Hi, my name is Viviana. I am a woman in her mid forties.

I would have liked to have written a submission for the Productivity Commission about what I believe are the priorities for a Disability Care and Support Scheme.

However, at the moment, I am having great difficulties with my health, my care and support, and my adaptive technology, all at once. I have decided to include a presentation I produced 2 years ago instead. It's about everyone's right to mental health. I hope you will see how relevant it still is…

My severe physical disability has been a huge part of my life..

The fact that I have Complex Communication Needs has always been an added hindrance.

Communication, and making myself understood to others, has always been a struggle, but one that I have never given up on.

Many of my frustrations have stemmed from not being understood, being misinterpreted, or simply, ignored.

Today, I will illustrate, and share some of that frustration.

I will also touch on subjects such as, family support, coming to terms with life, and how professional help assisted me through difficult times.

Where to begin?

Perhaps at the very beginning!

My parents migrated to Australia from northern Italy, both leaving their entire family behind.

Slowly, but surely, Mum and Dad adapted to life in this strange new land.

My birth was an extremely traumatic time for my parents. I guess, it was no picnic for me either, but I can’t say I remember much of it!

Mum and Dad, were always aware that my disability was physical, not intellectual. While they were very protective, they encouraged me to give everything a try.

At 18 months, I began what was to become a lifetime of therapy. I soon learnt to sit up on my own.

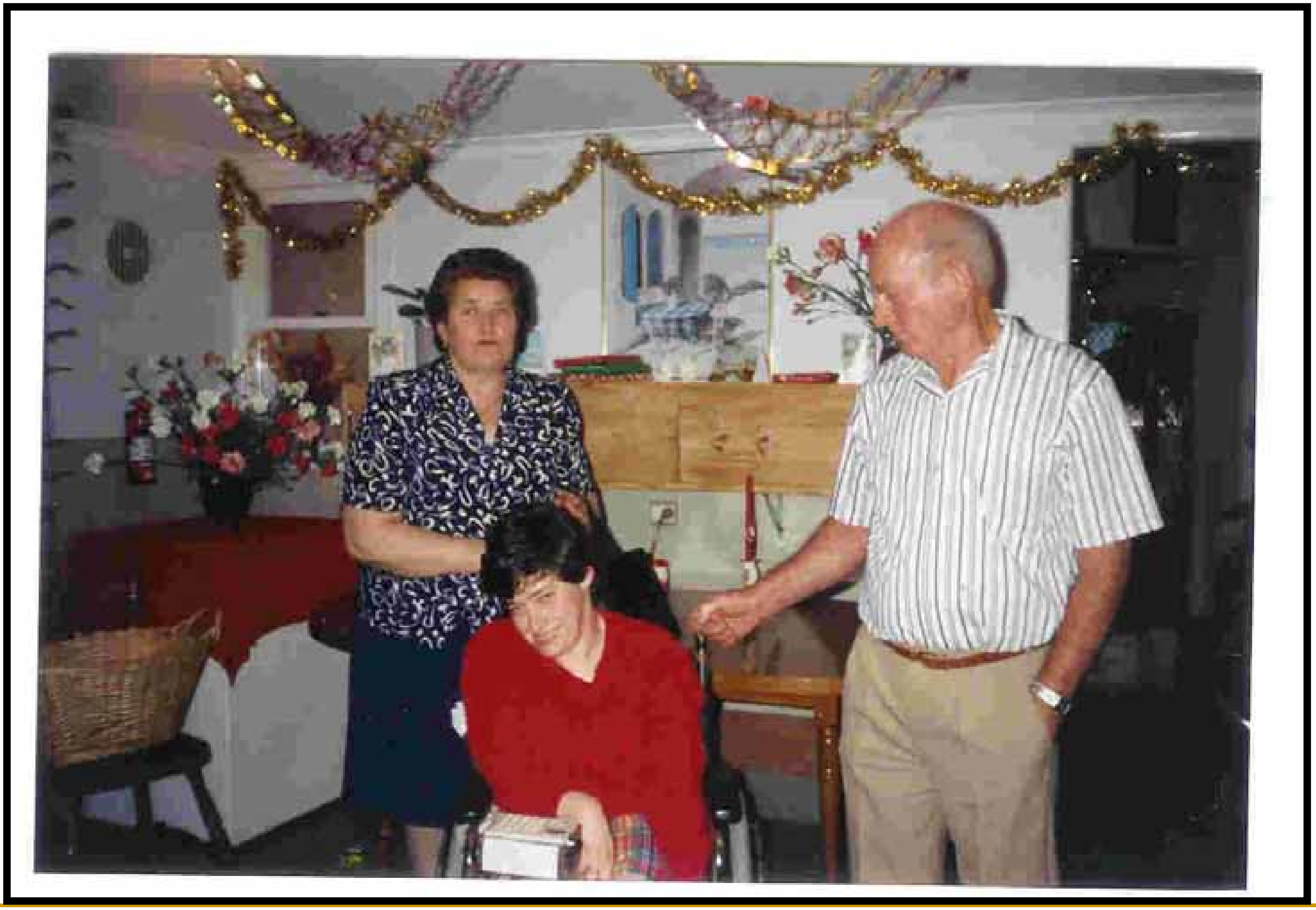
I started to bunny hop. I bunny hopped everywhere, even on concrete. This horrified Mum, who always kept me spotless.

I spent a fair bit of time having physio, in the hope, I would walk in some way. This is a photo of me in plaster.

But, even back then, I knew my own mind, and thought, If I show that I can do things, people would accept me as a normal child.

I slowly realised, not everyone saw life the same way.

The support of my parents has always been extremely important to me. Equally so, has the support of my brother, five years older.



My brother was my first role model. He was the first person who understood my speech.


„Rex"

I tended to cling to my brother, when I was a child. This didn’t suit him at times. Thinking back, I must have made parts of his life quite difficult, because I wouldn’t let him out of my sight.

I realise, that my childhood and upbringing, was quite different from other children.

There were very few times that I played with the kids in my street. I always seemed to be watching from a window, or from my front yard. It never occurred to me that I could join in. Well, not really.

I sometimes ventured outside with a neighbour, who spent some time with me. But it was seen as a game of doctors and nurses. Guess who the patient was?

I recall an incident playing with two of my neighbours, who left me sitting in a corner, while they discussed the outcome of the game we were playing.

At first, I accepted this, and sat quietly. As time passed, I realised they had forgotten me. My part in the game wasn’t important to them. My Mum noticed, so she came and took me inside.

When my neighbours came to see where I had gone, I let out a scream. Mum and I told them to go home, right away. That incident, and many others, showed me how many people perceived my disability.

My childhood wasn’t sad though, I attended school at Yooralla from 1968 to 1979. I participated in many different activities, as well as gained an education.

Looking back now, I realise that what I learnt at school barely skimmed the surface. I sometimes wonder if it was because of my Complex Communication Needs.

Did I miss out, because I could not quickly answer questions in class? Was I overlooked, because my words took ages to get out?

Like any girl, I had my fair share of teenage angst.

However, due to having complex communication needs, it was very difficult to express that angst.

I recall talking to a Counsellor at school, about my teenage problems.

Unfortunately, the session wasn’t private, as the counsellor could not understand me. She needed Mum, or someone else to translate what I said.

Needless to say, our conversation was not as deep as it could have been.

Communication is the key to a fuller, more meaningful life. I’m sure of this.

Technology helped opened the door to the wonderful world of communication for me. My first talking device was a Canon Communicator. It gave me so much confidence.


Canon CC-7S
CANON COMMUNICATOR
POWER
BUZZER
CTRL
MSG
SOUND
UP
LW
FIGURE
1/2
1/4
3/4
1/8
3/8
5/8
7/8
7
8
9
4
5
6
0
1
2
3
Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M

For the first time, I could type what I wanted to say, anywhere, and at anytime, to almost anybody. People started to listen.

They realised that they didn’t need to be a rocket scientist to communicate with me.

I participated in a women’s writing group, and successfully completed two writing courses, using my communication device. Life was fantastic!

However, the wonders of technology have not taken away my disability. I still can not speak clearly.

There are times that I keep my thoughts and words to myself, just because it’s easier. How many people, who have Complex Communication Needs, do this, I wonder?

In recent years, my family have gone through some difficult periods. Despite that, I always try to smile, and get through, as best I can. Do you remember the Monty Python saying. Always look on the bright side of life!

Sometimes, that’s easier said, than done, though.

One evening, at the end of October 2002, my Mum had a seriously bad fall. Unfortunately, that day is etched in my memory!

I'll never forget trying to tell Dad, that something was wrong. My speech failed me, but somehow, he got the message. It's amazing how much those who know, and love us, are able to understand us!

Mum was taken to hospital, with concussion, and a dislocated shoulder. Dad and I, managed to organise a place at a respite house for me. At other times of crisis since then, respite just hasn't been available.

My poor Dad had some difficulty making himself understood. Therefore, navigating the system, was quite a challenge. Together though, we managed.

Luckily, I kept my emotions, under control, as did Dad.

I was used to going to respite, however, this being the first time as an emergency, I was very anxious. My stay ended seven weeks later, but things at home never were the same.

My Mum wasn’t able to care for me, without help. Care attendants started coming in, morning and night. Mum found this extremely hard to accept. (Mum still struggles with carers coming into our home).

Christmas 2002, is one I’d rather forget.

I became quite depressed, due to the many changes in my life. It felt like my life had been turned up side down.

Mum's shoulder worsened. My sister in law lost her battle with Multiple Sclerosis. We all resigned ourselves to the fact, that life, as we knew it, would never be the same.

Luckily, at that time, I was introduced to a Psychologist from Scope. He had the time, and patience to guide me through a tough transition of change and loss.

Of course, as with any disability service, there were considerable time and funding constraints.

It really helped to have someone who I could tell my problems to, without feeling guilty. I used my communication device a lot. I also showed him some of my writing and poetry, to explain myself further.

My Psychologist has specialised skills in counselling people who don’t use speech, to communicate.

It would be very difficult to receive Psychology services from someone without these kind of skills.

He understands that my life experience carries with it, specific challenges, and is extremely sensitive to those. He also understands, that counseling someone who does not use speech, requires more time and specific techniques.

Unfortunately, Psychologists like him, are few, and far between.

As far as having communication options, I feel I am one of the lucky ones. I have several communication systems, that allow me to communicate affectively. I also have many willing listeners. I feel very fortunate.

Not everyone, however, who has Complex Communication Needs, has an adequate communication system, to enable them to be heard. I wonder, how do these people, keep their emotions under control?

The Bridging Project is a wonderful initiative of Scope, and Monash University’s, Center for Developmental Disability Health Victoria

Dr Nick Hagiliassis PhD, Research Coordinator, Scope, describes the Bridging Project like this:

“The Bridging Project aims to progress the knowledge and resource base, to ensure that individuals with complex communication and mental health needs have access to quality services. The key message has been about the inclusion of people with disability, in particular those with complex communication needs, in mental health services. Further information on the Bridging Project (including access to resources developed through this initiative) can be found at: www.bridgingproject.org.au/”

I believe, it has the potential to make a significant difference in the lives of people like me, who may not be able to express their thoughts, and feelings as well as others.

Mental health is a human right. It is not something that is reserved solely for people who communicate using speech.

The Bridging Project is working toward ensuring that everyone, particularly those with complex communication needs, realize their right to mental health.

To conclude, I would like you to read my poem entitled, Tapestry.

I hope you enjoy it.

Thank you.

TAPESTRY.

Is life for me so different?
Of course it is.
But different to what?
Different to whose?
How is it not the same?

I breathe the air everyone does.
I've learned painful lessons.
I've experienced love and loneliness.
I become angry.
and feel foolish as everyone.

I've been hurt, and caused pain
to the people I care the most for.

I've shed tears in the middle of the night,
over the smallest and silliest memory.

My life is just that.

Life .

Every experience you have,
every good one,
every bad one,
will sew, your own tapestry.

Lay your unfinished tapestry next to mine, and,
compare it…

Is life, for me, so different?