

PRODUCTIVITY REVIEW DISABILITY CARE and SUPPORT – PUBLIC INQUIRY CR JANE MURAS, CITY OF CAMPBELLTOWN

I must first say that I have tried to answer these very complex questions but do not feel that I can answer them fully and have based my answers on my own councillor and personal experience.

MAIN POINTS:

- 1. Make people with disability and their issues “Visible” in the community.**
- 2. People who apply for the scheme who have disabilities need additional support.**
- 3. There is a lack of accessible information.**
- 4. Funding based on need instead of categorization of disability.**
- 5. There needs to be ‘value adding’ concept to disability as an issue.**
- 6. Applying for jobs and feeling like a ‘second class citizen’.**
- 7. Disability Awareness training in schools and in the community.**
- 8. Teaching resilience and self esteem to kids with disability.**

BACKGROUND

My name is Jane Muras. I am a mother. I am a councillor with the City of Campbelltown Council and was elected to represent the Woodeforde Ward of the Campbelltown Council in 2006. I am a woman with an Acquired Brain Injury as a result of a car accident in 1982 crossing Magill Road. I was 10 years old and walking home from school with friends.

In 1997 I went to Sweden to pursue a theatre exchange with the Moomsteatern (theatre for people with disabilities) and in 1999 to Los Angeles for the International conference on arts and disability to investigate the transformative power of theatre in the lives of people with a disability. I am mother to my 3-year-old son and I am stepmother to 3 teens also a step-grandmother. My son was born in my first year on council. I have tried successfully to manage my family life as well as my council duties.

I have performed in a one-woman show at the Paralympics 2000 in Sydney and then toured it internationally (Vancouver and Los Angeles) and been invited to perform at a festival in England. I have performed it here in Adelaide as well. I have sung with the Tutti Ensemble (Mixed Ability Choir) and been involved with No Strings Attached Theatre of Disability as well as many other creative outlets. I have been on the board of directors for Arts in Action.

I have received support throughout my life from friends and family local businesses and concerned organizations. I have received financial support and typewriters from various community groups such as Lions, Rotary, Soroptimists, Kiwanis and Zonta International as well as various local businesses within the Campbelltown and wider community. I have recently been presented with the John Legoe Award in the Encouragement tier from the Local Government Association of South Australia.

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I wanted to stand in the election because I felt that I did not see and had not seen many programs and services for people in my local community. My passions in life are around making facilities and equipment accessible so people can engage with the community in which they live. By dismantling architectural barriers we can learn from each other.

Specifically, we should have at least one fully Disability Discrimination Act compliant playground to be used by all in this council area. We still do not have this despite my efforts. Currently we have playgrounds altered to make them accessible to people. I felt as though I didn't see the word "disability" used in policy. Our library and council chambers, at the time, did not have disability toilets and the disability toilets that were labeled as such certainly did not meet size requirements for ease of room to move. Accessibility was an issue for some people.

1. Make people with disability and their issues "Visible" in the community.

Cr Jill Whittaker and myself sat down and came up with a series of questions that tried to identify populations of people with disability in the area to get something happening in this regard. After finding out that a substantial number of people in our community had a disability, in varying capacities (Approximately 8000 in a council population of approximately 48 000), I set about to address this situation. I lobbied the council to establish an Accessibility Advisory Committee. This was successful and the new Accessibility Advisory Committee consisted of myself, Cr Judy Black, Cr Jill Whittaker, various people with disability from the community who are local residents wanting to make a difference. Some time later Cr John Kennedy joined. We have a great little Accessibility Advisory Committee to Council from a variety of backgrounds and the skill base is useful to draw from. We have lobbied for rolling access audits on council facilities.

As I am a mother with a small child, babysitting can be an issue when attending council or committee meetings. Trying to pay for babysitting for Council or LGA training, which amounts to approximately \$100 per 5-hour session or at least \$60 for the first 3 hours, is prohibitive when on the Disability Support Pension. Council does reimburse for some specified training but there are many other community events that I just can't go to if my partner is unable to baby-sit.

Who should be in the new scheme and how? Who is in need of additional support?

2. People who apply for the scheme who have disabilities need additional support.

People who apply and have disabilities need additional support. People applying need assessment and a history check for authenticity. What I regularly hear about from other people is there are categories of people with disabilities who do not 'fit into' already accepted models. They therefore are outside the accepted funding models, and not fitting into the criteria means there is no money to get what they need.

3. There is a lack of accessible information.

The issue is that so many people think that they are ‘time poor’ and as a consequence of this they may feel overwhelmed and unable to seek information beneficial to themselves. I think that information needs to be available in different formats, for example: Brail, different languages, comics, radio and so on. It should not be only available in written English.

The information has to be presented in a fun way and in a way that is going to capture people’s imagination because I have heard from many people that they have been to so many enquiries and talk fests and nothing actually results from it but another report, which is filed away and rarely looked at again.

Carers also need support.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

4. Funding based on need instead of based on categorization of illness or disability.

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

Each assessment could be a case-by-case basis. Every disability is somewhat different and the needs are different.

5. There need to be a ‘value adding’ concept to the issue of disability.

There needs to be a value added to this group. What is their value to society? What is their productive capacity? And what do they have to contribute? These are the questions that need to be asked and answered.

There needs to be an independent body or panel, following a charter that can allow people the opportunity to appeal. People need to be able to feel that they can take the opportunity to appeal and not feel as though that by complaining about a service they will be put in the ‘too hard basket’. The threat of the label ‘shuts people down’ and it is emotionally taxing. Labels are pertinent and threatening to people so they will not want to contribute information if they feel they will be penalized for it.

My grandmother frequently told me that she would not speak of an oversight or something she was not happy with in an attendant nurse because she was afraid of the repercussions from doing so. She thought that they might be upset with her. I hear this also from some people in the community who need care assistance that they will not speak of some thing that is bothering them because ‘it will do no good’ or that there may be repercussions in lack of care for the particular person.

How should the amount of financial support and service entitlements of people be decided (and by whom)?

In my experience it is relatively easy to be able to get a voluntary job. It is easy because nobody has to pay you. From an employer's perspective insurances and liabilities need to be paid for employers. I feel this may be why not all businesses are able to employ a person with a disability.

On completing my Social Work degree at the University of South Australia, Magill Campus in 1999, I was enamored with my own personal view that I was going to change the world to be a better place. I wrote numerous job applications in the process of getting a job, which after my training I believed was available to me. Naively I pursued this option believing there was equal opportunity.

The Adelaide Central Mission was a possibility, although at the time, I was involved in Theatre and went to the Paralympics 2000 in Sydney to perform my one-woman show entitled 'Bananas'. Through my performing and my own theatre school I was going to change the world.

6. Feeling like a 'second class citizen'.

Disillusioned with the options open to me through job applications, I was then to change the world to a more inclusive and accepting society by forming my own theatre school to hold classes for people with disabilities. I ran into the business insurance 'wall' that, I felt, acted as a barrier because of my disability and was emotionally taxing on me. The experience of trying to get insurance for my theatre company left me feeling like a **'second class person'**, even though the insurance agent that I encountered assured me that I was not. I certainly investigated the disability complaints avenue after that happy and uplifting encounter the outcome of which was to direct the agent to a course on disability awareness. I am not sure how affective that may have been to the person concerned.

What kinds of services particularly need to be increased or created.

7. Disability Awareness training in schools and in the community.

There needs to be more disability awareness training programs in schools. One of the Campbelltown Accessibility Advisory Committee members regularly phones me complaining that the high school kids on the bus tease her because of her disability with derogatory names such as 'spastic', 'spazzo', 'retard' and 'mental'. Such names can be taken as personally hurtful and are usually used for that effect. It shuts people down. 'Bullying' on buses by high school kids, on the way home from school was one of the reasons I originally got off of it to walk home and consequently my car accident occurred.

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Such names can also be used in popular songs that are listened to by many teens. I have become aware that the terms such as 'spastic' and other derogatory names are used as common slang words used by teens. Perhaps times are changing and in an effort to normalize these words some young and not so young people use them even though many people can still perceive them as hurtful.

Some members of our accessibility committee agreed that affordable housing for people with disabilities is a need and its availability should be increased. Perhaps local councils can assist in this regard. Support services should be determined by the people with a disability or the primary carer of a person with a disability because these are the people who know what they need. They also need to be affordable.

My mother was recently in need of purchasing a scooter (\$4000 approx) and a wheelchair (\$569 approx), which is way out of her price range as she is on a fixed income. It was only possible for her to get this equipment because she could receive an aged pensioner rebate. The additional weekly payback is still a stretch for her on her weekly budget.

As a councillor, what is reported to me is that it rarely happens that an officer in charge comes to check on people receiving support services so, that may be a role that people could fulfill. As a councillor, I have gone to visit people to help them and been shocked to see the state that they are living in inside their homes. On one occasion I went visiting a lady who was immobile in bed, and her carer, who spoke with an accent which was difficult to understand, told me that the lady received 3 hours of care a week and that nobody came to check on this elderly lady at any other time.

Campbelltown Council held a disability forum towards the end of 2009 to establish the needs of people with disabilities in the area and the result of that was that people felt there was not enough in the northeastern region for people with disabilities to occupy themselves with. They had to travel out of the area to occupy themselves. Cr Black and myself immediately set about making sure a local hall was available and accessible for such purposes. So Campbelltown Council, in association with DisabilitySA, got together with the intention to start a Disability Learning Group; it will be named by the people in the group and will center around a chair based exercise class, shared lunch and presentations from groups of interest in the community. This is one tactic that the council is starting to address this issue. I think it is only by making the issues of disability visible through such mediums as theatre, music, singing and art that we can keep disability in the forefront of peoples minds. The reality is that we are all mortal.

Council also has an idea for an end of year Parade which is something creative people can work towards being involved in from their respective community group contributing to a whole event. The parade idea gives people the chance to exhibit and add value through entertainment activities

How could the ways in which services are delivered – including their coordination, costs, timeliness and innovation – be improved. Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

8. Teaching resilience and self esteem to kids with disabilities in schools and the wider community.

Education. It's so important to have a sense of resilience and believe in yourself. It is important for kids to learn to believe in themselves and be encouraged to try. Young kids may not see barriers. When I was younger, the world for me was my oyster and it was up to me to enjoy and achieve what I could in this life. I have a loving family. They brought me up with this belief in **encouragement**. My mother encouraged me to be all that I could be and wanted to be. I think this is an important element to instill in children. Self-esteem is all-important when learning to live with life's challenges. Life can be challenging. I have pointed out earlier in this document just a few. Overcoming challenges are like jumping over hurdles or muddy puddles. Remove the barriers to participation in society. Remove the architectural barriers to engaging with society and perhaps this will affect attitudes.

Thank you for your consideration.