

# eVision July 2024

—  
Parents of Vision Impaired  
New Zealand Inc  
supported by Blind Low  
Vision New Zealand  
(formerly The Blind Foundation)



[pvi.org.nz](http://pvi.org.nz)  
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# CONTENTS

**Right:** Kids having fun at the previous Whaanau Waananga

- 4 From the Chair**
- 6 From the Editor**
- 8 Congrats to Our EO: Now a Winston Churchill Fellow**
- 10 PVI Board: Strategic Planning**
- 16 Meet Phil Parahi from the PVI Board**
- 18 What is Enabling Good Lives?**
- 20 Tips & Tricks for Navigating Your NASC**
- 22 Inclusive Education: Why It Matters**
- 24 PVI Events**
- 30 PVI Advocacy**
- 38 Donate to PVI**
- 40 Contact Us**

# FROM THE CHAIR

## TĒNĀ KOUTOU KATOĀ, WELCOME TO OUR MID-YEAR EVISION



**Right:** Krystal (Judith's daughter)

It has been a more challenging year than we expected, and the not for profit/community sector faces significant financial challenges, including uncertainty stemming from changes in government and economic pressures.

The disability sector has faced additional pressures, notable the 18 March announcement from Whaikaha – Ministry of Disabled People, and the subsequent changes. PVI's EO has done a significant amount of work bringing public attention to the issues, and we have seen some flexibility and funding restored. Nevertheless, the space is still in limbo and there remains a need for clarity and closure. PVI continues to seek clarity regarding the new rules and has requested a clear framework for providers and carers regarding what is appropriate spend.

As you are aware, the Board plays a crucial role in setting the strategic direction of our organization. While our current plan spans 2020-2025, it remains subject to ongoing refinement as a 'living' document. At our recent Board meeting, we reviewed the strategic plan to ensure its alignment with our objectives. A draft strategic plan is included in this eVision for your information, and we request your feedback.

We have had positive feedback from our events this year, and it has been encouraging to see families take up new ways of connecting online. As always, it is a privilege to serve PVI and to have a positive impact in the lives of parents.

Nga mihi nui,  
Judith Hyslop





# FROM THE EDITOR



## KIA ORA KOUTOU

Welcome to the second half of 2024. I hope everyone enjoyed their Matariki celebrations and school holidays are just around the corner, so hopefully you and your family have an enjoyable break. In the meantime, enjoy the read, the pictures, and getting an idea of what is happening around the country for our families.

Kia pai tō rā,  
Rebekah Graham  
National Executive Director, PVI  
[rgraham@pvi.org.nz](mailto:rgraham@pvi.org.nz)

Right: Lily on a custom trike by Trikes NZ



# CONGRATULATIONS TO OUR EO

**PVI WAS DELIGHTED TO SUPPORT REBEKAH'S APPLICATION TO THE WINSTON CHURCHILL MEMORIAL TRUST FOR A FELLOWSHIP. WE WERE EVEN MORE DELIGHTED THAT SHE WAS SUCCESSFUL!**

As a national group, with members across the country, PVI is in an ideal place to disseminate information and work with our partners to create and deliver parent programs which build capacity and capability, strengthen whānau networks, and enable parents/whānau to support their young person into employment.

For her Winston Churchill Fellowship, Rebekah travelled to London and Edinburgh and met with her equivalents and also with key staff at the Royal National Institute of the Blind (RNIB) who work with children, young people, and parents/families. She summarizes her key learnings and conclusions.



## Key Learnings

- Online programmes for parents: Being able to draw on an already developed parent programme designed for online use. This is a useful resource to discuss with our parents and tailor it to a New Zealand context.
- Accessibility: Seeing access requirements enacted in thoughtful ways opened my thinking to what is possible here in New Zealand. This ties into employment and training opportunities in a very practical way; if the work building is not accessible, how will our young person think that this is a career for them?
- Continual engagement with government agencies: Keeping the needs of our families and children in front of government agencies is essential. Keeping needs front of mind ensures decisions are made both short and long term to benefit our children.
- Developing youth activism: This is intentionally developed in Scotland through the Youth Parliament. Regular Zooms are held with young blind and low vision people who discuss the matters important to them. This process supports self-determination, develops political capability and capacity, and scaffolds interest in the process of enabling change.

## Conclusions

Overall, the Fellowship has encouraged me to keep advocating for parents and whānau. Seeing the high level of inclusion and support provided overseas has shown me what is possible. The areas of focus have been accessibility, parent/whānau involvement, and transition from school into education, employment, or training. Each of these areas has specific outcomes; overall the common theme is partnership and collaboration. That is, finding ways to partner with others who are interested in achieving particular outcomes so that it is not all reliant on myself or on PVI. This is healthier for me and more sustainable long term.

In June, Rebekah formally received her accolade from a completed Fellowship and can now call herself a Winston Churchill Fellow! PVI is proud to have been able to support this success.

**Right:** Joe Graham, Her Excellency The Rt Hon Dame Cindy Kiro, and Rebekah Graham in the Great Hall at Parliament **Above:** Dr Rebekah Graham (Churchill Fellow 2022) receiving her certificate from His Excellency Dr Richard Davies (Churchill Fellow 2018)



# PVI BOARD: STRATEGIC PLANNING



**OUR CURRENT STRATEGIC PLAN IS UP FOR RENEWAL NEXT YEAR, SO AT THE FEBRUARY MEETING THE PVI BOARD WORKED HARD TO BRAINSTORM AND REFINE OUR STRATEGIC GOALS FOR THE NEXT FIVE YEARS. THE BELOW TABLE SHOWS THE EVOLUTION OF OUR STRATEGIC GOALS OVER THE PAST TEN YEARS:**

2014 – 2019	2020 – 2025	2025 – 2030
<p><b>Supporting &amp; Encouraging Parents</b> Information sharing</p>	<p>PVI families lead interdependent, fulfilled lives, and realise their respective goals as parents, siblings, and vision-impaired persons.</p>	<p><b>Goal 1</b></p> <p>PVI supports whānau to connect with each other, and fosters positive relationships with communities and external organisations.</p> <p><b>Goal 2</b></p> <p>PVI supports families to understand the EGL principles and the live their best life.</p> <p><b>Goal 3</b></p> <p>PVI builds collaborative networks, increases PVI's visibility, and leads advocacy.</p> <p><b>Goal 4</b></p> <p>PVI is a dynamic and innovative organisation, now and into the future.</p>
<p><b>To Grow PVI</b> Advocacy</p>	<p>PVI families are connected to each other and to wider community supports.</p>	
<p><b>Building a Healthy Community</b> Collaboration</p>	<p>PVI builds collaborative networks and continues to foster positive working relationships with external organisations.</p>	
<p><b>Moving Forward Together</b> Consultation</p>	<p>PVI is a future-focused organisation that is adaptive and responsive to relevant changes.</p>	

**CONTINUED...**

**THE NEXT TABLE CAPTURES OUR BRAINSTORMING SESSION:**

GOAL	HOW	CONSIDERATIONS
<p><b>1.</b> PVI supports whānau to connect with each other, and fosters positive relationships with communities and external organisations.</p>	<ul style="list-style-type: none"> <li>• Seek appropriate video clips for website to inspire parents and children</li> <li>• eVision</li> <li>• Noho based waananga</li> <li>• Parent Liaison staff</li> <li>• Conference</li> <li>• Social media</li> </ul>	<p><b>Member Benefits: Are We Achieving Our Goals?</b></p> <p><b>Building Strong Relationships</b></p> <p><b>What Makes PVI Unique?</b></p> <p><b>Optimal Focus Areas for Our Efforts</b></p> <p><b>Should We Engage a Business Coach?</b></p> <p><b>Comparing Short-Term and Long-Term Contracts</b></p>
<p><b>2.</b> PVI supports families to understand the EGL principles and the live their best life.</p>	<ul style="list-style-type: none"> <li>• Workshops</li> <li>• Zoom</li> <li>• Conference</li> <li>• Links on website/social media</li> <li>• Parent liaison paid roles</li> <li>• eVision and newsletter/email updates</li> </ul>	
<p><b>4.</b> PVI builds collaborative networks, increases PVI’s visibility, and leads advocacy.</p>	<ul style="list-style-type: none"> <li>• Branding – social media, pamphlets, emails</li> <li>• External organisations</li> <li>• ECE, Plunket, P2P</li> <li>• Eye specialist services</li> <li>• Strategic relationships</li> </ul>	
<p><b>5.</b> PVI is a dynamic and innovative organisation, now and into the future.</p>	<ul style="list-style-type: none"> <li>• Empowering parents with wellbeing information and resources</li> <li>• Source new funding streams</li> </ul>	



Goal One 3  
 PVI builds collaborative networks, increases its visibility and leads advocacy

Goal Two  
 PVI supports families to understand + the ECL Principals and live their best life

Goal 3 4  
 PVI as an organisation is reflective, responsive, innovative, sustainable.

Goal 4 1  
 PVI supports whanau to connect with each other + foster positive relationships with community and external organisations

How  
 Branding → Social Media, Pamphlets, UTube, Instagram  
 PVI connecting external/relative organisations i.e. Parent, E.C. Centres, Parent Centre, Eye Specialist Services.  
 PVI continues strategic relationships at a higher level  
 Workshops / Zooms / Conference links on website + social media  
 Parent liaison (paid positions)  
 E. vision and updates.

Flight  
 Jacques 2.40  
 Tirzah 6.55

PVI is a dynamic and innovative organisation now and into the future

Empowering parents with wellbeing information and resources via social media and ...  
 source new funding streams

Seek appropriate video clips for website to inspire parents/child  
 E. vision  
 Noho based Whanau  
 Parent liaison

social media  
 conference

copy one  
 other channels

? Is it benefiting our members?  
 Building relationships  
 What is unique about PVI  
 Where is the best place to put our energies too?  
 Would it be worth engaging with a business coach?  
 Short term / Long Term contacts? (- as a separate aim of PVI)

Right: Whiteboard from the strategic planning session.

## PVI DRAFT

# STRATEGIC PLAN

## 2025-2030

### OUR MISSION

To provide a community of support for parents of a vision-impaired person

### OUR PURPOSE, AS ENSHRINED IN OUR CONSTITUTION

- To empower parents and whānau to support their blind, deafblind, and vision-impaired children.
- To improve the health, welfare, education, and social opportunities of vision-impaired children.
- To benefit the children and whānau of vision-impaired children within New Zealand.
- To promote, develop and maintain a nationwide support network.
- To promote and provide ongoing communication for parents and parent support groups of vision-impaired children.
- To foster communication and co-ordination of services between PVI, agencies and other community groups.
- To be proactive in all areas and concerns related to vision impaired children and their whānau/family. To be beneficial to the wider community.

### OUR VALUES

- PVI believes that blind, low vision and visually impaired persons and their families have the right to the same dreams, opportunities, and safeguards as all other citizens.
- PVI believes that all people are unique and different, and that each is capable of great things.
- PVI believes that all communities can fully include all blind, low vision and visually impaired persons and their families.

### OUR GUIDING PRINCIPLES

- We develop and grow to better meet the needs of our membership.
- We recognise te Tiriti o Waitangi/Treaty of Waitangi as Aotearoa New Zealand's founding document.
- We support the United Nations Convention on the Rights of Disabled Persons and the United Nations Convention on the Rights of the Child as they pertain to disabled children and their families.
- We aim to implement the Enabling Good Lives principles in our work.

### STRATEGIC GOALS 2025-2030

- PVI supports whānau to connect with each other, and fosters positive relationships with communities and external organisations
- PVI supports families to understand the EGL principles and the live their best life
- PVI builds collaborative networks, increases PVI's visibility, and leads advocacy
- PVI is a dynamic and innovative organisation, now and into the future

#### Growing | Connecting | Collaborating | Responsive

There will be opportunity to provide feedback and contribute into the strategic plan at this year's parent conference. If you have any feedback that you'd like to give now, please email it to our Board Chair, Judith, on [judith@pvi.org.nz](mailto:judith@pvi.org.nz).

## FROM THE PVI BOARD

## MEET PHIL PARAHI

## PEPEHA

**KIA ORA,  
KO PIRIPI PARAHI TOKU INGOA,  
KO TE TAPUAE O UENUKU TE MAUNGA  
KO WAIAUTOA TE AWA,  
KO TAKITIMU TE WAKA'  
KO TAKAHANGA TE MARAE,  
KO MARU KAITATEA TE WHARE,  
KO NGATI KURI TE HAPU,  
KO NGAI TAHU TE IWI**

**Kia ora koutou,**

My name is Phil Parahi, I'm married to Lisa and we are proud parents of three awesome boys each with their own special traits.

My oldest works with me in our family business (scaffolding); our middle son is also a scaffolder with another scaffolding company, and father to our beautiful granddaughter.

Our youngest, Roman, helped with the scaffolding business in the school holidays and was eager to learn the scaffolding trade when he finished school, but this was not going to be the case as you will read next.

Early January 2022 Roman complained about his vision, that it was getting blurry. We thought nothing of it but took him to the optometrist thinking he needed glasses. After seeing the optometrist, they realised that glasses weren't going to help so referred us to an eye specialist at Wellington Hospital. After the first visit and overnight stay with MRI and blood tests, they had an idea what it was, but we had to wait for the DNA results for a confirmation, which took a few agonising months with his vision deteriorating rapidly. We finally got the worst news

on 24 May, 2022: our son was diagnosed with Leber Hereditary Optic Neuropathy (LHON). It's a rare mitochondrial disorder that typically presents in young males with progressive visual loss due to optic neuropathy. LHON was the first disease to be associated with mitochondrial DNA point mutations and is, therefore, maternally inherited. Roman is the first in his maternal blood line to have LHON so it was very hard to come to terms with as we didn't know what we were dealing with. Although us as parents were struggling to come to terms with Roman condition, Roman stayed positive and never let it get to him.

We were introduced to PVI not long after this, and this became our family quickly. The support received and making us feel welcome helped in the healing process along with Roman's positive attitude.

I have no previous experience in the health sector. The reason I joined the board as the representative of Tangata Whenua was to take this journey with my son, contribute where I can, the ability to help others through the knowledge of the board, have a voice for those who can't and say when it matters.

**Right:** Illustration from Te Whai Waanaga: Kaupapa of Inclusion, Visibility, and Aroha





I WOULD HAVE  
BEEN LOST WITHOUT  
MY WHĀNAU.

I WANT TO MIHI  
TO ALL THE PARENTS

WE RECOGNISE CHILDREN  
WITHIN THE CONTEXT OF  
THEIR WHĀNAU

# WHAT IS ENABLING GOOD LIVES?

**ENABLING GOOD LIVES (EGL) AIMS TO WORK TOWARDS A FUTURE WHERE DISABLED CHILDREN AND ADULTS AND THEIR FAMILIES HAVE GREATER CHOICE AND CONTROL OVER THEIR SUPPORTS AND LIVES. THIS INCLUDES BEING ABLE TO MAKE BETTER USE OF NATURAL AND UNIVERSALLY AVAILABLE SUPPORTS.**

A core part of an EGL approach is investing into families, and to assist families and whānau to develop a vision and aspirations for what can be achieved for both the disabled person and their family members so that all have a “good life”.

Achieving this requires direct investment in the networks of disabled people and their family/whānau. Resources are provided to assist understanding, educate and promote increased knowledge of options, and to maximise choice and control. There are eight core principles, and these can be drawn on and used across all your engagements with the health, education, and disability sectors – sometimes it takes us as parents and family to get the thinking shifted in the people we deal with!

## Enabling Good Lives Principles

- Self-determination: Disabled people are in control of their lives.
- Beginning early: Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- Person-centred: Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
- Ordinary life outcomes: Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
- Mainstream first: Disabled people are supported to access mainstream services before specialist disability services.
- Mana enhancing: The abilities and contributions of disabled people and their families are recognised and respected.
- Easy to use: Disabled people have supports that are simple to use and flexible.
- Relationship building: Supports build and strengthen relationships between disabled people, their whānau and community.

# TIPS AND TRICKS FOR NAVIGATING YOUR NASC

## **IF YOUR CHILD IS BLIND OR LOW VISION, YOU ARE PROBABLY ELIGIBLE FOR DISABILITY SUPPORT SERVICES.**

You can find out what funded supports you can access by contacting your local Needs Assessment Service Coordination (NASC) organisation.

NASC's work with disabled people and their families to create a needs assessment and allocate different funding and support.

Each region in New Zealand has its own NASC—most of them have different names. You can find the contact details for your local NASC (or NASC equivalent, as is the case with Mana Whaikaha in the Mid Central region) via this link:

[whaikaha.govt.nz/assessments-and-funding/needs-assessment-services](https://whaikaha.govt.nz/assessments-and-funding/needs-assessment-services)

Parent to Parent have compiled an excellent resource for navigating the NASC, what the process is, and how to prepare.

- Think about your support needs and make some notes. Be realistic and factual.
- Think about a usual day, week, and weekend in your and your family's life.
- Try not to rush this process—spend a week or two jotting down notes so that you have a full and accurate record of all the support that is needed in all aspects of your life. It may be helpful to talk to other people in your life to get their perspectives too.
- If you are caring for a disabled child, think about every task that you (or others) do to support your child or imagine you are going away for a week and need to list everything that would need to be done while you are away.



# AN INTRODUCTION TO THE NASC

AN EXCERPT

Think about your support needs and make some notes. Be realistic and factual.



Think about a usual day, week, and weekend in your and your family's life.



Try not to rush this process—spend a week or two jotting down notes so that you have a full and accurate record of all the support that is needed in all aspects of your life. It may be helpful to talk to other people in your life to get their perspectives too.



If you are caring for a disabled child, think about every task that you (or others) do to support your child or imagine you are going away for a week and need to list everything that would need to be done while you are away.

# INCLUSIVE EDUCATION: WHY IT MATTERS



**INCLUSIVE EDUCATION HAS BEEN IN THE NEWS AGAIN, SO HERE IS A SHORT EXPLAINER ON WHAT INCLUSIVE EDUCATION IS (AND ISN'T!) AND WHY IT MATTERS FOR THE LONG-TERM OUTCOMES OF OUR CHILDREN.**

Inclusive education is a fundamental human right for every child with a disability. An inclusive education system is one that accommodates all students whatever their abilities or requirements, and at all levels – pre-school, primary, secondary, tertiary, vocational, and life-long learning.

**There are four 'levels' of education accessibility:**

- Exclusion: students with disabilities are denied access to education in any form.
- Segregation: education of students with disabilities is provided in separate environments designed specifically and only for disabilities, and in isolation from students without disabilities.
- Integration: placing students with disabilities in mainstream educational institutions without adaptation and requiring the student to fit in.
- Inclusion: education environments that adapt the design and physical structures, teaching methods, and curriculum as well as the culture, policy and practice of education environments so that they are accessible to all students without discrimination.

When disabled learners receive a quality, inclusive education they are more likely to achieve outcomes such as completing secondary schooling and going on to further study and employment. There are a number of flow-on benefits from this, for the individual, for employers, and for society in general.

For example, research on the Special Olympics programme utilised the talents of people with intellectual/learning disabilities as co-researchers in the data collection process.

**The researchers with intellectual/learning disabilities were able to:**

- Establish an easy rapport with study participants.
- Contribute to the comfort of the participants in the study.
- Expand on interview questions in novel and different ways.

There are lots of ways to be inclusive: ensuring adequate funding, resourcing, social and practical supports, and access to a variety of training opportunities - all in a sustained systematic fashion, makes a huge difference to the learner, the family and whānau, the school community, and to wider society.



## BLENNZ & INCLUSIVE EDUCATION

Two learners, Brianna who is blind and Brayden who has severe low vision, and their RTV. Their story and success illustrates what effective inclusive education looks like in practice, and how important the transition process is in contributing to this. Having two students transition to the same high school, and at the same time, required detailed planning and preparation.

**Above:** Image from BLENNZ website of Brianna and Braydon using their AT in class



# PVI EVENTS



**OVER THE COURSE OF THE CALENDAR YEAR, PVI AIMS TO HOLD VARIOUS EVENTS AND ACTIVITIES TO CONNECT PARENTS TO EACH OTHER AND TO AVAILABLE SUPPORTS.**

Our core event is our annual conference and AGM; we also hold Zoom webinars, local coffee mornings, and waananga. A short summary on each is provided below. If you'd like more information, want to host a coffee morning, or have other ideas, please contact Rebekah on [rgraham@pvi.org.nz](mailto:rgraham@pvi.org.nz) or Justine on [justine@pvi.org.nz](mailto:justine@pvi.org.nz).

Above: The Novotel Hotel



## 2024 PARENT CONFERENCE

We are delighted to announce that we have confirmed the follow speakers for this year's parent conference:

- Rachael Wiltshire from Auckland Disability Law will speak on cyberbullying – what are your child's rights and what can you do as a parent?
- Sarah Mitchell, Head of Employment and Youth Transition for Blind Low Vision NZ will run a workshop on Transitioning from school – supports available for employment and training
- Susan Jackman from Hapai Access Card will outline what the card is and how it can benefit you and your family
- We have a touch tour and audio description for the International Antarctica Centre
- And more planned!

We are trialing a new registration process that links directly with our online database. Parents can now register online here: [share.hsforms.com](https://share.hsforms.com)

**REGISTER HERE**

Above: The Novotel Hotel Conference Room

## PVI CONFERENCE 2024 PARENT REGISTRATION

Conference Starts: 3pm Friday 18 October  
Conference ends: 11am Sunday 20 October  
Venue: Novotel, Christchurch Airport

The full conference package for parents includes the following:

- Friday afternoon session (3pm to 5pm)  
Friday meet & greet (drinks and nibbles provided)
- Full conference day Saturday (9am to 4pm, lunch provided)
- Conference dinner Saturday night (cash bar)
- AGM Sunday morning

We do request that all PVI parents attend the AGM.

PVI will arrange and pay for the following for PVI parent members:

- Return air fares (within New Zealand)  
Accommodation (own room) Friday night and Saturday night. This includes breakfast Saturday and Sunday morning.

All other costs (e.g. airport transfers, Friday night dinner) are parents own. As this is new process for us, please do let us know if you find any hiccups or quirks to sort.



## CONTINUED...



## WHAANAU WAANANGA

In May PVI held a two-day noho-based waananga for whaanau Maaori. This year we stayed at Vaughan Park Retreat Centre in Long Bay, Auckland. The weather was stunning - if rather on the brisk side! The kids loved walking to the beach (and swimming! In the sea!! Brrr!!!)

It was a great time to hang out as families, cover some key information around navigating the blind and disability sector, and for our kids to meet other kids like themselves.

Lily, Stellan, and Robbie got on swimmingly!

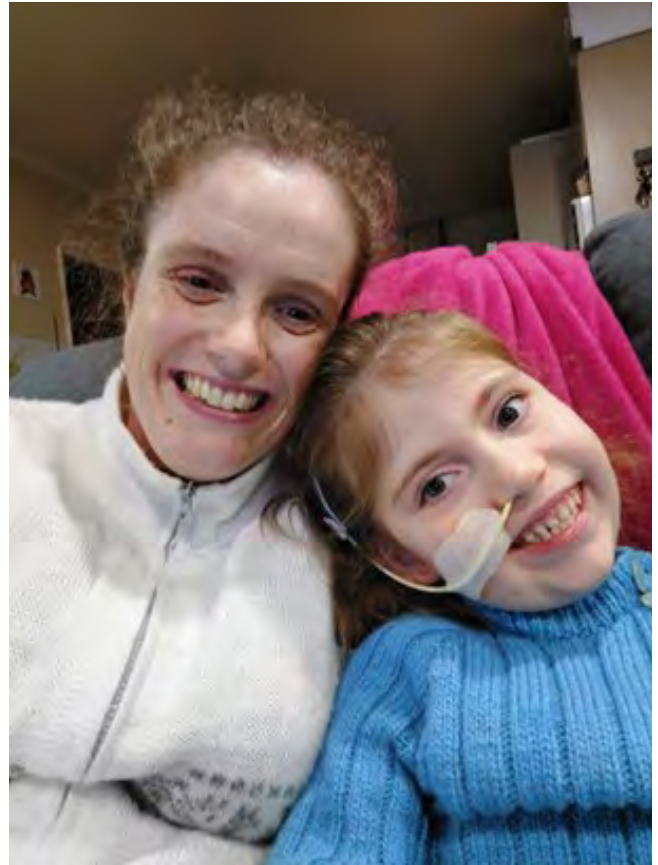
PVI is keen to organise another waananga for next year (if we can source the funding!)







## CONTINUED...



Right: Rosemary and Patricia

## PUKEKOHE COFFEE MORNINGS

Since August, Rosemary has hosted a coffee morning in Pukekohe for local PVI parents. It has been a great opportunity to connect with other parents who are going through similar experiences.

Rosemary gives an update below:

We currently hold a coffee morning on the third Tuesday at 10.30am every month at Columbus Coffee in Pukekohe Mitre 10 Mega. It is nice and accessible for wheelchairs and prams as well as having a play area for children who might attend that are more able bodied. We've all definitely made some new friends.

PVI buys a drink for each attendee and sometimes we've hung out for hours chatting about our lives and comparing experiences.

Our December Christmas coffee morning was our most successful with lots of parents and their children attending. We had cookie decorating for each child and Columbus Coffee kindly surprised us by decorating our table and providing Christmas crackers which made it all extra special.

As we've come into the winter months, attendance has waned a bit, but that sometimes has meant that I've been able to have a good one on one conversation with a parent. As we all know, in winter appointments and bugs all come into play and I was unfortunately forced to cancel May's coffee morning due to my own daughter being in Starship with a nasty winter virus.

I plan to keep hosting the coffee mornings over the next year although there might be some changes as I receive feedback. If you'd like to attend one of our coffee mornings but you haven't been able to due to day, time or any other reason please reach out to me by email so we can discuss future events. [rosemary@pvi.org.nz](mailto:rosemary@pvi.org.nz)

Our next coffee mornings will be held at Columbus Coffee Mitre 10 Mega Pukekohe: 16 July at 10.30am

If you are elsewhere in the country and would like to have a coffee morning in your area, reach out and let us know so we can apply for future funding and help you organise and connect with other

## ZOOM WEBINARS

PVI held a new parent series and an advocacy series during Term 2.

Rachael Wiltshire from Auckland Disability Law held two webinars; one on legal matters around supported decision making, and one on your child's rights in education. Both webinars were well received.

Our new parent series was also a hit! Holding a 10am and 7pm one with the same material worked well, and we will definitely be repeating the format and the material on a regular basis for parents. One of our parents since created the following one-page document:

If you're reading this, it means that you've just been dealt some difficult news about your child. It's tough, but know that there is a lot of support for you, your whānau and of course your child. Here is a simple initial checklist to help you get started. This list was created by a new parent, for new parents.

- Head to the Parents of Vision Impaired
- Facebook page to join! - [facebook.com/groups/194420327255/](https://facebook.com/groups/194420327255/)
- Contact your local BLENNZ coordinator - [blennz.school.nz](https://blennz.school.nz)
- Download the Vision Book from the PVI website - [pvi.org.nz/wp-content/uploads/The-Vision-Booklet-min.pdf](https://pvi.org.nz/wp-content/uploads/The-Vision-Booklet-min.pdf)
- Apply for the Child Disability Allowance through WINZ - [workandincome.govt.nz/products/a-zbenefits/child-disability-allowance.html](https://workandincome.govt.nz/products/a-zbenefits/child-disability-allowance.html)
- Register your child with Blind and Low Vision NZ, this will help ease the transition when they hit 18 - [blindlowvision.org.nz](https://blindlowvision.org.nz)

Most of the people mentioned on this list are open to answering questions and giving reassurance because they just get it. Moving into this space can be really scary, overwhelming and just too much. But take in as much or as little, take in what works for you and your family but know you have support. Don't be afraid to ask questions, actually, get good at asking them because you never know what you might learn. Kia kaha! You got this!



WHAIKAHA MINISTRY OF DISABLED PEOPLE

# PVI ADVOCACY



**SINCE THE SHOCK 18 MARCH ANNOUNCEMENT BY WHAIKAKA – MINISTRY OF DISABLED PEOPLE, PVI HAS JOINED ALONGSIDE OTHER PARENT AND FAMILY LED GROUPS TO, INITIALLY, PROTEST THE REMOVAL OF CHOICE AND CONTROL, AND, SECONDLY, TO REQUEST THE RETURN OF FLEXIBLY FUNDING TO FAMILIES.**

**"MANY OF OUR CHILDREN CANNOT ATTEND SCHOOL FULL TIME DUE TO SCHOOLS BEING ILL SUPPORTED TO INCLUDE DISABLED LEARNERS."**



Rebekah has been actively working with a wide variety of sector organisations, including speaking publicly about the impact these changes have had on families.

While there has since been a restoration of funding and some flexibility returned, accessing one's disability supports remains unnecessarily confusing and stressful.

One report contributed into was A Thousand Cuts, a report by Fairer Future Coalition, which showcases the cumulative costs to individuals and families as a result of Government reductions, cuts, and decisions. The report records around 30 Government policies that are detrimentally affecting disabled people and their families.

More recently, Rebekah represented PVI at a series of disability sector meetings with the Minister for Disability Issues, Louise Upston. At these meetings, Rebekah highlighted the following:

- The need to shift the language from a deficit based health model ("most in need") to one that supports early intervention, prevention, and long-term thinking. Our children benefit enormously from early intervention and support and should not be penalised for early intervention achievements. Rebekah also noted that taking a social investment approach means recognising that early intervention and support for families pays dividends long term.
- Funding restrictions leaving families in precarious situations and unable to afford much-needed respite for their physical and mental wellbeing as well as a lack of suitable care facilities for children with complex needs.
- Intersections across education and health; many of our children cannot attend school full time due to schools being ill supported to include disabled learners. This has flow on impacts for parent well-being and employment.

While progress is slow, we are heartened that the Minister is meeting with key leaders in the disability sector, is listening, and we remain hopeful that the disability sector will continue to support disabled people and families in the ways that work for us.

**Left and Above:** Rebekah enjoying meeting people in person

## LOCAL AND NATIONAL BODIES

# PVI ADVOCACY

**WHERE RELEVANT AND POSSIBLE, PVI WRITES AND SUBMITS WRITTEN AND VERBAL SUBMISSIONS TO INQUIRIES, SELECT COMMITTEES, AND LOCAL COUNCILS. WE HAVE TEMPLATES! IF YOU WOULD LIKE TO SUBMIT ON A VISION AND/OR DISABILITY RELATED MATTER THAT AFFECTS YOUR FAMILY AT YOUR LOCAL COUNCIL, OR EVEN NATIONALLY, DO GET IN TOUCH AND WE CAN SUPPORT YOU TO DO SO.**

This is a short list of submissions that PVI has made in the past year (1 July 2023 to 30 June 2024):

- 4th Universal Periodic Review: feedback on recommendations
- Advisory group - review of Human Rights Act and health/disability consumers rights
- Auckland Long Term Plan submission
- Budget Policy 2024 and Oral presentation to Finance and Expenditure Committee on the Budget Policy
- Climate Adaptation Inquiry
- Clinical governance framework: collaborating for quality draft feedback
- Consultation on draft Code of Insured Persons' Rights now open
- Draft Government Policy Statement on land transport 2024 - Consultation document
- Dunedin City Council: submission on destination playgrounds
- Endorsed the Child Rights Alliance NZ joint submission against the repeal of Section 7AA
- Endorsed Disabled Person's Assembly (DPA) Open letter to the Minister for Disability Issues: Enable disabled people, family and whānau to thrive
- Hamilton City Council Long Term Plan
- Hamilton City Council: playgrounds
- Immunisations: A Guide to the Strategic Approach to Immunisation in New Zealand from MOH
- Inquiry into the 2023 General Election
- Royal Commission of Inquiry into COVID-19 Lessons Learned
- Social Services and Community Select Committee: Accessibility for New Zealanders Bill (written and verbal submissions)
- Submissions to Hamilton City Council regarding transport options, including pedestrian and bike paths



## PUBLICATIONS

## PVI ADVOCACY

**ALONGSIDE EVISION AND SUBMISSIONS, PVI SUPPORTS STAFF TO CONTRIBUTE TO VARIOUS PUBLICATIONS TO SHARE PARENT PERSPECTIVES AND TO BUILD THE GROWING BODY OF EVIDENCE THAT BETTER OUTCOMES ARE ACHIEVED WHEN YOU WORK WITH FAMILIES/WHAANAU AS A GROUP, RATHER THAN JUST THE CHILD.**

This is a summary of formal work that was published in the previous financial year (1 July 2023 – 30 June 2024):

- Brown, C., Graham, R., Wallace, A., & Hogan, A. (2023). Policy Brief on disability support: Stop driving disabled children into poverty. Child Poverty Action Group, Auckland, NZ  
[cpag.org.nz/policy-briefs/disability-support](http://cpag.org.nz/policy-briefs/disability-support)
- Graham, R., & Corlett, R. (2024) Parent perspectives on engaging with educators and specialist staff. Journal of South Pacific Educators on Vision Impairment (JSPEVI) 16(1), 38-44.  
[spevi.net/jspevi](http://spevi.net/jspevi)
- Graham, R., & Masters-Awatere, B. (2024) Māori whānau of a vision-impaired student reflect on navigating the education system. Journal of South Pacific Educators on Vision Impairment. (JSPEVI) 16(1), 31-38.  
[spevi.net/jspevi](http://spevi.net/jspevi)
- Graham, R., Bridgette Masters-Awatere, B., and Cowan, C. (2023). What do we know about the intersection of being blind and being Māori in Aotearoa New Zealand? Taking an applied community psychology approach to a systematic review of the published literature. Journal of Community and Applied Psychology.  
[onlinelibrary.wiley.com/doi/full/10.1002/casp.2700](https://onlinelibrary.wiley.com/doi/full/10.1002/casp.2700)

- Masters-Awatere, B., Cormack, D., Graham, R., Boulton, A., Brown, R., Tangitu Joseph, M. (2023). Whānau experiences of supporting a hospitalized family member away from their home base. Kōtuitui: New Zealand Journal of Social Sciences Online.  
[doi.org/10.1080/1177083X.2023.2227234](https://doi.org/10.1080/1177083X.2023.2227234)
- Masters-Awatere, B., Graham, R., & Cowan, C. (2024) Working together to support self-determination for tāngata kāpō Māori: An exemplar. Int. J. Environ. Res. Public Health 2024, 21(3), 343;  
[doi.org/10.3390/ijerph21030343](https://doi.org/10.3390/ijerph21030343)  
[journal.mai.ac.nz/10.20507/MAIJournal.2022.11.1.1](http://journal.mai.ac.nz/10.20507/MAIJournal.2022.11.1.1)
- Rush, E., Graham, R., & Wensley, D. (2023). Policy Brief on food security: Ensure food security for all children. Child Poverty Action Group, Auckland, NZ  
[cpag.org.nz/policy-briefs/food-security](http://cpag.org.nz/policy-briefs/food-security)

**Top Right:** Rebekah Graham alongside authors.

**Middle Right:** Illustration by Pounamu Wharekawa (Ngāi Te Rangi) **Bottom Right:** A screenshot of SPEVI 2023 Session 22: Parent Perspectives On Engaging With Educators And Specialists featuring Rebekah Corlett MNZM, Rebekah Graham and Aimee Peterken.



SPEVI 2023 Session 22: Parent Perspectives on Engaging with Educators and Specialist ...

Rebekah Corlett MNZM (she/her)

Rebekah Graham -PVNZ

Aimee Peterken

SPEVI

0:09 / 28:14

YouTube

A screenshot of a video player showing a virtual meeting. The title is "SPEVI 2023 Session 22: Parent Perspectives on Engaging with Educators and Specialist ...". There are three video thumbnails. The top left shows Rebekah Corlett MNZM (she/her). The top right shows Rebekah Graham -PVNZ. The bottom center shows Aimee Peterken. The SPEVI logo is visible in the top right of the bottom thumbnail. The video progress bar shows 0:09 / 28:14. The YouTube logo is in the bottom right corner.

## POSITIONS VACANT

## PVI ADVOCACY

## BANZAT REPRESENTATION

We are after a new PVI representative to BANZAT!

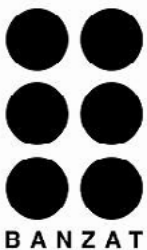
Parents of Vision Impaired NZ is one of the five founding organisations of The Braille Authority of New Zealand Aotearoa Trust (BANZAT). Of the eight countries that are members of the International Council on English Braille, the Braille Authority set up in New Zealand is the only one with a formal appointee by parents of blind and vision impaired children. PVI's membership is very important to BANZAT trustees.

BANZAT's purpose is to set standards and to make rulings on braille code usage within New Zealand, maintain awareness and consistency with current international developments in all braille codes, accredit practitioners involved in braille production, promote braille as the prime literacy medium for blind people and promote best practice in teaching, acquisition and distribution of braille.

Meetings are a mix of zoom and face to face meetings. Travel is paid for as well as meetings (up to \$1100 per annum) so you don't need to take annual leave if your employer can't afford to pay you to take time off for meetings.

Ideally, you'd be able to read Grade 1 Braille by sight or by touch. PVI's outgoing parent representative, Justine, notes that it really helps to have a Braille user in the family.

If you are interested in this position, please email [rgraham@pvi.org.nz](mailto:rgraham@pvi.org.nz). If you want to know more, you are welcome to email Justine on [justine@pvi.org.nz](mailto:justine@pvi.org.nz) to ask her about her time on BANZAT



Above: Person reading a braille book

# DONATE TO PVI

**DID YOU KNOW THAT, IF YOU  
DONATE TO PVI DOES, YOU CAN GET  
A CLAIMABLE TAX RECEIPT AS WE  
ARE A REGISTERED CHARITY?**

You can donate via our Givealittle page, and the receipt will be emailed to you automatically:

[givealittle.co.nz/org/parents-of-vision-impaired-nz-inc](https://givealittle.co.nz/org/parents-of-vision-impaired-nz-inc)

**DONATE HERE**

Above: Group of runners in a marathon.





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Jacque Smith

**TANGATA WHENUA BOARD REP**

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