.org This website explains how some vision impaired 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. Email **general@rnzfb.org.nz Free-phone: 0800 24 33 33**

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 Impaired 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.bookdepository.co.uk: - Cheap normal print books, price includes postage

Have you tried **Tumble Books?**-through public library digital books.

The BLENNZ Library...fantastic range of books

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

Whats App - application to download which enables pictures to be sent for free by cell phone.

Market Place - Phone app

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.**

Have you tried the PVI closed facebook ? It might be well worth a visit as many PVI parents mainly mothers are using it. Enter/to join: Parents of Vision Impaired (NZ) Incorporated, note only registered parents of PVI are allowed to join. Great avenue for sharing and learning

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.

Pacific Vision: 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

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. 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:

Mr. Grant Davies: 09 473 4013 dandgdavies@xtra.co.nz
Mrs Paulette Francis 09 835 1232
paulettefrancis66@gmail.com

Central N.I. Representative & PVI Treasurer:

Mr. D Fairgray: 027 286 7798

Lower 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

PVI is grateful for the financial support from: The "Royal New Zealand Foundation of the Blind", Lotteries NZ, John Illot Trust Wellington, CoGs Hamilton, Masonic Lodge Hamilton, Lions Huntly, The Office of Disability Issues re the "Thorndon Project - Stories to Tell", WEL Energy Trust, Trust Waikato and BP.

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

Wellsford: Kim Lewin 09 422 1012

North Harbour: Linda Moore Carter 09 442 1330

Auck. Central: **Vacancy please apply**

Auck. South: Kawaljeet Singh 09 299 8028

Auck. West: Paulette & Rodney Francis 09 835 1232

Auck. East: Kawaljeet Singh 09 299 8028

Tirzah Shepherd 09 530 9539

Hamilton: Maxine Jeffery 07 853 7006

Tauranga: Linda & Don Fairgray 027 286 7798

Rotorua: Lex & Helen Craig 07 349 3191

Wairoa: Riripeti Paine 06 838 3949

Napier: Lou Halbert 06 845 4706

Taranaki: **Vacancy please Apply**

Wanganui: Amanda & Rex Van Elswijk 06 345 0327

Manawatu: Jane Hoani 027 878 8441

Wellington: Christine Pask 04 527 7585

Joanne Beaver 04 589 3719

Kapiti: David & Rhonda Heather 04 293 6539

Blenheim: Jane Sheat 027 713 5524

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