



Parents of Vision Impaired NZ Inc

Parents Resource Kit

Creating a pathway towards life without limits

“Ko te aka o toku mana kua herea mai rano mai te rangi ki te whenua “

“A strand of my mana has been eternally tied from the heavens to the earth “



The heart and vitality of any parents support network revolves about the exchange of experience, challenges, successes and failures with our disabled children.

The network and support experiences are quite a unique experience as parents families proceed on their journey with their children. Parents are neither heroes nor cowards, but ordinary men and woman who try to face the reality of their child's disability with determination and courage, we all remember well the shock we experienced upon learning of our child's disability which most of us new nothing about. Suddenly we were challenged big time. In an instant we were expected to absorb and make decisions.

To begin the journey- we begin to ask questions, to search for information about disabled kids. Confusion and frustration were common feelings as we were advised by the medical profession, educators, social workers, rehabilitation specialist, friends and others to treat the child like any other child.

Much of the advice failed to address specifically the day to day realities of caring for our new arrivals, emotionally or physically. No one told us that we might experience a period of 'grief' as a result of not having the perfect child. No one told us that this might be a lingering experience for many or indeed, never go away.

We started on that rollercoaster of emotion that many of our closest friends and relatives could not understand. Some of us felt such emotions as fear, grief, sadness and not always a lot of self-esteem and confidence.

While most of our parents do discover ways to cope, sometimes we have been afraid to be honest about our feelings, worried about what professionals might think. We each in our own way need time to acknowledge, accept and understand our child's visual impairment. In some cases it may take years before a realistic definition of a child's condition, treatment and future prospects, is understood especially when the child has complex needs and several disabilities.

From this configuration emerged our parent support network. We found other parents and families and the sharing began. We suddenly had an instant engagement with another mother or father, who knew instantly on emotions, our predicament or our space. We found families who had solutions to problems we agonised over, we found families who could advocate who could climb the odd bureaucratic mountain, beat down the professional "security" door.

Our parent group in New Zealand had its beginnings in 1983/84 when a small group of six parents met in Auckland for a weekend. We came away saying we were all talking the same language, had the same dreams and aspirations for our kids, and the things we wanted to change.

So Parents of Vision Impaired New Zealand was born! We had in those early days a small grant from the Royal New Zealand Foundation of the Blind to run a newsletter. This early support was converted into substantial support that enabled us to employ an executive officer, to form a committee that could travel and meet, and begin the essential tasks of networking with our parent families, and advocating for our "kids".

As an organisation we have participated fully in the development and growth of a new education model for New Zealand that is now regarded internationally as a world leader. Parents are represented in that forum, and as a result we have a very close collaborative relationship with the Ministry of Education. In other sectors we have important relationships with the Ministry of Health, and the Ministry of Social Development. Twenty years ago we were spectators, today we are partners. Twenty years ago it was an adversarial environment, today it is a collaborative environment.

We reflect on a quotation from a NAPV Newsletter our kindred parent group in the USA.

*Regardless of our son's and daughter's disabilities, our real job as parents is to harness all the confidence and courage we can for us and model that for our children. On this journey together we all need plenty of it. And in modelling it early on, we help our sons and daughters prepare for the day we won't be with them except for that which we taught them. In doing so, we will find many wonderful people who will make all the difference in our world. We will encounter many difficult people and institutions and policies. When life becomes difficult, advocacy begins in a new way. The word advocate comes from the Latin "advocatus" which literally means "to call, or to answer the call to help another." This is the parent's task. This is the task that requires confidence and courage.... All that we can muster. Someone once said, **"In this life, trouble is to be expected. Misery, though, is optional."***

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



**PARENTS OF
VISION IMPAIRED (NZ) INC.**

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Providing A Community To Support Parents Of Children With Vision Impairments

HELPING PARENTS & WHANAU GAIN ACCESS TO RESOURCES THAT SUPPORT & EMPOWER THEM TO RAISE CHILDREN WITH VISION IMPAIRMENTS.

Raising Children With Visual Impairments Can Be Challenging. PVINZ Are Here To Help You Overcome Those Challenges

Welcome to the home page of Parents of Vision Impaired (N.Z.) Incorporated - simply known as "PVI".

PVI enrolls and supports parents who have blind or vision impaired children, and over the years PVI has grown to its present size of over 2000 parents nationwide.

**Our favourite whakatauki is from :
The Whale Rider by Witi Ihimaera**

*Kia hora te marino
Kia whakapapa pounamu te moana
Kia tere te karohirohi
I mua I to haerenga
Kia tau te rangimarie
May the calm be widespread
May the ocean glisten as greenstone
May the shimmer of light
Ever dance across your pathway
May you always find peace.*



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