Submission to the Senate Inquiry into violence, abuse and neglect of people with disabilities.

I am convinced that boredom is one of the greatest tortures. If I were to imagine Hell, it would be the place where you were continually bored.

Erich Fromm, *The Dogma of Christ*

It is not inequality which is the real misfortune, it is dependence.

Voltaire

In this submission, I am not going to dwell on the raft of physical, emotional, psychological, emotional and financial abuse that have been the lot of many people with disabilities, particularly those with cognitive disabilities who usually do not have the capacity to defend their own interests. I am sure you will hear many harrowing examples of these in the course of your inquiry. Rather I want to address the abuse of omission, the process whereby people with disabilities are dependent on others, do not learn new skills, lead boring, unfulfilled lives and do not exercise personal sovereignty over their own lives.

In our disability organisations, we strive for two outcomes. We want good things-independence, skills, resilience, inclusion, participation- to happen. We want bad things-harm, death, all types of abuse- not to happen.

However I believe that an equilibrium of comfort is reached by organisations and indeed the wider service system that could be described as one where nothing bad happens (or at least significantly less bad than in the past) but equally nothing good happens.

It is not difficult to understand why this is the case. In Australia the requirement that organisations provide a safe environment for the people they serve is underpinned by common law and legislation. So if you have your arm broken, your money stolen or your pajamas go missing from the laundry, the individual or their agents could assert that the organisation did not fulfill its duty of care and could take legal action. This is the “energy”-fear of being sued- that keeps the bad things from happening.

As well as common law a major force that has seen this duty of care taken seriously within South Australia and other jurisdictions has been the involvement of the coroner. It is probably timely to reflect on some history in looking at the role of the coroner.

If you have read the personal stories of people living in large residential services in Australia and the United States, you would start to get a rough idea of the scant regard that was given to the lives of people with intellectual disability. It was highly likely that the doctor whose negligence or lack of interest might have contributed to your death would be the person signing your death certificate. It would be filed, never to be seen again let alone examined and queried. You were truly “A nameless number on a list that was then lost”.

Some years ago this changed in South Australia; the coroner now investigates the deaths of all people who live in institutions and group homes. He also regularly investigates the deaths of people with intellectual disabilities where it appears the death was caused when services or systems have stuffed up. The coroner has not been slow to direct criticism to organisations and individuals who have not fulfilled their duty of care to individuals who have died. To receive criticism from the coroner is rightly embarrassing and if repeated a CEO sacking offence. It is my view that meeting your duty of care so that you don't get sued or get a thrashing from the coroner has contributed more to preventing the “bad” things happening than much of the training in service philosophy and values!

So if common law and the coroner have largely kept the “bad” things in check, why are the “good” things not happening? Firstly, I need to justify my assertion that largely the “good” things are not happening.

What constitutes the “good” things? Of course this will be a very personal question that some of us take a lifetime answering as we grapple with desires, fears, relationships, aspirations, careers, guilt – a pot pourri of factors that make us who we are. Most of us seek happiness through the things that are important to us – our relationships, our accomplishments, our work, our status, our contributions, our talents or our possessions. Often, we find that some of these are not the source of happiness we had thought they would be – that the Porsche and the penthouse are but two additional places where we can reflect on the emptiness of our lives. For others, the acquisition of material things is indeed a source of great happiness.

A common theme though is, whatever it is that we desire, our chances of success will be enhanced if we have opportunities to gain skills and if we are truly in control of our own lives. Richard Trudgeon, in his book “Why Warriors Lie Down and Die”, cites lack of control as the major cause of the malaise of the Yolnu people in the Northern territory. I believe that developmental opportunities and personal sovereignty are the keys to all the “good” things that are important to us. The two are of course inter-related; it is though our acquisition of skills as we grow and develop that we are able to take more control of our lives.

Indeed the importance we place on these two “good” things in our own lives is reflected in the principles of the United Nations Convention on the Rights of People with Disabilities. Oh! And not to mention the vision and mission statements of hundreds of disability organizations!

Ironically and sadly duty of care is regularly referenced to prevent learning and its inherent risks. Learning is a risky business but that is no reason to deny people with intellectual disabilities opportunities to learn and develop. Furthermore and unfortunately, I am unaware of any case where an organization has been sued for failing to provide developmental opportunities to the persons they support. It is therefore not surprising that the bias of organisations is towards the things they can be sued for ie ensuring that the bad things don’t happen.

It is my belief that within many organizations these two “good” things are missing. You are not in charge of your life and largely you will not have opportunities to gain new skills. If this is the case why is it so?

Personally I don’t think it is through malice; I think we must put it down to organizational entropy! It is easier to feed everyone at the same time; it is easier to prepare meals than to assist individuals to prepare their own meals; it is easier if everyone goes on the same excursion. It doesn’t take much imagination to add to the list. Despite what is written in vision and mission statements, the dominant culture will prevail. The reality of our practices bears little relationship to what we espouse as our values. The dominant corporate culture instructs new employees “this is how we do things around here.”

Within an institutional setting, “how we do things” often includes getting client chores done as quickly as possible so that staff can then spend time socializing. If residents are ambulant, their activity for the day is often to “mill” until the next meal or intervention. This was dramatically demonstrated by work undertaken by the late Prof Jim Mansell and Prof David Felce in the UK, who discovered that in a four hour block for an individual resident in a large residential service, there were only twelve minutes of interaction with staff and only four minutes of that interaction was positive.

Resulting from the Mansell/Felce revelation was the development of the “active support” model of support, now almost *de rigour* in service organisations in Australia, based on person centred planning and a developmental approach to supporting residents.

But the question must be asked “Why was this necessary?” If we read their mission statements one could assume that active support and its commitment to skills development was already the modus operandi of organizations. Well yes, it was a part of the documented way of doing business, but the real way of doing business was about ensuring comfort levels for staff.

You could imagine how well received a new staff member in this environment would be who, through his/her training or intuitively, wanted to do more time consuming “developmental” things! In my recent discussions with students in the Disability

Studies course at Flinders University, most of whom have worked in providing hands-on support, I heard many stories of how they had tried without success, to enthuse colleagues to work developmentally.

Finally why are the good things not happening? It is both pleasing to note the arrangements and reporting structures that all jurisdictions have put in place to report on the “bad things”. Nothing similar exists to report that the good things are happening. In 2012/3 I undertook a review of day programmes for the South Australian Department of Communities and Social Inclusion. I wrote in the report of that review:

> *“….even when we concentrate on the stated aims of the Program, it is difficult to conclude that they are taken very seriously. They would imply growth and development. How is that monitored, measured and reported? The sad reality is that it is not. It would not be dissimilar to an education system where there was no way of assessing whether students were learning. There is currently no system to measure development or achievement of goals, and the Department of Communities and Social Inclusion (DCSI) requires no reporting on them. We also found a dearth of reporting to boards on this. This lack of a system at the Program level to monitor, measure and report on participant outcomes and the quality of services is the key reason for the malaise we found in many parts of the Day Options system and which we describe in this report.”*

I was of the view that this was perhaps an aberration, that there was better reporting of outcomes in other service types or in other jurisdictions. In a Practical Design Fund project a colleague and I undertook for the Commonwealth Department of Social Services, we found not one organisation that reported on outcomes to its board or funders. We heard of one man in his fifties whose plan included going fishing and despite this being in his plan for three consecutive years, he had never been fishing. We could not but come to the conclusion that we are not taking the good things seriously. Our rhetoric is not match by the reality of what happens in the lives of people with disabilities.

The reality is to this day that many people with cognitive disabilities lead empty, boring lives, devoid of the skills that might assist in taking control of their lives, and are eternally dependent on others. When they react to this in the only way they can communicate, through their behaviour, we lock them up, tie them up, drug them up, euphemistically calling it restrictive practices rather than battery or false imprisonment. In my view they are being abused and it is time for this to stop!