

My name is Dr. Peter Gibilisco. I would like to provide you with some details about myself.

I have achieved great academic success. My qualifications include: a Bachelor of Business; a Bachelor of Arts; and a Master of Arts and Doctorate of Philosophy from the University of Melbourne. Each of the steps I have made through higher education has deepened my desire to promote and harness the capabilities of people with disabilities.

I have had to struggle with a disability and consequent socioeconomic obstacles since I was a teenager. I was diagnosed with Friedreich's ataxia at 14. It is a progressive disease, causing impairment to the nerves, and so a failure of timely muscle reactions throughout my body. The messages sent from the brain via neurotransmitters are slower and weaker than they should be. In turn, muscular growth is hampered, giving rise to severe deformities, limitations and other problems. For example, I have had to deal with severe scoliosis and cardiomyopathy. By 23, I was reliant on a wheelchair, but now I'm simply too uncoordinated (unco) to make use of an electric one. The condition also leads to severely slurred speech, which by the time I was 40 meant my communication was also seriously impaired. Also, my eyesight is now becoming severely hampered.

I lived on my own in Dandenong for 21 years, contracting support my supports directly. During this time I was never funded to undertake the duties of an employer, which included: rostering, managing and overseeing payroll, WorkCover insurance, occupational health and safety, and arranging for flexible employment of employees.

Three and a half years ago, aged in my late forties My disability had progressed and I applied for an Individual Support Package to increase the level of funding I received in my home. When my application was denied, I knew that moving into Shared Supported Accommodation was a step I needed to take, although this realisation was devastating at the time. I took up a place in a YPIRAC funded house. I was most apprehensive about losing flexibility of support and the implications of standardised support.

## **Term of Reference (i) what have you achieved by virtue of YPIRAC funding and what are you afraid of losing?**

I have had some good times being a member of this house, but these times have been overshadowed by standardising actions. I am a very intelligent man with a severe physical disability, I have no cognitive disability and find it difficult to be treated like I have a cognitive disability. I believe myself to be an authority on the subject of Building Community Connections and Belonging within the YPIRAC funded houses.

### **Shared Supported Accommodation as an alternative to Residential Aged Care**

In Shared Supported Accommodation, staff can support residents and take them out into the community when they chose to go out as more time has been allocated to give them the support they need and encourage them to gain their independence back, unlike in aged care settings. In residential aged care, the routine in the morning is a bit of a rush as there are so many residents to be done within a limited time, therefore the only social inclusion they get is from within the facility, like playing bingo, engaging in music sessions etc. In residential aged care, the time to access the community is limited because the residents are old and can't do much.

In aged care settings, there are personal care workers, division 2 nurses and division 1 nurses present. And so, aged care is developed according to the practice of efficiency that tends to drive standardised policy of human support.

The fundamental support required for younger people with disabilities is different to the aged care model; that is maintaining care that is both individual and flexible. In shared supported accommodation nurses are not here, but they come when an appointment is booked with them, similarly a GP or other allied health professional can be booked.

### **Dignity of risk should be a disability right**

There is a concept called 'dignity of risk'. This refers the right of everyone to pursue activities that have a level of risk, for example, going swimming or surfing. People with disabilities are usually in the best position to instruct their own support services. Dignity of risk should mean that support services encourage the disabled to make their own informed choices.

Recognition of this will facilitate a better relationship between the support workers and the disabled.

### Standardising and the need for individual support

When I lived in my own place, I used a sling for transfers. When I moved into Shared Supported Accommodation I was told the sling did not meet the standards of the House. It was explained to me that another person using this sling had died; it was deemed unsafe for that person therefore it was unsafe full stop. But I had successfully used the sling for fifteen years.

I'm concerned that disability services need to avoid processes which standardise disabilities. Each person needs to be understood and respected in his or her own terms. I have had 15 years experience with my sling and I should have been allowed to demonstrate its features, to emphasize how it posed no great risk for me.

I could enter this house only after a total rearrangement of most of my equipment, which I have been using for many years. And all of a sudden, the equipment I had used was dispensed with because it apparently did not meet the safety standards of the new house. Standard procedure is one thing; care in supporting those with disability ought not be neglected. But this aspect of my move have cost me a lot of money and caused emotional turmoil.

Sure, because of very slurred speech, I have difficulties communicating with management, but they should reckon with me as someone who is qualified (I do have a PhD and have studied sociology, economics and management). And if they are not taking my opinions into consideration, then they should know they are making me feel as if I am a person with a cognitive disability. I am very supportive and sympathetic of many clients in this house who have cognitive disabilities, but I am not one. I am also supportive and sympathetic of the workers. They need to be encouraged to take the views of clients – in this case like myself – into account.

### **My Ideal World**

My dilemmas and my conquests have increased my conviction that somehow we—all of us—need to find a way to view and support people with disabilities in proactive and caring ways.

Taking equal opportunity as an overarching principle for a way of life that is flexible enough to assist diverse disablement in diverse ways. We need simply to face up to people with severe disabilities as people. We need a flexible and empathetic approach, aligned to an appreciation of the diverse social abilities, responsibilities and opportunities that become evident when people interact with each other as fellows, as equals.

### The potential of Synergy as a way forward

Consider the dynamics of mutually beneficial partnerships between attendant carers and the people they care for, people who, rather than being merely disabled should be viewed as those with many different abilities.

The underlying goal of mutually beneficial partnerships is to chart the further education of those directly and indirectly related to disability work. The aim is to identify the pathways that are courteous, mutually beneficial and helpful. The pathway needs to be identified so that by travelling it together, both parties can truly share life together. The potential benefits for developing such mutually beneficial partnerships are substantial.

The synergistic outcomes that can flow from this form of flexible support can be demonstrated through my own (unpaid) work output. Synergy is a term that is popular in most Human Resource Management departments. Simply defined it means that the whole is greater than the sum of its parts, i.e.,  $1+1=3$ . In my case the synergistic partnership between my support worker and me allows me to flourish in my role as a disability activist

For example, the synergy that is provided to me through the intervention of flexible disability support provides me with the means to achieve many of my goals in life. This approach to personal care is cohesive and flexible and humane. It allows me to manage the complexities of my life and desires. It helps me to attain my full human potential when and where my bodily abilities are lacking. For example, my progressive illness creates a deterioration of motor skills, which leaves all my physical attributes severely disabled. However, I am still able to perform research and write articles at a significant rate beyond that of many paid workers in the disability sector. Basically my performance is created through the synergy gained mainly through the work of my support worker.

This synergy explains the transformation that takes place in people with such different abilities and support workers, where the mutual benefits that occur will provide for a more proficient and humanly thoughtful disability sector, providing for a more inclusive society. Synergy becomes a fundamentally conscious event, which motivates, transforms and unifies all of life with a concerted and organised combination of such people of different abilities and support workers—this then, in my view, is the path to unify and enhance the disability sector.

Where I live now is not my ideal. What I need is 24 hour support, but flexible support. When there is time during the day I need academic support worker need to come in and do little bit of support for my typing, and check my sentence structure.

I cannot see why I should have confirm my support needs with service manager as this limits my control over my life and also creates negative impacts on my life. For example this severally hinders my self-esteem. For example if I am going out for meetings, movies, shopping I would like flexible support which does not involve asking the service manager.

This negativity impacts medically on my senses and therefor limits my life pursuits.

### **Evidence and Supporting Information**

My website is: <http://petergibilisco.com.au/>

My book is titled: Politics of Disability