

Submission

Productivity Commission Inquiry Human Services

Focus: Informed Choice

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Matt Burrows is the CEO of Therapy Focus, one of Australia's leading providers of professional therapy services. Matt is currently enrolled in the DBA course at Curtin University with the John Curtin Institute for Public Policy. His supervisors include Professor John Phillimore and Professor David Gilchrist. This submission is based on excerpts from Matt's candidacy proposal for the DBA which is due to be presented for consideration in the latter half of 2016.

The title of Matt's proposed thesis is "What governance frameworks are effective at empowering vulnerable people as consumers?" with particular reference to people with disabilities in Australia.

The aim of the research is to identify the shortfalls vulnerable people have experienced to date with various empowerment initiatives, and explore possible solutions in governance frameworks that could be used to better empower them in exercising choice and control.

The objectives of the research are to:

1. Develop a shared understanding of what empowerment is, and what its relationship is to self-determination;
2. Delineate between popularly used concepts in the literature including consumer, client, customer and citizen;
3. Determine what the most commonly used governance frameworks are for delivering social programs for vulnerable people, specifically people with disabilities; and
4. Determine, from the perspective of vulnerable people, whether or not they are empowered, and if not, then explore the reasons for this, and what can be changed so that they do feel more empowered.

The Australian Human Services Sector, consisting of such services and supports as are provided in Aged Care, Disability Services and Child Protection, has been the focus of considerable reform in the last five years. A key aspect of this reform has been to attempt to place users of services in a position of choice and control such that outcomes of services are better focused on users' needs and desires, in turn becoming less programmatic and siloed. This policy change has been developed within the broader philosophical framework of market economics, where market-style solutions to service resourcing and access are being preferenced.

Largely, these services are provided by Not-for-profit entities and a significant proportion of funding is derived from public sector agencies so that funded organisations are delivering Human Services public policy objectives for all three levels of government.

As such, all jurisdictions in Australia, including the Commonwealth, have adopted a policy suite to effect this change in service focus which usually translates into procurement reform. Indeed, in the minds of policy makers, this reform process is commonly conflated to the phrase "Person Centred Care and Individualised Funding". The National Disability Insurance Scheme (NDIS) is arguably the most significant—by size and popular recognition—example of this form of procurement reform.

With the introduction of the NDIS, people with disabilities are being promised more choice and more control in their lives. This submission will examine this promise in the context of governance models that allow for service delivery organisations to meet their clinical, occupational health and financial obligations while also meeting the expectations of choice and control harboured by service recipients.

The submission's author has been interested in social justice for over two decades - from writing about immigration policies and their impact on refugee crises, to working in Aboriginal Affairs in the remote desert regions of Western and Central Australia. Through the health and education sectors to now working in the field of disabilities, it seems to this author that the same united cry can be heard - "Nothing about us, without us" (Charlton 1998). This sentiment played out publically in February 2016 upon the handing down by Malcolm Turnbull of his first Close the Gap report as Prime Minister. The response from the Social Justice Commissioner, Mick Gooda, sums up the feeling of many vulnerable people:

"The Prime Minister has been quoted extensively in saying, 'Do things with us not to us'. Bill Shorten said exactly the same thing. We have heard these words before. We take them with good heart but there's got to be a carrying-out of that new relationship so I think we're entitled to be a little bit cynical about it until it starts happening." (NITV 2016)

This cry is still ringing out today as Australia embarks on a NDIS. It has been long in the making. Following a call for self-determination for people with disabilities that came from an international conference in Seattle in 2000 (Bach et. al. 2000), came the principles reflected in the United Nations Convention on the Rights of People with Disabilities (United Nations 2007), to which Australia is a signatory. The NDIS was originally conceived by the Productivity Commission (Productivity Commission 2011) and made policy with the Australian Government passing legislation to create the Scheme in July 2013. At the heart of this bold new Scheme are the principles of choice and control (NDS 2016), principles that were so important to the conference attendees in Seattle in 2000.

It is noteworthy that vulnerable people from vastly differing cohorts have long reported a sense of disempowerment (O'Brien 2015). The activist movements of all minority groups representing vulnerable people have at some point called for more control over matters affecting their lives. From Mental Health, Indigenous Affairs, Disabilities, Aged Care and any other human service sectors, where a presumed lack of competence on behalf of those being cared for can lead to surrogate decision-making, and where systemic advocacy is a necessary reality, there is evidence of disempowerment. This submission will take into account literature referring to differing sectors, as it establishes the common issues in relation to empowerment of vulnerable people in making informed choices. However it will more specifically address the literature on the disability cohort as the author currently works in this field.

From reviewing the literature it is clear that a modern participation framework, centred around co-design and co-production, has evolved. The policy environment has changed from the radicalism of the 1960's (Arnstein 1969) through the neo-liberalist ideas of the 1970's to 1990's (Alam 2009), to the calls for self-determination from Seattle 2000 (Bach et.al. 2000), to citizen participation in co-production (Janamian et al. 2016) and co-design (Evans 2015). This evolution is even more clear in the mental health sector, where the transition has been from incarceration and institutionalisation (no power) towards community living and supports (power) guided by consumers active in the governance structures (Gooding 2016).

The UN Convention on the Rights of Persons with Disabilities sets its Purpose from a human rights perspective, stating the intention for signatory states to

"...promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN 2007)

This rights based approach is further emphasised in the preamble, with specific mention of how these rights manifest in relation to decision-making on matters that impact upon them:

"...persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them." (UN 2007)

It beckons the question why, if so clearly articulated in a UN Convention that is so widely subscribed to, should people with disabilities still feel so marginalised? Why do they feel so disempowered in a policy environment that should actually support empowerment and self-determination?

To understand this, it is important to first define empowerment. Obviously it is a precursor to self-determination, which may be ascribed the measurement outcome function. But what then constitutes the input to that outcome? It is clearly more than simply being consulted; there must be a function of being actively involved in the decision-making (Ranson and Stewart 1989, p17; Farrell 2000, p32). Indeed there must be a responsibility associated with the function and a consequence, both individual and public, of not exercising that responsibility with accountability (Wright 2015, p66).

The consequence for the individual is quite obvious – to forego access to valuable resources and/or services. The public consequence is less obvious, but more insidious. It relates to the ongoing application of resources without success. No doubt this is how many feel in the Aboriginal Affairs sector as we observe the 25th year since the Royal Commission into Aboriginal Deaths in Custody,

only to see incarceration rates have increased from 1 in 7 just prior to the Royal Commission to nearly 1 in 3 by 2014 (Creative Spirits n.d.).

Therefore the definition of empowerment, based on participation of consumers, must encompass a transfer of power from the public to the individual (Arnstein 1969, p216) as well as the exercise of independence and sense of individual effectiveness (Alam 2009, p279). Only in considering the duality of empowerment, as is evident in citizen theory (Ranson and Stewart 1989, p13), will we see self-determination manifest for vulnerable people.

As self-determination manifests itself, it is important to determine in what realm and to what degree. Many researchers reflect on the notion of consumers as sovereign beings, i.e. people that can effect influence from economic, political or social perspectives (Dahlberg 2008, p265; Litva 2008, p81). What is evident in both the literature reviewed and in contemporary service provision is confusion about terminology. When is a person a consumer, a client, a customer, or a citizen? Can that person be one and all of these things, depending on their actions or even on their perspective?

For the purpose of this submission, a consumer is defined as a person who consumes, or uses, something. A consumer may exhibit behaviours, or act, so as to perform an economic function, like purchasing a service (customer). A consumer may be a partner in a professional relationship (client) like a patient receiving clinical care. Or a consumer may be acting to contribute ideas so as to advocate for others with similar conditions, or simply for the betterment of the greater community as a whole (citizen) (Farrell 2000, p32). Broader functions like those of customer or citizen may be performed, but the base function being assumed in this submission in relation to vulnerable people is that of consumer. In this manner, it does not matter when an author ascribes a different function to the cohort e.g. a citizen purchasing services as an individual (Gooding 2016, p42) as we can assume that author is also including the base concept of the consumer. This is important when we consider that

“...sometimes user participation – not control – in decision making is the end goal.” (Litva 2009, p89)

By having a clear understanding of the different roles that a consumer can have, it becomes easier to consider the role vulnerable people take in differing governance models. From the legislated school governing councils in the UK (Farrell 2000) to the policy-led NHS community control (Department of Health 2005; Litva 2009) and the semi-regulated environment of the NDIS and associated National Standards for Disability Services (Department of Social Services 2013), the role of the consumer in governance is increasingly being mandated.

The literature is almost unanimous in its call for more research to verify the participation of consumers in service design (Timberlake 2014, p912-3). Likewise there seems popular support in the literature to determine where the current mandated provisions for consumer involvement in governance is failing (Timberlake 2014, p913; Alam 2009, p287-9; Dahlberg 2009, p270; Wright 2014, p66-68; Litva 2008, p89-90).

Whilst the literature has for the most part pointed to highly developed conceptual frameworks that are embraced in policy design, it also points to systemic failure to achieve outcomes for the key stakeholder, the vulnerable person. To be effective, the consumer governance framework must be both a good idea and must be executed well also. It seems the latter has not always been the

priority in public policy, as forensic analysis of experiences in the NHS have concluded for example (Litva 2009).

It is important we take stock of previous experiences in empowerment and build on them. Again, the Aboriginal Affairs sector gives us a poignant reminder of the importance of learning from past mistakes, with former Prime Minister John Howard justifying the abolition of the statutory body Aboriginal and Torres Strait Islander Commission as a failed experiment in separate representation and elected representation (Parliament of Australia). That failure was widely reported as simply “a failed experiment in self-determination” (Crikey).

The move is evident to genuinely involve vulnerable people in decisions that impact upon them. The move to co-production, co-design and co-creation is topical today in both industry (Janamian 2016, pS12; KPMG 2015) and academia (Wampler and Hartz-karp 2012; Alford 2014). With clarity of vision on what constitutes value creation for the consumer, the platforms for engagement are becoming increasingly sophisticated. Ranging in type (eg cognitive, emotional, behavioural), level (from non-engaged to highly engaged), and in duration (one-off, recurring and continuous), opportunities are being created in many sectors to purposefully engage with vulnerable people to co-create (Janamian 2016). In the words of these authors, this is changing the role of consumers:

“...from being ‘users and choosers’ to becoming ‘makers and shakers’ of services” (Janamian 2016, pS12)

Whilst these may be buzzwords of the new millennium, bordering on being a fad (Alford 2009, p24), it should be remembered that success of the co-design will be measured in genuine empowerment of the vulnerable person. Done well it could realise substantial benefits, but done poorly and it may do more harm than good and serve to further disempower the person it was intended to benefit (Evans 2015).

In an advance on just engaging consumers, there is a move to tailor governance practices to serve vulnerable people. The establishment of micro-boards is a relatively recent development, with legal entities being established with those closest to the vulnerable people in charge of decisions, taken in conjunction with the vulnerable person (Jay 2011). With provision for self-managed funding under the National Disability Insurance Scheme, this could well be an idea that grows in popularity in the near future. Given its small and intensely personal nature, it could see a whole new level of engagement with people with disabilities. However the same fundamental flaws will need to be addressed, regardless of how small and intense the relationships in the governance model.

Forcing co-design and co-production on to the sector may be another option to progress empowerment. In British Columbia the government has introduced the Representation Agreement Act 1996 which seeks to mandate supported decision-making based on informal relationships which explicitly presumes the capability of all individuals to make decisions affecting their own lives (Jay 2011). Whilst noble, without monitoring of compliance backed by a regime of sanctions or rewards to incentivise compliance, it will only contribute to the malaise of flawed engagement frameworks already in existence (Wright 2015, p66).

The literature all points to a building momentum that recognises the value of consumers participating in the design, implementation and use of services and products.

Academic literature and government policy adopts the consumer as a central stakeholder in service design, whether the consumer is partaking in the role as a consumer, client, customer or citizen. Indeed it has evolved from a spectrum type framework like the ladder proposed by Arnstein, through more pragmatic versions like the Shand and Arnberg public participation continuum, through matrices and into maps (Bishop 2002, p14-29). Yet the literature review suggests consumers still feel very much on the outer.

Key flaws obviously exist in the design of the consumer participation. Broadly speaking the flaws identified in the literature can be summarised as follows:

1. Access to information – too little or too much – to guide decision-making for informed choice (Alam 2009, p284; Timberlake 2014, p913)
2. Diminished value of skillset of consumers (as directors on Boards) in comparison to professional skills (Wright 2015, p67; Farrell 2000, p35)
3. Diminished value of consumers (in comparison to professional people) as a stereotype of social standing and/or financial means (Wright 2015, p67)
4. Access to viable and dynamic markets to exercise choice and control, particularly relevant in regional and remote centres (Alam 2009, p288)
5. Resources sufficient to influence market-type decisions (Alam 2009, p289; Gooding 2016, p41)
6. The will to act as customers and exercise economic power over decisions (Timberlake 2014, p905)
7. The will to break from the assessment-type status-quo and risk trying something new (Alam 2009, p289; Dahlberg 2009, p270; Timberlake 2014, p905)
8. Complacency and a tendency to revert to technical solutions and/or “packages of care” rather than individualised and tailored care (Alam 2009, p287; O’Brien 2015)
9. The will to genuinely engage consumers in decision-making (Janamian 2016, p514, Timberlake 2014, p913)
10. A framework that requires, monitors and enforces genuine engagement of consumers (Wright 2015, p66; Litva 2009, p89-90)

These flaws are drawn from numerous case studies across US, New Zealand, UK and Australia. There is considerable overlap of the flaws identified from cohorts of people that are completely independent from each other, aside from the fact they are in relation to vulnerable people acting as consumers. In addressing these flaws, it should be remembered that not all consumers want to exercise choice and control. Some have an emotional bond to what is and what was, and some may be overwhelmed by the reality of their newfound obligation, especially if it means choosing ahead of professional expertise like medical advice. (Timberlake 2014, p904-5)

The gap that seems to be missing in the research is an agreed consumer governance framework that establishes a set of definitions, stratifies engagement, measures empowerment, and verifies self-determination as an outcome. This was well summarised by Litva et al as:

“... (it) remains highly problematic until it is recognised that different users will take different role perspectives and desire different types of involvement in different aspects of the policy. Thus large, all-encompassing strategies of user involvement may only appeal to a limited range of users, and this could impact significantly on their use and usefulness.” (2009, p 89-90)

In addition to these flaws in assumptions, there may also be a gap in our understanding of outcomes. This is certainly the view of Dahlberg, Todres and Galvin who suggest without considering the existential benefits of lifeworld care, including the key components of vulnerability and freedom as well as vitality, movement and peace, one will never move beyond the simple paradigms of patient-led or person-centred care (2009, p270). However whilst they raise a compelling argument in the case of an Alzheimer's patient, it may be more important for us to concentrate on the practical and present rather than the abstract and existential, lest the gap become wider on all the Indigenous social improvement metrics and the National Disability Insurance Scheme reforms forever remain in trial format, at least in Western Australia.

In conclusion, the author applauds the Treasurer for instigating this public inquiry and directing the resources of the Productivity Commission to explore the concept of informed choice. This submission hopefully identifies some of the areas that might be further explored in the inquiry process. Informed consent cannot be superficial; it must be tested in some way against the will of the consumer.

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