

VISION

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

PVI's Whakatauaki/Proverb:

*Kia hora te marino, Kia whakapapa pounamu te moana, Kia tere te karohirohi,
I mua I to haerenga, Kia tau te rangimarie.*

*May the calm be wide spread, May the sea glisten like greenstone,
May the shimmer of summer dance across your pathways, May you always find peace.*

Issue 99

August/September 2013

Parents/Caregivers sign the DPA petition to repeal the New Zealand Public Health and Disability Amendment Act (No 2) 2013.

www.dpa.org.nz/news/3-news/242-petition-against-family-carers

This law discriminates against disabled people and their families/whanau who choose (as is their human right) to have family members as their carer/s. The Act means no spouses/partners can be paid to be carers. Family carers can be paid less than other carers. Disabled people and family carers cannot appeal this decision via the courts. It is a breach of our human rights.

If we as parent/caregivers do nothing, then this legislation will stand.
You need to ensure that you let your National MP know.
They (National) think they can get away with it.
This legislation is in breach of our human rights.
Will this cost the National Party your vote?

The **Green Party** has said they will repeal this legislation if they are part of a new Government



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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Parents of Vision Impaired (NZ) Inc is on facebook



From your National Office

Greetings fellow Parents,
Spring is here, **new life**, warmer days with more daylight.

PVI Parent Support Worker — Waikato

Pictured to the right is the new Waikato PVI Parent Support Worker, Justine Edwards. Justine is the proud mother of 3 = Giana, Kadence and Robbie. Giana is totally blind aged 6, a very confident wee girl. Kadence I have yet to meet, but Robbie aged 6 months comes into work frequently, is absolutely gorgeous. It is a battle between Lyn and myself re who gets to cuddle him first!



Justine works 5 hours per week ringing parents in the Waikato. She is getting positive feedback from not only parents but the RNZFB Child and Family Worker and the local Resource Teachers of Vision. We are delighted that Justine has found the time to support PVI parents and as she says, the support is two way. Justine is currently putting together a Waikato family camp earmarked for March 2014, we are thinking Raglan beach.

PVI Parent Support Worker—Wellington

Mary Fisher pictured right is better known for her swimming exploits, seen here receiving her Order of Merit honour. What many may not know is that Mary is the PVI Parent Support Worker for the Wellington region. Mary is also supported by her mother and Gary Veenstra of the Royal New Zealand Foundation of the Blind. One of the many great qualities of Mary is her ability to listen well and respond in a manner that is thoughtful and calming. Mary is employed for 5 hours per week and is also exploring a possible family camp in Wellington..



Proxy Voting Forms for the AGM:

If you cannot attend the AGM this year, but wish to vote at the AGM you can download the Proxy Voting form from the PVI website: www.pvi.org.nz on the home page under latest news etc.

The AGM is to be held at the Heartland Hotel, 14 Airpark Drive, Auckland Oaks, Auckland commencing at 11:15am. All are welcome, please advise our office 0800 312 019 of your attendance.

“Next issue of Vision is our 100th”:

We invite you to share a story, for this auspicious occasion then please let us know. “100 issues of Vision” and what has changed...lots in some ways, little in others. Those that can tell a good story, get writing and send to: paul@pvi.org.nz by Friday 18th October 2013

PVI SALES

PVI has available for you to purchase the Caitlin Smith CD “Stories to Tell” the CD is Jazz and very easy listening. A PVI fundraiser from the Thorndon Project — Stories to Tell. Music reviews to date tell us the CD is a 3.5 out of 5, this from just one recording session. \$25 per CD, contact the office for further information

"A dream written down with a date becomes a goal.
A goal broken down into steps becomes a plan.
A plan backed by action makes your dreams come true."



Keep an Attitude of Gratitude

(from the book Attitude is everything by Vicki Hitzges)

Years ago, I was the public relations director for motivational guru, Zig Ziglar. At the time, he was arguably the best known, most loved speaker in the world. When audience members heard Zig, they witnessed a man chockfull of energy, vitality and joy. Having worked closely with Zig you saw on stage was the real Zig Ziglar. In fact, I can't remember ever seeing him when he was not happy and upbeat. The Zig I knew was one carbonated guy.

Every time Zig answered his home phone, he picked up the receiver and said with gusto, "This is Jean Ziglar's happy husband!" And he meant it!

Awhile back one of Zig's closest friends and I were discussing Zig's aura of happiness. "Completely genuine", his friend said. **"I have never seen him down."** Then he added thoughtfully, but with love, "Hardly what you would call normal."

"What's Zig's secret?" I asked.

"I think," he said, "it comes down to feeling grateful. Never met a guy more grateful than Zig. Period."

You'd think anyone that grateful must have had an easy life. But that's not so. Zig started out poor. Dirt poor. His father died when he was six, leaving his mother to raise 11 children alone. The family was virtually penniless. Yet despite their poverty, Mrs. Ziglar instilled a strong work ethic in her children and raised them to believe that both she and GOD loved them. She also instructed her children to practice saying "please and thank you." Those lessons stuck. Her formula of work, love and faith made their difficult lives easier. Gratitude made their lives enjoyable.

Zig once told me, "When we neglect to require our children to say "thank you" when someone gives them a gift or does something for them, we raise ungrateful children who are highly unlikely to be content. **Without gratitude, happiness is rare. With gratitude, the odds for happiness go up dramatically.**"

Remember what Mum said... Always say "please and thank you."



Zig and his wife, Jean, "the Redhead" (the pet name he gave her), had four children—Suzan, Cindy, Julie and Tom. Suzan, the oldest, not only inherited her mother's looks and vivacious smile, she also inherited a passion from both her parents to encourage others.

One day Suzan fell ill. Within a short time, she was fighting for her life. The doctors prescribed steroids that made her bloated, large and uncomfortable. In a matter of just a few months, the unthinkable happened—Suzan died. Jean and Zig were heartbroken.

At the viewing at the funeral home, I was struck by how upbeat Zig appeared. Despite his grief, he was his usual self: He smiled and shook hands with friends and offered comfort to others who grieved. His strong Christian faith gave him hope that he'd see Suzan again. But there was something else: "We have no regrets," Zig told several well-wishers. **"She knew we loved her. We feel no regret." Even in his deepest sorrow, Zig counted his blessings and that buoyed his sagging spirits.**

Years ago, Zig created the popular phrase, **"Have an attitude of gratitude."** According to Zig, "The more you recognise and express gratitude for the things you have, the more things you will have to express gratitude for."

Keep an Attitude of Gratitude

(from the book *Attitude is everything* by Vicki Hitzges) Continued

I know firsthand that giving thanks brings joy. Awhile back, I heard Oprah Winfrey urge viewers to keep a Gratitude Journal. It pretty schmaltzy to me, so I didn't do it. But Oprah was a jackhammer. Day after day, week after week, she kept pounding on the idea. I'd catch her show here and there. Same thing: Keep a Gratitude Journal. A few months later, I was speaking to a government group and staying in a cruddy hotel. I was seated at the hotel's indoor restaurant by a swimming pool reeking with enough chlorine to purify the Love Canal. As I waited impatiently for my meal to arrive, I suddenly remembered Oprah's directive. What the heck? I had a pen and some scrap paper.

I listed my mother who spent time each day praying for me. I wrote down my father who deeply loves me. My kind, funny brother and his family. Friends. Laughter. For the fact that I had a place to sleep that was safe. For a private bedroom. (You start listing—you begin to get thankful!) **I quickly listed about 30 things and noticed that not only did I have a lot to be thankful for, but suddenly I was in a terrific mood!**

“Gratitude unlocks the fullness of life. It turns what we have into enough, and more. It turns denial into acceptance, chaos to order, confusion to clarity. It can turn a meal into a feast, a house into a home, a stranger into a friend. Gratitude makes sense of our past, brings peace for today, and creates a vision for tomorrow.”

Melody Beattie—Therapist, Author

Publisher Malcolm Margolin was grateful for something that's right outside our doors, but most of us have never taken the time to experience it. He wrote,

“The next time it begins to rain....lie down on your belly, nestle your chin into the grass and get a fog's eye view of how raindrops fall....The sight of hundreds of blades of grass bowing down and popping back up like piano keys strikes me as one of the merriest sights in the world.”

That might strike you as advice from a person with not nearly enough to do, but personally, I like it. If Margolin can feel joy in soggy clothes looking at wet grass, you and I can find all kinds of things for which we can give thanks!

Try it! ——— Count your blessings, Jot them down.

At least stop and think of as many things as you can that you're thankful for right now. It worked for Oprah, Zig, Margolin and me. Give it a shot. If you want to feel happy, try on a attitude of gratitude for a change in your mood, your outlook and you.

“Feeling gratitude and not expressing it is like wrapping a present and not giving it.”

William Arthur Ward

Jane Wells retires



On Wednesday 10th July 2013 BLENZ a farewell function was held for Jane Wells, Principal of BLENZ who was retiring after 34 years of working in the field of blindness education.

Jane Wells began her career in working with children and young people who are blind and low vision in 1979 when she took on the position of coaching students after school at Homai College and 34 years later retires after a rich and rewarding career in this specialist area of education.

She was always the most passionate advocate for our children. Some of us older parents will remember Jane as often the woman behind the scenes an almost reluctant leader. When appointed as Principal, her natural leadership skills became very evident. A careful listener, a thorough planner, and absolutely dedicated to improving education and social outcomes for our children, Jane was a genuine advocate for our children and families. Jane, enjoy your retirement, a well earned one!

Love from us all at PVI



PVINZ

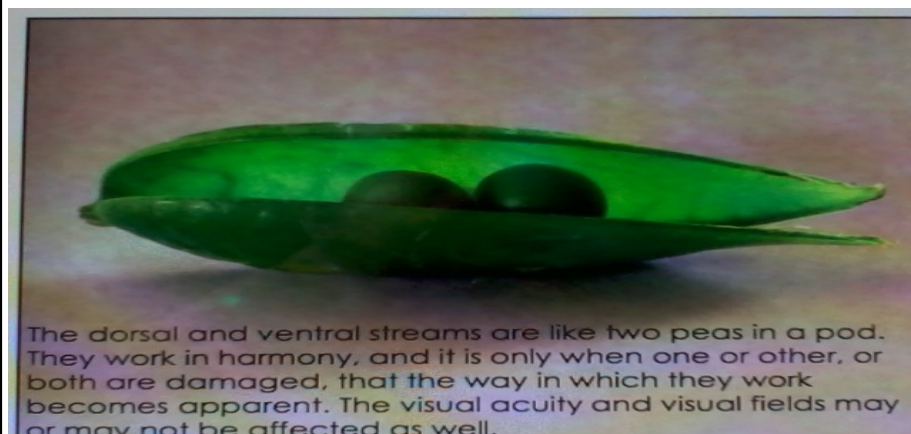
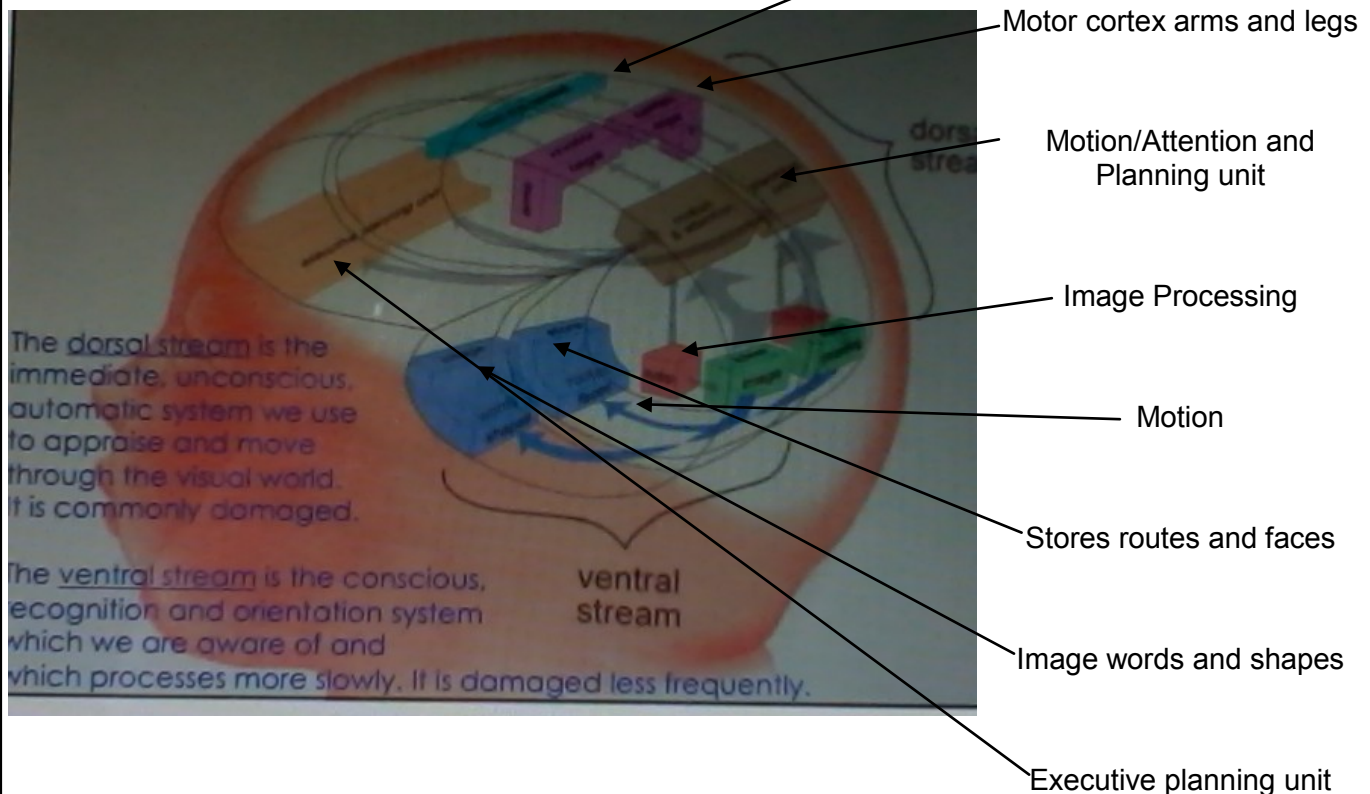
SPEVI CONFERENCE - 2013

(SOUTH PACIFIC EDUCATORS IN VISION IMPAIRMENT (INC) by J Hyslop

Wow, who would think that this conference was in January of this year?? I'm still talking about it and sharing some of the wisdom others shared with us at this amazing event. One of the stand out speakers for me was undoubtedly Gordon Dutton, from Scotland. A very learned man and extremely grounded. It was so refreshing to hear him say "**spend time listening to parents of their children – you will learn more in an hour than looking at scans and reports**". He had me 'hooked'. Following on from Dionne's article, I would like to share some of my favourite slides from the three sessions Gordon Dutton presented. One of the things I was astounded to learn was how much of the brain is taken up with 'vision' and why we should call "**CVI**" **Cerebral Vision Impairment** rather than **Cortical** Vision Impairment.

His first key note presentation, entitled "CVI in children; designing strategies to help"

Parts of the Brain that has a 'vision' component



Loved the way Gordon described the dorsal and ventral streams of the brain. It made a lot more sense!

SPEVI CONFERENCE - 2013 (cont by J Hyslop)

The Visual Limitations Caused by Damage to the Brain in Children Include:

- Deficits in accommodation (>40%) & eye movements
- Those of impaired primary processing of the image which may affect
 - Visual acuity, contrast sensitivity, colour vision, visual fields, and the perception of movement
- Those affecting the dorsal stream, impairing
 - The ability to give attention to, and thus see, the components of a crowded visual scene - and -
 - The use of vision to guide movement
- Those affecting the ventral & ventro-dorsal streams (Which are less common) Involving:
 - Recognition of what is being looked at
 - and recognition for route finding

The Visual Limitations Caused by Damage to the Brain in Children **Lead to problems:**

- **Accessing information**
 - Whether it is in the distance, such as a letter box or a tree
 - Or whether it is for near, such as pictures and text
- **With visual guidance of movement**
 - Whether it is the guidance of the upper limbs, to reach out and pick something up
 - Or whether it is the guidance of the lower limbs, to walk freely and confidently
- **And with social interaction. It may be difficult to**
 - To see someone in a group, owing to visual acuity or visual field loss, or dorsal stream problems
 - To recognise their face, owing to poor acuity, contrast sensitivity, or agnosia
 - To see the language within facial expression (for the same reasons)
 - Or even to see a hand in an absent lower visual field, for a hand shake

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The social problems due to CVI

| Problems | Approaches |
|---|---|
| <ul style="list-style-type: none"> • Labelled as having 'behavioural problem' • Self Conscious • Feelings of isolation | <ul style="list-style-type: none"> • School Support • Identify problems and solutions • Encourage child to overcome them • Well known peer group • Buddy system • Find activities child enjoys and can excel in |

Take home messages

Vision is fundamental to optimal child development

- ✓ All aspects of impaired vision need to be identified, and acted upon, by staying within visual thresholds
- ✓ Visual acuity is often nearly normal in CVI, which is by far the commonest cause of visual impairment in children
- ✓ The change in attitude and approach which accompanies the understanding of visual behaviour can be life changing (for infants to teenagers).

Take home messages

Allocation of resources is currently constrained by:

- ✓ Adult parameters of vision
- ✓ Measures which take no account of perceptual or cognitive dysfunction

This needs to change!

**Children are not little adults.
Adults are just big children!**

This is only a 'taster' of Prof Gordon Dutton's work. The PVI Board are currently exploring ways that more parents can benefit from his wisdom – watch this space! **Judith Hyslop**

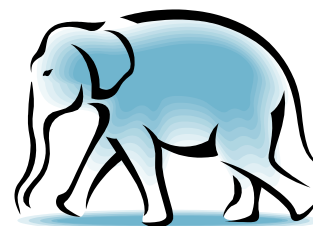
PVI has copies of all of the presentations on CD – I recommend that you have a look. J.

Do you have an elephant in the room?

The Elephant in the Room

What is the elephant in the room?

- It can be a situation, topic or problem that two individuals—or a team — is aware of, but are unwilling to openly identify or discuss.



When do certain situations, topics or problems turn into elephants?

- When they pose a threat (e.g. when my sense of competency is threatened)
- When they have the potential of embarrassment (e.g. when I am made to “look bad”)

Why is the elephant allowed to hang around?

Because in calling attention to it...

- I might hurt or damage a relationship
- I might say something I'll regret
- I might be perceived as negative or antagonistic
- I might be retaliated against
- Sooner or later someone else will identify it and bring it out in the open
- It just might disappear on its own (wishful thinking)

How do we name it, discuss it and resolve the elephant's presence in a safe productive way?

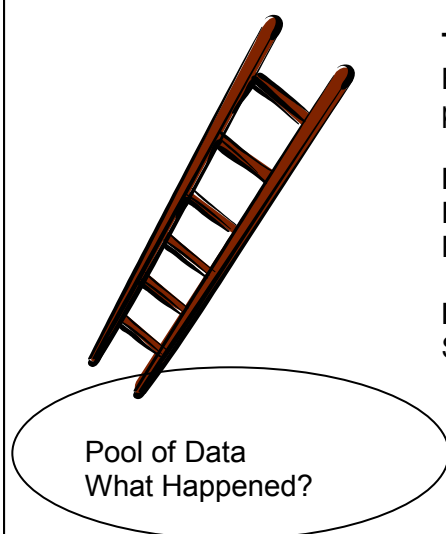
By using the following communication strategies:

- 1: The ladder of inference
- 2: Advocacy and inquiry
- 3: Addressing the Right Issue (CPR)
- 4: Paraphrasing and Perception-Checking
- 5: Giving feedback

The Ladder of inference is a model that can help us understand how we select, interpret and process information. It will help us:

- Improve our reasoning
- Understand our thinking diverges or converges with the thinking of others
- Better use information to make decisions and draw conclusions

Elephant Strategy 1: Using the ladder of inference



Take Action:

Based on our understanding of the problem

Draw conclusions:

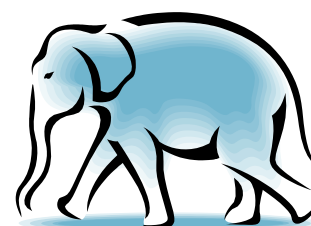
Explain and evaluate what happened
Propose action

Interpret data:

Shaped by our values, beliefs, assumptions, attitudes and past experiences

Select Data:

What and why do we select what we do?
What do we ignore?
What determines our selection?



Do you have an elephant in the room? (cont)

Using the Ladder of Inference to generate productive conversations will:

- Explore our own reasoning process
- Draw out more information from others
- Identify where our views differ



Start by reflecting on these questions:

- How is it that we see the issue, problem or situation differently?
- What does the other person see that I maybe missing?
- What can I learn from others perspectives?
- How can I discover the reasonableness of the other person's perspective?

Elephant Strategy 2: Advocacy and Inquiry

Advocacy and Inquiry are two tools to help you climb up and down the Ladder of Inference. They are not necessarily either/or tools; instead they can be used together to:

- Surface the undiscussables
- Narrow the gap between differing points of view
- Bring clarity to a conversation

Advocacy is expressing a view or making a statement about your position. It allows you to: -

- State your assumptions
- Explain the context of your point of view
- Give examples of what you propose and what is driving your action
- Welcome debate

Phrases for Effective Advocacy

- "Let me you what I am thinking and why...."
- "And here's an example"
- "I'd like to share what led me to this conclusion."

Inquiry explores the views of others through questions.

It allows you to: -

- Diffuse defensiveness
- Invite alternative perspectives or opinions
- Lessens the pressure on the other person to prove their point

Phrases for Effective Inquiry

- "What do you mean by?"
- "Could you give me an example?"
- "What is your reaction to what I have just said?"
- "Do you see it the same or differently?"
- "What did I say that triggered your comment?"
- "What is your understanding of what I am proposing?"

Elephant Strategy 3: Addressing the Right Issue

A "**crucial confrontation**" takes place when three elements are present:-

- 1: The stakes are high
- 2: Opinions vary
- 3: Emotions run strong

How do you know you are naming the right elephant in a crucial conversation?

You can unbundle the issues by practicing **CPR**.



Do you have an elephant in the room? (cont)

Content

What is the problem at hand?
Discuss the issue itself

Pattern

Is there a pattern of behaviour you need to address?
Discuss the fact that the issue keeps recurring

Relationship

Is the problem leading to a loss of trust or respect?
Discuss the fact that the issue is affecting the overall relationship between you and the other person.

Guidelines for unbundling the issue or problem:

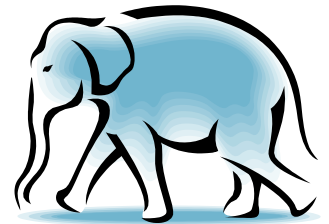
- 1: Resist jumping to quick conclusions
- 2: Describe the problem in neutral terms
- 3: Reduce the blame by investigating what others might have been up against led them to think and act the way they did
- 4: Summarise the learning
- 5: Mutually design ways to alleviate the problem in the future

When having a crucial conversation, create a safe environment by reinforcing the “MUTUALS”:

- **Mutual Understanding**
- **Mutual Trust**
- **Mutual Respect**

Elephant Strategy 4: Paraphrasing and Perception checking

Paraphrasing and Perception Checking are two tools that will assist you in moving up and down the Ladder of Inference to better understand what was motivating the other person to do or say what he or she did.



Paraphrasing: An Advocacy statement that puts into our own words what we believe to be another person's point of view without inserting our own inferences.

- It mirrors—through —your own words—the key meanings that the other person has expressed (What I hear you saying is....”)
- It summarises what is important to the other person
- It provides an opportunity for a high-level inquiry to ensure accuracy of the paraphrase (Did I capture what you said accurately?” Is there anything you would like to add or change?”)

Perception Checking: A tool incorporating observation and inquiry which avoids jumping to conclusions and diffuses defensiveness.

It has three parts: -

- 1: A description of the behaviour you noticed
- 2: Two possible interpretations of behaviour
- 3: A request for clarification and how to interpret the behaviour

Example 1: -

- 1: I noticed that you seemed to be running behind schedule on your advising appointment lately and we've gotten a few complaints about people having to wait longer than they expected to.
- 2: Could it be that the front office staff are booking your appointments too close together or are the issues that you are discussing with the students more complex lately?
- 3: Is there something I can do to help you make your appointment flow more smoothly?

Example 2: -

- 1: This morning when you got up and left the meeting abruptly without saying anything...
- 2: I wasn't sure if you were frustrated with the way the conversation was going or if you had an appointment you needed to get to?
- 3: What was up?

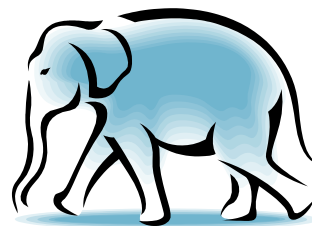
Do you have an elephant in the room? (cont)

Elephant Strategy 5: Giving Feedback

Use **A.I.R.** To share your concerns and give feedback.

Awareness: People may not be aware of what they are doing and the repercussions their actions or behaviour may be having. The following phrases can create awareness:

- I don't know if you are aware that....
- I'm sure it wasn't your intention to....
- Perhaps you didn't realise that...
- As you may already know....
- I noticed that...
- I'm getting the impression that....
- It seems that...



Impact: What are the repercussions of the person's behaviour? The following phrases can assist you in sharing with them the consequences of their behaviour:

I'm concerned that...

I worry that....

"I feel that..."

"When you do.....it makes me feel..."

"When you sayit affects the team by...."

Request: What do you want the person to do differently the next time? What specific changes would you like to see? The following phrases can preface a concrete request and keep it from becoming a demand:

"Would you be willing to..."

"Could you please...."

"Next time I would like you to..."

"I would rather you..."

"How can we resolve this....?"

"What are our options?"

"Would you consider?"

"Let's..."

"Can we...."

Kindly permitted to print by Mimi Murray—"The Elephant in the Room". murray@brandman.edu

Retina Youth

Our young adults are invited to join "Retina Youth". Retina Youth is a sub committee of Retina NZ Inc. and is funded by the Royal New Zealand Foundation of the Blind. Their goal is to find and support young people aged from 15-35 suffering from Retinal Disorders. Retina Youth really is a place for these young adults to get together, a place to express themselves, a place to live, learn and to grow.

What They Do:

Their aims are to promote and foster: Public awareness of retinal disorders amongst youth; information about retinal disorders and services for young people with retinal disorders; mutual support by and for people with retinal disorders (and their families), and research into retinal disorders, their causes and effects, treatments and eventual cure.

They produce an awesome quarterly newsletter for anyone keen for a good read, and co-ordinate a telephone-based peer support network that provides non-medical advice and information free to callers within New Zealand.

They are always grateful for donations to Retina NZ's research fund to support medical and scientific research into retinal disorders.

To join them, jump onto facebook and join our group there. We keep the group closed because it is important that the content discussed on the page is amongst those who can relate and offer the support needed. Search 'Retina Youth'. They are currently designing a new website. Check it out.

www.retina.youth.co.nz



Parents and Advocacy...if we don't, who will?

Passion, dedication, empathy, and education, the hallmarks of advocacy, are traits that can prompt a seemingly ordinary person to perform extraordinary feats. One such achievement was the enactment of the [American with Disabilities Act \(ADA\)](#) which in reality began many years prior to its implementation on July 26, 1990.

The road to the ADA was long, bumpy and full of obstacles, from 1817, with the founding of the American School for the Deaf (the first school for disabled children in the western hemisphere), to 1986 when the outcome of a report, [Toward Independence](#), indicated federal civil rights legislation was needed to protect people with disabilities. Apathy, ignorance, superiority, intolerance and to some degree even class and/or status are ugly words that only begin to describe some of the atrocities that people with disabilities had to endure prior to safeguards being put in place to protect their rights. Even before Hitler, in 1883 Sir Francis Galton created the term eugenics which subsequently started a movement supported by many Americans whereby laws were put in place to prevent people with disabilities from moving to the U.S., marrying, reproducing and in addition many were institutionalized and put through forced sterilization procedures. Eugenics is defined by Webster's Dictionary as "a science that deals with the improvement (as by control of human mating) of hereditary qualities of a race or breed."

I was thrust into advocacy 19 years ago when my middle son, Devon, was in first grade and I received an urgent phone call from the principal asking me to pick up my son because he had a violent outburst. I knew Devon had some behavioral issues as I had him tested twice previously (at three and five years of age). The first diagnosis was inconclusive and the second resulted in an attention deficit hyperactivity disorder (ADHD) finding, which required medication and therapy. While I knew it would be a matter of time before the phone call from Devon's school requesting a meeting, I wasn't prepared for the meeting itself and felt blindsided as I faced a room full of school officials. Here my little six-year old was hospitalized (a little over a month) due to the severity of his outburst and I was under the impression I was going to meet with the principal and teacher although in actuality it was my introduction to the special education pre-evaluation process.

Words cannot express how I felt at that first meeting with school officials but that conference laid the foundation for how I would advocate for Devon until he graduated high school. From daily report cards that had to be signed off by me and the teacher to weekly calls, emails and regular meetings, I was in constant and consistent contact with the school to ensure that they were following proper special education protocols. Being organized has always been one of my greatest gifts and this made it easy to research, learn and document everything related to the Individualized Education Program (IEP) process. One of my greatest achievements during this experience was calling a special meeting with the school superintendent to discuss the principal's privacy violation concerning his inquiry into a special program that he thought would "benefit" my son. This faux pas gave me the leverage I needed to have my request granted for my sons to be taken from this school and put into another grade school in the district. The successful outcome of this and similar advocacy situations allowed me to identify a process that works for me:

- Get angry then lose the anger and replace with passion and professionalism
- Zoom out and look at the big picture; understand the desired outcomes
- Zoom in and analyze the details; research and learn everything about the issue at hand
- Develop a plan of attack; I prefer using an outline to organize my thoughts in a logical format
- Document, document, document and copy all the key players
- Hold key players to accountability
- Follow up

Personal experiences have clearly demonstrated to me that the causes of disabilities are as varied as the types and I've learned that while some factors such as heredity could determine a person's likelihood of inheriting one, in general, disabilities do not discriminate. A disability can occur at any point in life, from birth onward, for any reason and can take on many forms including but not limited to psychiatric, physical, learning, blindness and deafness. In view of the range of types and causes, the same disability shared by two different individuals may present itself inconsistently between the two.

For example, there are many types of legal blindness and though I might share the exact same condition with someone else our vision would still vary simply because the spectrum of vision loss is so vast. If ever there was a reason to reserve judgment, I would have to say it would be where people with disabilities are concerned. Misconceptions abound not only about the disability itself but also with the limitations placed on those with a disability. [Lives Worth Living](#), a movie on the disability movement, clearly shows that when people feel a passion for change, they can make it happen regardless of their circumstances. Seeing people with disabilities crawl up the stairs at the Capitol to demonstrate the physical barriers they have to overcome is awe-inspiring.

To live with and overcome the apparent physical obstacles and indivisible barriers in order to carry on with life is remarkable and takes a certain amount of fortitude that many people would not understand. This is one of the reasons why I am so very grateful to the many friends and acquaintances placed in my life with whom I can look to as personal mentors to help me navigate the world with my disability. Many of these extraordinary people are the very advocates like those who preceded them, pre-ADA, who have, and are, impacting positive change in the world so that perhaps within next generation words like inclusion and acceptance will no longer be necessary because this will be the new norm.

Though the ADA, considered the most comprehensive disability law in history, was signed into law by George W. Bush on July 26, 1990; it required governments and programs on the local, state and federal levels to be accessible, that reasonable accommodations and modifications be provided in the workplace, restaurants, stores, public transit, communication, etc. there is still a great deal of work to be done. With the ever evolving advances in technology, we have to be mindful of those who may not have the same access to information; we have to remain vigilant to the point of changing legislation to set new policy direction. In addition, like those before us, we need to continue to handoff the baton through public awareness, education, commitment, and advocacy to make the world a better place. Read Judy Scott's [first hand account](#) of the signing of the ADA.

“International” - From Fiji — Work challenge for the disabled Daniel Naidu

WHEN Setareki Macanawai, CEO of the Pacific Disability Forum, sits working at his computer, one would hardly guess he is blind.

As part of the 'Include Disability, Employ this Ability' (IDEA) project, organised by AusAID, Mr Macanawai yesterday spoke to the media, promoting equality in the workplace for disabled people.

"I lost my sight at the age of 17 during my final year at Marist Brothers High School, and the onset of a disability on a young person's dreams, in terms of living an independent and successful life, it's huge," Mr Macanawai said.

He said to move on from sustaining a permanent disability, he had to adjust his goals and expectations, and importantly, accept his position. He said while getting accepted to educational institutions was a challenge, "patience, commitment and sacrifice was needed".

Mr Macanawai trained to be a schoolteacher and eventually worked in social welfare before taking up his current position. He said the attitude of people in Fiji towards disabled people had generally improved over the past 20 years.

"I think general awareness of the public is improving, but I believe it is the situation of an employer, having to employ a person with disability, or when the principal and having to enrol a person with disability, I think this is the true test of where we're at in terms of accommodating persons with disabilities in the workforce and education system."

To help disabled people succeed, Mr Macanawai says the government must have "a real political will", and employers must invest in these people with "reasonable accommodation", and that disabled people must put in the extra work as well.

"For me, I use the computer. I can't see the computer but what is making me use the computer when I use Excel, spreadsheet, email, and so on, I have a special software — reasonable accommodation, and I think that is what employers need to be willing to acknowledge and support."



United Nations Convention on the Rights of Persons with Disabilities wish to hear the voice of youth 16-25 year olds...

Greetings Paul!

Hoping you can assist with some participants for the study.

Call for project participants

In 2008 New Zealand ratified the United Nations Convention on the Rights of Persons with Disabilities. This means the government has obligations to disabled people under the terms of this convention.

The project involves interviewing disabled people aged 16 to 25 years of age, about their life experiences. Their stories will allow us to assess the government's performance in meeting those obligations and highlight any areas they need to improve.

The information obtained from the interviews is confidential. The interviews will be incorporated into the final report in such a way that no one will be able to identify who the subjects were.

For ethical reasons we will require both the consent of any young disabled people, between the ages of 16 and 18, and their parents.

We are seeking sixteen to 25 year-old disabled youth, who want to be interviewed. We also want to include all impairment types, to ensure we gain everyone's perspective.

If you are interested in being interviewed for this research, please contact either Nathan Bond on email nathan.bond@paradise.net.nz -phone or txt [+64 0220140173](tel:+640220140173). Or e-mail the project coordinator: Pam MacNeill, on pmacneillconsulting@gmail.com - txt or phone 0274 575461.

We are extending the project so can take names of youth to interview, up to September 13 2013.

I would greatly appreciate it if you could please forward this message and attachments to all your disability community networks.

Warm regards

Pam MacNeill

M-Phil, Dip Rehab, Dip SocWk, CQSW, Dip Bus

Pam MacNeill Consulting – creating the solution to meet your needs!

Co-producer/Facilitator of the award winning DIScover workshops: EEO

Trust Diversity Awards 2012 and NZ Recreation Association outstanding project of the year award 2012

PVI Response:

I spoke with Pam seeking clarification on this matter. Particularly the voice of younger children and their families/parents....The answer was they understand this is not being heard and the Canadian people who are driving this research on behalf of the United Nations also understand there are gaps.....

Youth in the above U.N terms is categorised at 16-25...I believe the U.N. have a problem or perhaps it is the Convention that has the problem...?

I think we should be asking of our own country to set an example and demand that the voice of the younger children and their families with disabilities is heard..... What do you think? Perhaps a letter to the Human Rights Commissioner might be in order...What do you think?

Paul.

Nothing about us without us!

Invitation to Participate in Survey on Improving Employment Services

Hi all, this notice was received from DPA (Disabled Persons Assembly) FYI and distribution:

Invitation to Participate in Survey on Improving Employment Services

Improving Existing Employment Services for Disabled People is an action point in the government's Disability Action Plan. To progress this work MSD has convened a group of representatives from the disability and mental health sectors, as well as officials from MSD and ACC. Together the group is jointly developing and informing the process to improve employment outcomes for disabled people.

The first step in this work is to undertake a comprehensive survey to better understand what employment supports (both contracted and non-contracted) are currently being offered, and to identify barriers and trends in the labour market. There are two versions of the survey - one for providers of services and one for disabled people.

The survey has been written and developed by the representative group and the data will be analysed by an independent contractor. The survey takes approximately 10 - 15 minutes to complete.

The survey is now open, and providers of support services and disabled people are invited to participate. To access the survey, click on the links below or cut and paste them into your web browser.

Survey for Disabled People (accessible to screen readers)

<https://www.surveymonkey.com/s/NJNJVQX>

Good Morning,

We wanted to let you know that on Wednesday 24th July Statistics New Zealand will begin collecting data as part of the 2013 Disability Survey. Interviewers will be conducting phone and face to face interviews with both disabled and non-disabled people until October 2013.

The Disability Survey remains the most detailed and comprehensive source of data on disabled people living in New Zealand. The information helps government to evaluate and develop policies and legislation on issues that affect disabled people. It helps service providers monitor the effectiveness of existing services for disabled people, and to help develop new services.

This survey follows the Census and uses Census data for sample selection. The previous iteration of the survey was run in 2006 – you can view the results [here](#)

Information gathered from the survey will be released in 2014. We will advise you of the date closer to the time.

For more information, visit [About the 2013 Disability Survey](#).

“Saying or doing nothing is not an option!”

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 biopic lens that in some cases enables them to drive legally!

www.aniridia.net: Aniridia Foundation International.

www.aniridia.org: Aniridia support

www.albinism.org.nz New Zealand's website for those wishing to know more about Albinism.

www.nzord.org.nz This website has links to many international sites containing information concerning rare disorders. This site is the New Zealand link.

www.rnzfb.org.nz The website of the Royal New Zealand Foundation of the Blind. 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.facebook.com/pages/Homai-Formats-Library

As A PVI parent you can join the Homai Library facebook team.

<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.

PacificVision: email Barry at barryb@pvi.co excellent low vision equipment.

Parents: - Feel free to write to the following Members of Parliament **the good news (Positive Advocacy) or bad news concerning either your child's needs or yours as a parent!**

Prime Minister: pm@ministers.govt.nz

Minister of Education: hparata@ministers.govt.nz

Minister of Disability Issues and Lead Minister of the Carers Strategy: tturia@ministers.govt.nz

Minister Maori & Assoc Min Education: psharples@ministers.govt.nz

PVI Regional Support Vacancies:

We need more parents to volunteer as Regional Representatives in the following areas: -

- Northland
- Sth Auckland
- Waikato

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
paulette.francis@vodafone.co.nz

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 The Jack Jeffs Charitable Trust.

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: **Vacancy please apply**

Wairoa: Riripeti Paine 06 838 3949

Napier: **Vacancy please apply**

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