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Advocacy as market stewardship in social care quasi-markets

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ABSTRACT

Quasi-market approaches to social care provision are being utilized across the world, with stewardship of these markets becoming an area of interest and concern for governments and scholars. The market-stewardship literature mainly focuses on the role of central governing bodies, however non-government actors also play important stewardship roles. This paper examines stewardship activities conducted by advocacy organizations in a social care quasi-market – the Australian National Disability Insurance Scheme. We argue effective market stewardship requires central agencies to support these activities and suggest development of a distributed stewardship framework joining up work of central agencies with local-level actors.

KEYWORDS Market stewardship; quasi-market; personalization; advocacy

1. Introduction

Recent decades have seen market-based approaches for the provision of social care gaining in popularity with governments across the world, with many countries implementing personalization schemes in areas such as aged and disability care (Dickinson 2017). Personalization aims to increase choice and control for citizens through the use of individual budgets or vouchers which allow consumers to purchase the services and supports which best meet their needs (Dickinson 2017; Carey et al. 2018). Such schemes have emerged in response to growing human rights demands for personal autonomy, empowerment and choice for citizens as well as a perceived need for greater efficiency in government services and spending (Carey and Malbon 2020; Needham and Dickinson 2018; Bovaird 2014). ‘Quasi-markets’, where services are provided by competitive providers but purchasers of services are funded by the state, have become a common way of implementing personalization schemes, being seen as a way to balance the dual agendas of choice and control for participants and efficiency for governments (Carey, Malbon, and Blackwell 2021; Malbon et al. 2019). However, recent research argues some users may derive more benefit from personalization schemes due to holding greater levels of social, cultural and economic capital, which enable them to better navigate complex administrative processes (Carey, Malbon, and Blackwell 2021; Malbon, Carey, and Meltzer 2019) with inequalities further exacerbated due to the way personalization systems are designed (Carey, Malbon, and

Blackwell 2021). Ensuring social care quasi-markets are functioning optimally is important on a number of levels. Firstly, the functioning of these markets ensures that care needs are being met. Secondly, there is a broader equity requirement by governments regarding the provision of essential state-funded services. A crucial part of ensuring equity is enabling participants to access, navigate, and exercise choice and control in personalization markets. The Australian case to date shows this requires robust market stewardship (Carey, Malbon, and Blackwell 2021).

Most literature on market stewardship of care quasi-markets has positioned government as the sole actor in supporting market functioning (Dickinson et al. 2021; Gash et al. 2014). However, a small but growing body of literature mainly focused on the Australian National Disability Insurance Scheme (NDIS) has started to examine what role local and non-government actors play in social care quasi-market shaping (Carey and Malbon 2020; Malbon and Carey 2021; Kelk 2020). This study expands on this work by investigating the market stewardship role of disability advocacy organizations in the NDIS. Although these organizations alone cannot fulfill the sole role of market stewards they form an important part of the local market system. Understanding their role in quasi-market shaping can help identify better ways to link the actions of government and non-government actors to create more effective market stewardship in care quasi-markets such as the NDIS.

Through interviews with representatives from disability advocacy organizations, we examine activities these organizations are undertaking that contribute to market stewardship in the context of the NDIS. The NDIS is one of the largest and more administratively complex personalization schemes in the world, requiring a diverse national disability care market to meet the policy aim of choice and control for participants (Dickinson et al. 2021). As such, market stewardship of the NDIS has been frequently raised as an area of concern (Dickinson et al. 2021; Commonwealth Government of Australia 2013). We find advocacy organizations playing a large role in helping the market function through a range of activities including information provision, one-on-one advocacy, peer support and systemic advocacy.

While previous market stewardship work has focused on the supply (or service provider) side of the market, in social care quasi-markets where equity of access to the market is important, the demand side of the market is also a vital component of market stewardship. Many of the stewardship activities of advocacy organizations are helping shape the market from the demand side. This is important for considering how market stewardship of social care markets should be structured and administered. Based on our findings we suggest market stewardship in the NDIS is a distributed activity rather than being solely the domain of central government. This has implications for the stewardship role of government where rather than simply acting to 'intervene' when there are market issues, government takes on a much greater supporting role by identifying and bolstering local-level stewardship activities. Thus, market stewardship of social care quasi-markets requires joined up working between government and non-government actors. Recent work on 'joined up government', 'collaborative governance' and 'whole of government' approaches (Askim et al. 2009; Carey and Crammond 2015; Emerson, Nabatchi, and Balogh 2012) can help inform on how distributed stewardship could work in social care quasi-markets.

2. Background

In this section, we provide background on stewardship of social-care quasi-markets and challenges associated with stewarding these markets. We then discuss the NDIS, the personalization market used as the case study in this research and the structure and function of disability advocacy in Australia before presenting the methods and findings.

2.1. Market stewardship in social care quasi-markets

Social care quasi-markets cannot simply operate in the same way as standard markets because they are intentionally implemented and shaped by government for the purpose of delivering social supports (Kelk 2020). As such, these quasi-markets must also reach different standards and have different goals than traditional markets as governments have a responsibility to ensure citizens can access services and supports in an equitable way (Dickinson et al. 2021). Stewardship of these markets thus also needs to be different to that of conventional markets, especially since care market failures can have dire consequences (Dickinson et al. 2021). Market stewardship in the context of public service quasi-markets has not been well defined but is broadly conceptualized as actions and regulations to ensure the market can function effectively so the policy goals and outcomes for which it is intended can be realized (Kelk 2020; David and West 2017). As noted earlier, the literature has almost exclusively focused on actions governments need to take to successfully steward social care quasi-markets (Dickinson et al. 2021; Malbon and Carey 2021; Gash et al. 2013). For example, a number of authors have argued there are important roles for central government in stewarding care markets which include acting as the principle rule setter for market operation in areas such as eligibility, regulatory requirements on providers, and workforce issues including quality and safeguarding (Needham and Dickinson 2018; Malbon et al. 2019; Gash et al. 2013). However, when central governments hold sole responsibility for market stewardship issues can arise, such as a lack of control over informal rules developed at a local level (Malbon and Carey 2021) and information asymmetries where information flows are reduced between local markets and central governing bodies (Carey and Malbon 2020; Ostrom 2010; Hayek 1945).

In response to issues arising over central government stewardship of social care quasi-markets some scholars have begun to focus on stewardship actions of local level and non-government actors. Malbon and Carey (2021) looked at the role of Local Area Coordinators in the Australian National Disability Insurance Scheme and found that although they can perform important market shaping activities these are occurring at the periphery of their work due to the administrative structure of the scheme. Carey and Malbon (2020) also conducted a case study of an independent information provision organization, concluding that information sharing on availability and quality of services is an essential part of quasi-market stewardship. This is a point also made by Kelk (2020) in her exploration of consumers information preferences to inform market stewardship. As she discusses, while government may be positioned as the main market steward there are often many actions being undertaken by a variety of non-government actors who may not be seen as formal market stewards, but whose role influences market development and facilitates choice and control for consumers. This is important to consider not just from a marketization perspective but to ensure the social justice aims that underpin personalization schemes can be met.

In personalization systems service users are positioned at the centre of their own care, where they are expected to be active agents able to effectively utilize the system to meet their care needs. However, the unprecedented emphasis placed on the ability of individuals to be able to advocate for their own needs and navigate complex administrative systems means individuals with higher levels of social, cultural and economic capital (e.g. good literacy, higher socio-economic status and English speaking) are more likely to derive greater benefit from personalization systems (Carey, Malbon, and Blackwell 2021; Malbon, Carey, and Meltzer 2019). This has the potential to not only entrench existing inequalities but widen them (Malbon, Carey, and Meltzer 2019). In this context, activities focused on ensuring citizens are able to equitably access and navigate personalization systems become important market stewardship actions in their own right, yet have received little attention in the quasi-market stewardship literature. As Malbon et al. (2019) argue, market shaping in social care quasi-markets ‘must go beyond ensuring minimum protections and efficient use of resources and extend to ensuring that public good is fairly distributed’ (9).

A number of theories and frameworks examining governance occurring outside of central structures and at different levels, including by non-government actors and communities, have been developed in recent decades (Sovacool 2011). These include ‘joined-up government’, collaborative governance, and polycentric governance approaches (Carey and Crammond 2015; Emerson, Nabatchi, and Balogh 2012; Christensen and Laegreid 2006; Keast 2011). Key to these approaches is the idea of ‘joining up’, integrating and facilitating interactions and collaboration between different levels of decision-making from the local to central. For example, Carey and Crammond (2015) developed a joined-up government framework with a specific focus on increasing capabilities for joined-up work between local and central governance. This emphasizes the need for actions at both the local level such as information sharing, local control, and networking between government and non-government actors, as well as development of higher order capabilities including strategic focus on collaboration, changes to structures and processes, and a mandate for change to occur. These types of approaches are useful to consider for quasi-market stewardship, which as we demonstrate in this paper is a distributed activity occurring at both local and central levels. Effective stewardship will need to consider ways in which the activities across different actors and levels can occur with integration and collaboration.

By investigating the market stewardship actions of advocacy organizations, we contribute to advancing knowledge on how social care quasi-markets can best be stewarded and the stewardship role different actors play within the system. As we explore in the discussion, this can help with the development of frameworks to support the joining up of stewardship actions occurring at a local level with actions of central agencies.

2.2. Case study: National Disability Insurance Scheme

Australia’s National Disability Insurance Scheme (NDIS) is one of the nation’s largest social policy reforms and its most ambitious foray into developing a personalization quasi-market (Olney and Dickinson 2019). The central aim of the NDIS is to give participants choice and control over the services and supports they use through the provision of individual budgets. The scheme commenced in 2013 at a number of trial sites and was then progressively rolled out across the

country with almost full rollout achieved in July 2020 and 432,649 participants accessing the scheme (Roll out in Western Australia began late, and is earlier in its implementation stage) (NDIS 2020). Participants have a diverse range of ages and disability type and come from all geographical areas across Australia including urban, rural, and remote areas.

The administration of the NDIS rests with the National Disability Insurance Agency (NDIA), an independent statutory agency tasked with implementing the scheme. Officially, the NDIA holds prime responsibility for market stewardship with its Market Enablement Framework stating this involves ‘monitoring, evaluation, oversight and, where necessary, intervention’ (NDIA 2018). Since 2018 the NDIS Quality and Safeguards Commission has had a market stewardship role via its ability to suspend or ban NDIS service providers. The NDIA describes its stewardship roles as including building consumer and community capacity, providing information, changing market settings (such as pricing guides, operational guidelines and safeguards), and commissioning a service if there are significant risks or other alternatives are not available (NDIA 2018). However, there has been contestation over who is actually responsible for stewardship of the NDIS, in particular, for ensuring participants can exercise true choice and control and that disability markets are robust with a sufficient and diverse range of providers (Dickinson et al. 2021; Hansard, Commonwealth Government of Australia 2018; Joint Standing Committee on the NDIS 2018). As Kelk (2020) points out there are also many stakeholders including federal and state bodies, advocacy groups, and peak bodies who may perceive they have a role in shaping the NDIS market. As we explore in this paper advocacy organizations are one such group conducting a wide range of stewardship activities.

Those eligible for the NDIS (have a permanent and severe disability and aged 65 or under) can apply to be a NDIS participant via the NDIA using an ‘access form’ and also need to provide evidence from medical and health professionals or other service providers to make a case for eligibility. Once eligibility is approved participants attend a planning meeting to set goals and decide which services and supports are necessary. After a plan is in place the onus is on the participant to identify and secure services from a service provider market. Originally, this was supported by Local Area Coordinators (LACs), however over the implementation of the scheme LAC roles have become almost exclusively focused on plan creation rather than plan implementation (Malbon and Carey 2021).

Recent research has found the NDIS to be administratively burdensome for individuals (Carey, Malbon, and Blackwell 2021) with participants experiencing ‘administrative pain points’ (p.5) from accessing the scheme, obtaining a plan and ensuring it meet needs through to implementation of plans. Similarly, in a review of the NDIS Mavromaras (Mavromaras et al. 2018) found 96% of participants needed the assistance of others to navigate the planning process but also that those who could access an advocate had plans that increased in dollar amount. Other studies have also demonstrated participants perceive their choice and control has been limited by issues such as difficulty conveying their needs and goals around services and supports and a lack of knowledge over which services exist (Olney and Dickinson 2019; Warr et al. 2017; Mavromaras, Moskos, and Mahuteau 2016). This highlights the need for independent advocacy as a key component of good market stewardship to support choice and control and enable equitable access to, and use of, the scheme.

2.3. Australian disability advocacy

The Australian Government Department of Social Services defines disability advocacy as ‘Acting, speaking or writing to promote, protect and defend the human rights of people with disability’ (Department of Social Services 2018). Independent disability advocates assist people with complex and often serious issues (Department of Social Services 2018) which includes supporting them:

- To understand their rights
- Through tribunals such as the Administrative Appeals Tribunal
- To resolve issues and provide information on government benefits and support services

There are currently around 110 government funded independent disability advocacy organizations in Australia across all states and territories (AFDO 2022). These organizations promote their services through a variety of means including social media, webpages, phone lines and community expos, as well as referral from other parts of the system such as the health system and NDIS. It is important to note that independent advocacy is not available as a NDIS funded support in recognition of the conflict of interest that may arise when a NDIS service provider also provides advocacy services. Additionally, the *National Disability Insurance Scheme Act* (Commonwealth Government of Australia 2013) stipulates that an independent advocate cannot be:

- A staff member of the NDIA
- A staff member of the NDIS Quality and Safeguards Commission
- A registered or unregistered NDIS provider, including support coordinators

In Australia disability advocacy funding is currently a shared responsibility between state and territory governments and the Federal Government, with the Federal Government funding around half of all disability advocacy services through the National Disability Advocacy Program (NADP) (Department of Social Services 2016). However, advocacy funding has been described as ‘woefully inadequate’ with only 0.03% of people with disability receiving support through the NADP (Victorian Council of Social Service 2016). Additionally, the roll out of the NDIS has brought changes to disability advocacy funding resulting in uncertainty around continuation of many advocacy organizations due to the way funding is shared between state and federal governments (Daly, Barrett, and Williams 2017). As such, many organizations have needed to conduct intense lobbying activities to ensure funding continues (Smith 2018). These activities themselves are often unfunded. This underscores the importance of recognizing the market stewardship role of advocacy organizations in the NDIS and the need for dedicated and ongoing funding as part of a distributed stewardship framework.

3. Method

This study is part of a broader research program examining the implementation of the NDIS. Ethics approval was received from the University Human Ethics Committee, UNSW (Ethics number HC200396). The research aims to investigate the market stewardship activities being undertaken by independent disability advocacy

Table 1. Location of advocacy organizations interviewed.

State/Territory	Number of organisations interviewed
Northern Territory	2
Tasmania	2
South Australia	3
Western Australia	3
Queensland	3
New South Wales	3
Victoria	4
National	5

Table 2. Disability type represented by advocacy organizations interviewed.

Disability type	Number of organisations interviewed
Spinal cord injury	1
Indigenous people with disability	1
Down Syndrome	1
Autism Spectrum Disorder	1
Intellectual disability	2
Children and young people with disability	2
Developmental disability	2
All disabilities	15

organizations who assist people in the NDIS. To investigate the types of activities being undertaken, 34 individuals from 25 different advocacy organizations across Australia were interviewed (see [Table 1](#)).

Organizations ranged from representing all people with disability to being specific to a disability type (i.e. autism, spinal cord injury and intellectual disability) (see [Table 2](#)). All organizations were not-for profit and were funded by either the NDAP or state or territory government funding, thus being independent of the NDIS.

To recruit participants, an online search was conducted to identify disability advocacy organizations across Australia. A total of 123 organizations were identified and emailed an invitation to participate in the research with a specification for participants to be someone at the organization involved in ‘helping people get what they need from the NDIS and/or helping the NDIS work better’. Twenty-five organizations agreed to participate.

Interviews were conducted over the phone using a semi-structured approach with questions focusing on the types of activities being conducted to help people get what they need from the NDIS, challenges involved with these activities, and which activities have been most successful. Interviews were recorded and transcribed verbatim by a paid transcription service. Interview data was coded using an interpretivist approach with ‘like’ data grouped into categories (Blaikie 2010) with the use of NVivo qualitative data analysis software. More focused coding was then completed on the initial categories to create more refined codes (Strauss 1987). The main codes identified were activities directed at participants, health care professionals, and systemic advocacy activities. These are explored in the findings section below.

4. Findings

Our interviews show advocacy organizations are playing a significant role in supporting NDIS participants to understand, navigate, access, and gain full benefit from the scheme. This is being achieved through a variety of activities, such as information

provision, one-on-one advocacy, capacity building and peer support. Organizations are also participating in systemic advocacy activities as well as providing support for other actors in the system such as healthcare professionals.

As this interviewee identifies, although this work may not be directly perceived, or labelled, as market stewardship the implicit assumption is that it will contribute to an improved system:

The organization has a long history but in recent years it's been funded by the Commonwealth Government directly to provide an advocacy service to people with disabilities. The intention, which isn't explicit but I'm sure is the case, is that we will be part of the process of making the NDIS work better [P11]

In the sections below, we explore in more detail the types of market stewardship activities advocacy organizations are conducting and some of the challenges they face working in the NDIS system.

4.1. Information provision

Research shows participants' level of knowledge and understanding of the system or 'bureaucratic accessibility' significantly influences how well choice and control can be exercised in personalization systems (Carey, Malbon, and Blackwell 2021; Malbon, Carey, and Meltzer 2019; Fleming et al. 2019). Personalization schemes require participants (or their representatives) to have exceptionally high skill levels in managing budgets and navigating extremely complicated administrative systems (Malbon, Carey, and Meltzer 2019). Almost all organizations interviewed commented on the administrative complexity of the NDIS:

The scheme is far more complicated and far more bureaucratic and far harder to navigate than anyone could have ever imagined. [P4]

As one advocate pointed out, the system is so confusing that even staff working as advocates themselves struggle to navigate it:

We've got people that are working in this space, highly functional people that talk about the fact that it is so hard . . . they just sit there, going, "I struggle with this system so much" . . . And we can't help but think, Gosh, if we've got staff feeling like this, what about everyone else? [P24]

As a result organizations report a large part of their work involves information provision to support participants' understanding of the scheme. This takes a variety of forms including phone and internet assistance, in-person assistance and provision of written materials. As this interviewee explains, advocates are acting as translators of complex information:

. . . half of the barrier at the NDIA is that they've created a whole new language for people to understand . . . and the language continues to change, and it's not in the lexicon of people with disability just yet to understand that . . . We often act as a translator to be able to disseminate. [P10]

In a scheme of high administrative complexity these types of translation activities are essential to support the market, given informed consumers are central to market effectiveness.

Advocacy organizations are also providing one-on-one advocacy for those requiring extra support. We find organizations assisting people on an individual basis across the entire spectrum of NDIS involvement from accessing the scheme, planning their supports and finding providers:

We support people to enter the NDIS and address any issues they may have in testing their eligibility, their planning meeting, working with providers, engaging providers, we support all of their life with the NDIS. So we do a lot of one-on-one work with people and sometimes it's relatively quick and sometimes takes weeks. [P12]

A significant part of advocates work also includes assisting participants in a tribunal setting. If participants find their plan unsatisfactory they can have it reviewed by the NDIA. If this is unsuccessful, the next recourse is appeal at the Administrative Appeals Tribunal (AAT). Recent reports and a major independent review of the NDIS have found what can be funded under the NDIS is confusing and ambiguous (Productivity Commission 2017; Tune 2019) resulting in a growing number of appeals to the AAT. Many advocates discussed how those with advocacy support to take their review to the AAT are able to gain more from their plans than those without this support:

We had a two-speed economy where people with advocacy would have a bit of a fight and end up with what they wanted and in some cases more than what they needed, whereas people without advocates were just stuck. So that's a lot of a concern. [P11]

This finding is significant from both an equity and market stewardship perspective. When a growing number of participants are forced into the situation of having to resort to an appeals process to gain access to services and supports they are entitled to this curtails choice and control, which is essential for the market to work as intended. Further, from an equity point of view many participants may become overwhelmed or unable to go through a stressful legal process:

The feedback I had from him was that everything was just overwhelmingHe didn't understand the process ... He was too scared and intimidated by NDIS and the lawyers and the requests that they were making of him. In the end he just sent an email to the lawyers going, "You know what. I give up. You guys have won. I don't want access to this horrible scheme of yours." It's sadly not the first story, and it won't be the last. [P11]

The independence of advocacy organizations from service providers and the NDIA is also an important factor in market stewardship. For a market to function well consumers need access to trusted sources of help and advice to support their decision making and enable them to purchase services in a complex environment (Kelk 2020). Many advocacy organizations discussed how their independence from the NDIA was an important way to build trust with participants who may feel fear or intimidation in having to interact with the larger system of the NDIS who are funding their supports:

... unfortunately, with the NDIA ... people don't get the response that they need or are communicated with in a way that makes them feel intimidated to pursue it ... There's a lot of fear, it's a big system ... there's a lack of confidence in having negative or unproductive conversations with your same body that's funding you. You'll find people will be reluctant to keep pushing someone within the NDIS because they don't want to be perceived to be a problem. [P35]

Independence from service providers is also important to reduce conflict of interest and maintain integrity within the system:

There needs to be people that say, “We’re actually not a service provider. We don’t compete with service providers. We don’t want to offer you anything. That means you can come to us, doesn’t cost anything, and you will get support for what you need I think there’s fundamentally something about integrity that sits with that, regardless of how good a provider can seem in separating them out. [P31]

Marketized personalization systems are based on the premise that consumers will be able to effectively navigate and make informed choices in their interactions with the system. Our research shows that in reality many participants in the NDIS require extensive support to understand the administrative complexity of the scheme and navigate how it works including appeals processes. This has significant implications for market stewardship given the work of advocacy organizations is directly contributing to increasing the effectiveness of the demand side of the market.

4.2. Capacity building

Literature examining the information economy as part of a market stewardship approach highlights the need for capacity building and training for consumers (Baxter and Glendinning 2011; Edgman-Levitan and Cleary 1996; Hibbard, Slovic, and Jewett 1997; Maglajlic, Brandon, and Given 2000; Walsh et al. 2012). This was echoed by advocacy organizations who recognize the need to build the capacity of people to be able to advocate for themselves and make choices as consumers in the NDIS market. Organizations are assisting with this through organized workshops designed to increase the skills of participants to autonomously make decisions and advocate for themselves:

We do a lot of self-advocacy workshops where people develop the skills and the confidence to make decisions for themselves and have the confidence to do that . . . that’s across the board and that’s in terms of confidently navigating that with your family, with your mother and father, with your service provider, with the group home that you’re living in . . . So, lots of self-advocacy work. [P21]

Effectiveness of personalization quasi-markets relies on participants being aware they have choice and control over their supports and services. Part of this process is having the ability to change providers if they are not meeting needs or lack quality and being able to envisage new types of services and supports. Capacity-building activities target these skills:

We’ll run workshops . . . talk about raising expectations and values and roles within community, and what this means in dreaming bigger and those sorts of things, and they can be looking at how their NDIS plans can be used more in that capacity. We’ve run this series of those kinds of things to help people think a bit differently about how they can use their funding. [P24]

Peer support groups run and facilitated by advocacy organizations are another way of building participant capacity that helps support the market:

I think within the market it’s a critical piece for people with disability to be able to support each other to navigate the system and the market, whether it’s from the areas of in terms of self-management and being able to share their experiences as employers and navigating that whole space, through to even the basics of planned utilization [i.e. how the NDIS works]. [P32]

In particular, sharing information on services and supports is a significant market stewardship action, linking participants to services they need but may not have been aware of. Some organizations described how peer support groups undertook market shaping by identifying services and supports for others:

A lot of the time [peer group] members tell me, “I didn’t know I could get that but coming to this meeting I know I can get that through the NDIS,” or “I didn’t even know this service was available until you came along, or you told me that you received that service. [P27]

Discussion is also happening on quality of services that in a price set market becomes a key differentiator for participants when they make choices on where to spend their funds. Peer groups play an important market stewardship role in sharing information on what quality supports look like:

Another person would share their story of employing their own support workers . . . Finding the right supports and what you look for in a support worker. And helping people identify what’s a good support and bad support. [P21]

4.3. Supporting other actors in the system

While advocacy organizations direct most of their attention to participants, many commented they also help support other actors in the system including health professionals, service providers and Local Area Coordinators (LACs). In the original conceptualization of how the NDIS would work LACs were positioned as the means to connect people with services, acting as the ‘glue’ in the NDIS market at the local level (Australian Productivity Commission 2011). However, in practice this has not happened to the extent needed, with the role of LACs significantly affected by the politics of the implementation of the NDIS (Malbon and Carey 2021) such as pressure to roll out the scheme ‘on time and in budget’ (p.14). This has seen the LAC role re-shaped around key performance indicators leaving little time for them to spend on market information and market shaping activities (Malbon and Carey 2021). In the light of this some advocacy organizations have stepped in to fill the gap, even when they are not funded for this type of work:

There isn’t that information coming from anywhere else, we try and fill that gap. As an example, I’ve done training – at our cost – this isn’t funded, by the way, but all the training for LAC Partners here in WA around individualized living One of the LAC partners when they’re sitting in the room with people to look at options, they’re not really aware about genuine planning . . . So just building their capacity. So we are trying to fill the gaps, if you like, to support people to think differently. [P31]

This type of activity helps the market function by supporting those working within it to better understand participant needs as well as increasing awareness of the different service and support options available.

Other advocacy organizations are supporting health care professionals, such as doctors and allied health workers to better understand the NDIS. NDIS participants must obtain reports from these professionals to support their claim for services and supports. Yet many interviewees discussed a lack of knowledge among health professionals on NDIS systems and what is required to support a participant’s claim. This can indirectly impact the market when people are unable to access the scheme or access

services they need due to inadequate or incorrect reporting. Resultantly some advocacy organizations conduct activities to support health professionals to write effective reports, which in turn assists participants:

We identified that GPs and Allied Health professionals have very low understanding of what they needed to do . . . So we developed a GP toolkit and then a patient information booklet so that they could understand what are the key things and what does a functional assessment look like. [P32]

These kinds of activities underscore the importance of recognizing that market stewardship actions need to occur across the system and across different actors within the system.

4.4. Systemic advocacy

Information provision and flows between central authorities and local actors is an important component of market stewardship. For example, the provision of data on demand and supply has been argued as key to an effectively functioning public service market (Malbon et al. 2019; Gash et al. 2013). The need to provide information and feedback to the NDIA and government was discussed by many advocacy organizations who dedicate time and resources to systemic advocacy.

As Hayek (Hayek 2007) identifies, the speed at which information flows between local levels to central agencies can be a problem in centralized systems, such as the NDIS, with negative impacts on market functioning. A common theme to emerge from interviews was that knowing the right people within the NDIA is critical to how fast information can be exchanged between local and central levels. Some organizations reported they have been able to develop trusted relationships that have assisted and speeded up information exchange:

We were able to communicate really, really well with the NDIA and the establishment of some of their sub departments were really responsive to our feedback, so we've been kept in the loop ever since. [P10]

Advocacy organizations are uniquely positioned to be able to provide information to the NDIA on what is happening at the local, on the ground level from an independent participant (rather than provider) focused point of view. This is instrumental for good market stewardship and functioning of the system, a point clearly made by this organization:

When we advocate and say that these things are cropping up, or these trends are occurring, NDIA can understand that we're not speaking from the providers for profit perspective. We're an independent organization, that contributes to systemic reform in that way. We're best positioned, because we are on the ground, experiencing and tracking data and hearing of people's stories at a grassroots level. But we've made some very strong high up connections to be able to feed that information up . . . it's almost like you translate it into another language, whether that's data, policy, case studies, complaints, and then you deliver that message, and you deliver those observations and do it that way. I think that's been really instrumental. [P10]

From a market perspective, systemic advocacy work can help address issues such as market gaps. Advocacy organizations are uniquely situated to have knowledge of local-level conditions and market issues that can benefit decision-making happening at

a central level. As noted by this organization, work occurring at a higher government level cannot necessarily capture the issues occurring at a local level. Systemic advocacy is an essential stewardship activity to enable information flows back up the system:

One thing we can do, we are able to easily identify gaps. We can see where those needs are and what particular services are required and what those particular service's needs are . . . We're able to feed that information up to government. There are a few advisory groups such as DHHS, they have their NDIS working framework and they have a taskforce that aligns with that. However, it's a very high level and it's not capturing the wealth of concerns that there are for disabled young people at an individual level. [P20]

However, some smaller organizations reported they do not always have access to formal mechanisms that provide direct lines of communication with government or the NDIA, and being able to feedback information is dependent on who you know:

Unfortunately in the NDIA, they still seem to work in a very siloed way, so the trick seems to be finding the right person within the NDIA. So, it is a little bit relationship dependent. There is only a couple of mechanisms which are sort of formal mechanisms to kind of feed it back in. The rest of the time is very much informal kind of finding the right person in the NDIA and flicking the right switch. [P4]

A lack of formal mechanisms for information flows between central agencies and non-government actors can impact on how the market functions when information on participants or provider needs takes a long time to communicate or achieve change:

I think some of the systemic changes that we've wanted to see, that's been harder to have input. As with any advocacy, it is a slow process. We raise something and it takes three years to see an outcome sometimes. [P28]

I do think we have been effective in collating all the feedback and playing it back to the NDIA and government about what's working and what's not. Have we got all of the changes that we've been wanting? No. Has change been slow? Yes. But I think that we have been part of pushing for the big macro changes that we want to the NDIS, like greater flexibility in how people use their funding and things like that. We've been part of that broad coalition of people that have been pushing for that. [P4]

This is important from a market stewardship point of view given that macro factors such as flexibility in how participants use funds can have a significant impact on the market by increasing choice and control for participants (Baxter 2013). Advocacy work that pushes for macro-level changes thus needs to be recognized as a vital market stewardship activity.

4.5. Funding for advocacy

As discussed in the Background section, disability advocacy funding in Australia is underfunded and uncertain. This was a common theme advocacy organizations discussed in this study. A key message was a lack of funding means organizations are unable to meet demand for advocacy services:

We don't receive enough money to do the work that we do. It's just a capacity issue . . . The way in which we've needed to turn people away or track the demand that we can't cater for, because we don't have the funding, really affects our ability to do that effectively. That, for us, means that . . . we can't respond to individual issues. [P10]

The short-term nature of funding grants also adds to uncertainty and impacts on organizations ability to provide continuity of services:

We're funded by grants. But that's got its own problems in the sense that there's no continuity of service from the perspective of the grant period, where you never really know whether you're going to get a further grant. You can only really invest in your business in terms of the time that you actually receive the grants. [P13]

A lack of funding impacts the market when participants are unable to exercise choice and control or access services they need due to a lack of support to do so when advocacy organizations lack capacity to help more participants. Adequate advocacy funding is also an equity issue and this can have flow on effects for market issues, such as quality and safeguarding:

The amount of times that we do stuff as advocates, that we feel probably should be funded, but isn't, especially around rights and people getting the services that they paid for or are paying for to having safe places, all that sort of safety stuff, that Quality and Safeguards should be doing, that aren't. [P26]

Despite systemic advocacy activities being important for good stewardship as discussed above, organizations are also often not funded, or funded inadequately for this work:

We do need to continue the systemic advocacy to try to reform the systems that create and perpetuate individual issues arising. It definitely is worth our while. But, for us to pursue this to the extent that's necessary, capacity holds us back, because we've experienced unprecedented demand and increases in that demand every day and each year. We've never had funding that reflects the growth in demand. [P10]

Systemic advocacy is an important component of market stewardship as it allows for issues within the system (e.g. market gaps or administrative burdens for participants) to be highlighted and fed back to central decision makers as demonstrated above. Without adequate and certain funding these types of market shaping activities are reduced or unable to occur.

5. Discussion

As personalization approaches that use quasi-markets to provide social care have grown in popularity internationally, there has been corresponding interest and concern over the way these markets should be stewarded. As well as providing choice and control for consumers, quasi-market systems need to also ensure this occurs in an equitable way. Further, their failure can have dire impacts when people are unable to gain access to services they need. However, most of the stewardship literature has focused on the actions central governments can take, with little attention to the stewardship role local level non-government actors have within the system. In this paper, we explore how advocacy organizations are playing an important role in conducting local-level market stewardship activities that also support equity in personalization schemes. We thus make the case for development of a distributed stewardship framework that joins up the actions of government and non-government actors.

Quasi-markets, like traditional markets, comprise both a supply and demand side, although market stewardship research and practice literature has mostly focused on top-down activities directed towards assisting suppliers to provide services identified by government as needed to meet consumer demand. However, Kelk (2020) argues

that if market stewardship of quasi-markets takes a top-down approach that focuses only on providers and the supply side of the market it runs the risk of maintaining a system that does not reflect consumer needs or promote innovative and responsive services, nor allow people to exercise true choice and control. Thus, for effective market stewardship to occur both supply and demand sides of the market must be considered and supported.

Social care personalization systems that use quasi-markets place the consumer at the centre of decision-making, thereby demanding ‘sophisticated consumership’ by users of disability services (Kelk 2020). From a market perspective, without consumers who can strongly advocate for their own needs, have the skills and resources to navigate complex administrative systems, and possess the ability to make informed choices over their purchases, a public service quasi-market will not function effectively. Yet recent research reveals personalization systems can favour those with higher social, economic, and cultural capital (e.g. good literacy, high education levels, high socio-economic status, English speaking and the ability to advocate for themselves or have someone advocate on their behalf) (Malbon, Carey, and Meltzer 2019). Access to advocacy and support networks can, however, help bridge the divide between those with higher and lower levels of capital (Needham 2013; Williams and Dickinson 2016). As such, activities that provide advocacy for those unable to self-advocate, promote capacity building, and help individuals decode the administrative complexity of personalization schemes are important not only from a social justice perspective but must also be considered an essential component of market stewardship. By examining the stewardship activities of advocacy organizations that act to support participants, we provide a focus on market stewardship for the demand side of social care quasi-markets, thus contributing to the literature gap in this area.

Our research shows advocacy organizations are conducting many activities that support consumers in the NDIS market. Much of this work is directed towards assisting and supporting participants to understand the extraordinarily complex NDIS administrative systems that act as a barrier to individuals’ decision-making capabilities and increase their administrative burden (Carey, Malbon, and Blackwell 2021). Information provision activities are facilitating understanding of NDIS systems. That this information is independent (from service providers and central governing agencies) is especially important with recent evidence showing that NDIS participants need to trust the purveyor of information in order to feel they are informed enough to make decisions in the complex and uncertain NDIS environment (Kelk 2020). Advocacy organizations are also providing individualized advocacy to support those who lack skills or resources to self-advocate or understand the complexities of NDIS administration. Recent research reveals the NDIS is so administratively complex that even participants who attended NDIS information sessions felt they were unable to navigate it (Lakhani, McDonald, and Zeeman 2018). Confusion has been compounded by the inaccurate and inconsistent information participants often receive from central agencies, something noted by recent reviews of the scheme and in the literature (Tune 2019; Australian National Audit Office 2016; Meltzer, Purcal, and Fisher 2016). This underscores the importance of individual advocacy as a market stewardship activity – supporting participants to understand their rights and choices within the scheme is essential in a quasi-market system that has choice and control as a central tenet of effective market functioning.

Hand in hand with individualized advocacy support, organizations also recognize the need for capacity-building activities that develop consumers' skills for self-advocacy. This aligns with research showing participants in personalization schemes who can self-advocate are more likely to achieve better outcomes, with other participants who cannot realizing less benefits (Booltink, van Genugten, and Lako 2015; Botti and Iyengar 2006; Carey et al. 2018; Williams, Dickinson, and Robinson 2011). This highlights that a market based on the underlying assumption that all consumers can exercise optimal levels of choice and control is at risk of less effective operation, or in the worst case, failure, when this assumption does not hold in reality. In the absence of reforming administrative systems to be less complex, activities that foster informed choice and self-advocacy skills are needed as part of an over-all market stewardship approach in personalization schemes.

A number of studies have reported on limitations when care markets are centrally managed. Temple's (Temple 2006) analysis of centralized efforts to direct markets provides evidence of the way a lack of top-down knowledge can result in poor market stewardship when local on the ground market conditions are not used in central decision-making. Additionally, in examining the workings of public service markets in the UK Gash et al. (2013) reported that uncertainty about whose job it was to perform essential market oversight functions impacted negatively on the functioning of care quasi-markets. While the NDIA has responsibility as the main market steward in the NDIS, recent research reveals poor and inconsistent information from the NDIA is creating uncertainty and turbulence in the sector for both providers and participants (Tune 2019; Carey et al. 2021). This highlights the importance of good information flows between local actors and central bodies for effective market stewardship to occur. Most organizations we interviewed recognized the need for systemic lobbying activities to gain attention of central decision makers and enable information on local-level market issues to flow up to central bodies. However, while there are currently some formal mechanisms in the NDIS for larger and more prominent non-government actors to feed back information to central agencies, our interviews suggest that these mechanisms are not facilitating timely exchange of information and many smaller organizations struggle to have any direct communication with central agencies at all. Additionally, local actors, such as advocacy organizations, are often not funded for systemic advocacy work which impacts on the time and resources they can devote to raising awareness of market issues.

As well as lack of funding for systemic advocacy, as noted in the Background section overall funding for advocacy organizations in Australia is dependent on federal and state and territory governments deciding on the level of funding to be distributed and the timeframe, with funding often being short term and uncertain. Gash et al. (2013) note that for social care quasi-markets to function effectively funding must be at an appropriate level to ensure a scheme can meet the policy aims for which it has been designed and that overall funding levels were of critical importance in all the markets they studied. Given the important demand side support advocacy organizations are providing in the NDIS market inadequate funding for these activities can have flow on affects for the quasi-market and market stewardship when participants are not adequately supported to access the scheme or in choosing their own services and supports. This underscores the need for central government recognition of the role non-government actors such as advocacy play in market stewardship and appropriate and ongoing levels of funding provided to organizations to cover these types of activities.

While there is no doubt that centralized efforts to steward quasi-markets are essential for effective market functioning, the ways in which other local level non-government actors, such as advocacy organizations are shaping and stewarding quasi-markets need to be acknowledged, integrated and supported. Given there have been recent calls from major government agencies for better market stewardship of the NDIS (ANAO 2016; Productivity Commission 2016) the findings from this paper highlight the need for increased attention on the potential for integration of local market stewardship with stewardship by central government bodies such as the NDIA, NDIS Quality and Safeguards Commission and the Department of Social Services. Currently, this is not occurring with the NDIA continuing to take a ‘top-down’ approach, while at the same time there are growing concerns over market failure in some parts of the NDIS (National Disability Services 2019; Souza 2019). Further, social care quasi-markets like the NDIS should not in fact be considered as one market but rather a collection of sub-markets that operate across diverse geographies and care needs (Dickinson et al. 2021). This means market knowledge is highly localized, which increases the difficulty of centrally run market stewardship. Both joined-up government literature and some economic schools of thought correspondingly emphasize issues which can occur with a fully centralized governance approach and suggest ways to achieve collaboration between local non-government actors and central decision makers (Carey and Crammond 2015; Emerson, Nabatchi, and Balogh 2012; Ostrom 2010; Hayek 1945). For example, Carey and Crammond’s (2015) joined up government framework shows the importance of activities such as networking and collaboration, cross-sectoral forums and secondments and board appointments, to increase information exchange. Hallsworth (2011) similarly argues for finding a balance between centralized co-ordination while allowing for and supporting emerging local-level actions.

Based on the theories and models discussed above, we recommend the development of a supportive architecture or framework for distributed market stewardship in the NDIS. This would help with joining up the stewardship work of non-government actors, such as advocacy organizations, with actions of central agencies. Consistent with the literature on what works for joined-up government approaches (Carey and Crammond 2015) such a framework would need to consider both ‘hard’ (relating to structure) and ‘soft’ (creating institutional and cultural change) elements (see Table 3). A distributed stewardship framework would also need both vertical (links between central and local-level actors) and horizontal (links between actors at the same level) integration (see Table 4).

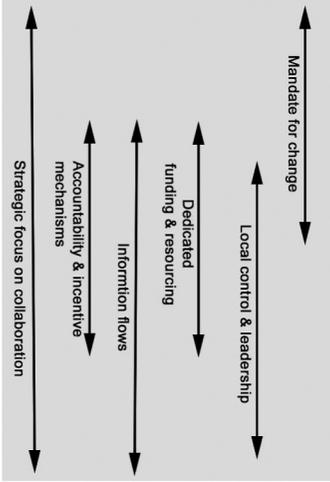
Gash et al. (2014) reported that in social care quasi-markets it is common for there to be uncertainty and ambiguity over who holds accountability and responsibility for market oversight and over who is responsible for performing market stewardship

Table 3. Elements of a supportive architecture for distributed market stewardship.

Hard elements	Soft elements
Mandate for change	Intentional focus on collaboration and partnerships
Decentralised control	Capacity training and skills development
Committed and flexible funding/resourcing (to be used across different levels)	Information sharing and information flows
Mechanisms for incentives and accountability	

Adapted from Carey and Crammond (2015).

Table 4. Horizontal and vertical integration in distributed stewardship

Integration Level	Horizontal integration	Vertical integration
<p>Central Government</p> <hr/> <p>Government Agencies</p>	<p>Shared objectives & targets</p> <p>Training & skill development</p> <p>Changes to processes</p> <p>Changes to structure</p>	
<p>Local Level Partnerships</p>	<p>Networking events</p> <p>Secondments</p> <p>Cross sectoral forums</p> <p>Information sharing</p>	
<p>Service Delivery</p>	<p>Information sharing</p>	

Adapted from Carey and Crammond (2015).

actions. This is apparent in the NDIS where there is no reporting or collection of data on the stewardship activities of non-government actors. A framework for distributed stewardship therefore needs to include a mandate for change to enable central agencies to identify and support the stewardship actions occurring at a local level. For the NDIS, this would need to come from central agencies, such as the NDIA and preferably be written into the *NDIS Act* to enable dedicated resourcing and funding for local-level stewardship activities. In a distributed stewardship framework decentralized control and vertical and horizontal integration could be achieved through the formation of local-level NDIS market networks or partnerships that comprise two or three local government areas. These could be similar to the independent Primary Health Networks Government currently funds to manage health regions, but with a focus on NDIS market stewardship. These partnerships would ideally include non-government local-level representatives (i.e. from advocacy organizations, information services, healthcare professionals, online services platforms and NDIS private consultancy businesses) as well as representatives from central government agencies, such as the NDIA and NDIS Quality and Safeguards Commission.

Without robust market stewardship the NDIS market risks poor functioning, and at a worst case, market failure. Further, recent research suggests inequity issues with the scheme are already becoming apparent, with administrative burdens exacerbated for certain groups (Carey, Malbon, and Blackwell 2021). Our research shows advocacy organizations playing an important and significant market stewardship role in the NDIS through activities that not only increase choice and control for participants but help ensure equitable outcomes across the scheme. A limitation of this study is there is likely to be a range of other non-government actors conducting stewardship activities that were not examined. These other actors would need to be integrated into a distributed stewardship framework. Future research should therefore examine the market stewardship role of other local level non-government actors in the NDIS

to inform how stewardship is being conducted across the system and enable a more comprehensive framework of distributed stewardship to be developed. Additionally, any fully formed distributed stewardship framework would need to consider some of the pitfalls of partnership and joined up government working such as identified by Dickinson and Glasby (2010) and Carey and Crammond (2015) and ways to mitigate these.

6. Conclusion

Effective market stewardship is needed for quasi-care markets to flourish and meet the policy aims for which they are designed. Conversely, poor or absent stewardship risks dire consequences when it leads to market failures and consumer inequities where citizens are unable to access the services and supports they need. Our research shows local-level advocacy organizations are playing an important market stewardship role in the NDIS, despite the NDIA being positioned as the main market steward. Yet much of this work is not being recognized as market stewardship by central agencies and government nor being appropriately funded and resourced. We thus argue for the development of a framework for distributed stewardship in the NDIS with collaboration and connection between local level and central actors to enable better and more timely information flows and committed resourcing for local stewardship activities. This would help the scheme meet its policy aims of choice and control and contribute to increased equity for participants, thus fulfilling both a market and social justice role. Principles of joined-up government working can help inform a distributed stewardship framework where central agencies continue to oversee the market but local-level stewardship actions are acknowledged, integrated and supported.

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