

# eVision December 2025

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



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# A WORD



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## FROM THE CHAIR Stacey Dodd

This year we welcome in our new Board Chair, Stacey Dodd.

Stacey has been a board member for PVI since her election in 2014. She is based in the North Island, residing in Whangārei. She has a Bachelor of Social Science majoring in Psychology and Sociology and a Graduate Diploma in Primary Teaching. Stacey has a 12-year-old son, Thomas, who has complex needs including his vision impairment, cerebral vision impairment. He has a sister, Mia, a busy toddler!

Stacey is passionate about supporting and empowering the parents and caregivers raising children with disabilities and that early intervention is key to a firm foundation for the whole family unit. Inclusion and access are paramount to these supports and advocacy is a crucial part of this and this is where PVI can step in and help.



# 2026 PVI BOARD

**WE WELCOME OUR NEW PVI BOARD MEMBERS FOR 2026 (IAN AND ALEX), WHO JOIN AN AMAZING TEAM OF PEOPLE PASSIONATE ABOUT SUPPORTING PARENTS:**

**Upper North Island Board Representative and Board Chair:** Stacey Dodd, Whāngarei.  
Email: [stacey@pvi.org.nz](mailto:stacey@pvi.org.nz)

**Upper North Island Board Representative and Vice Chair:** William McGrath, Pokenō.

**Anywhere in New Zealand Representative and Treasurer:** Tirzah Shepherd, Auckland/Tāmaki-Makaurau

**Central North Island Board Representative:** Dan Barratt-Boyes, Tauranga.

**Tangata Whenua Board Representative:** Alex Maddox, Tāmaki Makaurau

**Tangata Whenua Board Representative:** Justine Edwards, Kirikiriroa. Email: [justine@pvi.org.nz](mailto:justine@pvi.org.nz)

**Lower South Island Board Representative:** Currently vacant. Previously held by Judith Hyslop, Dunedin/Ōtepoti. Email: [judith@pvi.org.nz](mailto:judith@pvi.org.nz)

**Upper South Island Board Representative:** Currently vacant.

**Lower North Island Board Representative:** Ian Brooke, Palmerston North/Te Papaioea.



# THE YEAR IN REVIEW: QUICK STATS

WHILE MUCH OF WHAT WE DO IS HARD TO MEASURE, SOME THINGS CAN DEFINITELY BE EASILY COUNTED. BELOW ARE SOME OF OUR QUICK STATS FROM 1 JULY 2024 TO 30 JUNE 2025:





# THANK YOU TO OUR FUNDERS!

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PVI IS THANKFUL TO THOSE ORGANISATIONS THAT PROVIDE SUPPORT AND FUNDING SO THAT WE CAN CONTINUE TO DO WHAT WE DO!

THIS YEAR WE HAVE RECEIVED FINANCIAL SUPPORT FROM THE FOLLOWING ORGANISATIONS:



We are also thankful to those individuals who choose to donate to us. Thank you all for your donations, kind words, and support - they mean the world to us and help us keep going during the hard times.

You can donate to PVI via our give a little page: [givealittle.co.nz/org/parents-of-vision-impaired-nz-inc](https://givealittle.co.nz/org/parents-of-vision-impaired-nz-inc)



# WELCOME TO HOLLAND

By Emily Perl Kingsley

©1987 by Emily Perl Kingsley. Source: [emilyperlkingsley.com/welcome-to-holland](http://emilyperlkingsley.com/welcome-to-holland)



**THIS STORY IS OFTEN SHARED WITH PARENTS AS THEY EMBARK ON A NEW AND UNEXPECTED JOURNEY INTO PARENTING A VISION IMPAIRED CHILD. IT IS A CREATIVE WAY OF THINKING ABOUT THE CHALLENGES WE FACE, REFRAMING THEM, AND REALISING THAT IT MAY NOT HAVE BEEN WHAT WE PLANNED, BUT IT IS STILL VERY MUCH A RICH AND REWARDING JOURNEY.**

"...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland."

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

# COLLABORATIVE WORKING

**PVI CONTINUES TO WORK  
ALONGSIDE AND SUPPORT THE  
WORK OF THE FOLLOWING  
ORGANISATIONS AND GROUPS:**

- Access Matters Aotearoa
- Carers Alliance
- Federation of DIAS Organisations
- Kāpō Māori Aotearoa
- Parent/Family/Whaanau Network

This year saw PVI signing a Tatou Pounamu or Memorandum of Understanding with Kāpō Māori Aotearoa. We continue to work closely with each other to support whānau and ensure that all our families thrive.



# NATIONAL ADVOCACY: SUMMARY OF ENGAGEMENTS

## PARENTS OF VISION IMPAIRED CONTINUES TO KEEP THE NEEDS OF PARENTS AND WHĀNAU OF BLIND, DEAFBLIND, LOW VISION, AND VISION-IMPAIRED CHILDREN AND YOUNG PEOPLE IN FRONT OF GOVERNMENT OFFICIALS, MINISTERS, AND VARIOUS CONSULTATIONS.

The following is a summary of some of this advocacy work undertaken between June and November 2025.

### **Inquiry into the harm young New Zealanders encounter online**

PVI highlighted that our children face additional online risks. This makes it harder for young people to identify inappropriate content, recognise grooming attempts, or report cyberbullying. We supported mandatory accessibility standards for social media platforms used in New Zealand, accessible reporting tools, and digital safety education that is tailored for disabled learners, alongside stronger accountability for tech companies whose platforms are widely used by children and teens.

### **Office of the Auditor General - new work underway: How councils plan for and provide for disabled people**

Rebekah met with officials from the OAG to discuss how council facilities and services, including playgrounds, swimming pools and libraries, are accessible (or not!). Inclusive planning and design improve outcomes for everyone and can reduce future costs. The OAC has started new work looking at how councils support the participation of disabled people in their communities. The work of the OAG will highlight good practice and, where needed, suggest improvements the three councils can make as they plan for and provide facilities and services.

Read more about this work on their website: [oag.parliament.nz/media/2025/designing-for-disabled-people](https://oag.parliament.nz/media/2025/designing-for-disabled-people)



# NATIONAL ADVOCACY: SUMMARY OF ENGAGEMENTS

## **Healthy Futures (Pae Ora) Amendment Bill**

PVI's submission expressed our concern that this Bill undermines equity, weakens accountability, and risks worsening already stark health disparities for disabled children and their families, particularly tamariki Māori with vision impairment. There is clear evidence that having health targets distorts priorities, encourages gaming of data, and sidelines complex patients. Disabled children fall into the "too complex" category and risk being deprioritised under the type of target-driven systems this Bill would implement.

## **Submission to the People's Select Committee on Pay Equity**

The reversal of pay equity has a significant flow on effect for many paid family carers. We noted the impact on mothers in particular, the need to pay carers appropriately in recognition of the expertise needed in caring roles. We highlighted the need for stable, consistent support and for strong and continuous relationships with carers and related workers in the sector.

Application of univariate  
Limit Theorem



Central limit theorem  
random samples drawn from a population with mean  $\mu$  and variance  $\sigma^2$  are approximately normally distributed with mean equal to  $\mu$  and a variance of  $\sigma^2/n$ .

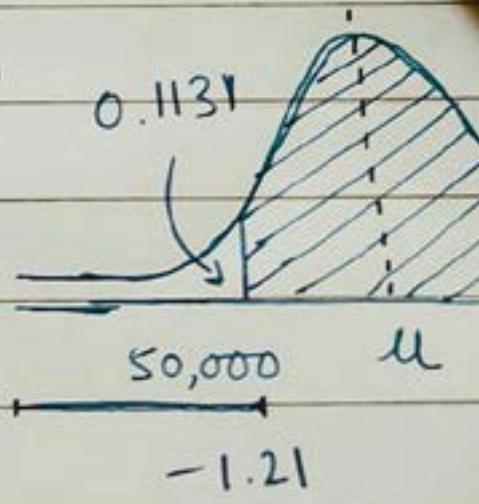
use of confidence intervals, DOE, regression analysis, analytical techniques, data

Normal Distribution.

$$\mu = 58200 ; \sigma = 6750 ; P(X \geq 50000)$$

$$Z = \frac{X - \mu}{\sigma} = \frac{50000 - 58200}{6750}$$

$$Z = -1.21$$



# NATIONAL ADVOCACY: SUMMARY OF ENGAGEMENTS

## **Local Government (System Improvements) Amendment Bill**

PVI noted the need for safe, accessible local environments for our children and young people. However, accessibility is still not treated as a core requirement in council planning. We raised concerns about public spaces, transport, playgrounds, footpaths, and crossings in our lived environments that remain unsafe or impossible to navigate independently. Accessibility must be embedded as a non-negotiable requirement in all local government decision-making, ensuring councils work directly with disabled people and parent groups, and establishing consistent accountability for meeting accessibility standards across the country.

## **Public Service Amendment Bill**

Government agencies continue to produce information, websites, forms, and educational resources that are not accessible for families. We noted the need for mandatory accessibility standards across the entire public service and for specialist disability advisors to be involved from the early stages of policy development. There is a need for genuine partnerships with disabled communities and parent groups, rather than last-minute consultation after decisions are already shaped.



# NATIONAL ADVOCACY: SUMMARY OF ENGAGEMENTS

## Redress System for Abuse in Care Bill (209-1)

PVI welcomed the government's commitment to the Royal Commission's findings – Whanaketia: Through Pain and Trauma, from Darkness to Light (June 2024) – and the attempt to implement a redress scheme for survivors of historic abuse in state or faith-based care. We noted our concerns regarding certain provisions in the bill, particularly the presumption against financial redress for survivors who have been convicted of serious violent or sexual offences. From our perspective as whānau supporting disabled children and young people, such a presumption risks retriggering trauma, perpetuating structural inequities, and undermining the restorative purpose of redress. We strongly supported a comprehensive, accessible statutory redress system that acknowledges and repairs the harms suffered and urged the committee to amend the bill to ensure fairness, equity, and the upholding of human rights.

## Early Childhood Education Reform Bill

In our submission, PVI noted that ECE is often their child's first experience exclusion, due to underfunding, a lack of teacher training, and delays in receiving early intervention support. Our submission noted long waits for specialist services, the absence of accessible materials, and environments that can be unsafe or poorly adapted for low-vision needs. We called for early identification pathways, timely access to specialist support, dedicated funding for accessible learning materials and environmental adaptations, and mandatory training so that every ECE can confidently and safely support children with vision impairments.



# PVI PARENT CONFERENCE & AGM



**THIS YEAR WE HELD OUR PARENT CONFERENCE AND AGM AT THE NOVOTEL ROTORUA LAKESIDE, FROM 10-12 OCTOBER. THIS VENUE WAS CLOSE TO NEARBY RESTAURANTS, ROTORUA LAKE, AND A RANGE OF WALKS AND ATTRACTIONS. OF PARTICULAR INTEREST WAS THE HEATED SWIMMING POOL AND RANGE OF HOT TUBS FOR HOTEL GUESTS.**

## An invaluable weekend of connection, learning, and hope

We also had 13 organisational delegates attend from BLENNZ, Blind Sport, Kāpō Māori Aotearoa, and Blind Low Vision NZ.

PVI arranged and paid for flights for parent delegates who lived more than three hours' drive away, and supplied petrol vouchers on request. PVI arranges accommodation at the conference venue for parents/whānau; this is included in the conference fee for families in attendance. PVI heavily subsidises the travel and accommodation costs for families as one way of supporting parent attendance, and to encourage rest and respite. Many families set up regular weekly payments several months in advance in order to pay the conference fee.

Thank you to Blind Low Vision NZ for your continued and ongoing support for our parent conference.

### **Conference Theme: Navigating Change, Empowering Futures**

We had 56 parent/whānau delegates, and four children attend our conference. Parents/whānau came from across the country:

- Northland
- Auckland and surrounds
- Hamilton
- Tauranga
- Lower North Island
- Christchurch/Canterbury
- Dunedin/Otago

# OVERALL VALUE AND IMPACT



**FEEDBACK FROM CONFERENCE ATTENDEES DEMONSTRATES THAT THE EVENT WAS HIGHLY VALUED, INFORMATIVE, AND EFFECTIVE IN ACHIEVING ITS AIMS OF CONNECTION, LEARNING, AND EMPOWERMENT FOR PARENTS AND WHĀNAU OF VISION-IMPAIRED CHILDREN.**

## Attendees consistently described the conference as well-organised, engaging, and worthwhile

Across all sessions, the average satisfaction rating was consistently high (4.5–4.8 out of 5), indicating strong relevance, usefulness, and a positive overall experience.

Attendees consistently described the conference as well-organised, engaging, and worthwhile, with many noting that it provided vital opportunities for connection, information sharing, and support. A number of participants described it as the best or most useful event they had attended, with several first-time attendees noting that it helped reduce feelings of isolation.

### **Connection and Community:**

The most valued aspect was meeting and connecting with other parents and caregivers.

*The best part was meeting new parents sharing our stories and connecting together. Thank you for making this affordable and reachable.*

### **Learning and Empowerment:**

Sessions were described as informative, practical, and useful, helping parents better navigate systems such as NASC, disability, and education supports.

*Very, very informative. We have learnt so much at this conference.*

### **Organisation and Accessibility:**

The event was widely praised for its smooth organisation and positive atmosphere. Suggested improvements included printing materials, venue signage, and fine-tuning session timing.

*Conference was very well organised and lots of time for connection.*

### **Affordability and Reach:**

Attendees expressed deep appreciation for the conference being accessible and affordable, enabling families who might otherwise be excluded to attend and benefit.

## CONTINUED...

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### FRIDAY - WHAKAWHANAUNGATANGA AND OPENING

The Friday evening session successfully set a positive tone. Attendees particularly valued the welcoming atmosphere, opportunity to connect, and interactive icebreaker. Feedback praised the engaging and entertaining approach undertaken. Suggestions focused on refining the icebreaker format, improving room comfort (air conditioning), and creating small-group discussions by child age or stage to strengthen peer connections.

*“Long day of travelling so it was great to keep it casual and interactive with the opportunity to meet and great. Enjoyed this over going straight in to listening to presentations.”*

*“Loved the meet and great and the get to know you game.”*

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### SATURDAY MORNING - INFORMATION AND PARENT STORIES

The morning sessions were highly rated, with attendees finding them relevant, informative, and emotionally resonant. Presenters Paul and Simone and parent speakers Alex and Elizabeth were commended for their clarity, empathy, and real-world insight. Parents especially valued hearing personal journeys, noting that these helped them feel understood and less alone. Common suggestions included allowing more time for speakers and audience questions and adding case studies or practical examples to deepen understanding.

*“Paul and Simone were awesome, very informative and gave an easy overview of what the changes for NASCs were.”*

*“Thoroughly enjoyed the sessions, very informative.”*  
*“Beautiful session, the connection, grief and journey along the way was so relatable, brought tears to my eyes. Alex’s talk was so interesting and I’m curious to learn more.”*

*“It was fantastic to hear what Alex is embarking on! Hearing from parents is always so encouraging and helps to reinforce the fact that we are not alone on our journey.”*



## CONTINUED...

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### SATURDAY AFTERNOON – AGENCY PRESENTATIONS & TRANSITIONS

Sessions featuring BLENNZ, BLVNZ, and Blind Sport NZ were appreciated for providing updates and introductions to key people and services. The interactive sports demonstration was a highlight. Attendees suggested clearer structure, more interactivity, and dedicated time for Q&A. The final session on transitions to adulthood received slightly lower ratings, largely due to information overload and timing at the end of a full day. Participants valued the topic but asked for smaller, more tailored workshops and better pacing to support information retention.

*“Really liked Neve Billing and direction of blind low vision with the schools awareness workshops. I had not known about Blind Sport NZ until Helen did her chat.”*

*“A lot of information, relevant information and good to know there are these types of services out there.”*

*“I found it very useful and informative as my child will be transitioning to adulthood soon and would require the support to transition to the appropriate provider and she gets the support along the way. Prior planning is so important.”*

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### SUNDAY WORKSHOPS – A NEW FORMAT

The introduction of Sunday morning workshops was a clear success. Attendees enjoyed being able to choose small-group discussions that felt relevant and personal, describing this as a “fun and relaxed way to finish the weekend.” Sessions such as “Dad Chats” were particularly praised for providing targeted peer support and open conversation. The format fostered deeper connection and reflection and will be continued in future years.

*“Loved meeting others, overall vibe, conference dinner and workshops Sunday morning.”*

# Parents of Vision Impaired NZ



Providing a community to support parents of children with vision impairments.



[www.pvi.org.nz](http://www.pvi.org.nz)

## CONTINUED...

### THIS YEAR'S CONFERENCE CLEARLY DEMONSTRATED ITS ONGOING VALUE AS A CORNERSTONE OF PARENT EDUCATION, CONNECTION, AND EMPOWERMENT FOR FAMILIES OF CHILDREN WITH VISION IMPAIRMENT.

#### It provides:

- Accessible, practical information directly relevant to navigating complex systems of care and education.
- Emotional support and peer connection, reducing isolation and fostering collective resilience.
- Opportunities for direct dialogue with service providers, professionals, and parents.
- A strong sense of community and advocacy, reinforcing PVI's role as a trusted, parent-led voice in the sector.

#### As one participant summarised:

*"[it was my] first conference so I wasn't sure what to expect. It was a bit overwhelming at times, but good to meet other people. Especially as we have felt a bit isolated since our child's diagnosis and therefore it was useful to chat with others who have/are going through the same things we are."*



# ENABLING GOOD LIVES (EGL)

## PRINCIPLES IN ACTION

**WE AT PVI CONTINUE TO EMBRACE EGL PRINCIPLES AND APPLY THEM AS MUCH AS POSSIBLE. THIS GRAPHIC FROM INTERACTIONS IS A GREAT OVERVIEW OF HOW THESE PRINCIPLES SUPPORT POSITIVE OUTCOMES ACROSS THE LIFE COURSE OF THE DISABLED PERSON AND THEIR FAMILY:**

### Key challenges in the disability sector

The process and pathway into supports is narrowing, and parents too often receive confusing and conflicting messages. Alongside this, there is a growing lack of trust with government agencies. Having to go to multiple agencies to receive support (e.g., Total Mobility application, BLENNZ support, BLVNZ support, NASC and needs assessment, SESTA application, local agencies like RDA and Parafed) is time consuming and requires a parent to navigate

multiple relationships and organisations. Overall, the disability sector is confusing and overwhelming. It takes increasing amounts of time for parents to know what they are entitled to and what supports are available to them, and sometimes requires multiple phone calls and visits.

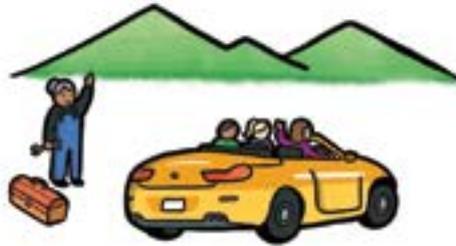
PVI works hard to assist parents to feel confident in navigating the sector, and concurrently advocates within the sector for simpler, easier to use supports.

# Enabling Good Lives Principles



## SELF-DETERMINATION

Each person is in control of their own life



## RELATIONSHIP BUILDING

Each person and family/whaanau is supported to build and strengthen relationships with their natural supports and community



## PERSON-CENTRED

Each person has whole-of-life supports that are personalised (it will be different for every person and every situation)



## MAINSTREAM FIRST

Each person has opportunities to do everyday things in everyday places with everyday people at everyday times



## ORDINARY LIFE OUTCOMES

Each person has aspirations and goals like others at similar stages of life



## MANA ENHANCING

Each person and their family/whaanau has their abilities and contributions recognised and respected



## EASY TO USE

Each person has supports that are simple to use and flexible

## BEGINNING EARLY

Each family/whaanau is supported from the beginning to be aspirational for their child

# COMPASSIONATE HELPING

PAUL LARKIN



## PAUL WAS A SPEAKER AT OUR PARENT CONFERENCE.

He spoke about compassionate helping – that helping, or caring, is a relationship – our connections, roles, hopes, and history mean there is no cheat sheet. Support, or caring, for basic necessities is a special form of helping.

Compassionate Helping is to struggle with each other to move toward something better. He shared a simple, four-point checklist for helping that is helpful:

1. Have you been asked?
2. Are you qualified?
3. Do you want to?
4. Is the person seeking the change doing their part of the work?

**Paul Larkin**  
Email: [paul@700.consulting](mailto:paul@700.consulting)



Above: Session this morning with Paul Larkin exploring the idea of "Help That Is Helpful."

## CONTINUED...

# A CHECKLIST FOR HELPFUL HELPING

## 1. Have you been asked for help?

- **Purpose:** Permission  
Permission gives clarity, and allows struggling with, rather than for or against.
- **Risk:** Dependency or Resentment
- **Work around:** We can always ask someone who we know is struggling if they would like our help.

## 2. Are you qualified to help?

- **Purpose:** Safety and Accountability  
This helps us maintain healthy boundaries and that help given is safe and helpful.
- **Risk:** Safety (for both people).
- **Work around:** we can still be helpful by helping others connect with services, or bring a qualified person in to their team of helpers.

## 3. Do you want to help?

- **Purpose:** Permission, Boundaries, and Personal Wellbeing  
This helps us maintain healthy boundaries, and our own wellbeing, as we help.
- **Risk:** Burnout, Error, Resentment, Being asked when needed in future?
- **Work around:** It is ok for helpers to ask for help too, or to take a moment.

## 4. Is the person being helped doing 51% of the work?

- **Purpose:** Ownership of personal behaviour and growth.  
We are only responsible for our own behavior.
- **Risk:** If we take responsibility for another's goal, we build over-reliance, or resentment.
- **Work around:** Can we redefine the goal or chunk it down to things the person can succeed in taking responsibility for?  
This builds self efficacy.

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# HAVE YOU HEARD ABOUT FLYING KITES?

## GOAL PLANNING & NAVIGATION SERVICES

- In person in Auckland and online nationally, no eligibility criteria.
- People who are stuck and want some tailored support to build momentum.
- Leaving home, leaving school, finding meaningful days, planning for the future.

### Finding you great support people

- Online nationally, no eligibility criteria
- Job ads just for your role, focused on interests, values and goals
- Finding your people, in your community, who want this job
- Phone Ainsley 022 528 5543 or Sarah 022 013 2580
- Email [hello@flyingkites.org.nz](mailto:hello@flyingkites.org.nz)

[flyingkites.org.nz](http://flyingkites.org.nz)

Flying Kites don't hold government contracts, which means they can be flexible to your needs. They do charge fees that most people pay for from Individualised Funding





# COMPLEX CARE GROUP

**COMPLEX CARE GROUP IS A NATIONWIDE DISABILITY INFORMATION ADVISORY SERVICE CONTRACTED BY MINISTRY OF SOCIAL DEVELOPMENT DISABILITY SUPPORT SERVICES.**

The initiative supports those with very high and complex disability needs – run by Lisa Martin. They help families navigate the disability sector, identifying supports they may be eligible for and how to implement those supports.

**They provide information, advice and support via:**

- Phone 027 266 7690 or 0800 852 693
- Email [complexcaregroup@xtra.co.nz](mailto:complexcaregroup@xtra.co.nz)
- In-person meetups
- Online workshops and support groups
- Facebook page (public facing):  
[facebook.com/complexcaregroupand](https://facebook.com/complexcaregroupand)
- Facebook group (closed group for parents only):  
[facebook.com/groups/complexcaregroup](https://facebook.com/groups/complexcaregroup)

[complexcaregroup.org.nz](https://complexcaregroup.org.nz)



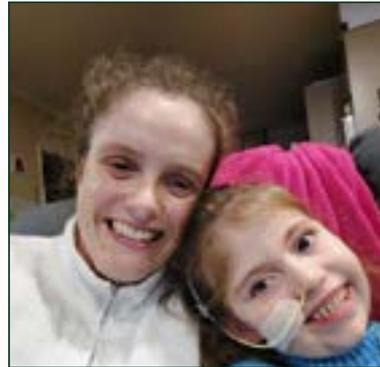


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PARENTS OF VISION IMPAIRED NEW ZEALAND INC  
SUPPORTED BY BLIND LOW VISION NEW ZEALAND  
*(FORMERLY THE BLIND FOUNDATION)*

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