



## *NEWSLETTER*

October 2014

### EDITOR'S CHATTER

Hello Everyone,

We are now in spring and enjoying the warm weather, although we have had some chilling days.

The spring is a sign of new life, as we share lovely colours of spring bulbs, flowers and flowering trees, and seeing new ducklings in the ponds, lambs and calves been born in the rural areas.

Summer is now around the corner and hopefully we will have a good summer this time.

Take care.

Lorraine

## PRESIDENT'S PATTTER

Well I am pleased to announce the arrival of 11 gorgeous piglets. We now have a family of 18 pigs, 9 cows, 10 chickens, 1 rooster, 2 turtles, 2 cats and 2 dogs. All the animals prove a delight for our five grandchildren to feed.

This year we have managed to secure funding from the Ministry of Health Disability Support Services to fund our executive and management meetings. This allocation of funds is for travel, communication support persons and administration. This funding is to be an annual allocation.

On the 10<sup>th</sup>, 11<sup>th</sup>, 13<sup>th</sup>, 14<sup>th</sup> August 2014 we completed the Communication Support Persons Training held in Wellington. For this training we brought out two trainers from Senses Australia, Karen Wickham and Angela Wills who have over thirty years of experience between them. We had eleven people participate in the training and I went as an observer.

The training was intense covering eight modules.

1. Role of Communication Support Person
2. Communication
3. Orientation and Mobility
4. Deafblind Awareness
5. Task Analysis
6. Psychosocial Implications of Deafblindness
7. Person Centred Planning
8. Equipment

At the completion of the training all participants completed a practical and theory test, they then did an evaluation on the

training. The evaluation papers proved how beneficial this training was to all involved.

The Annual General Meeting for Deafblind (NZ) Incorporated will be on the 18<sup>th</sup> October 2014 at the Corpthorne Hotel Commodore Christchurch Airport, Christchurch. The theme for the Annual General Meeting is Deafblind Survival in Disaster which is being opened by Sir Robert Parker former Mayor of Christchurch City.

Deafblind (NZ) Incorporated has been doing a Capability and Capacity building as part of being involved with the Disabled Peoples Organisation. I would like to thank the support groups for their valuable input into this process. We hope to have this completed by the end of the month and will send this out to the support groups on completion. Part of this work is to build Deafblind Capability and Capacity into the work we are doing with Government regarding the Disability Action Plan and advise being sought by Government Agencies. We need to ensure that Deafblind have a voice.

I hope everyone has managed to visit our website [www.deafblind.org.nz](http://www.deafblind.org.nz) and we look forward to everyone contributing and their feedback.

Merv Cox

President

Report on the 9<sup>th</sup> Australian National Deafblind Conference  
held in Sydney, Australia on 7<sup>th</sup> and 8<sup>th</sup> June 2014.

I attended the 9<sup>th</sup> Australian National Deafblind Conference along with Warren Persson and our communication support people. As this was a full on conference we decided that to get the most out of it I would attend one seminar while Warren attended another. This worked well to get the maximum benefits from the conference.

The conference was held at the Mercure Central Sydney Hotel, situated in the heart of Sydney. The accommodation was easy access with straight lines making it easy to get around and the staff were excellent.

The theme of this conference was Access To My World which themes included advocacy, communication/technology, early intervention, support and service provision.

Key note speakers Sven Topp, Sharon Barrey Grassick and Steven Ripley presented on Haptic communication and Interactive communication.

Sven Topp spoke at length about Haptic and explained that Haptic is any form of non-verbal communication involving a sense of touch, one of these forms is a glove which converts text messages from your mobile phone by way of taps and swipes to your fingertips and palm.

Sharon Barrey Grassick spoke about the congenital deafblind children and how important the first two years of their lives is in regard to communication. Technology is fantastic but has its limits, the communication needs to be appropriate to the client. It is essential that all people having direct contact with a child who is deafblind can interact and communicate effectively with that child. There is a new National Disability Insurance scheme

operating within Australia, this has formed a lot of concerns as there is no training or standardised assessments involved.

Steven Ripley from Vision Australia is a communications trainer. His speech was about walking with the deafblind person but still letting them be in control. It was an interesting rendition of when out and about with a deafblind person how you would stop and smell the roses, how you would touch and feel to give insight of what is happening to the deafblind person opening up their world.

There were presentations on the National Disability Insurance Scheme with a lot of providers having concerns that it will meet the needs of the deafblind.

A group of deafblind people have set up an advocacy group in Melbourne with the help of funding. These people have realised that the voices need to come from deafblind people. They are hoping to grow this into an organisation that advocates for deafblind people.

The next presentation was reflecting on my experiences of teaching Tadoma by Dr Paul Pagliano. This was about the way Helen Keller learnt to talk which involves placing your thumb under a persons chin, the first finger over their mouth, second finger on the top of their cheek, second finger in the middle of their cheek, third finger at the bottom of the cheek and the little finger under the jaw. This method was stopped being used in the 1950's/60's and there is discussion as to whether this should be reintroduced.

Reaching rural and remote communities in Western Australia by Angela Wills from Senses Australia. Her presentation was about the strategies they have to use to reach the deafblind people in remote areas, every year this necessitates two trips which takes days to complete. They have deafblind training which they do with the service providers in the rural areas so

that the people working with the deafblind on a regular basis have understanding of deafblindness and their needs.

Embracing the Depth and Inclusiveness of Deafblind Communication Through the Use of Supportive Touch by Melissa Lee Evans from Senses Australia.

Service Me, Not my Disability / Sticklers Syndrome by Emma and Eddy Gordon. This presentation was from a young boy who is 14 years of age and his experience of going to doctors and specialists and wanting the information himself to be respected like any other person. Eddy was accompanied by his mother Emma Gordon.

The Impact of Communication Guide Support for Clients with Acquired Deafblindness by Matthew Wittorff from Senses Australia. In Western Australia they ran a pilot for communication guides which they received funding for. They ran it for three years and did research to establish the benefits, this was hugely successful and has now been completed. This research information is now being used to acquire more funding to enable more deafblind people to have communication guide support.

Defying Adversity by Eddie Szczepanik from Western Australia. This speech was about a group of deafblind people with Ushers Syndrome who are walking the Bibbulmun Track which stretches 1000 kilometres from Kalamunda in the Perth Hills to Albany on the South Coast. This track is going to be done in stages due to the the support needs and the expanse of the terrain to be covered. The first part of the trek was completed over four to five days. You can follow their progress by their website [www.defineadversity.com](http://www.defineadversity.com)

The Individual Empowerment of Deafblind People in the NDIS by Thuy Van Do and Justine Lorenz from the Deaf Society of NSW. This was an inspiring speech about deafblind working

together to get the best out of the National Disability Insurance Scheme.

Communication through Technology by Tricia d'Apice from the Royal Institute for Deaf & Blind Children. This speech covered the use of hearing aids, cochlear implants, technology such as computers with voice output, ipads, iphones etc in the use of schools.

Miniguide Workshop by Jeremy Hill from Guide Dogs NSW/ACT. The Miniguide Mobility Aid helps people know when an obstacle is coming up, you can adjust it for different measurements, you can also use it to avoid overhead obstacles like trees. This aid does not replace the cane or guide dog but is used in conjunction with these.

Some of the keynote presenters also gave an overview that support workers for deafblind people need to have training and be standardised over Australia especially because of the National Disability Support Scheme now in place.

On the evening of Saturday 7<sup>th</sup> June a conference dinner was held at the Mercure Central Sydney Hotel, Grand Central Ballroom in which I had the honour to give a presentation on behalf of Deafblind (NZ) Incorporated. I spoke about Deafblind (NZ) Incorporated who we are, what we do, the services that are available in New Zealand and that Australia and New Zealand need to be more connected in the deafblind community.

Warren and I found this conference to be invaluable connecting with other deafblind people, finding out about the different services provided in Australia, connecting with the Australian Deafblind Council and forming new partnerships.

Merv Cox

9<sup>th</sup> National Deafblind conference 2014  
6 – 8 June Sydney

The conference began with a welcome by Uncle Chikka Madden who did a national welcome to the people and the land.

We were then welcomed by the chairman Frank Deane from Forsight Australia who empathise the conference theme of “Access to my world” and pushing that all people should be getting a “fair go”.

It was two full days of workshops. Some of the workshops were all together and then during other periods of the time there were two different workshops going at once.

It was privilege for me to go and to be able to learn so much valuable information and make new networks with Australia

The workshops that I went to are as follows:

#### **SATURDAYS**

- **FCS – ADHC Welcome** - Jim Logley from CE Family and community services
- **Keynote Speaker** – Sven Topp from Australian Deafblind Council
- **The Convention on the rights of person with Disabilities & National Disability Insurance Scheme** - Philip French from People with Disability Australia
- **Strategies to Negotiate the world of sight and sound** – Rebecca Dunkley from Guide Dogs NSW/ACT
- **Touch the world** – John Evernden from Accessible Public Domain (NSW)
- **An O&M perspective when teaching long cane skills with people with ushers** – Paul Garwood from Association for the Blind WA
- **Mixing original methods with main-stream devices: Braille Technology meets smartphones for deaf-blind** – Sam Taylor from HumanWare (NSW)

- **Discover the world from me to you** – Patricia Rolland and Anna Sullivan from Vision Australia
- **Social-Haptic Communication with Music and Theatre** – Dennis Witcombe and Michelle Stevens from Able Australia and Deafblind Victorians
- **Service Me, Not my disability/ sticklers syndrome** – Emma & Eddy Gordon from Deafblind Association of SA Central
- **Conference Dinner**

## **SUNDAY**

- **Keynote Speaker** – Sharon Barrey Grassick
- **The Impact of communication guide support for clients with acquired deafblindness** – Matthew Wittorff from Senses Australia
- **iLearn Share – Peer Training Model** – Claire Tellefson from Able Australia
- **S911 Lola – GPS and 2-Way Voice Communication** – Robin Way from Jeenee Mobile CCA (NSW)
- **Dance for Deafblind** – Kirsty Fromholtz from Forsight Australia
- **Communication through tactile Auslan** from Monash University
- **Support Workers where to from here?** – Carla Anderson from Able Australia
- **Communication and Guides** – Steve Ripley from Vision Australia
- **Conference Closing**
- **Video on Rubella Networks**

So some of the highlights for me during the conference was that I was really impressed with the discussion that was had about the National Disability Insurance Scheme, there still seems to be some finer points to work on like who is going to pay for the training of the support workers.

The one on O&M Perspective when teaching long cane skills with people with ushers was very interesting as it was valuable to see the new technology that can work alongside the cane ie: using a laser cane.

Social-haptics communication with music and theatre was amazing as it showed another way on communicating with someone who is deafblind.

GPS and 2-way voice communication was all about a system they have over there that allows you to be connected to a services provider and when in need of help this service provider can help you get out of a difficult situation i.e: you get on a bus and get lost, through their services a GPS can find you and tell you when to get off and where to walk.

Probably the most enjoyable for me was Dance for Deafblind. Kirsty showed us how her training in Occupational therapy is able to help Deafblind and getting movement back into their body parts.

The Dinner was amusing, lots of laughter, great stories and lovely food.

The advent in my prospective was a huge success.

We meet a lot of new people and did a lot of networking and for me it was a great privilege to go and learn and would be honoured if I was able to attend again

I would like to thank the Executive Team for allowing me to go.

Warren Persson

## **DEAFBLIND (NZ) INCORPORATED AUCKLAND SUPPORT GROUP**

We have had some very interesting meetings over the last few months and have welcomed new members John McPeak, Louise Smith, Matthew Neighbour (from South Auckland) to our group as well as Mike Wilkie, which has made our meeting times very worthwhile.

Merv and Cheryl have been attending our meetings and have been able to convey the feedback and other important information to the members.

Long-time member Terry Free has not been at all well and has recently been in hospital (now discharged), his past contribution to Deafblind will be missed by us all. We thank Terry for everything he has done and wish him well for the future.

We will not be meeting again until 21<sup>st</sup> February 2015 as the next two months will be very busy for the members, in October we have the Deafblind (NZ) Incorporated Annual General Meeting which is being held in Christchurch. Anita Gilbanks (secretary for the Auckland Support Group) and John Tunnicliff (president of Auckland Support Group) are standing for the executive this year. Also on Labour Weekend Anita and David Gilbanks and Karen Mummery are attending the annual National Camp at Matamata which is run by Elevate Disability Trust (formerly Christian Ministries With Disabled Trust).

Our Christmas function is to be held on Saturday 6<sup>th</sup> December 2014 at the Onehunga Workingman's Club.

Anita Gilbanks

Secretary Deafblind Auckland Support Group

## **DEAFBLIND [NZ] INC CANTERBURY SUPPORT GROUP**

In June we held a very pleasant lunch and afternoon to celebrate Helen Keller's birthday. About 50+ people attended including deafblind persons, their supporters and carers, family, friends, Blind Foundation staff, volunteers and community agencies. One of our members, Chris Wiberg demonstrated Tai Chi, another Barry Gernhoefer told a pleasing story of his life playing bowls at a local and national level, John Taylor gave an amusing description of the time he met Helen Keller in Melbourne many years ago when Ms Keller performed a handstand: she was only 76 then! Deaf Foundation Recreation officer, Heather McGill organised a game testing people's senses of smell, taste & touch which had many amusing results.

Lunch was a convivial time and our member Maisie Aydon cut the birthday cake that was enjoyed by all.

July and August our meetings were involved in discussions being conducted by Julian Inch as Mentor for DeafBlind within the umbrella of Disabled Peoples Group. The first meeting members gave many opinions of life as a DeafBlind person and on the second occasion the summary of opinion was discussed. It was a very worthwhile time and gave a huge insight into opinions, wishes and needs. We hope our contribution was worthwhile.

Sadly, recently one of our members Shelley Lurajud died in Timaru. Sympathies were sent to her family and members remembered the amazing life Shelley had led as an inspiration to everyone, deafblind or not.

In September we are looking forward to an outing for coffee on a bright sunny day, we hope. After the intensive discussions a fun outing is well deserved.

David Wilson

Chairperson

Helen Keller Day – Deafblind (NZ) Incorporated Lower North  
Island Support Group

We all had a lovely morning which began with a very good speech from Lorraine Nilsson about Helen Keller, this was then followed by Lorraine cutting the cake. At this time we all sat down and had an enjoyable morning tea. After morning tea we all had an activity to do which was to give the sighted people there an idea of what it was like to be completely blind and deaf.

The activity was 8 items were put on a table and we had to discover what they were while we were blind folded. It was a great experience in trying to figure out what the 8 items were.

We also had hand massages available where some of us had their hands done. It was great.

My mum came along with me and really enjoyed herself.

Warren Persson

## AMANDA CAMERONS STORY

Hi everyone, Amanda Cameron here. I have been asked to write a story about what I've been up to lately which is para-cycling.

It all began with a show on Attitude TV sometime last September, it was about different athletes with different disabilities participating and competing in sport and it inspired me to look into a sport that would be suitable for deafblind. I sent a few emails around asking for more information and I had a response from Paralympics NZ (or PNZ for short). They asked if I would be interested in tandem cycling. My first thought was no way as I could not imagine me on a bike let alone a tandem bike! I was never a big fan of annoying skinny cyclists wearing lycra but I encouraged myself to give it a try and so accepted the challenge.

They sent me down to Invercargill to meet the team and watch some tandem racing at the velodrome. At this stage there was two other tandems, another girl with Usher Syndrome named Philipa Gray. You might recognise her name from having won medals at the London Paralympics a few years ago. The second tandem was Emma Foy, a visually impaired cyclist. They both have their own pilots who they race with on the tandem.

So the PNZ staff gave me a solo bike and a wind trainer which is an A frame thing that the back wheel of the bike sits on so I can train indoors. From there, it was all on!

I started training with a basic programme from Jono - my coach and I went on a tandem bike for the first time this January in New Plymouth at a cycling talent ID camp. It was fun, my

sighted pilot was Gabby. I decided to carry on with the training and it increasingly got harder. I started training out on the tandem in Wellington once a week with a training partner, riding up to 3 hours every weekend.

The first event I went to was club nationals at Cambridge with a 25km time trial. It was really fun, I came third out of four tandems with an average speed slightly higher than 'A' grade standard set by PNZ. I was pretty pleased with this after only having been in the sport for such a short time.

The following week was the world cup in Italy. The 30km time trial and 89km road race were both on flat roads with no hills so they were both fast races. I came 10th in both and am pretty happy with an even faster average speed. It was tough but not as tough as the next event... I had been selected to go onto the world championships in South Carolina 3 months following it but as I had booked some travelling with my partner, this meant I had nearly 2 months off and only just over a month to train again. It was incredibly tough, though this time I was competing in just the road race - an 82km course and it was 38 degrees that day. I fought hard during the race and finished with a less than satisfactory result but I am so proud of myself how far I have now come in nine months. My dream is to try go to the next Paralympics in Rio in 2016 and I am feeling more motivated than ever to train and race harder in the events to come. For now I'm having a short break before focusing on training again.

If you want to know more about tandem cycling, then please feel free to email me. Thanks for letting me share my story!

## **MINISTRY OF HEALTH DISABILITY SERVICES INDIVIDUALISED FUNDING**

Individualised Funding is a way of paying for Home and Community Support Services, which lets you directly manage the resources you have been allocated for disability supports. Home and Community Support Services include help with household management and personal care.

Individualised Funding gives you increased choice and control to choose who provides this support, and how and when you use it. Your options range from engaging support workers and planning how your supports will be used, to employing your own care providers and managing all aspects of service delivery.

### **What you can use Individualised Funding for**

Individualised Funding can be used to:

- purchase support services provided by support workers (employees, contracted personnel or organisations) and pay costs relating to the employment of support workers
- employ support workers as long as they are not the spouse/partner or parents of the person with the disability, and as long as they do not live in the same house as the person with the disability.

Individualised Funding doesn't cover costs related to medical supplies, equipment, home renovations, leisure, recreation and personal or family costs, and can't be used to increase the personal income of an individual or family.

### **Who can get Individualised Funding?**

If you can manage your own services, or have someone in your support network willing to do so, then Individualised Funding may be right for you.

You can get Individulised Funding if you:

- are eligible for Ministry-funded services
- have been allocated Home and Community Support Services
- have talked to a Needs Assessment Service Coordination organisations (NASC) to see if Individualised Funding is suitable for you.

Talk to your local NASC to learn more. They'll do a needs assessment, which takes into account essential need and natural supports available to you.

If you can access home and community support services, and wish to use Individulised Funding, they can make a referral to an Individulised Funding Host of your choice.

### **Individulised Funding Hosts**

If you want to use Individulised Funding to manage your support allocations, you must do this through an Individualised Funding Host organisation. These are organisations contracted by the Ministry of Health to support people using Individulised Funding.

Individulised Funding Hosts will:

- help you understand Individulised Funding
- help you learn how to organise, setup and manage your supports
- administer payments for the support services
- help you manage your responsibilities – this includes reporting back to them on the support hours used, so that they can be paid for.
- required to ensure that the service is working well and report back to the Ministry.

All Individulised Funding Hosts provide this level of service for a fee set by the Ministry. If you want Individulised Funding Hosts to take on the responsibility for recruiting, training and paying your support workers and possibly managing the legal aspects

of your service, your Individualised Funding Host may do so for an extra fee determined by them.

## COOK'S CORNER

### CINNAMON BUNS

1 lge cup Flour

1 Tbsp. Butter

½ cup Sugar

1 tsp. Cream of Tartar

½ tsp Baking Soda

Pinch of Salt

Rub butter into sifted dry ingredients

Add one beaten egg with ¾ cup milk

And vanilla

Grease patty tins.

Mix 3 tsps sugar and 1 tsp cinnamon.

Sprinkle half on bottom of patty tins

and rest on top of buns.

Cook 8 – 10 mins at 400 degrees F

Place above ½ way in oven.

It is yummy.

DEAFBLIND (NZ) INCORPORATE  
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