**For sale in a market: who and what will protect my dignity?**

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**CRU Building capacity for lifelong inclusion | Brisbane | 15-16 March 2025**

I am torn.

Those of you who know me might not be surprised. But this seems like one of those intractable dilemmas that bedevil us when we set our direction against prevailing trends. I watched a deeply compromising wrinkle be ironed into the NDIS in its early days. A wrinkle which is damn hard to shift. In 2012 I was appointed to the National NDIS Advisory Committee and have recently been appointed to the NDIS Independent Advisory Council. From 2014-2016 I was a Chief Investigator in the formal Evaluation of the Trial of the NDIS. I am currently a participant in the scheme.

So here is my present dilemma. How do I tell the story of the latest processes of commodification of people with disability, highlighting a subterranean, persistent and distorting aspect our disability service system in its capacity to humiliate those who seek paid supports, naming the naivety, co-option and complicity of the disability movement in cementing these processes, while holding as real and provocative the hope that this is not how things need to be? I want to speak a hard truth within the context of real possibilities to move the world closer to the liberation and flourishing of disabled people and our kin.

To do this, I invite you to join me in being ‘half a shade braver’ as the poet David Whyte calls it. This is his invitation for us to be seen and heard, to perceive what is no longer relevant, and creatively engage in the future. To do this we need to look with honesty at the latest changes in health and human services that threaten the full and dignified humanity of those seen as disabled.

We know that most participants in the NDIS and those using a full range of services and supports are pleased with the opportunities that have opened for them. But I am in a small minority. We also know that those who experience corrosive and cumulative disadvantage, whose capacity is constrained through a combination of impairment and oppression, whose families are alienated, disempowered or stretched beyond endurance, whose conditions present complicated and hard to address needs that disrupt their days are those who will not find customer power sufficient to address their vulnerable rights and dignity. It is these people and their kin who occupy my thoughts today.

Commodification, the process of turning something, or in our case, someone into an object to be bought and sold, is not a recent phenomenon in disability world. Ever since disability services emerged in Australia, we have been used to raise money for those who declare themselves our carers and supports. When I was working on the socio-cultural history of disability I came across documents generated across the last 150 years to induce governments and charities to shell out for those positioned as hopeless, helpless, destined for exclusion, ineducable and ungovernable, admirable in their attempts to overcome, pathetic in their incapacity to contribute, dependent, a spur to heroic medical intervention, deserving of compassion, care and containment. Here is a quote from an article from 1992:

*Governments expect us to count clients, display them, sell them, and exploit them. It can be the most disgusting act of indignity imaginable and says much about Government expectations of welfare agencies. (Usher 1992)[[1]](#footnote-1)*

This is evident in our current world. What does this mean in our relationship with the NDIS and the expanding services market? I am going to describe what Avishai Margalit, a Jewish political philosopher calls *indecency*. He says that an indecent society is one which uses its institutions to humiliate its citizens. He stresses, and I want you to remember this, that there is no inherent indignity in disability. Your dignity is not compromised by your need for others to assist with bodily functions or to hold you in times of high mental distress. For humiliation to be real, the target does not need to experience shame at an emotional level, rather they are subject to processes and relationships which require them to show neediness, becoming subject to loss of autonomy and, at times, self-respect. Margalit also describes a civil society as one in which the citizens treat each other with respect. It is possible to build a decent society by forging respectful institutions while not living in a civilised society, because violence and uncivility have not been eradicated in intimate and social group relations. Sadly, however, the two are likely to be present at one time. Margalit also distinguishes a just society which directs it resources to a range of groups or individuals, from a decent society. As Leadbeater puts it:

A welfare state might deliver a just distribution of income and benefits, but only at the cost of a highly intrusive, de-humanising bureaucracy, which humiliates people by turning them into little more than ‘numbers’.

There may be some gains on the civility front, but I fear losses here as well. We hear the r-word in common usage, children still report bullying and shaming at school, I personally deal with slights and putdowns in my daily round and diversity claims are increasingly viewed as lacking merit, cynically fuelled by advocates who tell clearly inadequate people that they have a right to recognition, respect and rights fulfilment. This requires our persistent vigilance as it gets sucked up into policy and practice.

Here is broad brush overview of how we, in the disability movement not only failed to avoid indecency but may have unconsciously contributed to it. I think that the NDIS brings us closer to justice but fails in the test of decency. There is more money in the system and more people can access resources for daily support. But these advances have come at a cost. That cost is a new manifestation of commodification.

Over the last 15 years several policy pulses have shaped the experiences of current participants. First, our claim for change in the system established under the Disability Services Act of 1986 and various state-based legislations introduced in the early 1990s, was met with a growing international trend toward the marketisation of the service system. The disability movement argument that individualised funding arrangements would offer more choice and control was distorted into a dominant view that efficient markets would guarantee service quality and customer choice. We hold, within living memory, knowledge of what a free market looks like in disability. This knowledge went unheeded as economic and financial arguments took hold in the political process. Up to the late 80s in Australia governments did little to regulate disability services. Models such as grouped living, segregated employment and limited community involvement, underdeveloped rehabilitation and persistent abuse and neglect were the result. I can see that these models are starting to take over again. For evidence, just look at the number of disability badged vehicles on our streets, (using presence in the community as a marketing opportunity), the obduracy of grouping home life, the persistence of segregated education and static employment outcomes. Heed also the stories of people being passed from one provider to another, as a back-room paper transaction. The much-vaunted reform potential of free market service system is slow to emerge! It is not surprising that people are talking about being valued only for the size of their package.

Second, at this time the global disability movement ran an argument that support requirements should be determined through functional assessment, rather than assumed in diagnostic predication. This claim was well grounded in an analysis that diagnosis should not been as destiny. (This body leads to this life …) The shadow of this approach however was to retain a notion that the person’s impairments are the main obstacle to a good life. To see that the only thing that matters in a person’s life is to shift the balance from limited function to supported function. This leads to the prevailing view that that the way to maximise the package is to maximise the functional deficits of the person. The result is a splintering of the person; a limited understanding of genuine, fundamental need; a tying of life goals to performance; a shift in responsibility for change from environments that thrive on exclusion back to the person (the child and their family) to demonstrate efficient use of resources. Full assessment based on a deep understanding of the person, including but not limited to investigation of impairment, was diluted by eligibility models based on narrow functional and diagnostic tests, privileging professional power over a rich understanding of the person and their worlds. This utilitarian approach, manipulating the lives of people into an acceptable image rather than building a truly personalised approach, has led to a superficial customer-isation across many of the providers.

Third, when we become a customer in a market, we are enlisted into a fragile system that cannot focus on our needs and desires. A customer is only ever valued for their purchasing power. Personalisation distorted into customer-isation neglects our civil and political rights, cares not for our dignity nor whether what we bought works for us. Satisfaction ratings are a thin message telling us little about how our flourishing is bolstered by these resources.

Finally, perhaps the most damaging part of this process…this wrinkle … is how the claim for choice and control in our daily lives became trapped in the market world such that the ultimate measure of our power is viewed as the capacity to change provider. Sadly, we can see how easily we were co-opted here. The need for choice and control was a plea for democratisation, not for becoming a customer. Democratisation was and is a claim made against a history of limited or no self-determination (and I mean this for all people). It speaks to how daily life is lived with a positive vision about our place as citizens. The democratisation approach is about amplifying voice and vision of the people affected, not a changed accountancy framework.

So, you can see how disappointed I am that at each crucial step in the evolution of the NDIS the messages received from the disability movement and the disability community were interpreted through the dominant trend toward marketisation. And further, that the emergence of new players in the service world favours those who whole-heartedly embrace a view that customer-isation is an expression of choice and control. These new players (not all I hasten to add) do not seem able to link valorisation with the functional approach, to see the significance of relationship in moving beyond simply servicing bodies while being seemingly unaware of the lurking indignity in being valued only for the dollars.

To return to my present dilemma. My intention has been to demonstrate how the messages of the disability movement were distorted under the pressure of marketisation policies. Sitting in this uncomfortable truth I must ask: How do I find a provocative hope and realistic change path that restores dignity while supporting justice?

Change requires a commitment to transformational values in conversation with open-hearted and open-minded others as well as political moments to influence. With regret I must say that I do not have a detailed plan for change as I am still trying to locate opportunities in our current context, but I can discern something of its direction. I look forward to hearing your thoughts and plans. These however are the stars by which I will guide my work and my life in disability world. My five commitments as I strive to be half a shade braver.

1. I will not deny the shadow of our recent history, including how our claims can feed forces that appear beyond our control.
2. I will take up the challenge to link rights and dignity according to the purpose statement of the Convention on our rights: to promote respect for inherent dignity.
3. I will celebrate what we all know…that freely given relationships, social role valorisation and a developmental commitment to liberation and flourishing provide an antidote to all the shaming the world can throw at us. You are the geniuses and the experts in this world, and I can see its fruits daily.
4. I will not shrink my focus to designing processes that preserve dignity for the NDIA alone but require it of the services/support market.
5. To maintain this wide focus, I will explore the possibilities in schemes such as the Presence approach developed by Sandra Bloom who has pioneered the Sanctuary model of trauma-informed work with service-dependent people and service organisations:

* Partnership and Power
* Reverence and Restoration
* Emotional Wisdom and Empathy
* Safety and Social Responsibility
* Embodiment and Enactment
* Nature and Nurture
* Culture and Complexity
* Emergence and Evolution

So, before I finish, I offer this challenge. Let us keep learning about having difficult conversations focussed on truth telling, truth hearing, solution seeking and change building. Let us learn how to ask positive, non-conditional, unlocking questions, as it is these questions that will set the direction of our growth. Inquiry is always intervention, and a beginning point in releasing our capacity to build an inclusive world for all.

And in the spirit of turning things upside down to enliven our perceptions I am now going to acknowledge that we are present in the sacred, sovereign country of Jagera people and the Turrbal people and acknowledge the cultural wisdom present here today and throughout all disability worlds in Australia. We are here in solidarity, knowing that the mechanisms of The State and The Market to control, segregate, incarcerate, disenfranchise and dehumanise produce shared pathways for First Peoples and disabled people delivering a compounding effect in the lives of First Nations people with impairments. We are here in solidarity, knowing that the work for liberation and flourishing calls us into deep listening and discovery of shared goals, shared work and shared conversations and shared celebrations. The amplification of leadership of disabled people cannot be built on the silencing of others who know only too well the sharp moments of discrimination always based on so many ways of saying you are not worthy to live among us, to work with us, to lead us into a prized future.

An inclusive future for all must be realised and sustained by amplifying the leadership of those who Jeannette Winterson describes as the bearers of the difficult beauty necessary to disturb the world. # Nothing without us. Nothing.

1. *Market principles and welfare* https://aifs.gov.au/research/family-matters/no-36/market-principles-and-welfare#:~:text=One%20of%20the%20forms%20this,by%20the%20word%20'privatisation'. [↑](#footnote-ref-1)