REPORT BY COUNCILLOR JUDITH BLACK
TO
PRODUCTIVITY COMMISSION

DISABILITY CARE AND SUPPORT

IMPROVING THE SYSTEM

ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY

- The roles of service providers, people with disabilities, their carers and governments

My intervention as a single parent (& carer) or admission

to this scene was by way of my daughter being knocked down by a vehicle on Magill Road, Tranmere on 2nd July 1982 on her way home from Magill primary school.

At the time I was running a new company (which I discontinued one or so months later at a loss, as my daughter needed 24 hour care), living luckily with a parent in a big home on Magill Road Tranmere, with a huge support group of family, organisations (to which I belonged) & friends; with the very strong support of Dr Donald Simpson & his team, it was like starting a uni degree venturing into this unknown world.

WHO GETS THE POWER? I read in this paper that 'perhaps more control could be given to patients and carer' it must be remembered that this group of people are quite often experienced in their career path and quite able to make decisions for the good and service to their child/patient.

In 1971, I found that once the line or link to decision making was made that the process was much smoother and change could be effected. Recently in 2010 with an aggravated chronic problem exasperated, I found that people in a similar situation or friends were of quicker expert help than the ‘power’ organisations in authority. Now, this is no reflection on those organisations rather a lack of funding on the part of their authorities to appoint more assistance to reduce waiting lists. In 2008, while my mother (whose carer I was) became progressively more ill and frailer she waited for a place in a program that would give her more assistance and rehabilitation & she died in April 2009.

WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?

- **HOW COULD A SCHEME ENCOURAGE THE FULL PARTICIPATION BY PEOPLE WITH A DISABILITY AND THE CARERS IN THE COMMUNITY AND WORK?**

My experience is that this group of high achievers do not need encouragement to look for work; they need actual jobs offered to them, volunteer or paid. As someone with a chronic illness I have served the community in a volunteer capacity for 12 years, before that I worked in various industries and government since I was 15 years old. My daughter

applied for hundreds of positions with a Bachelor of Social Work, volunteer experience and work experience to no avail. Currently I am aware of an experienced person working for a local volunteer organisation continually overlooked for a position in the group.

I have endeavoured to answer the Statements and key questions directly first. My personal submission I will write tonight. To outline, I cared for one of my aunts for 18 years, my daughter from 1982 until 1990 & my mother from 1995 until her death in 2009.

Yours sincerely
Judith Black

My Aunt

With my aunt, I helped her to budget, manage her capital & expenditure, withdraw her pension, pay her accounts, took her shopping each fortnight and delivered the goods; I was on 24 hour call if there were problems but mostly, aunty ran out of bread and milk no matter how much was in the freezer. One daughter was married with a young family and the son lived in Sydney & Rome at the time. Aunty lives in residential care & has suffered mild dementia

****

My daughter received a severe closed head injury at the age of nine. The taxi driver who covered her with his coat after the accident is a City of Campbelltown JP. A friend of the family, a double certificated nurse said to keep doing things as if Jane was awake, so we read stories that she loved, brought in her Tai Kwan Do clothes & dancing music, her friends from Magill Primary, the teacher and headmaster all visited, her room had cards all over the walls; Jane was in hospital for 5 weeks and came home still in a coma from which she awoke after a week or two to learn to speak, walk, laugh & smell all over again. My father lent me money and I employed a daughter of one of Mum’s friends from Athelstone to take the day shift and I took the night shift. Janey rarely slept. Whenever she was awake we treated the time as day and filled her days with learning & practising all those normal every day things that she had forgotten or lost. Some institutions where she went as a day patient wanted us to keep her back to re learn steps of schooling that she had missed. We discovered that every time a flow chart was prepared of what was expected of Jane, she usually outpaced the charts. Her treating lead doctor now a Professor retired said that as long as we could keep up with her she would continue to improve. We never admitted tiredness. After 5 months, with constant interference in our lives by the doctors from the insurance company, I decided to return to Darwin where Jane was born as I had contacts there (I had been Secretary of St Mary’s Primary School Committee). The nuns said that they would allow Jane to attend a normal class which is what we had wanted to do in SA but were unable to by the school (Magill

Primary, Regency Park & the Education Department). We did return to Darwin and Jane attended St Mary’s School and later St John’s where she learnt typing and with assistance from I think Lion’s (her father was in Lions) Jane received her first typewriter, a Casio. This enabled her to keep up with her lessons. One of Jane’s residual problems was a tremor in her right hand which makes writing in a normal legible script almost impossible.

We swam and walked and played and Jane improved immeasurably. However the insurers appointed a doctor from the ‘old school’ who wanted to put Jane on epilepsy drugs simply because that was a possible outcome of a sever closed head injury. I maintained that she had no symptoms and that this intrusion was unwarranted. I moved in April 1983 to an Ashram on the east coast of NSW where Jane was given yoga lessons daily, contact with the outside world was minimal and we saw no insurance doctors for three years. During this time Jane’s emotional clinginess changed to that of a normal young girl, she lost the weight that she had put on toward the end of 1982, her gait became normal and she could run, climb & swim like any other teenager.

In 1986, Jane left to live with her father in Darwin and later her grandmother in Adelaide. During these years we often saw that we could do something to assist Jane become more independent but were inhibited for lack of funds. Mum sold my engagement ring for basic necessities being unable to obtain funds through the Public Trustee or the court case. The court was waiting for Jane to grow before considering an award. Dr Simpson obtained a place for her at Pembroke with head mistress Di Medlin’s assistance and over two years Jane competed her Matriculation to go on to study Liberal Studies at Adelaide Uni. In 1973, Jane was awarded an amount, friends advised us to hold out for more however we accepted the amount with no recompense for myself or my mother as we didn’t have ‘jobs’. Then we had to fight for the right for Jane to manage her own money. Family recommended a psychologist who assessed Jane as being able to manage her finances. We invested it wisely & purchased real estate in NSW. Jane went to study Drama in Leichardt NSW and later apprenticed herself to a clown in Sydney, where after numerous adventures I joined her. In 1995 we returned to Adelaide to help care for my mother who had been given three years to live. Jane enrolled in a Bachelor of Social Work which with a note taker Anna Williamson, was later completed in 2000.

When Jane was looking for a job, HIH collapsed and it was difficult to find employment or insurance as a disabled person. Jane turned to her experiences and with the help of an Agency developed a ‘one woman show’ which continued to receive invitations for performances from all over the world. Pat Rix of Tutti Ensemble fame rewrote the previous show which gained a Season at the Para Olympic Arts Festival in Sydney in 2000. Jane later toured & had shows in Vancouver, Los Angeles & Adelaide. With these Shows Jane received payment for performances only and had to find sponsor ship for travel expenses and rehearsal, to appoint a Director &

accommodation. Local Lions, Rotary, Alfresco's, Soroptimists, Italian Airways and many others gave support.

During the years, Jane looked for jobs and when none were forthcoming she studied Auslan, Massage Therapy & other subjects. In 2006 she became a Councillor with the City of Campbelltown. In 2007 she had a child, a handsome boy who was not bothered that one side of her body was not as strong as the other and came normally just the same. She became the Chairperson of the Disability (later Accessability) Advisory Committee of the City of Campbelltown which has several independent members and completed an Audit of Council buildings, footpaths, tennis clubs & Council Reserves which gradually are being implemented.

Jane at times still speaks slowly when she is tired * on occasion can limp but if you are interested in talking to a passionate person who has assisted people with a disability in many ways over the years to continues to work hard for her community, you have found a person who will always tell you directly without guile. Jane learnt to manage her compensation & has more than the equivalent of the amount that she was awarded. Along the way she has achieved a Certificate of Commendation for 'Shine On' Awards, her story was one of those used to launch fundraising for the Chair of Neurological Research at Adelaide University, was a finalist in the Young Australian of the Year Award in 1999 & received one of three Community Services Award along with Mia Hanshin, received standing ovations and curtain calls for her one woman show in Australia & internationally, invited to perform in Stratford on

Avon and received an Award for encouragement in the John Legoe Local Government SA Branch 2010 Award.

My mother

In 1995, on returning to Adelaide to care for my mother who at the time lived with my younger brother, my duties were mainly to withdraw the pension and pay accounts as directed and purchase food. Occasionally I found people to assist mum. Around 2005 Mum had a fall in the shower and lost her ability to walk, although in great pain she learnt to transfer with the aid of equipment until she could manage on her own again. In 2007 she moved into my place wheelchair bound and I went to live with my daughter in the granny flat. Mum was a great cook, mother and Nanna & spent many hours preparing food for many family functions. Gradually however she developed vascular problems and her legs became ulcerated. Mum wouldn’t have an operation to remove half her leg & spent time every day with a nurse changing her dressing as various infections made the ulcer painful and it grew bigger. This meant that she felt unable to have a lot to do with her great grandchildren not wanting to spread infection, we all grew used to washing our hands before and after visits long before the spread of swine flu made this a necessity.

Myself

Recently a chronic problem flared up which inhibited my ability to walk without severe pain. I had to learn to manage the pain and realising that I needed to keep active, I bought a Shop rider or gopher, a folding wheelchair & a walker. The wheelchair is needed at night to take away the danger of falls

& consequent set backs. The gopher allowed me to continue as Treasurer of a local Community Centre, to keep active & keep up with constituent’s enquiries. I use the walker now during the day to walk my 10,000 steps and can walk unaided in familiar places.

When I was confined to the wheelchair (a manual one) I decided to go around the block to keep up some exercise & resilience. I found that current footpaths are not made for people who wish to propel themselves. I believe that warrants for footpath construction have been developed for a previous lifestyle that of an era where Carers propelled patients and could manage the camber of the footpaths which slope to the road to assist water carriage away from private property.

Pram ramps also slope with raised dots for the blind. It is impossible for a reasonably strong person to manually propel a wheelchair up one of these latest ramps. I say latest because they a newer than most around my block. I had to leave the safety of my wheelchair to ‘walk’ the chair up the slope, with the brakes on, like a walking frame. When my daughter and I visited the local zoo which was only recently redeveloped (with the advent of the pandas), the footpaths leading in and within the zoo rarely have places to manually propel a wheelchair. The right hand needs to constantly restrain the right wheel to prevent it directionally turning to the road edge of the road, an inheritantly dangerous situation. The left hand needs to direct the wheelchair forward. The forward slope for the new front entrance (so making an independent person reliant on assistance) has no guided rail for a wheelchair bound person to enter the flat part leading to the pay- in part. Generally I proceeded diagonally. There are also no signs asking patrons to take care for the wheelchairs. Within the zoo again the pathways slope to the edge. Slopes generally supposedly to enable wheelchair bound or walker usage persons to negotiate paths to buildings are generally too steep and require diagonal perambulation zig zagging up or down the path. I have had it reported to me that the slope at the Wine Centre in Adelaide ‘kills’ so I have never gone that way, preferring to be dropped off at the front of the building.

Able bodied people do not I believe test run these so called conveniences, i.e. they don’t put themselves in the shoes of the user groups’ preferring often to fit the pram ramp in between services, without due trials. They also obstruct disabled conveniences thoughtlessly e.g. an electricity box obstructs the footpath around the south western corner of Marian Road, Firle. It is almost impossible to access the push button for the lights (which also have a blind sound accessory) for crossing Marian Road, Firle to Glynde side of the Road. Gophers can enter buildings and staff in banks allows them, staff in Council buildings allow them & their passengers to enter but I understand from a constituent to deter pedestrians that the new tramways have a barrier to wheelchair bound passengers attaining the platforms (I saw one of these in the city not looking wide enough for a chair to enter.

Entrance Doors often are overly heavy even for Disabled toilets, our Council I am happy to say as an automatic opening door in the Function Centre

On the whole though since I have been overcoming these latest challenges in my life, I have met many kind and thoughtful people, holding doors mostly open for my passage & a Council that has put ‘money where its mouth is’

Judith Black
Councillor City of Campbelltown May 1997- November 2010.
Deputy Mayor 2003-2005
Mother, grandmother, step-great grandmother, aunt, sister.