

SPECIAL ISSUE • The many faces of disability in evidence for policy and practice

debate

Why is lived experience important for market stewardship? A proposed framework for why and how lived experience should be included in stewarding disability markets

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Background: Many countries use market forces to drive reform across disability supports and services. Over the last few decades, many countries have individualised budgets and devolved these to people with disability, so that they can purchase their own choice of supports from an available market of services.

Key points for discussion: Such individualised, market-based schemes aim to extend choice and control to people with disability, but this is only achievable if the market operates effectively. Market stewardship has therefore become an important function of government in guiding markets and ensuring they operate effectively.

The type of evidence that governments tend to draw on in market stewardship is typically limited to inputs and outputs and has less insight into the outcomes services do or do not achieve. While this is a typical approach to market stewardship, we argue it is problematic and that a greater focus on outcomes is necessary.

Conclusions and implications: To include a focus on outcomes, we argue that market stewards need to take account of the lived experience of people with disability. We present a framework for doing this, drawing on precedents where people with disability have contributed lived experience evidence within other policy, research, knowledge production and advocacy contexts.

With the lived experience evidence of people with disability included, market stewardship will be better able to take account of outcomes as they play out in the lives of those using the market and, ultimately, achieve greater choice and control for people with disability.

Key words market stewardship • lived experience • disability • outcomes

Key messages

- Market stewardship is key to guiding quasi-markets, including in the disability sector;
- Evidence guiding market stewardship is often about inputs and outputs only;
- It would be beneficial to also include lived experience evidence from people with disability;
- We propose a framework for the inclusion of lived experience evidence in market stewardship.

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Introduction

For some decades, governments around the world have used market forces to drive reform in disability services. Initially, this typically took the form of a purchaser/provider split, where services were divested from governments into private and not-for-profit providers. More recently, we have seen a shift towards personalisation policies and the individualisation of disability budgets, where an amount of money is allocated to a person with disability who has responsibility for purchasing services from a quasi-market (i.e. a market run by government). Yet a range of studies have found that quasi-markets do not always operate effectively and in some cases there is evidence of significant market failure (Considine, 1999; Adnett and Davies, 2003; Glasby and Littlechild, 2009; Baxter, 2013; Braithwaite, 2013; Fleming et al, 2019). Market stewardship (that is, efforts to guide and steer markets towards policy objectives) has therefore increasingly been identified as an important function in ensuring that market efficiencies are realised alongside equity considerations. The literature on market stewardship is limited, but what seems clear is that the type of evidence often drawn on to undertake ‘stewardship’ activities pertains more to inputs and outputs, without sufficient regard paid to outcomes for people with disability (Gash, 2014; Carey et al, 2017). We argue that the lack of focus on outcomes is a significant gap, given that individual funding schemes are intended to give individuals greater choice and control over services. If markets do not function effectively then good outcomes, and choice and control, cannot be achieved.

In this discussion piece, we argue that if governments drew on different forms of evidence they would be more equipped in effectively stewarding disability markets. Specifically, we propose that by actively including lived experience evidence into market stewardship processes, there would be a greater likelihood of ensuring more effective markets. Further, we set out a framework for *how* to include lived experience evidence, based on three principles: (1) meaningful and flexible participation by people with disability; (2) accessibility; and (3) amplification of the voices of people with disability. We argue that, with this approach, there is a greater likelihood of disability markets being steered in a way that reflects the nuances of the lives of people with disability, beyond what usual service, pricing, and supply and demand information can show.

To make this argument, our paper first explains the concept of quasi-markets and the need for market stewardship. We then discuss the way evidence is used in market

stewardship and make a case for the inclusion of lived experience evidence. Finally, we offer the framework mentioned above for *how* to include lived experience evidence.

Quasi-markets and the need for market stewardship

Market-based reform has become a tool of choice for governments around the world in transforming publicly-funded service sectors (Carey et al, 2017; Dickinson, 2017; Fleming et al, 2019). Proponents of such reforms argue they can be effective in driving efficiencies and creating services that are better tailored to what consumers want (LeGrand and Bartlett, 1993; Miranda and Lerner 1995; Girth et al, 2012). Whether this is the case is hotly debated, and there are vast numbers of publications that consider whether or not markets are achieving better tailored services and meeting citizen needs (for example, Warner and Hefetz, 2002). Regardless of this ongoing debate, the reality is that quasi-markets are now central to public service systems in many countries.

Quasi-markets (that is, markets run by government) do not operate like conventional neoclassical markets and require stewardship to make sure they are effective in meeting their policy goals. Conventional markets are based on a supply and demand relationship, where some individuals miss out on or receive lower quality of a product or service. Further, unlike conventional markets, change in price does not provide information about variations in supply and demand. Information about supply has to be gathered and distributed in other ways. Within quasi-markets, governments play a role in attempting to balance considerations of efficiency and equity (LeGrand and Bartlett, 1993). In this sense, there is a crucial role for market stewardship within quasi-markets to guard against market failure.

Market failure can take many forms. It can variously mean: there are insufficient numbers of providers available; providers undergo issues meaning they can no longer deliver services, leading to individuals being without essential support; providers do not give individuals what they want; services are unsafe or of poor quality; and a range of other issues where individuals are unable to secure the services they require using their budget. We have seen market failure emerge in relation to a range of quasi-markets, including childcare (Sumision, 2012) and employment (Considine et al, 2015).

One example of where a quasi-market is currently being expanded is in Australian disability services. Following many years of campaigning and advocacy by disabled people's organisations and allies (for example, the Every Australian Counts campaign, led by the National Disability and Carer Alliance) and ratification of the *UN Convention on the Rights of Persons with Disabilities*, Australia designed and began implementing a new system for disability services in 2013: the National Disability Insurance Scheme (NDIS). The NDIS is an individualised funding scheme for eligible people with disability who have significant and permanent impairments. As Needham and Dickinson (2018) note, there are dual logics inherent in the design of the NDIS. On the one hand, the scheme was a response to calls over many years from people with disability, with the rationale being to give users increased choice and control over the services they access; that is, the NDIS is a way of realising the human rights of people with disability. On the other hand, the NDIS is also a clear exemplification of the idea that the role of government should be small, confined to setting the rules of the game and funding services, with markets taking the role of ensuring effective and efficient supply. These logics sit relatively comfortably alongside one another

in the design, but frequently generate tensions in the scheme's implementation. Given some of these tensions, market stewardship has increasingly been recognised as necessary to ensure effective operation of this quasi-market (Gash, 2014; Carey et al, 2017; Reeders et al, 2019). Yet, research examining how to steward quasi-markets in the NDIS and more broadly has found that, at present, we have a highly limited evidence base regarding what levers exist for governments or other actors and how effective these are (Malbon et al, 2019; Carey et al, 2020). Yet, despite limitations in research-based evidence to support market stewardship, policymakers must still make decisions and take action.

The use of evidence in market stewardship

In this section, we consider the types of evidence that governments draw on in market stewardship. We argue that to date, market stewardship evidence typically focuses on inputs and outputs, not the outcomes of care processes (Carey et al, 2018). Data such as number of services delivered, price points, and numbers of providers in a market are some of the types of evidence used to assess whether a market is functional (Productivity Commission, 2017; NDIA, 2019; Tune, 2019). For example, there is considerable concern over parts of the NDIS market where there are insufficient providers, with stewardship actions focused on moving more providers into those markets (Earnst and Young Consulting, 2019). This focuses on inputs, but does not take into consideration either the quality of the inputs or outcomes for individual service users. Another example of this inputs-focused approach is a continued focus on 'price points' in the scheme, to ensure providers are sustainable. While it is important to keep providers in the scheme, the focus on price is divorced from a discussion of quality or evaluation of outcomes (NDIA, 2017; Tune, 2019).

As the previous examples demonstrate, the types of data typically used for market stewardship may give some broad perspective on the market, but they tell us little about the outcomes for people with disability: whether the market is working for them, if it results in the services they need, how they experience those services, what the options available are like from their perspective and how they, as users of services, might suggest solving problems in the market. This situation aligns with a long history of research and policy systems generating data about people with disability that is overly positivist and disconnected from their lived experiences (Dowse, 2009). It also mirrors data systems that have been critiqued by disability advocates for commodifying and objectifying people with disability, and that have led to advocacy calls for 'Nothing about us without us' (Goodley, 2011).

Furthermore, a perspective that simply examines inputs and outputs also tends to conceptualise governments as fulfilling the function of market stewardship alone. However, although governments have responsibility for ensuring how market stewardship is undertaken, and some parts of market stewardship can only be done by government (that is, setting prices and rules for quasi-markets), this does not mean that governments *alone* are market stewards. This function conceived more broadly recognises the role of local-level actors in fulfilling it, including but not limited to service providers, users of services, advocacy organisations and other intermediaries. Drawing on examples from the NDIS, Box 1 provides some suggestions of ways that evidence for market stewardship may be shifted when these groups work together and lived experience is drawn on.

Box 1: Examples of market stewardship decisions that lived experience could usefully inform

Assessing the risks of market failure in rural and remote areas

There is currently significant concern that there will be NDIS market failure in rural and remote areas, due to insufficient competition to incentivise service providers to deliver in these regions. Looking at this issue simply on a basis of inputs, market stewards might take action to incentivise additional service providers into these areas by, for example, offering differential pricing or pump priming providers. However, what this traditional approach does not show is the quality of the services in these areas and whether people with disability actually get what they want from the existing services – and these are inherently lived experience concerns. If market stewards instead drew on outcomes data driven from a lived experience perspective, they might find the current single provider in a region highly effective in tailoring services to the needs of local individuals. Therefore, the risk of market failure might be considered lower and/or the solution might instead be to provide further support to the single provider.

Assessing whether essential services are personalised and high quality

Some services commonly purchased within the NDIS are essential for daily living – for example, personal care services (that is, showering, dressing, feeding). The essential nature of these services means that people with disability will purchase them irrespective of quality from providers because they need them to go about daily life. However, the traditional input and output data used by market stewards showing that these services are purchased does not allow assessment of whether the services are personalised and high quality – for example, whether they are culturally safe and sensitive and accord with the needs of individuals. The essential nature of the services may mask these issues. Drawing on lived experience evidence of how people with disability perceive these essential services, beyond only input and output data of how often they are used, would provide a better understanding of the marketplace, especially whether people are purchasing services only because they are essential or rather because they are actually high quality.

In many other disability policy and research settings, the response to disconnection of evidence from lived experience has been the application of a range of collaborative approaches for bringing ‘knowledge from experience’ together with evidence-based policy and research (Smith-Merry, 2020). These approaches aim to bring ‘formal evidence together with local knowledge and experiential expertise’ (Durose and Richardson, 2016; Blomkamp, 2018: 733), thereby increasing the likelihood of better connecting with the outcomes that users of services seek on the ground. Furthermore, these types of approach aim to make lived experience information interpretable by policy actors (Smith-Merry, 2020), meaning there is a mechanism to help policy actors understand what the potential outcomes of policy are like in real people’s lives. These approaches are also enmeshed with a growing movement towards user-led services, supported by empirical evidence that service users are able to feed sophisticated understandings of outcomes into policy design processes, but

only where there are mechanisms for their thorough inclusion in the policy process (Beresford and Branfield, 2006).

Within public policy, mechanisms for implementing these ‘knowledge from experience’ approaches range from *co-design* and *co-production* (that seek the involvement of users of services as active participants in designing and delivering services, respectively, together with other policy actors), to *human-centred design* (that more minimally or less actively involves users of services, but still prioritises their needs and aspirations based on information they provide) (Blomkamp, 2018). A similar range of processes are used within disability research more generally, where the models of inclusive, participatory and action research also seek to involve people with disability in actively guiding and directing the creation of knowledge about disability, rather than only seeing them as passive research participants (Zarb, 1992; Balcazar et al, 1998; Walmsley, 2004; Garcia-Iriarte et al, 2009).

Despite the extensive use of these approaches for bringing ‘knowledge from experience’ together with evidence-based policy and research, and the increasing focus on user-led services (Beresford and Branfield, 2006), it appears that these approaches are yet to be applied to stewardship of disability markets. Drawing on precedents from where this range of approaches have been applied elsewhere, the remainder of this paper therefore suggests three key principles as a starting place for how lived experience evidence may be drawn into market stewardship. Recognising that including lived experience evidence is likely to be difficult in this policy setting that has not so far broached this approach, the paper aims to stimulate thought not only on why lived experience is important for market stewardship, but also, in a practical sense, to give guidance on *how* lived experience evidence may actually be included within market stewardship processes.

Principles for including lived experience evidence within market stewardship

Based on precedents from the range of approaches for drawing ‘knowledge from experience’ into policy and research discussed above, we suggest the following three principles for the inclusion of lived experience evidence from people with disability within market stewardship. The principles contain options for both a strong *co-design* or *co-production* approach, as well as a less intensive *human-centred design* approach, to show different options for how such evidence may be included (Blomkamp, 2018).

1. Invite meaningful and flexible participation from people with disability

A fundamental principle of including lived experience evidence in market stewardship is that there need to be meaningful and flexible ways of inviting the participation of people with disability. This means paying attention to how people with disability can and want to contribute, and making sure their participation is not tokenistic.

Involvement of people with disability should be part of the model of market stewardship. As demonstrated by the range of approaches for the inclusion of ‘knowledge by experience’ discussed above, there are different options for how this might happen. A *co-design* or *co-production* style approach would ensure that people with disability are contributing directly and purposefully to the design and implementation of market evidence and decisions from a defined and designated role within a market

stewardship team. In comparison, a *human-centred design* style approach might occur where existing market stewards have a mechanism to collect lived experience evidence from people with disability that have a bearing on stewardship decisions, and then steward accordingly. These two models differ in how directly people with disability contribute to market stewardship decision making, with the first involving active and formative input, and the second involving the use of lived experience statements from people with disability as part of the evidence base on which other decision makers identify actions.

There are follow-on implications of either model. For instance, if people with disability take up a *co-design* or *co-production* style role, then they will need to understand much more about the relevant market information and about what market stewardship is, how it works and the language and terminology of the market. In comparison, if their lived experience statements are included as evidence in a *human-centred design* style role, then a lesser level of knowledge may be suitable, as other people would be involved in interpreting their words and/or information into the language of the market and into concrete decisions; that is, the onus would be on government and other decision makers to understand the lived experience information from people with disability in market terms, not on people with disability themselves.

Irrespective of which model is used – or if options for both are used alongside each other – it is important that neither role is tokenistic, and that people with disability are truly contributing their lived experience evidence in a meaningful way. In this respect, it is important that it is not only one single person with disability contributing alone – even if using the model of having a designated role for a person with disability to contribute directly, it is important that more than one such role is created, so that the voices of different people with disability can be heard (including people with different types of disability) and, as a group, they can have a presence within evidence generation for the market. Further, guarding against tokenism would also require market stewards and policymakers to understand and appreciate the many forms that lived experience testimony can take, and to avoid a narrow conceptualisation of what counts as evidence for market stewardship. In practice, this may mean being able to accommodate a range of communication methods and support needs within the evidence generation process – this links to the issue of accessibility, which is the basis of the second principle of including people with disability in market stewardship, discussed further below.

2. Make market stewardship information accessible to people with disability

A second key principle is that for people with disability to contribute lived experience evidence to market stewardship, information about the market and about the activities of market stewardship needs to be accessible to them. Here, accessibility means that the written information, concepts and considerations involved need to be presented in a way that people with disability can ‘seek, receive and impart information and ideas on an equal basis with others’ (UNCRPD, 2006, Article 21). While this sounds straightforward, given that lived experience evidence has not so far usually been part of market stewardship, there is a likelihood that much of the background information to market stewardship is not so far expressed in an accessible manner.

The accessibility of information about market stewardship would be particularly (although not exclusively) important where people with disability are involved

through the *co-design* or *co-production* style approach discussed above, where they actively contribute from a designated role for the contribution of lived experience to market stewardship. For such roles to be meaningful, there is a need for any tools and information supporting the role to be made visually, technologically and cognitively accessible. Ensuring accessibility would mean producing the relevant information for the roles in well-known accessible formats, such as sign language (for example, Auslan, British Sign Language), large-print and Braille, and ensuring it meets international accessibility standards, such as the Web Content Accessibility Guidelines (WCAG). However, producing the tools and information accessibly also means considering other emerging accessible formats, including providing Easy Read information¹ for people with intellectual or learning disabilities who want to be involved (Change People, nd). Furthermore, accessibility is not only about producing information in accessible formats, but also about providing appropriate supports – which often means having skilled and trusted support people available to assist (Meltzer et al, 2018). Overall, without accessible formats and support people available, people with disability are unlikely to have access to the necessary information about the market and market stewardship activities to perform their role. Importantly, which accessible formats are provided will have a direct relationship to which people with disability can become involved in the decision making, as different formats cater to people with different support needs. Thus, to avoid market decisions with gaps for people with particular disabilities or support needs, a comprehensive set of accessible tools and information is required.

Further, to be truly accessible, there is also a need to bridge the language of the market and the language that people with disability are likely to use in their everyday lives. There is already common critique within disability advocacy and research of how the lives of people with disability are frequently converted into the language of the service sector – where people with disability become ‘service users’, the people they share important relationships with become ‘informal supports’, their self-care routines become ‘personal care’, or their social lives become ‘community participation’ (Neary, 2018; Shannon, 2019a; 2019b; Meltzer and Davy, 2019). It is therefore important to understand that while market stewards currently commonly reference aspects such as inputs and outputs or economic concepts such as ‘thin markets’, people with disability are unlikely to see the realities of their everyday lives and services in these terms, and it is important to be sensitive to the likelihood that they will not want to speak of their own lives and service experiences using depersonalised terminology. Being accessible then means drawing together people’s everyday way of speaking with the usual market terms and not requiring people with disability to always ‘talk the language of the market’ to contribute to decisions – yet there should still be capacity to understand their lived experience using an economic framing when required. Attaining this balance may be difficult, but it is an important component in creating accessibility within market stewardship evidence.

3. Amplify the voices of people with disability

A final principle for the inclusion of lived experience evidence in market stewardship is ensuring there are strategies for amplifying the voices of people with disability within the evidence generation process, so that market forces can respond to what

people with disability actually say they need, not what policymakers, service providers and other market stakeholders may determine they need.

There is a long history of professionals from a range of fields (including medicine, social policy and social support), as well as family, speaking *for* people with disability, rather than advocating *with* them and enabling others to hear their perspectives (Jones, 2004; Dowse, 2009). This situation has meant that charity, dependency and welfare models of disability have prevailed in the past (Goodley, 2011). While the move to personalisation and a market-driven model of disability services is meant to represent a more empowered position for people with disability, there is substantial evidence that people with disability still need significant social capital to be able to advocate for themselves on an individual level within this model, and that, without sufficient social capital, there is a danger of their voices not being heard and of them not getting what they need (Malbon et al, 2019; Carey et al, 2019).

This history and current situation has implications for the roles of people with disability in market stewardship decision making, as it implies a need for purposeful amplification of the voices of people with disability themselves and a structure to ensure their views are acted upon. Currently, much work within disability advocacy focuses on this type of amplification, including by offering training in leadership so that people with disability feel confident in their roles, designing organisational structures that prioritise hearing from people with disability, making lived experience appointments so that people with disability are situated within key governance and decision-making roles, and providing resources for the support that they may need in their roles and to have their voices heard (Meltzer et al, 2018; Power et al, 2013; 2016; Disability Leadership Institute, <https://disabilityleaders.com.au/>). Making sure that these types of amplification approaches are also common where people with disability are drawn into market stewardship activities is important, and will help to ensure that the evidence heard is really that of people with disability themselves.

Conclusion

In this paper, we identified how the types of evidence that are often drawn on for market stewardship so far usually pertain to inputs and outputs, without sufficient regard paid to outcomes for people with disability. We argued that this is a significant gap given that personalisation and individual funding schemes are intended to give people with disability greater choice and control, and if markets are not guided by information about outcomes, then this choice and control cannot be achieved. We therefore set out to examine how lived experience evidence might be drawn on within market stewardship, to give greater information about outcomes from the perspective of people with disability themselves.

Based on precedents from the range of approaches for drawing ‘knowledge from experience’ into policy and research, this paper considered how people with disability may contribute lived experience evidence to market stewardship and proposed three principles for this purpose. First, the inclusion of people with disability in market stewardship needs to be both flexible and meaningful, with consideration given to whether people with disability have a more active and substantive *co-design* or *co-production* style role or a less substantive *human-centred design* style role, where others make decisions based on their testimonies. Second, information about market stewardship needs to be accessible to people with disability, particularly where they

take up a *co-design* or *co-production* role. This includes both the production of relevant information about the market in accessible formats, with support people in place, and an understanding that people with disability will not always want to 'talk the language of the market' when they contribute lived experience evidence. Finally, there need to be structures for amplifying the voices of people with disability, so that it is truly their empowered perspectives that become market stewardship evidence.

With these principles in place, we argue that there is a greater likelihood of disability markets being steered in a way that reflects the nuances of the lives of people with disability, beyond what usual service, pricing, and supply and demand information can show. With these mechanisms for including lived experience evidence in place, we suggest that there will ultimately be more opportunity for understanding the outcomes from disability markets, not only inputs and outputs, and therefore that disability markets will have more capacity to truly meet and foster choice and control for people with disability.

Notes

¹ Easy Read information is designed for people with intellectual/learning disabilities and/or low literacy. It has only the key points of information, simple phrasing, large-print text, lots of white space on the page, sans-serif fonts and pictures/graphics to support comprehension (Change People, nd).

Research ethics statement

The authors have declared that research ethics approval was not required since the paper does not present or draw directly on data/findings from empirical research.

Contributor statement

All authors (AM, HD, EM and GC) contributed to the conceptualisation, literature analysis and writing for this paper.

Conflict of interest

The authors declare that there is no conflict of interest.

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