

HURRY UP AND WAIT

By Beverley Grammer





So we are waiting, waiting for a better future, waiting for more money, waiting for the day when we reach the ultimate point of...if only...because it is just around the corner

People with disabilities and their families, providers, funder's we continue to wait for the world to change, when we continue to wait with little progress we experience all these things – isolation, rejection, anxiety and stress, and reliance that one day someone will make things better.

Hi my name is Bev G and I want to share with you some of the challenges and experiences I have faced in my life to illustrate the impact of people and systems on my life.

So who am I?.....



To the system I am...

Kugelberg Wolander syndrome

NHI AVNO553

Severely disabled dependant for all cares

SIL, HH, PC

Complainer

Fully continent

Equipment recipient

Invalid beneficiary



A huge cost to the health system



Community services card 096 6885 111

To the people who love and respect me I am:

- Bev who has a stylish set of wheels
- I am the coolest aunty who buys the best presents
- I keep a good house - Good shopper of nice food
- I am a shop-a-holic who likes clothes, shoes, and eating out
- I am an advocate for other disabled people in the community
- I am a business woman who likes to be her own boss
- I am a good employer
- I am a loyal friend who is always at the end of email, phone or a glass of wine

So what do I do?

So what do I do now?

- Run my own business up2date – consultancy, recruiting, information, training
- DPA National Executive Committee Member
- Health and Disability Commission Advisory Council Member
- Office for Disability Issues Advisory Council Member
- Lotteries Commission Committee Member
- Total Mobility Management Committee Member
- Director of Access Ability Ltd, Standards Plus, Voice Advocacy Board
- BOP District Health Board DSAC Member
- Ohope Beach Lions Club Member and Bulletin Editor

I don't tell you this to brag or as an advertisement for myself but to show that I am not only a recipient of services in the community but I am an avid contributor. Something that never features in a Needs Assessment process.

Confessions:

- I don't do well as a passive receiver of services
- I don't hold a great deal of patience for the speed and timeliness of services

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That is why I have entitled this presentation Hurry up and wait, because I believe we often forget that the people we deal with have lives, and that timeliness and usefulness of services is paramount in what is often a jam-packed schedule for families. Let quit doing services people don't want.



Bev at 27 weeks

Born at 27 weeks showed I couldn't even wait to be born, born at 3 months premature I have always been in a hurry. This is probably the only ever single time my mum and dad have not had to wait for a milestone or service in my life.

Since then they have taken up knitting, stamp collecting and watching paint dry to fill the void of what has been 28yrs of hurry up and wait.

Siblings...

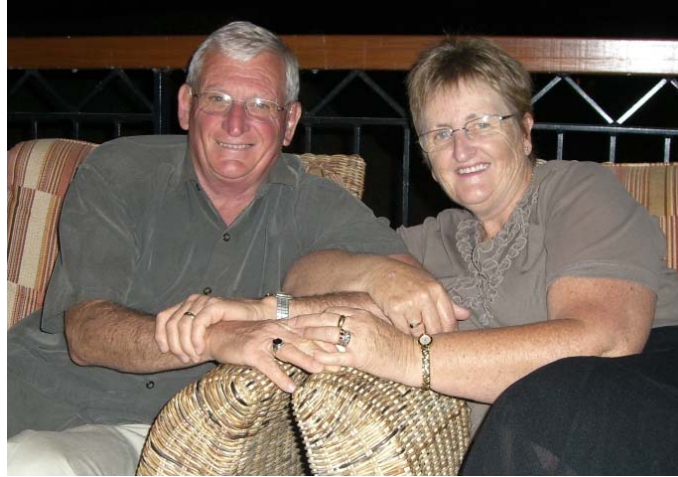
My brother Shayne and
Sister Tracey.

I'm am Shaynes
bridesmaid



I am 1 of 3 siblings, 1 brother and 1 sister and I have the most amazing parents and extended family.

Mum & Dad – 40th Wedding Anniversary



I'm Aunty Bev!



My niece's Liv & Winslet



Nephew Sam

One of my greatest joys in life is that I am aunty Bev - I am an aunty to 2 neices and 1 nephew, Liv, Winslet and Sam

The Nana's



92yrs



95yrs

and these are my grandmothers who are 95 and 92yrs old.

I am also thankful for many friends and colleagues, I have been so blessed when it comes to being loved.

Hurry Up and Wait

“To prepare quickly for an activity that is then delayed”.

Sound familiar?

So true is this statement - And yet I am sure that patience and waiting must be a virtue that all disabled people and families have in fact must be born with, because that's all we seem to be asked to do.

We wait for appointments

We wait for equipment

We wait for diagnosis

We wait for taxis

We wait to be let out of institutions

Hell we even wait to be accorded our right in the society

**How often do we hear
the words –**

“we have achieved a lot but it
won’t happen over night”

the problem with this in this context is, we are asking peoples quality of life to wait, we are asking people to put their lives on hold, not many of us would stand for that.

Fortunate times in the sector:

- After institutionalisation as we know it,
- During the time of common sense
- Before the ridiculous time of systems, policies and regulations which now rule the lives of disabled people and their families.

I was born into a very interesting time, a time when walking down the street in my push chair meant that many friends and acquaintances stopped and chatted and commented on what a beautiful baby you have to when this pushchair turned into a wheelchair caused previous acquaintance and friends of mum and dad to cross the road when they came to them in the street, but in a number of only 4 years could change to an incredibly supportive community.

However I am fortunate to be able to say I have been brought up in a very fortunate time in the sector,

The shift:

- From communities which are supportive, responsive and useful to each other to:
 - Paying for friends,
 - Not knowing our neighbours
 - Running a disability sector in a business model with competition and constant need to fit eligibility to receive supports which may be multiple and from a multiple number of providers.

So what is a good life, what would it look?

To me a good life is considered a life where:

- I am an individual and am seen as such
- Where I can control and determine how I live, even if I make the wrong decisions
- Where I am seen and appreciated for what I can contribute, even when this is not much.
- Where I can be as independent or as interdependent as I want to be, as I need people in my life.
- Where I have expectations of myself by myself and others and I am challenged

Being born with a congenital condition means that I was born with my impairment and I know, no different. I am who I am and I am proud of who I am and what I do with my life, not because of my disabilities but because of my abilities.

However in order to achieve what I have achieved and to continue to pursue a good life I must not determine to funders and systems my abilities but rather my inabilities in order to fill a need, and be eligible for support.

Can you believe disabled people can be so resourceful and adaptive we can fit our lives into HH PC SIL.

**Continuing to do what
I'm not supposed to:**

- Survive the winter of 1980

In my life I like to be a quiet rebel.

Mainstream Education



It wasn't deemed needed for me to attend my own school – I had a entire BOT ban me from their school so I wouldn't spread my “wheelchair germs” to their children however they did this indirectly, they didn't tell us the real reason, they did this by refusing to build appropriate facilities e.g. ramps to enable me to attend.

So I travelled each day to school in town where I was embraced and **mainstreamed, this was in a when this was not even a term known “mainstreaming” but was a sense of what was right to do.**

I had friends, I had teachers who took me swimming and camping and whom never expected teacher aides or specialised funding. Instead I had a classroom who took responsibility for ensuring each others participation, students even did my physio with me. Today in my work I support students and families who can't even enroll their children without ORRS funding, Teacher aides, IEPs and Behaviour management plans. When did we go so overboard.

Guiding...



I then followed in my mother and fathers footsteps by doing guiding and scouts, this was on reflection such an opportunity of inclusion and awareness raising. Again I made friends who came to stay and who in turn had me to stay – believe it or not without a caregiver. We shared birthdays and parties and I was transported to church, activities without TM vouchers. To illustrate what worked I recall I had a really amazing brownie leader, once we were on camp and we were due to go on a hike up a very large mountain, and it was expected I'd go too, she and my fellow brownies made a large sling out of a sheet to carry me up there and proceeded to do so. There was no OSH plan, no risk minimisation assessment we just did it and achieved it and remember it for a lifetime. I was then a leader which was an amazing experience and awareness raising in action. I taught girl guides, this includes pitching tents, building fires, cooking, hiking, you name it we did it, the first hurdle was always the parents, they were always weary that I be responsible for their kids, but when they saw the results this was great, they were the best at pitching tents and did it without assistance.

High school friends...



School was a really enjoyable time for me, well most of the time...

Mostly because it was with my friends and also because it was in between the constant hospital spells which happened at least once a month and for no less than 3 weeks at a time.

But despite our attempts of a normal relationships and school existence it was always other people who ruined it.

A perfect example is a time when my best friend who I'd had since primary school was called into a family meeting by a teacher of ours because she was concerned my friend was missing out on a normal social life, which meant she needed one without me. Probably with the girls who smoked, wagged and had sex, this was much more socially appropriate and just what my friend needed.

The sad thing is if my friend wasn't who she is she could have done exactly that, listened to so called professionals and left me behind and missed out on what has been and continues to be an amazing friendship. But she didn't and I remember just how baffled we were when we reflected on this experience.

We always say these things are meant to happen for a reason, to teach people something, and the fact that my friend didn't comply might have made to usual person a little more aware, but this teacher learnt nothing from this experience and eventually when on to award my friend a prize at senior prizegiving for being my friend, with the service club donated gift and everything, which really annoyed my friend because she was a major academic.

Survive surgery & intubation



So as if these challenges didn't keep us amused I then became very unwell and was told I had a maximum of 3 years to live, again people with news.

It was decided to do a never done before surgery to straighten my spine, it was put to me, do you know you will probably die? and if you do this and if you dont die then you will never come off the respirator so you better hurry up and learn an alternative form of communication, another hurry up and wait situation.

But as mentioned I never do as I am told and after 14weeks in starship, being hung from my skull to increase my lung function for surgery I had the surgery and 48hrs later was breathing against the respirator which meant they had to remove it. I had a fantastic time in starship I met celebrities, I had lots of friends whom I still keep in touch with and was a point in my life which made me appreciate the good things in life.

The equipment process

- 5yrs waiting for the processing, trial and fitting of equipment
- I grew out of chairs while waiting
- Chosen trial equipment has gone off the market while waiting

Equipment is definitely a hurry up and wait event, I have waited 5 years since starting the assessment process to get this chair that I sit in before you. Such that I have grown out of chairs, had chosen trialed chairs go off the market all while waiting for funding.

The dreaded Transition Phase

Where things became tricky now was I was leaving school and at 18yrs I still had not recieved any outside care. We were in desperate need of sleepovers as I wake up to 15 times a night, I was fully dependent for personal cares which were now not appropriate for family to do.

So we did the usual 4hrs and 14pages of needs assessment and planning for the next 5yrs, I hate planning I dont even make new years resolutions – but this detailed plan including care, equipment and when I was to leave home, was completed and signed off in in blood and it was sent to the usual culporates for approval, my life , their approval. But I never did as told so who cared. The plan was then off to a provider with the allocated resources and a usual support plan and system was implemented, but this was not working for me,

Why the system didn't suit me:

- I had no relationship with the randomly selected staff
- We needed a large number of hours for a minimal amount of money.
- This meant burning the wick at both ends, a high turn over of support workers
- My life was on standby as I just didn't fit the mould.

But talk about these very things, large amount of care, money etc and for me believe it or not, when you think of what I do with my life, my only other option was residential care, now my mum works in a rest home and there was no way, and thankfully I had others in my life who felt the same way.

But just as someone could ruin my chances for a good life, someone was able to positively impact my life. I was then reassessed by someone who asked the right question...

**“What would it
take for you to
live how you
want to?”**

At first I didnt understand, I had been working on my list as long as my arm of what I couldnt do to prove my helplessness and had perfected this over many years, and someone wanted to know about what I could do and how to fill the variance.

After some readjusting...

My answer:

- Flexibility in use of support
- A wider reconnection with people in my community
- A job
- More responsibility and say in who provided my support
- Better use of limited resources,
 - less use of it in administration

5 years later

- I now manage my support in a way which works for me – random coffee trips, holidays, work travel etc
- I worked for an agency and now work for myself having gained a large network in the sector
- I joined a service club and am a active member and love the social component of being part of a group.
- I recruit, interview and manage my support staff
- Use resources flexibly, and on a needs basis, and have minimal administration

What I have learnt:

- People who have been prepared to look at my situation as unique, and with the need for unique solutions
- Expectations put on me by others, to do, achieve and be pushed and learn from my mistakes
- Persistence
- Not settling for less
- The right people
- Being a contributor to my community
- Having, maintaining & sustaining relationships
- People who listened
- Making decisions with people
- Learning together that we wont always get it right, but that is OK
- People who don't give up on you

- People who have been prepared to look at my situation as unique, and with the need for unique solutions

I wasn't just a number, a statistic, I wasn't made to fit my life into a menu of services on offer.

- I always had expectations put on me by others, to do, achieve and be pushed and learn from my mistakes

We only have drive when we have expectations placed on us, also when people have expectations of you this tells me that they believe in you, they see your worth and we need more of this of disabled people in the sector.

- Persistence – belief that you are the expert of your own life. Even when others thought they were

When I came to the realisation that I had a unique experience, that I knew what was best for me and could empathise with others with disabling experiences, this was a turning point both in my confidence and also my careers, also in the sense that I could realise who I am is ok, and this is the biggest gift I try to share with other disabled people.

- Not settling for less – always imagining bigger and better

When you know whats best for you, you really have to fight hard to hold on to this and to push to ensure this is know, but it is also really easy to settle to minimum for the sake of sanity and it is at this point we need supporters who also know your vision and will not let it slip.

- I have been around, sort out and coerced good people to be in my life, this includes providers who listen and communities who want to support me.

- Being a contributor to my community – service clubs, as a friend, as a provider

We often forget that disabled people need valued roles, this could be a friend, colleague a good cup of tea maker.

- Having, maintaining & sustaining relationships

Contributing is the best way for relationships to thrive and establish. Relationship never sustain themselves when they are one sided. Also their needs to be importance placed on this e.g someone sending a bday card for you when your sick. It is these people who will be there for us.

- People who listened

You cant listen and hurry people up at the same time.

- Make decisions with people

Then they will know what is happening, lessening anxiety and stress on situations

- Learning together that we wont always get it right, but that is OK

I would rather have someone try something with me and go horribly wrong that I would like to wait and only do things, tried and tested and predictable. And this only works if when it doesn't work you stick together.

- People who dont give up on you

Common theme:

My life is not where it is because of Services, Professionals, Interventions, or Modifications I am here because of PEOPLE who care.

The Common theme in this whole experience is that it is the people who make the difference. Even if we do it in an individualised way, person to person to one person at a time we can just as easily disappoint people one person at a time.

The Barriers:

- Peoples attitudes,
- Who makes the decisions
- Who creates the rules

CHALLENGE

YOU can choose to make a positive difference in someone's life, because it is **PEOPLE** who have Attitudes, Make decisions, Create rules and can **CHANGE OUR LIVES.**

A THANKYOU

This is thank you to my PEOPLE

