This submission is in letter-form, I hope you don't mind. It would be good to have this submission finally acted on because I have written it so many times before to no avail.

Rightly or wrongly I consider myself unique having lived with severe Cerebral Palsy all but the first few months of my life, having worked in the disability field, having been a form of carer to my ailing mother and house partner and being the biological mother of woman who has a mildly Autistic teenager. To learn as much as I could about disability, I have attended countless lectures and forums throughout my life.

With the advance of medical science, babies and people who would have passed away just a few years ago are surviving only to become a burden and a drain on society. No-one has any idea how much it hurts me to see people with intellectual and/or physical disabilities being herded around the community like sheep or looked after in a group home like animals at the zoo. I could have been undoubtedly one of those poor human creatures too if I had not been at the right spot at the right time and seized opportunities.

Through environmental circumstances and complications of disability, I have had to rehabilitate myself at least three times so far in my life. The problem is people who are able-bodied tend to view people who have disabilities as helpless people who have to be cared for. Since it is instilled in people with disabilities that they have to be dependent on people who are able-bodied, people with disabilities in the main have low self-esteem and believe they need people who are able-bodied around them in every aspect of their life. To my knowledge, there is nowhere in the world a rehabilitation centre staffed with doctors, therapists, specially trained people with disabilities, computer programmers, carpenters and engineers who are broad minded and patient enough to teach individuals with disabilities living skills. Why do I include specially trained people with disabilities, computer programmers, carpenters and engineers as staff of a state of the art rehabilitation centre?

Here are a few examples where I could have or did use the skills of these people to enhance my own or other people's independence.

Being a teenager and not being able to take oneself to the toilet independently is very frustrating. There is still no-way I can stand on my feet without hanging onto a grab-rail. This makes pulling my underwear down and up from a standing position impossible for me. A lady who fully understood my desire to toilet myself independently as she also had a severe disability, offered to assist me to find a way where I would be able to take myself to the toilet independently. A few weeks later I was able to take myself to the toilet independently for three weeks in every month and after more training/discussion sessions, I was even able to toilet myself independently during that awkward week of the month.

Another example to demonstrate how beneficial it would be to have specially trained people with disabilities included in rehabilitation teams, years ago now I was staying with a person who had mild Cerebral Palsy. The carer had left for the day and had forgotten to open the tin of fruit for dessert. I said to the person they would have to open the tin of fruit themselves. Flying into a tantrum lasting two hours, the person told me that rehabilitation experts had said their hands would never be able to open a tin. When the tantrum had subsided, I told the person that I would guide them to open the tin of fruit. The end result being an open tin of fruit.

Eighteen years ago I suffered a complication to my disability that suddenly left me without any strength or movement from my upper neck down. The day after successful major spinal surgery, I discovered I still could not turn myself over in bed. When the physiotherapist came to see me, I asked her to teach me to turn over in bed. The physiotherapist replied that I needed to rest after my surgery and I would have to accept I may never be able to turn over in bed again. Angrily, I asked the physiotherapist to start my rehabilitation immediately before my muscles had time to die. I also said to the physiotherapist I would instruct her how to teach me to turn myself over in bed. Three days later I could turn myself over in bed again.

Despite my operation being a huge success, it was and still is far too painful for me to use a keyboard with my hands and arms. Due to my speech impediment and the energy it takes for me to utter sounds, which may resemble words, my electric typewriter was my only means of intelligent communication. My speech impediment also makes present day speech recognition programmes for computers useless to me. Years went by without me being able to communicate to my satisfaction, until I read in a magazine that the Spastic Centre of NSW was marketing a new American programme whereby a computer is operated by a switch. Excitedly I made an appointment with the Spastic Centre.

Despite me not being able to be gainfully employed even with this programme, I convinced the Commonwealth Rehabilitation Service to purchase a copy of the very expensive computer programme for my use. Imagine how unhappy I was when just before delivery, the salesperson from the Spastic Centre telephoned to say I needed somebody with computer knowledge to take delivery of the computer programme, to learn how to set it up as well as maintain the computer programme for me. He said that a person with a disability would not have the Intelligence or dexterity in their hands to maintain this programme. A volunteer from the local community centre was found.

Spending some time at my home after the computer programme was delivered, the volunteer from the local community centre set the programme up as though it was for his own use. I could no longer use my computer with or without the new American computer programme. We telephoned the volunteer to ask him to restore the computer programme to the original settings, but the volunteer told my house partner he could not remember anything about the new computer programme.

There was nothing for me to do but to pull out the instruction manual and learn everything I needed to know about the expensive new computer programme. As I didn’t want anybody ever again touching my computer with the delicate American computer programme, my next task was to design my own work- station and have it made up somehow.

For the last thirteen years I have been able to drive my electric wheelchair up to my computer and independently write on it with the aid of the computer programme. The computer programme is terribly slow to say the least (I am nearly into my third week of writing this letter). Unfortunately, people who have no movements in their arms would be unable to use this particular programme independently and even for me this programme would need further refinement to make it easier to use.

With computer programmers sensitive to the needs of adults who have profound physical limitations, computer programmes could be developed to enable ease of communication.

There are many computer programmes on the market for children and people who are intellectually impaired, but nothing really suitable for a person of average intelligence with little or no verbal communication and no body movement. I hope I have illustrated sufficiently how vital it is to have computer programmers and carpenters as part of a rehabilitation team. Now, I shall endeavour to explain why engineers should be part of a rehabilitation team also.

More than thirty years ago when my mother put me into a nursing home for young people with disabilities, I applied to the Commonwealth Rehabilitation Service to make me more efficient at making my own clothes. I needed specialised clothing for smartness, independence with taking myself to the toilet and to avoid skin irritations. The assessing occupational therapist at the Commonwealth Rehabilitation Service told me never to touch knitting needles or a sewing machine again. The occupational therapist went to great lengths to explain that owing to the amount of spasm I have, I would stick a knitting needle through my hand and a sewing machine was far more dangerous.

With this in mind, I went shopping for yarn and a few pairs of steel knitting needles. After successfully completing a couple of garments, I look down at my hands. There were no holes in my hands where knitting needles had been poked through but my fingers were not as stiff from lack of exercise as they had been before I started knitting. My next escapade was to peruse the open market for a suitable sewing machine for me with my disability.

These days for recreational purposes, I draw and embroider motifs on my computer for my sewing machine to stitch out at a later date. Designing and making my own clothes enables me to toilet myself independently.

From time to time over many years I have enlisted the skills of engineers to make me various gadgets to enable me to perform desired tasks independently. Just one of my stints was to call the local Technical Aid to the Disabled volunteer to ask him to put a handle on an obscure looking medicine container lid. When asked about my motive, I explained it would make it ever so much easier for me to pick up a sewing machine bobbin and place it on the spindle for winding.

On my house partner’s death six years ago my daily personal care hours were reduced to much less than half our combined daily quota. To avoid having to be placed in a nursing home, I had to rehabilitate myself to survive on my new limited number of daily personal care hours. I even amazed myself at the result of my rehabilitation technique.

Three years ago my two children and I agreed that due to the severity of my disability and my advancing age, it was becoming far too dangerous for me to live on my own in Sydney and have no family around me for support in emergencies. My son had a house in country NSW and my daughter who hadn't really spoken to me in decades, lived with her family on Queensland's Sunshine Coast. There being no beds at the time available in aged care facilities in country NSW near my son's home, my local health care team placed me in an aged care facility not far from where I lived. In that aged care facility I was so unhappy my friends went to great lengths for permission for me to return to my home until I was able to find a more suitable aged care facility for myself.

In the aged care facility, I was told proof of my dementia was I had completely forgotten how to walk. Apparently further proof of my dementia was I could never remember walking in my life. I was definitely NOT permitted to view any medication administered to me and on hot days I was clad in winter clothing as old people feel the cold. Being allowed to use a computer was out of the question because I didn't have the intelligence and I might electrocute myself. Luckily, no-one interfered with me reading books!

Recovering at my home after my aged care facility ordeal, one day the telephone rang. It was my daughter telephoning from Queensland's Sunshine Coast ordering me to sell my semi-detached home in Sydney and promising me that once I arrived on Queensland's Sunshine Coast, her family would assist me to find a suitable aged care facility where I would be happy. That sounded very good to me. I was aware my daughter had acquired a disabling illness and could not offer me any assistance from herself.

On my arrival on Queensland's Sunshine Coast, my daughter decided that I was definitely not the frail, demented old woman her brother had described but rather the same mother she had known and loved as a tiny tot but in an older body. It was decided that with the money I received from the sale of my semi-detached home in Sydney, I would purchase a house large enough for my daughter and her family to live with me. With professional personal carers assisting with my personal care needs mornings and evenings, I would have people around me most of time in the event of an emergency and my daughter wouldn't have the burden of having to pay high rent on a large ground level apartment. My daughter had to become use to me taking off around the area alone on public transport the same as I was accustomed to do in Sydney.

Seeing RED when my son-in-law told me that he would ask a disability organisation for advice on the modifications for my new home, I told him I was not buying the house for the average person with a physical disability. It was intended to be a private home and I was quite capable of informing workers what modifications would be necessary for my daughter's and my needs.

A similar incident occurred with the people erecting my pool fence. They told me I needed to put the gate near the ramp to enable my carers to wheel my shower chair straight into the pool. I told them I was paying them and I require the gate near the barbeque area. (Due to my weak chest I am not likely to use the swimming pool much for swimming but I love sitting in my electric wheel chair in the barbeque area and watching my grandchildren frolicking in the water. In time, maybe I shall be watching my great grandchildren frolicking in the water).

As I want future generations or people with disabilities and their carers to benefit from what I have learned over the last half a century, over seven years ago I commenced lobbying the State and Federal Governments to revamp the rehabilitation system and use a similar technique I used on myself. In this way my life of suffering would not have been in vain.

Vivienne Newton..