

I am Okay until I am measured by the perceived norms

The context of this paper is the lived experience of Disability in New Zealand. . The policy, laws and media references referred to in the paper are all of New Zealand content.

With the combination of conditions I live with, you would expect me to have an Intellectual Disability but I do not for some strange reason and it is this ambiguity and its accompanying inelegance that gets me into trouble.

Employment

The Human Rights convention on the rights of the disabled which has been signed by the New Zealand Government says all disabled people have the right to paid employment. My lived experience proves otherwise and it is this I wish to present and the difficulties employers have in employing me.

When I was 17 I applied for a job in the Central Sterilisation Unit, thinking “yes I can do this job”. But at the Job interview I discovered I could not open the surgical instruments consistently. I did not get this job.

When I was 18 I applied for a job in a school kitchen as a cook’s assistant, part time. I was successful in gaining employment. My role was changed to give a more structured working day to accommodate my disabilities because I was honest and reliable.

The discoveries in this role where that I could not work and talk at the same time. Also the cook could not understand why I could not chop beans straight into a pot. I had to chop them on a board. The staff also noticed that I manoeuvred the big pots differently to the way they did it because I could not always make my body do what I wanted it to do. I had this job for 1year.

When I was 19 my mother had heard a radio interview about the rehabilitation league and decided that they may be able to help with getting me a full time job. They could, but I was expected to do things without knowing why I was doing them. The rehabilitation League also was not used to dealing with people who could think for themselves.

When I was 20 I applied for a job caregiving in a rest home. I held this job until my mother died and my body slowed right down. I was on a sickness benefit for 18months.

When I was 22 I applied for a job as a telephonist for an insurance company. At the interview the company thought I might find the role boring because I was very intelligent.

Two years into the role I had a change of Manager and the new boss started questioning why I was employed, because his opinion was that I was not pronouncing the ends of my words. I thought this would have been picked up in the first interview if it was an issue. I went up to Human Resources and one of the PA’s saw me on the

way very upset, so she intervened and explained the situation to the Human Resource Manager.

While learning to use the switchboard I went very white one day, because of brain over load. My immediate colleagues thought it was a stroke and I found myself educating them about my disabilities.

I had a SPELD report done when the company wanted me to move up scale. This was because my disabilities prevented me from doing what they wanted me to do and it gave the company a better understanding of my disabilities. This played directly into the things that are affected by my disabilities. While working for this company I read a CCS magazine article about a conference on Dyspraxia and thought this reads like some of the things I have had difficulty with, so I went to the Dyspraxia Association conference where my suspicions were confirmed and people told me that yes what I was describing, was classic developmental dyspraxia.

I was made redundant from this company when I was 30. The company could not employ me anywhere else because of how my disabilities played out in the work place. The switch boards were removed and the company moved to new telephones which were answered by the call centre. To work in the call centre you had to be able to multi task and write letters, without the help of other people.

All of the above work issues I had to educate people about, as they were issues other people wanted to know about and how they arose. I did not have supported employment people educating, advocating or sorting out issues for me. I did it on my own I also got Jobs on my own.

My thesis is Yes disabled people have the right to paid work in the work force, but only if they can do what an employer wants, and do it the way the employer wants it done. Today's work force has changed as well with the expectation that every body can type at a reasonable speed and multi- task doing several things at once and not making mistakes when interrupted.

Palliative Care

In 1999 about the time I was made redundant, there was a news paper article in the World section of the Dominion Post about a person in Switzerland with Diabetes Arthritis and Depression who had committed euthanasia to die. The response from the New Zealand media was this person should have had palliative care. However in this country you can only get palliative care if you have a terminal illness. None of the above conditions by themselves are ones you are going to die from.

If you look up the meaning of palliative in the dictionary it simply means to "relieve and support where there is no cure". There is nothing at all about dying. In this country the Medical profession and the hospice movement have taken the term palliative care and changed the meaning to only apply if you are dying from a terminal condition. This meaning is also applied to the Ministry of Health funding criteria.

The other Model that shaped my thinking was the Whare Tapa Wha model which is the work of Professor Dr Mason Durie constructing the concept of the Physical,

Spiritual. Mental and Whanau all being interconnected and needing to be healthy and present to make a whole person.

My Philosophy “Palliative Care for the non-terminally ill”,

I then reflected on my own situation and came up with a term “Palliative Care for the non - terminally ill”, .My philosophy on palliative care for the non- terminally ill is based on the Spiritual Emotional Physical Social well- being. These needs being nurtured to create the optimal quality of life for those who with permanent conditions that they will not recover from or die from.

In 2000 I made a decision to do the things I could do rather than trying to do the things I could not. After doing the “In Support of the Older Person Qualification” and the principal nurse saying they were happy with my care giving skills, but only in a voluntary capacity, because of how my disabilities play out in the work force means I am too slow to be paid an hourly rate for the work I do. Work and Income then sent me to a work track course. However everything I looked at work wise, my disabilities got in the way. 3 Doctors suggested that I go on to the Invalids Benefit. What I did learn from the WINZ course was to dress for success.

My self- developed Palliative Care Plan was to do more Tuesday morning workshops at Vincent’s Art Work Shop to increase my art skills and create my own style. I have with me a hammer made out of sellotape, some brooches I have made, and some mono prints. Attending Vincent’s Art workshop on most days gives me social inclusion, where I meet other people, and talk and work in an environment without the pressure to have to meet any performance standard but my own.

I also do some voluntary work at the national office of the Interchurch Council for Hospital Chaplaincy, with their monthly mailouts. I also worked at the Forest and Bird Society until they restructured and did not need volunteers to do what I did for them. This work also caters for my social needs and enables me to keep in touch with places of work.

I asked my GP for a referral to a physio therapist to learn how to stretch the muscles in my lower body properly. The GP said there are drugs for that but did not want to put me on them. I said I wasn’t thinking of drugs. I discovered at this appointment that my hips were stiff because of Cerebral Palsy. The physio suggested I go to the spa pool more often.

I have counselling which is more like supervision, every three weeks which helps to deal with the emotional pain which will always be there because of the difference between my intelligence and what I can physically do.

I also used to go to the Meet the Writers a night class at Onslow College until the adult education funding for this course was cut. I continue to try and find reasonably low cost courses that feed my intelligence i.e. through Victoria University Continuing Education, Spiritual Growth Ministries Trust and the Kapiti Workers Education Association.

In developing a Palliative Care Plan you need to work to a person's strengths and think about what makes a person resilient and give the person choices of things they may want to do.

My Palliative Care Plans often conflict with Work and Income policy that paid work should be the only outcome for people on an Invalid's Benefit. For example Case managers at WINZ think doing voluntary work means you should be able to find paid work, doing what you do voluntarily.

I went on Wanganui Summer School course in 2006. As a result of that my Case Manager at the time decided to set some employment goals with me. I was referred to a careers coach. They said I could "think" so their option was for me to do a business and administration level four NZQA qualification. The only problem was it was not thought through from the view point of my disabilities. To get the Qualification you had to be able to type at 25 words per minute. I type at 11 words per minute and have done since my fourth form at College. The Cerebral Palsy interferes. I had to get 100 per cent on the computer test which I never could achieve. Large chunks of this qualification were impossible because of my specific learning disability.

Training providers are not set up to deal with people with multiple disabilities. So there was no way I was going to gain this qualification.

I was then enrolled with Emerge Supported Employment. The Case Manager said it would be good if they could get me a full time job, but this agency did not understand developmental dyspraxia. I got the Emerge worker to talk to the principal nurse I had worked for previously who was happy with my skills, but only in a voluntary basis so the Emerge worker could understand the issues I face.

I also enrolled with "Temporary Solutions" who were able to match my skills to short term work i.e. being paid to attend meetings and being on interview panels, but it had its funding cut when the government changed direction.

When the Paula Webstock enquiry which looked at invalids sickness and domestic purposes welfare benefits, was presented to Parliament and political statements made, I wrote this poem

To walk on water
Make the impossible happen
The sparkles drift
To carry the impossible
To only fall over time and time again
Until the fairies carry one through the water
Beyond the pain of not achieving
Or fixing the deficits that prevent
But create havoc for work and income
Who want the impossible?
The sparkling
May be it will be a relief
To entrap the impossible

Author Rhonda Swenson

In working to my strengths some opportunities for short term work come up but not long term sustainable paid employment options.

For researchers some research done around the reasons why people are on the Invalids Benefit and what they do with their time told in narrative, may well dispel some of the stereotypes being portrayed in the media, and give government departments solid evidence to work with and deal with the issues I have raised, which are complex.

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