

WHERE HAS THE COMMUNITY GONE? A CRITICAL ANALYSIS OF THE DISABILITY COMMUNITY SERVICES SYSTEM IN A POST-NDIS WORLD

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Abstract

In recent years, Australia, like a number of industrialised nations, has embraced an individualised, and person-centred, funding system for the provision of disability care and support services, namely the National Disability Insurance Scheme (NDIS), moving from a welfare model, to an open and competitive quasi-market.

Despite its many benefits, however, this new environment presents us with, yet, another question – ‘Where has the Community gone?’

This paper looks at the slowly disappearing ‘Disability Community Services System’, exploring whether motivations for collaborative work between service providers has changed, and looking at the unintended consequences that come from such changes, such as possible negative impacts on both clients and practitioners.

An analysis regarding working collaboratively in a rapidly changing climate is presented, as well as an argument for safeguarding congenial relationships and ‘knotworking’, with some practical considerations, moving forward.

Introduction

A Community Services System is defined as a network of service providers, with the common goal being the “overall well-being of clients requiring the integrated and coordinated actions of many different agencies” (Vinson & Rawsthorne, 2013, p. 64). A romantic view of Australia’s Disability Sector, prior to 2013 (and the introduction of the National Disability Insurance Scheme (NDIS)), might argue that this was, indeed, the case - insisting that “various forms of care and support for people with a disability have long been a feature of the Australian social support system” (Australian Government Productivity Commission, 2011, p. 102), and that an effective disability community services system could be evidenced in the sector’s commitment to the National Disability Standards (first produced in 1993). This, particularly regarding the indicators of practice stating that services should work in partnership to support active community participation for people with disability, service delivery planning, and internal capacity to respond to diverse needs, and to establish and maintain a referral network (National Standards for Disability Services, 2013).

However, a contrasting and more realistic, perspective is presented in the Productivity Commission's inquiry into Disability Care and Support (2011), which found that disability support arrangements, prior to the NDIS, were, in fact, "inequitable, underfunded, fragmented, and inefficient" (p. 5), and gave people with a disability little choice and no certainty. Further, and in relation to the Disability Service System, the inquiry revealed "a lack of coordination, showing up through duplicated and inconsistent assessment methods for allocating services or funding, inadequate links between services provided by different governments, and insufficient information for planning and coordination" (p. 101).

This paper explores the Disability Service System post-NDIS, and asks 'Where has the community gone'? I present a critical analysis of the new space, and propose that despite the many benefits of the new National Disability Insurance Scheme, there are 'unintended consequences' of the NDIS, particularly the disappearance of the local Disability Community Service System, which, I argue, now presents us with a significant gap. Albeit far from perfect, disability service providers did, indeed, have "historical practices of communication and collaborative working" (Green et al., 2018, p. 5), where "knotworking" (Engstrom et al., 1999) occurred, and unique service specific skills were recognised and respected. My question is – are these collaborative relationships gone forever?

Background

Following recommendations from the 2011 Productivity Commission to replace the existing disability "system with a unified national scheme to fund long-term, high-quality care and support for all Australians who experience significant disability" (Buckmaster, 2016, p. 2), the National Disability Insurance Scheme (NDIS) was introduced and launched in Australia on July 1, 2013, and has since been progressively rolled out, nationwide, with the promise to "deliver life-changing support to an estimated 460,000 eligible Australians" by July 2020 (COAG Disability Reform Council, 2018, p. 4).

The way this care and support is now delivered, is the marked difference of the new system. That is, moving from a "one-size-fits-all" (Ramcharan, 2016) welfare model, where a small number of providers were allocated 'block' funds to deliver and distribute specific services to an open market where, instead, the person with disability gets an individualised funding package, and has choice and control in so far as which service to purchase, and from whom.

Proponents of the NDIS say "the market will drive innovation and provide individuals with value for money, much more effectively than so-called quality systems, which really are form-filling exercises" (Bonyhady, 2010, pp. 11–12, cited in Miller & Hayward, 2017, p. 131).

This system has changed not only the way people with disability interact with the Disability Services and Support Sector, but also the way individual service providers interact with one another. Most significantly, because they no longer receive a direct allocation of government funding, service providers are now required “to directly compete against each other to obtain the funds” (Miller & Hayward, 2017, p. 131) required to remain financially sustainable.

It is still relatively early to examine what this new “competitive quasi market” (Green et al., 2018, p. 5) means for an effective Disability Community Service System. It seems, however, that generally, collaborative relationships between providers is at risk as service goals are being forced to change, prioritising ‘staying in business’ over the “overall well-being of clients” (Vinson & Rawsthorne, 2013, p. 64).

Review of the literature

Clarifying the collaborative service system characteristics associated with effective outcomes, Vinson & Rawsthorne (2013) share findings from Provan and Milward (1995) that say “networks integrated and coordinated centrally, through a single core agency, are likely to be more effective than services integrated in a decentralised way among the service providers that constitute that system” (p. 65), reinforcing the idea that decentralisation changes service behaviour and aims.

Interestingly, the new disability system in Australia means services are now decentralised. Significant amounts of literature have addressed this global move towards “personalisation in the welfare sector” (Williams & Dickinson, 2015, p. 149), and discuss the tensions between individualised person-centred “service provision and empowerment on one side, and the promotion of a strong social contract, public trust in institutions, and collective identity on the other” (Williams & Dickinson, 2015, p. 149).

What is missing, however, from the scholarship, is an in-depth look into what a marketisation of disability services through the NDIS means for collaborative work. Graham & Barter (1999) point out that this is an important consideration as “motivations to engage in collaboration are necessarily influenced by differences in stakeholders in expertise, status, political power, and access to funding and to personal resources” (p. 7).

Whilst writing in this space is still scant, one very new piece of research by Green et al. (2018) looks at competition and collaboration between service providers in the NDIS, and predicts that “historical collaborative relationships of the past” (p. 14) are at risk, with early signs of provider behaviour change slowly becoming clearly evident.

Methodology

The methodology I am using for this analysis is the contested critical reflection as research method proposed by Fook (2011), in order to bridge research and practice. By engaging with praxis, that is, drawing on my own practice and current and emerging scholarship, I hope to “collect and create understandings” (Fook, 2011, p. 56) of my experiences as a practitioner working in the disability space in for more than a quarter of a century, in order to shed light onto an emerging, but important gap.

I have worked in the disability sector (in Australia, USA, and the UK), and in a variety of settings, since 1993. I have, you could say, grown up in the sector. My learnings, observations and reflections are informed by a strong Rights Perspective (UN Convention on the Rights of Persons with Disabilities, 2006), Person Centred Approaches (Thompson, Kilbane & Sanderson, 2007), and Anti-Oppressive Practice (Baines, 2007), and I am continually learning via relationships with people in my professional and personal life.

Findings

‘Data’ presented in this section are based my conceptualisations, with the aim of demonstrating that “complexity” from my practice perspective (Fook, 2011).

Reflection 1 – Working in Group Homes (1993-1998)

I was just 21 when I began an on again, off again, 5 year stint working in Group Homes. I worked with a number of teams, in various houses, doing shift work and sleepovers, and supporting many individuals with significant intellectual, and often dual diagnosis (psychosocial), disability.

I have fond memories of this time in my career, finding the work, at times, challenging, but mostly rewarding – feeling like I was part of a close-knit team, like family almost.

In this space, I quickly learnt, that one could only support the person with disability well by working as a partner of a network of service providers. This network included day programs, ‘sheltered workshops’ or ADES (Australian Disability Enterprises), supported employment services, medical and allied health practitioners, psychologists, recreation and leisure (including holiday) providers, faith based services, transport providers, and so on.

The coordination of these services was mostly the responsibility of an in-house key worker or case manager, and yearly ‘case conference’ or ‘individual service plan’ meetings were held, where all stakeholders were invited to discuss the wellbeing of a client.

My recollections about this particular Community Services System is that the relationships we had with other (external) providers were amiable, long-term, and mostly secure. Each service was there to provide a specific support, and we all knew and respected each other's unique roles.

Reflection 2 – The HACC (Home and Community Care) Days (2000-2012)

I worked in 3 services that were HACC funded, for a span of 12 years – supporting people and families with disability to live at home, and in the community.

I have strong recollections of feeling like I was part of a larger network whilst working in HACC. Most significantly, I recall HACC interagency meetings being a place where different service providers would come together, with common challenges and aims, and discuss strategies to best integrate, coordinate and refer to one another, in good will.

Many networks and relationships were formed in this space, not only between service providers, but also between individual workers. These mostly good-natured relationships encouraged collaborative work and referrals across service types, and for me, some of these networks still exist, many years later.

The HACC referral system required services to undertake only one assessment, and share the assessment amongst relevant providers, should gaps be identified, in order to provide a more streamlined and integrated approach to service delivery. How well this was actually working, however, is questionable.

As a HACC worker, I noticed that, mostly, individual HACC Services provided specialised support, such as Case Management, Respite and Recreation, Domestic Assistance, Transport, Home Modifications, Personal Care, and so on. These service specifications were, from the outside, seen as important – you knew who to go to for what, as they had a reputation, had been doing it for a long time, and were seen as 'the experts' in that space.

Reflection 3 – The 'Hard' Stuff

Believe me, it was not all roses, and throughout my long career, I can clearly identify points where I met with families in crisis, who were not receiving assistance they urgently required, and had been sitting on a number of waiting lists for years.

There is one meeting that I cannot forget, however. One home visit (I conducted on my own) shed light on a family in crisis. Mum did not appear to be coping at all, Dad was absent, and the young child with Autism required intense support. There was no extended family support, and the family were

receiving only minimal service, after being on a number of waiting lists for quite some time. I was deeply concerned about mum's wellbeing, and quickly began the implementation of an immediate crisis support and assistance plan.

The reality was, however, this was not an isolated case. In fact, there were many families and individuals in similar crises, with very few options for any support, let alone one that actually met their needs. These people were there, but often invisible, and only came to the attention of service providers when things were in dire straits.

Reflection 4 – The big change: NDIS (2010-2013)

I was working in a disability service right before the NDIS launch, and clearly recall the anxiety of, not only my employer, but also the providers around us. Questions like – Will we survive? Will we make it? How are we going to do things now?

Service providers were about to lose all their block funding, and either think about a different way of working, or suffer the inevitable consequences and, dare I say it, close down.

Since the launch of the NDIS in 2013, I have been working as a trainer supporting staff in the Community Services Sector, and have noted and heard many of their concerns. They have felt confused, uncertain, and pressured to work in a different way. It is now about numbers – billable hours. How many clients can we keep on our books? How many new ones can we attract? How do we market ourselves? What can we do differently? What supports can we add to our suite of services? Let's diversify! Let's advertise! Let's grow!

The world has changed, and as a close onlooker, I know that many long-term disability practitioners, including myself, are leaving the sector in droves - not wanting to work in an environment that feels more like a business, than a not-for-profit.

Reflection 5 – Client wellbeing

To be honest, I, too, was part of the grassroots movement – Every Australian Counts – where collective action and campaigning for the National Disability Insurance Scheme was crucial. And yes, I celebrated, as did many, when the NDIS finally arrived. But to say, more than 5 years down the track, that things are great, is highly exaggerated. Many people and families (with disability), who I have spoken with, are still overwhelmed, anxious and very confused. One NDIS participant disclosed, to me, feeling bullied and harassed by 'shonky' prospective providers, comparing their practices to large 'Telcos' – desperate to lock in a contract and sign a service agreement. This is not what we were campaigning for. This is not prioritising client wellbeing.

Reflection 6 – My professional experience in the context of this change (2013-2019)

Since the NDIS launch, I have been sitting slightly outside the Disability Sphere, and working, instead, at a non-government peak representing the voice of community organisations working with vulnerable children, young people and their families.

My work at the peak involved bringing about positive systemic reform that will deliver better outcomes to the lives of children and young people, including those living in out-of-home-care.

Interestingly and quickly in my new role, however, I noticed that collaborative work between systems (and, in particular, those interfacing with the NDIS) was becoming an important issue. I, especially noticed a significant gap concerning the interface work between the NDIS and the Child Protection and Family Support Systems, and further gaps in how the NDIS interfaces with other systems, such as Health and School Education.

What was becoming very apparent was that to ensure needs are being met for people with disability in all areas of their lives, collaborative work between systems (previously having very little to do with each other) was now seen as vital. Practitioners, such as Child Protection Caseworkers in the Child Protection and Family Support System, were now required to play a key and significant role in the implementation of NDIS supports for a child with disability, for example. This, you can imagine, requires new skills, knowledge, and collaborative networking for workers traditionally working in siloed systems, reinforcing the point that working collaboratively in a rapidly changing climate is crucial for client wellbeing.

Limitations

Before discussing the findings and considering implications for professional and community development practice, it is important, at this point, to acknowledge the limitations of this study. The most obvious being the methodology used. Critical reflection, as a research method, although highly contested, is used here to collect and create understandings of the practice experiences of the author (Fook, 2011). Questions around legitimacy of such a method is noted, as is the small sample size.

With only one research participant, talking about my own reflections and observations, it important to recognise that the results reported here cannot be generalised to all 'disability' practitioners. Instead, this paper draws on insider knowledge gained over many years, addresses a gap identified, and invites further research into this new dilemma.

Discussion

A Community Services System is defined as a network of service providers, with the common goal being the “overall well-being of clients requiring the integrated and coordinated actions of many different agencies” (Vinson & Rawsthorne, 2013, p. 64). The findings here reflect, and it can be argued that, historically, networks of disability services providers in Australia had “practices of communication and collaborative working” (Green et al., 2018, p. 5), as “a means of achieving objectives of social work intervention, such as improving “client functioning, or social justice” (Graham & Barter, 1999, p. 12).

With the advent of the NDIS, however, questions arise as to whether such relationships still exist, and if so, how long before they completely disappear?

To clarify, and as evidenced in our findings, this author does not argue that the NDIS is, mostly, a positive change for disability in Australia - largely removing the problem of people and families with permanent and significant disability going without essential support. However, despite the initial excitement, the introduction of individual budgets and personalisation (Williams & Dickinson, 2015) has not come without its challenges, many of which have been discussed and analysed in significant detail throughout academic and non-academic writing, and fall outside the scope of this paper. One ‘unintended consequence’ of the NDIS, however, that is getting little attention, is that of the disappearing (but arguably valued) Disability Community Services System. This is the issue that I would like to unpack below.

As noted in the findings above, since 2013, the Disability Services Sector in Australia has been required to undergo “a complete about-face” in organisational management, focusing now on business models to achieve short-term stability and long-term growth (Skelton, 2016, p. 458). New commercial practices (adopted by not-for profit organisations), including sales and marketing, merger and acquisitions, and billing and invoicing (Skelton, 2016), have come to the forefront, and competitive market forces have progressively taken precedence, claiming “increased efficiency, improved service delivery and outcomes, and lower costs (Green et al., 2018, p. 5).

In their study looking at how the introduction of a competitive market has impacted on collaboration between service providers, Green et al. (2018) “found that in the early stage of NDIS roll out service providers still perceived that the historical collaborative relationships of the past were largely being maintained” (p. 14), despite evidence of negative impacts on organisational behaviour, such as “the ways in which information was being shared between organisations and the way staff were able to manage their time” (p. 14). To add to these examples of organisation behavioural change, this author has also observed a clear decline in referrals (to competitors, for example), as well as a parallel increase in an organisation’s own suite of in-house supports to ‘sell’, including the new Support Coordination and Plan

Management roles, replacing traditional, less specific, and now obsolete, 'Case Management', for example.

As Green & Mears (2014) explain, disability may also and often "be only one service in a portfolio of several within an organisation" (p. 30), and the idea of a one-stop-shop seems to be emerging as prominent, where large organisations seem to be getting bigger, offering every service imaginable, whilst smaller and more 'boutique' Service Providers are becoming a rare breed. "Knotworking" (Engestrom et al., 1999), which is explained as "a flexible collaboration practice needed in tasks requiring multiple expertise" (Kerosuo, 2017, p. 2) seems less important in such an environment, where one could argue, all the experts are under one umbrella.

Furthermore, it is clear that the new environment demands 'measurable outputs'. This is marketing and selling as many specific time-bound supports as possible. Sadly, however, that is, primarily, where the problem with community development or collaborative work lies. This work is not regarded as a 'measurable output'. Providers cannot sell this, nor can they make any money from it, hence, most of this work is now placed at the bottom of the priority list (Onyx, 1996). The point is - the NDIS has eroded the Disability Community Services System, and the capacity of disability practitioners to be part of a community.

Implications for professional practice/community development practice

Despite its celebrated assertions, the introduction of the NDIS has been filtered through a neo-liberal context, and ignores the hidden costs of reduced instances of collaborative work and congenial relationships amongst disability service providers, and the respective effects on care coordination" (Green et al., 2018). Similarly, as stated earlier, decentralised networks are less likely to be effective, in terms of client wellbeing (Provan and Milward, 1995, cited in Vinson & Rawsthorne, 2013), compared to integrated approaches.

Care coordination has now become a solitary task, primarily and problematically allocated to NDIS funded (and time limited) Service Coordinators, who, often, are requested (by people with disability and their families) to work as traditional (and now obsolete) Case Managers, but do not have the capacity (by any means) to do so. With the potential of this work to be done holistically removed, the new way of care, or service coordination, presents us with a significant gap, and begs the question – who's responsible?

Furthermore, we are faced with a new dilemma, where individual workers, who now feel that their work has changed, and is isolating, time scrutinised, and more managerialised, are noticing an increasing gap between their underlying altruistic motivations for working in this sector, with the new path forward. "Workforce

problems such as high supervisory loads under the NDIS, multiple job holding, and major concerns about job quality, work time and financial security” (Cortis, 2017, p. 48) warn us about a possible ‘mass exodus’ of experienced disability practitioners, who demonstrate a resistance and unwillingness to work under corporate conditions.

More subtle forms of resistance in this new world, however, include workers who stay, and change very little, in terms of their practice, despite pressures from above. Rather, they attempt to maintain their relationships and networks at the periphery of their ‘primary’ work (Rawsthorne, 2018).

More research is urgently required to identify “strategies organisations can employ to maintain collaboration and collegially even when they perceive a threat of competition” (Green et al., 2018, p. 14), and ways to retain experienced workers in a new, but very different, community practice environment.

Perhaps this is an opportunity to consider whether “knotworking” (Engestrom et al., 1999), or collaboration, should be funded outside the NDIS, as, as it stands, there is currently “little or no allowance for” (Patterson, 2017, p. 10) it in the current pricing structure.

In a similar vein, funding for disability advocacy work sits outside the NDIS, and has also been contentious of late. For now, however, and after heavy campaigning, disability advocacy has secured NSW state government funding until 2020 (Michael, 2018), but, like collaborative work, will be at risk if it’s not recognised as a vital to the well-being of people with disability.

A similar argument was made by peak, National Disability Services (NDS), in 2014, who recommended that some non-individualised funding be allocated for activities such community development and the production of social capital. Such opportunities are said to be available through the ILC (Information, Linkages and Capacity Building) component of the NDIS – originally and formally called Tier 2. In reality, however, there is currently an environment of considerable uncertainty around this component of the NDIS, and “it’s still very early days for ILC” (McGarry, 2018).

Unlike the rest of the NDIS, ILC doesn’t provide funding to individuals, but rather, provides grants to organisations to provide information, linkages and referrals that connect people with disability, their families and carers, with broader systems of support. ILC’s stated aims are to facilitate capacity building supports for people with disability and their support network, and promote collaboration and partnership to create greater inclusivity and accessibility of people with disability (NDIS, n.d.), sitting comfortably as an activity of, and an opportunity for, community development and the production of social capital.

Smith-Merry (2017) sees the ILC as “an important tool in developing or enhancing services to meet the needs of people where services do not currently exist” (p. 11).

The challenge is, however, taking advantage of *limited* ILC funding opportunities, as soon as they’re announced. Current recommendations are that funding “applications should not be more than \$118,000 each and are required to be delivered within one year” (McGarry, 2018). This, I argue, is not enough, nor is it recurrent and secure.

Moving forward, and as a starting point in this new world, I propose an ongoing ILC funded local Communities of Practice, where a space could be created for practitioners to come together, in solidarity, and ensure that historical and congenial relationships do not disappear. Further, I argue, individual workers are more likely to remain motivated and closely aligned to the overall mission of their work when they feel part of something bigger.

Communities of Practice are groups of regularly interacting practitioners who take time to “engage in joint activities and discussions, help each other, and share information. They build relationships that enable them to learn from each other; they care about their standing with each other” (Wenger-Trayner, 2015, p. 2). They cultivate a community, as in this case – a Disability Community Services System – that could help “invent new practices, create new knowledge, define new territory, and develop a collective and strategic voice (Wenger-Trayner, 2015, p. 6). A good case, stating the value of such a community, would surely sway funders, hopefully seeing that the above benefits are worth investing in.

In addition, Communities of Practice provides a space for the ‘active practitioner’ to bridge social capital, linking them, and the people they are supporting, to a wider network, hence broadening opportunities (Oliver & Pitt, 2013).

Conclusion

This paper explores the notion of a disappearing Disability Community Service System, in a post-NDIS and competitive environment. A critical analysis of this new, decentralised space shows that despite the many benefits of individualised funding, such as empowerment; stakeholder, or provider, motivations to continue a commitment to practices of collaboration and ‘knotworking’ have been greatly influenced by a new neoliberal agenda. This, in turn, is argued to negatively impact upon the overall wellbeing of the person with disability (with care coordination, for example, becoming a significant and problematic gap), as well influencing the morale and continued commitment of individual practitioners (whose work has become more isolative and pressured).

More research is urgently required to explore this phenomena, as well as to identify “strategies organisations can employ to maintain collaboration and collegiately even when they perceive a threat of competition” (Green et al., 2018, p. 14).

In addition, a considerable discussion is warranted to explore whether recurrent and secure, non-individualised funding (like Information, Linkages and Capacity Building) could be allocated for community development activities that build social capital through, say, Communities of Practice, where a Disability Community Services System can continue to thrive, individual workers can remain motivated and connected to an overall mission, and the well-being of the client remains the goal and priority of practice.

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