A blind BIT OF difference

Blind Citizens NZ

Focus

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In this Issue

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Editorial by Allan Jones

Postscript to editorial – just as we go to print, information about System Transformation and live-streaming session opportunities has been publicised. Only those dates that will be relevant by the time Focus reaches you, are included. You will read later in this issue that Sacha O’Dea is a guest presenter at our AGM and Conference. Live streaming sessions are:

- **Family and whānau:** 26 September, 6:30 pm until 7:00 pm
- **Disabled people:** 27 September, 6:30 pm until 7:00 pm. Lorna Sullivan, Director of the Kaitūhono/Connector team will be joining Sacha O'Dea for this session.

You can choose to ask questions during the session on the YouTube page or email questions in advance to STfeedback@moh.govt.nz. If you do not want to be named during the live streaming sessions, please request this so that it is clear your name or organisation is not mentioned.

Buzz Words, which Crowd in on us

To begin this editorial I want to share three buzz words which now days we hear daily the first is “co-design” describing “a powerful force for creativity and collaboration” co-design” was mentioned about four times at the access matters launch at Parliament this morning.

The second word is the word “hubs” news-hub is a radio news network described as the centre of a wheel with protruding spokes.

The third word is a revival of the term “connecters”. In my childhood, connecters were clips, which connected aerials to coils on our crystal sets. In the transformation process, a connecter will be the first person of contact. Perhaps I could leave this discussion with the Peter Sellers famous quote “so much to learn so little time”. Happy reading

In Memory of George Phiskie

Readers of my age and many others will have a memory of George Phiskie, who died at the age of 96. This was just as the last edition of Focus was going to print.

George, like Cyril White, Terry Small, and Merv Reay, was one of those characters who was “larger than life”. I first met George about 60 years ago. George ran a pig farm at Waipu. Each year for a number of years, a team from the Foundation would travel up to Waipu to play hockey against a team of local farmers and Waipu identities. It was always an occasion to be enjoyed. In 1964 I travelled to Waipu with a university mate who was considering teaching in the far north. I spent an enjoyable three days with the Phiskie family. George was a great conversationalist.

Throughout the years, our paths crossed now and then. It was always good to see him, and hear a story or three from him. Go in peace George you left an impression – your love of life, and sense of adventure rubbed off onto many of us.

Ever tried Walking through a Mine Field

Finally, in this editorial I want to make some brief comments on David Seymour’s End of Life Choice Member’s Bill. In essence, the bill wants to give the right for persons 18 and over who are competent to make a decision, and who are suffering a grievous and irremediable medical decision, to ask a physician for assistance to end their lives.

As I complete my editorial, I received an article from George Taggart, which I am happy to include in this issue. George’s conclusion is different from mine in the sense that at present I lean towards supporting the legislation. George leans the other way.

I have been fortunate to hear two excellent radio programmes on this subject. The first being “our changing world” programme broadcast on May 24 of this year.

The second interview was broadcast on “nine to noon” on Friday 17 August - Katherine Ryan interviewed Paula Tesoriero Disability Rights Commissioner. Paula has misgivings about the legislation which I will come to later.

The “our changing world” documentary was compelling radio. It examined the setting up of a “citizens jury”, a group of 15 citizens picked randomly from the Dunedin electoral roll to examine this topic. At the beginning of the process, 14 members of the jury were in favour of the legislation. At the end of the process, 10 were in favour and five against. Radio NZ interviewed four members of the jury at the beginning of the process - three members were for, and one against. At the end of the process two were for and two against.

One guest speaker to the jury was Ken Joblin, Blind Foundation member. Ken spoke against the legislation suggesting that for disabled people, it could be seen as the beginning of a “slippery slope”. Lucrecia Sales’ mother spoke to the jury through a video link and like Ken, had a powerful impact on the jury.

One of the convenors of the jury described the process as “complicated, divisive, and contentious”. The discussions took place over three days. The process was described as respectful and humane. People really listened and respected the views of others. I would like to the Citizens Jury approach adopted in discussions we may have with the Blind Foundation on future matters of policy.

Blind Citizens NZ was fortunate to have Paula Tesoriero as a speaker at last year’s AGM and Conference. Paula is the Disability Rights Commissioner, and acting Chief Human Rights Commissioner. In my view, her knowledge of the disability sector and Katherine Ryan’s knowledge of the political system blended well in an interview broadcast on Friday 17 August.

Paula is of the opinion that New Zealand legislation is too broad. She was concerned that legislation was being muted, when health services and health outcomes are not where they need to be for disabled people. She also said that New Zealand’s domestic laws were not always in line with international obligations. The other really important point Paula made was that we must be clear not to convey that the lives of disabled people aren’t worth living.

The Justice Law Reform Committee received over 34,000 submissions. The Committee will hear approximately three and a half thousand people who wish to present their submission in person. What I liked about Paula’s presentation is that she raised several discussion points, which need to be discussed. One aspect that Katherine Ryan raised was “is despair an irremediable medical condition”. I would suggest that for some it is. Fortunately, many people on losing sight go through a process of despair eventually grasping a love of life again.

In Australia, the equivalent of our End of Life Choice State of Victoria bill is 130 pages long while our New Zealand bill is 15. The Victorian bill outlines a three-stage process with two medical practitioners. To access the Victorian legislation you must have lived in the state for 18 months and if possible administer the medication yourself. As I said at the beginning of this editorial, this subject is like walking through a “mine field”. One thing that I am sure of is that I will not be proselytising in favour of this legislation. People must be free to decide for themselves how they will approach it, and like members of the Dunedin Citizens Jury, I hope that I will maintain the position of listening to and valuing all views and opinions expressed on this vexing topic.

Waiting… Waiting… Why are we waiting?

From Jonathan Godfrey, National President

One of the things I struggle with most in life is waiting. I don’t mean waiting to listen to the news that won’t play until the top of the next hour because I can tell the time and fill in the minutes doing something else. Likewise, I don’t mind waiting for flights or other public transport that is running to a schedule. The kind of waiting that bugs me is the waiting for an uncertain amount of time. You know, that time when you sit or stand around wondering if the bus went already or you’re still waiting because you’ve got no idea when or even if it will ever turn up. I reckon disabled people do more waiting than do non-disabled people. We wait for taxis or public transport because we can’t drive ourselves. We usually have to wait for a book to become available in audio or braille because we can’t read it in print.

I guess many of you reading this column are waiting for something in the world around us to change, just like I am. We wonder why the people who had the power to include the features that would make it easier to use everyday products or services didn’t think of our needs when they had the chance; we might wonder why it is that even though good systems have been developed and implemented in other places, they haven’t yet reached our home towns.

The list of things that don’t work well for blind people continues to grow. The policy objectives for Blind Citizens NZ are developed by way of a blind individual raising their concern at a meeting with other blind people; it gets discussed locally and then nationally, and ultimately becomes policy because a resolution is passed at our annual conference. Sometimes these resolutions are very narrow in their focus, but I would argue that the resolutions that are robust to changes beyond our control are the ones that really provide the principles that guide the organisation’s leadership the best.

None of these resolutions leads to instant change though, and so even the leaders of our community must ask you to wait for change. The things that strike me the most are quite basic.

For example, the traffic lights around town that do (or unfortunately do not) emit a useful sound to help us know when to cross roads safely; the talking ATMs that allow us to withdraw cash independently; and the braille on buttons and audible announcements in elevators which mean we get out on the correct floor without having to wait for another person to come with us. In all three of these cases, the time between a decision to introduce these systems and the date when we can expect every crossing, every ATM, and every elevator to work for us is long. Did that mean the efforts of our forebears were wasted? I think not.

I expect to be able to cross roads safely today, I generally expect to be able to find an ATM that talks to me, but the elevator in almost every building on the campus where I work doesn’t work for me. Ok, Jonathan you can’t have everything so just be thankful all the offices you work in or visit regularly are at most two storeys above ground level.

My point here is that change doesn’t happen overnight, especially if we’re talking about the sorts of systemic change that will fundamentally improve our lives. This is why I worry so much when people decide that technology will make my life so much easier. Sure, I can do all sorts of things that perhaps I didn’t do ten years ago, but ten years ago I probably wouldn’t have had many of these technological improvements high on my list of things to fix. Don’t get me wrong, I love my technology. It has made it possible for me to have the career I want; it keeps me connected to my friends and family, and in some instances, it has helped me know how much longer I need to wait for the flight to start boarding passengers or for my taxi to arrive.

I have to accept that waiting for things to change is part of life. My desire for things to be put right is what pushes me to reach out to the people making decisions so that one day, just maybe one day, my needs as a blind person will be accommodated without needing me or anyone else to vigorously wave a massive Blind Citizens NZ flag in the faces of the decision-makers.

I think we have a lot to thank our forebears for. The coins we use, most notably the twenty cent piece, are the way they are because Blind Citizens NZ got involved in the project which saw NZ's coins change to a smaller size; we have talking ATMs around because Blind Citizens NZ lobbied hard over many years with the banks.

Do you remember the catch phrase "Money talks and so should ATMs" that was used when Blind Citizens NZ was making a big noise about silent ATMs? Does anyone say "thank you" when an interesting show comes on TV with audio description?

I hope you note that for the issues I've mentioned in this article and many others, we at Blind Citizens NZ can proudly stand up and say "we were there, trying to get something changed even though that might have taken years to come to fruition." It is still how we operate for the most part, although perhaps it is nice to note we've tried to pick a few important items of work that we can get done fairly quickly. "Quickly" is a relative term though. For example, two years ago, a resolution was passed at conference that called for a Braille Strategy to address a wide range of issues with the provision of braille. I'm pleased to advise that the leadership shown by Blind Citizens NZ in this space means that a Braille Strategy now exists and has been agreed to by the other key stakeholder organisations. We'll celebrate this achievement with the launch happening at our upcoming conference.

We worked with our DPO Coalition partners on an Accessibility Charter that has now been signed by more than 3/4 of the Chief Executives across central government agencies.

For the first time, blind people have explicit support from the most senior Government officials en masse, and we can now expect information to be made more accessible in future. Implementation of the Braille Strategy and the Accessibility Charter will take time, so we are waiting… waiting… patiently waiting, for now anyway.

On reading the first draft of this column, my partner Amy asked me what I expect of people out there. My experience to date tells me that talking to people to explain our concerns can and often does lead to understanding. Many people around us have little opportunity to change things for us in a systemic sense, but most do have the power and the willingness to help us sort something out in the here and now. The challenge for Blind Citizens NZ and all of us as individuals is to get the opportunities to have our stories heard by the people who can get that systemic change happening. Once the decision-makers learn what impact they can have on improving things for us, they then have a chance to actually do so. If we don't tell them, who will? If we don't tell them, can we blame them for not doing the right things for us? I contend that if we do tell them, and they still decide to ignore our needs, then and only then do we have cause for grievance.

So our work continues and yes! We must wait, but waiting patiently doesn't have to mean waiting quietly.

Editor comments: I have two comments to offer in response to Jonathan's thought-provoking piece. One of the worst times of waiting for me was as a child waiting at the airport to return to the blind foundation in Auckland. I wanted goodbyes to be brief and not lingered over. If the weather intervened, which it often did in those days, this would be a prolonged and painful process. In Wellington at present, many others and I are waiting to be able to read bus timetables with Blind Square. This very good service disappeared when the new reforms came in to being!!!

2018 Annual General Meeting and Conference

Raising Expectations: is blindness defining who we are?

From Rose Wilkinson, Executive Officer

We are counting down the days until this year's AGM and Conference. Based at the Brentwood Hotel, Wellington from Friday 5 to Sunday 7 October, we have an exciting and diverse range of speakers and topics. Annual General Meeting business happens over Friday and Sunday, while Saturday's open day is when you hear from guest speakers. AGM business this year will require members to talk about the Governance Review Panel's constitutional proposal, and to make decisions that may shape the future of Blind Citizens NZ. Having completed its governance review, the Board has information to share about its work, and it responds to non-constitutional items raised by the Governance Review Panel.

It is a privilege for the Board to have Hon Carmel Sepuloni, Minister for Disability Issues carry out the official opening on Saturday 6 October. Additional speakers and / or topics for the day include:

- Sacha O'Dea, Programme Lead, System Transformation, Ministry of Health;
- Launch of two pieces of work - Social Awareness project, and Strategic Framework for the Provision of Braille Services;
- Áine Kelly-Costello – Accessibility Legislation and the Access Alliance;
- Kylee Maloney – Member-for-Life: Embrace the Darkness;
- Leilu Harrington-Talbot (young person) – talking on topic;
- Making Disability Rights Real – Daniel Phillips Board Member will co-facilitate this session with a colleague from the Independent Monitoring Mechanism.
- Neil Annenberg, Chief Operating Officer, Social Investment Agency.

Often during the AGM and Conference there will be discussions that need wordsmithing for the future. This is where the role of the Resolutions Committee is important. The process starts with the Board appointing a convenor from amongst elected Board Members. Then a little closer to the three-day event, up to four people who have registered attendance for the full three days will be shoulder-tapped and invited to join the Resolutions Committee. Last but by no means least, the Board's recommendation to the AGM and Conference seeking endorsement of Resolutions' Committee.

At the September meeting, the Board started the process off with the appointment of a convenor. On this occasion, it made a considered decision not to follow its policy, which requires the Board to appoint someone on the Board to this position. Instead, the Board has appointed someone from outside the Board. It wishes to be transparent about its decision hence sharing this news ahead of the AGM and Conference. Vaughan Dodd has accepted the Board's invitation to take on the role of Convenor for the 2018 Resolutions Committee.

As we take advantage of this opportunity to give a little more airtime to publicise the AGM and Conference, we are mindful that around the time, you receive our September Focus issue, we will be about two weeks out from our three-day event. Perhaps you have been holding back to register and come along. If you have, then even at this late stage, feel free to contact our national office and check out the possibilities. In addition to the Brentwood Hotel venue in Wellington, the Board has agreed to run a pilot video-link. This will be in addition to our usual live audio stream – information about the live audio-stream will be publicised the week of 1 October on our National Feedback Line, email lists, Facebook and website. The Board's decision to pilot a video-link does not detract from encouraging people to attend Conference in person at the Wellington venue.

The video link is primarily for Auckland-based members who wish to be part of the three-day event but due to cost or other reasons, are unable to travel to Wellington. While we often provide live audio streams of sessions, this will be the first time Blind Citizens NZ has attempted to join two locations together in this way. We are working closely with Auckland Branch who will host Auckland-based members at the Blind Foundation's recreation centre, Awhina House. If you are in Auckland, and you are interested in finding out more about the video-link, please contact our national office (details at the end of this publication), or Auckland branch Secretary Mary Schnackenberg phone (09) 520-4242, or email mary@lansink.co.nz

Euthanasia Considered, From George Taggart

Editor Comment: the person young woman to whom George refers, was featured in an "insight" documentary broadcast on Radio New Zealand early August… Now to George's article…

I thought that I would try and write an objective summary of a couple of the pros and cons on what is likely to be an emotionally charged debate in Parliament later this year, namely whether to legalize euthanasia or not. Then I remembered that I have no faith in my or anyone else's ability to be objective. So while admitting to my prejudices they do not include a religious or moral perspective.

In fact, I have no idea right now as to what my position will be, come a referendum and I am hoping that writing down my thoughts on this very important topic will help me clarify my thinking.

The case for euthanasia as I see it is generally based on a diagnosis of a terminal illness, or in a recent case in Holland a twenty-nine year old with a chronic condition of mental illness.
I should add that the person involved is generally suffering from extreme pain.

The supporters of euthanasia generally base their case for changing the law, on dying with dignity, especially where extreme pain is involved and there is no doubt, there are some people in this very situation. In fact, it is this group of people who are highlighted whenever this crucial topic comes to the fore. It seems to me that after the initial diagnosis and sometimes a prognosis, the illness takes centre stage, as one treatment after another is tried, in an attempt to stop or delay the disease in its tracks. At this stage, I do acknowledge that new drugs have to be tried, in order for progress to be made but when does the cost to the person become unbearable. Unfortunately, what seems to happen is that the person becomes the disease and as such can be seen as a challenge to the experts. However, the cost to the person increases as the infamous side effects of treatments take their toll. Things may have changed since my experience of the health service however, to me there seemed a lack of a coordinated plan as each specialist dealt with their particular aspect of the person’s illness. As I have said above, the person takes second place to the disease.

It seems to me that the medical fraternities are in the situation of being as divided as the general population and to some extent it depends on which branch of medicine the practitioners are attached to. The specialists in palliative medicine say pain and other extreme discomforts can now be taken care of, while those involved in the treatment of the disease, have a new procedure that may or may not have the desired outcome.

Now of course there is not a strict demarcation on who has a particular view, this is why I say it is just as difficult for doctors to have an objective view as the general populous. Palliative care specialists on the other hand have the person at the forefront of their particular worldview. While palliative care is obviously a very important aspect of terminal illness there are more than the patient involved, in fact there is a family, community and societal interest here too.

Remember the concept of “unintended consequences”; there are examples of this concept at work in other examples of social legislation, [recall the Dutch example quoted above].

When the debate does occur there will be particular situations given as to why we should take one side or the other.

Individual rights are incredibly important, particularly in today’s society. Compassion towards another human being is a powerful influence and for those with a religious belief God gave life and only God should be able to take it away, on the other hand part of a religious belief as I understand it is compassion for ones fellow humans. As William Shakespeare would say ‘there lies the rub’. Those in favour of the rights of an individual to choose the time of their death should also recognise that individual rights are often totally swept aside when it comes to others desires, political considerations or even National interests. Wars are a good example of this. Also, remember the Lutheran pastor in Nazi Germany who said ‘they came for the mentally ill, but I am not one of them so I said nothing” - please pardon the para phrasing.

While I await the debate on euthanasia legislation with keen interest, I am leaning towards a no vote, my fears of others interest creeping forwards are very strong, but of course I am not at present, faced with such a personal choice.

Presenting our Stories at Parliament and More: An update on the Access Matters campaign

From Áine-Kelly Costello

I bring you this update as Community Organiser for the Access Matters campaign for an accessibility law at the heart of a more inclusive Aotearoa. The campaign is led by the Access Alliance, which Blind Citizens NZ is a member of.

I myself am a member of three Alliance organisations: Blind Citizens NZ, the Blind Foundation and Disabled Persons Assembly.

Over the past year, Access Alliance representatives have been busy meeting with MPs and Ministers to progress conversations about committing to and Accessibility Act. Minister for Disability Issues Hon. Carmel Sepuloni instructed her officials to do a stock-take of existing accessibility policy in Government, and that report has recently been completed, though not yet circulated. The Office for Disability Issues have also been examining how we can learn from international disability legislation here in New Zealand. Minister Jackson (Employment) and Minister Twyford (Housing and Transport) also showed considerable interest in the concept of introducing accessibility legislation when Alliance delegations met with them in June and July respectively. We have further established a cross-party Parliamentary Champions for Accessibility group, which is taking action alongside the Alliance to progress research around accessibility legislation and increase momentum for it to be introduced.

At a grassroots level, we’ve been calling for, and sharing, stories of access barriers that many of us face in our day-to-day lives, and how legislation may be able to help remove them. Our grassroots campaigners have been visiting MPs from Warkworth to Nelson, sharing their stories and presenting their MPs with a booklet of stories from the disability community. The stories illustrate access barriers across a range of areas including transport, education, employment and more – barriers, which an Accessibility Act could help to remove.

We stepped up the booklet presentation idea a few notches when on 4 September, Access Alliance representatives, disabled people and whanau, and supporters from other disability organisations and NGOs, gathered at Parliament.

Inside away from Wellington’s frigid and blustery weather, over 70 of us gathered to present a giant version of our booklet of stories to Minister Sepuloni. The Minister addressed the expectant crowd, assuring us that she would read all of our stories and encourage her fellow MPs to do the same.

She said that Government needed to do more to address the systemic barriers disabled people continue to face, and mentioned the research being carried out by her officials on accessibility policy within Government and international disability and accessibility legislation. Hon. Poto Williams, co-chair of the parliamentary Champions for Accessibility Legislation, (PCAL) also addressed the room. She reaffirmed the cross-party group’s strong support for this law, and the ongoing positive collaboration between PCAL and the Alliance.

Between now and the end of November, the Alliance will work with PCAL on some legal research, to start to map out what the scope of the Act could look like and how it will affect existing laws. This research will involve consultation with disabled people, among other stakeholders. I’m afraid we don’t have more detail to share yet about what that consultation will look like, but rest assured we will get that information circulated as soon as we can.

In the meantime, you are welcome to get in touch with me at akelly-costello@blindfoundation.org.nz or 021 0242 8066 with any questions or feedback. Alternatively, you can contact Rose Wilkinson, who is the Blind Citizens NZ representative to the Alliance Steering Group, which is the campaign’s governance mechanism.

Blind Citizens NZ - World Blind Union Committee

Expressions of Interest Needed

If you are interested in international blindness topics, and you have a yearning to put your interest to good use, we hope you will read on…

Blind Citizens NZ has a World Blind Union (WBU) Committee, the purpose for which is to support the role of the World Blind Union Representative. This committee comprises up to four financial Ordinary (voting) Members of Blind Citizens NZ, plus the World Blind Union Representative.

The term of office for all four positions is two years, and runs concurrently with the term of office for the World Blind Union Representative. The Board is calling for expressions of interest in the WBU Committee from amongst financial Ordinary (voting) members, to fill these four positions. Provided you are a financial Ordinary (voting) member, and you have an interest in international blindness matters, the Board welcomes receiving your expression of interest. This should include information that reflects your involvement in, and interest of Blind Citizens NZ and blindness issues internationally. There is a 1,000 word-limit. The Board will consider expressions of interest at its meeting on 23-25 November.

Expressions of interest close and must be received by **4pm, Monday 12 November 2018**. Please submit your expression of interest using one of the following options:

- Post: PO Box 7144, Newtown, Wellington 6242;
- Email: admin@abcnz.org.nz
- Fax: 04-389-0030

Cyril White Memorial Fund

Closing Date for Applications – 1 October 2018

The Cyril White Memorial Fund is a funding opportunity that encourages and cultivates leadership skills and qualities among blind, deafblind and vision impaired people. Blind Citizens NZ, together with the Blind Foundation, is responsible for publicising these opportunities. There are two funding application rounds each year i.e. 1 February and 1 October. This notice is for the October round of funding applications which closes at 4pm, Monday 1 October 2018.

Earlier in this Focus issue the Editor referred to White - a pioneer in the blindness advocacy movement who passed away in 1984. Established in his honour, the Cyril White Memorial Fund pays tribute to his work and achievements on behalf of blind people. Eligibility of applicants is primarily about members who are eligible for full registration with the Blind Foundation. However, projects that are likely to be of direct benefit or interest to blind and vision-impaired people are eligible for consideration.

If you have a project or activity and want to find out whether this meets the fund criteria, then do not hesitate to be in touch for full details. This way, when you submit your application, you will be confident you have ticked all required boxes, and most of all, that you meet the eligibility criteria.

Applications to the October Cyril White Memorial Fund round need to be received by 4pm, Monday 1 October 2018. These should be for the attention of: Cyril White Fund, C/ Blind Citizens NZ, PO Box 7144, Newtown, Wellington 6242. Alternatively, by email to admin@abcnz.org.nz including in the subject line, Cyril White Fund application.

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