

State of the Art

Tailored and Seamless: Individualised Budgets and the Dual Forces of Personalisation and Collaboration

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This article reviews the design and delivery features of individualised budgets for disabled and older adults to understand the mechanisms for disaggregation and collaboration in the way support is organised and delivered. Individualised funding is often assumed to be a fragmenting force, breaking down mass provision into personalised and tailored support and stimulating diverse provider markets. However, disability campaigners and policy makers are keen that it also be an integrative force, to stimulate collaboration such that a person receives a ‘seamless’ service. The article brings out these tensions within the individualisation of funding and support for older and disabled people in the United Kingdom and Australia, and considers whether there is scope for reconciling these dual forces.

Keywords: Individualised funding, personalisation, collaboration, adult social care, disability.

Introduction

Individualised funding has come into favour in many social welfare economies as a tool to redesign and reorganise disability support and adult social care. Espoused as a means of breaking down paternalism and standardisation and giving choice and control to users, individualised funding policy is also increasingly synonymous with marketisation of the public sector (Beresford, 2014; Needham and Glasby, 2014; Carey *et al.*, 2018a, 2018b). The risk is that the emergence of diverse and competitive markets can be a disincentive for collaboration efforts, a parallel reform objective to deliver holistic and better integrated support. Although personalisation of support and collaboration in provision of support are not necessarily mutually exclusive, their interplay is poorly understood and they can create different sets of incentives and tensions for agencies, organisations and users who are striving to ensure tailored and seamless supports. By drawing on examples from the United Kingdom (UK) and Australia, this state-of-the-art article brings to light how countries facing similar challenges of reconciling personalisation and collaboration design policy solutions and to what effect (Green *et al.*, 2018; Needham *et al.*, 2022).

In this article we first outline the historical shift to individualisation in disability support and adult social care and examine the extent to which collaboration and personalisation are complementary or in tension. The article will explore common insights and useful differentials between the UK and Australia. As set out in the Introduction to this themed section, both of these countries have reformed their disability and older persons' services in recent years, and both have attempted to combine the benefits of more tailored services with a more collaborative and integrated approach (Foster *et al.*, 2022 in this themed section). Indeed, there has been explicit policy learning between them in the development of reform initiatives (Needham and Dickinson, 2018). However, there are also illuminating differences between them. The Australian approach draws attention to personalisation and collaboration at the individual level for disabled and older people. In the UK, systemic integration (particularly between health and social care systems) has been pursued as a means of strengthening personalised and seamless supports for older and disabled people. The two countries are also on different trajectories in relation to the role of central government: Australian disability and older persons' services have become more centralised, with reduced discretion for the states, whereas the UK has devolved social care, such that there are increasingly different care systems in England, Scotland, Wales and Northern Ireland. This different trajectory means that the relevant unit of analysis may shift for different aspects of care, as in our discussion of Scotland below and in Rummery *et al.*, 2022 in this themed section.

Having looked at what the existing literature and policy context tells us about the tensions and synergies between personalisation and collaboration, we consider the question of whether there is scope for reconciling these dual forces. We also identify how future research can take forward academic scholarship and support improved provision for disabled and older people. This includes the importance of continuing to undertake research that involves people with lived experience as co-researchers (as some of the articles in this themed section have done) to co-develop insights. It is also important to understand the long-term impact of Covid-19 as a system shock which is likely to affect the future configuration of individualised funding for disabled and older adults.

Two routes to improving support for disabled and older people

Personalisation and collaboration are arguably two reform agendas, not necessarily in opposition but with inherent tensions, to address systemic failings in support for disabled and older adults. Working age disabled people and frail older people have historically relied on inadequate state services, which have either under-provided services (leaving families alone to address care needs) or over-provided (confining people in long-stay institutions). The carers' rights movement has drawn attention to the struggles that families face in meeting high level care needs (Rummery, 2022), while disability rights and aged care campaigners have heavily criticised the enforced segregation of disabled people (Fisher *et al.*, 2015), and inherent paternalism of traditional systems (Yeandle *et al.*, 2012). Change is also demographic: the proportion of people who are ageing with a disability, and living a much longer life, is growing, as are the expectations of people about what they might want from the state as they age. Northern Ireland's *Power to People* report (Kelly and Kennedy, 2017: 62) into social care reform expresses a sense that state provision has not kept up with social change:

Why, if the population's needs, expectations and aspirations have changed so much, is the so-called 'market' for social care still offering the same services and doing much the same things? If the media was run in this way, we might still be watching the same three channels on a black and white analogue TV!

Of the various proposals to bring services and supports for disabled and older adults 'up to date', much attention has focused on how to better tailor these to people's needs, capabilities and assets. Activism by people living in institutions, making demands for independent living, has combined with abuse scandals in the media to undermine institutional claims to be safe spaces (Morris, 1993; Commonwealth of Australia, 2020). Principles of inclusion and involvement in decision-making have become increasingly mainstream (O'Brien and Tyne, 1981), and professional authority has been challenged by user- and family-led initiatives such as person-centred planning (Cambridge and Carnaby, 2005). Disability rights campaigners highlighted routine human rights violations in many care systems and the need to adopt the social model of disability (Oliver, 2013). At the same time, there was increased recognition that 'ageing in place' should be the preferred model for older people's support, reserving residential care for those with the highest acuity (Day *et al.*, 2017; Pani-Harreman *et al.*, 2021). These various forces have coalesced to ensure that support for disabled and older adults has been reimagined in ways that are person-centred and facilitate choice and control by the people using them. In the UK and Australia, new and individualised approaches took hold, along with service models which took some account of user choice and control (Foster *et al.*, 2012; Purcal *et al.*, 2014; Glasby and Littlechild, 2016; Day *et al.*, 2017). This was part of a broader international movement, with reforms to individualised funding for disabled and older adults in a range of countries, including Netherlands, France, Belgium, Austria Germany, Canada and USA (for an overview, see Gadsby *et al.*, 2013).

The term personalisation as a descriptor for care reforms has been used extensively in England (see e.g. Beresford, 2014; Needham and Glasby, 2014), Australia (see e.g. Foster *et al.*, 2012; Carey *et al.*, 2022) and Norway (see e.g. Christensen and Pilling, 2014). It has been described as starting with the person and their goals rather than the service (Carr, 2010), with the aim of moving away from a 'one size fits all' service model (Carey *et al.*, 2018b). Although services can be personalised in a range of different ways (Foster *et al.*, 2012), personalisation has been particularly associated with the individualisation of budgets such that people with eligible needs receive a cash allocation rather than a service. Whereas other forms of 'person-centredness' in care services may be more subjective and harder to observe, the transfer of financial control has been seen as giving disabled and older people a tangible lever to bring about change (Hatton and Waters, 2014). The 'user' becomes a commissioner of services and supports in a mixed economy of care (Yeandle *et al.*, 2012; Carey *et al.*, 2019).

The idea of disabled and older people as commissioners of their own support raises potential challenges surrounding individual choices and coordination of multiple service providers and systems (Foster *et al.*, 2012, 2021). There is an awareness that complex social problems cross vertical service demarcations and require a 'whole person' approach (Kickbusch and Gleicher, 2012; Hudson, 2015). However, services and supports for disabled and older adults remain structurally separated from closely related services such as health, housing, education, and employment (Productivity Commission, 2011a, 2011b; Cooke and Muir, 2012). By encouraging integration, coordination, or

collaboration (the terminology is different in different places), the aim is to deliver services that are less fragmented. This can go from informal linkages between agencies to coordinated efforts where provider agencies and institutions adopt joint planning and management and integrated systems of care and support (see review by Foster et al., 2021).

There are clear overlaps between the personalisation and collaboration agendas. We could argue that both are part of what Hupe (2017) calls 'subject centrism' in welfare services in which the person receiving services becomes the focus. Nonetheless, personalisation and collaboration offer different routes to person-centredness, and different understandings of when success has been reached. Personalisation is often explained and justified as a way to fragment 'one size fits all' provision, breaking down block services and standardised packages so that people can have a pick and mix of options. Choice and control have been key principles here, seen by many as essential to human rights and self-determination – although there are also synergies with neo-liberalism and marketisation (Needham, 2011). In contrast, collaboration is about bringing things together, joining up, and is inherently an integrative force. It is part of the 'joining up' aspirations that Rhodes (2000) found to be replacing both the silos of traditional welfare states and the fragmentation of new public management (see also Davis and Rhodes, 2000). In a context of disability support and older persons' services, collaboration has particularly focused on how to incentivise inter-organisational cooperation so that people receive holistic support.

Below we trace the development of these two reform agendas in the distinctive policy contexts of the UK and Australia, and in relation to individualised funding for disabled and older adults. We then go on to discuss where this leaves our understandings of personalisation and collaboration and where a future research agenda might helpfully be focused.

The UK: personalise and integrate

Individualised funding for disabled people in the UK dates back to the creation of the Independent Living Fund in the mid-1980s and to experiments in direct payment allocations, which were passed into law in the *Community Care (Direct Payments) Act 1996* (Glasby and Littlechild, 2016). Initially limited in its scope and influence, over time this has evolved into a duty for all people in the UK with an assessed care need to have access to individualised funding. This can be in the form of a direct payment, or be a notional budget held by the state or a third party. Expectations relating to personalisation are set out in statutory guidance that accompanies the *English Care Act* (DHSC, 2017, section 4.46):

Local authorities should facilitate the personalisation of care and support services, encouraging services (including small, local, specialised and personal assistant services that are highly tailored), to enable people to make meaningful choices and to take control of their support arrangements, regardless of service setting or how their personal budget is managed.

Although direct payments are UK wide, devolution of powers to new governments in Scotland, Wales and Northern Ireland in 1998 has led to the evolution of somewhat different care systems. Scotland has developed Self-Directed Support as a principle of care

services and both Wales and Northern Ireland increasingly also use the term self-directed support rather than personalisation. This vocabulary differentiates their approach from what is seen as the more market focused approach in England (Pearson *et al.*, 2018). Despite differences of rhetoric and emphasis, the broad strand of policies relating to individualised funding are similar in the four nations. It is also the case that all four nations have made relatively slow progress on the individualisation of funding, particularly in terms of direct payments. Direct payment spend as a proportion of total care spend remains less than 10 per cent in all of the nations of the UK, and is lowest in Scotland at around 3 per cent (Atkins *et al.*, 2021: 44). There is a frustration among advocates of personalisation and self-directed support that take up appears to be falling rather than rising (Kings Fund, 2021).

Collaboration as a principle of reform is usually referred to as integration in the UK and is particularly focused on improving links between the health and care systems. It is universally accepted that there is an overlap between people's health and care needs, and that a lack of integration between these two systems (and associated services such as housing or employment) must be addressed. Insufficient collaboration leads to delays in hospital discharge, insufficient data sharing and uncertainty about where responsibility lies for paying for certain services (Miller *et al.*, 2021). All four nations now have some structural integration between health and care services and plan to increase this further (Atkins *et al.*, 2021). Northern Ireland is the furthest ahead on structural integration having had combined health and care services since the 1970s, although this has not translated into better support for the person using care services (Dayan and Heenan, 2019).

Miller and colleagues (2021) argue that integration efforts tend to be focused on 'macro' level integration rather than the micro and meso forms of integration in which services collaborate around the person. Reviewing ten years of integration efforts in England, Miller and colleagues (2021: 3) contend:

[S]uccessive English governments had been unduly focused on the 'structural' elements of partnership working, which failed to acknowledge the reality of the ways that organisations and professionals develop relationships and trust in order to be able to work together.

Similarly Audit Scotland (2018) found that progress towards integration has been slow. A Scottish government consultation on reform of the care system noted the limits in what had been achieved on integration to date:

The aim of integration was to improve people's experience of social care, and to focus on early intervention and preventative approaches, rather than only intervening when people reach a crisis. This has not worked as well as it should have done, particularly due to a lack of collaborative leadership in some areas (Scottish Government, 2021: 51).

Progress on integration in Wales has similarly been slow, with the Wales Audit Office's (2019) review of the Integrated Care Fund finding little evidence of improved service outcomes. In all the nations, problems of structural complexity and lack of parity of esteem between health and care have become incorporated into integrated structures rather than resolved by them. In England and Wales, where public spending on care is lower than in Scotland (Charlesworth and Watt, 2019), local authorities are under intense

pressures with rising demand and shrinking capacity to respond. Workforce shortages are acute and providers are fragile in terms of financial viability. These factors have been magnified by Covid-19 (Daly, 2020).

Australia: individualise and coordinate

In the last decade, Australia's predominantly block-funded approaches for disabled and older people have been progressively replaced by individualised funding to provide more user choice and control and create a competitive assemblage of diverse markets. This includes the National Disability Insurance Scheme (NDIS) for children and working age disabled people (Olney and Dickinson, 2019) and the Consumer Directed Care (CDC) initiative for older Australians (Hodgkin et al., 2020). As in the UK, these reforms have sought to address inadequacies in social services and supports for disabled and older people. As a backdrop, the Productivity Commission (2011a) cited chronic underfunding, fragmentation and inefficiency as longstanding problems of the disability support system in Australia, giving disabled people little choice, no certainty of access to appropriate supports and limited scope to participate in the community. Similarly, limited user choice, market failures and increasing expectations of older people for independent living were strong drivers for recommending shifts to consumer directed support for older Australians (Productivity Commission, 2011b).

Whereas the UK is travelling in the direction of more devolution to its component parts, in Australia the reforms have led to greater national mandating of provision (Purcal et al., 2014). While individualised funding was evident in some states before the NDIS (see Fisher et al., 2010), funding was usually paid directly to organisations rather than to individuals (Chenoweth and Clements, 2009; Purcal et al., 2014). The NDIS (legislated in 2013, with gradual roll-out completed in 2020) is based on a universal approach to individualised funding support, which therefore represents a radical departure (Purcal et al., 2016). It provides non-means tested access to individualised funding to purchase support services for citizens who acquire a disability before the age of sixty-five years, have a high level of needs and meet the eligibility requirements. Supporting approximately 484,000 Australians with a disability (NDIS, 2021), NDIS funded packages are uncapped and calculated based on what is 'reasonable and necessary'. NDIS participants can purchase their supports from various service providers they choose (either NDIS-registered and/or unregistered depending on their plan management arrangements) with capped prices for individual services.

A potentially positive aspect of the NDIS design for personalisation and collaboration is the option for users to self-manage their NDIS plan and flexibly choose providers and/or employ their own support staff. Self-managed plans allow greater control over personalising and coordinating supports and sometimes leads to innovative packages to overcome market limitations (Purcal et al., 2021). Yet, the option to self-manage is not always appealing and concerns remain that disabled people with the most complex needs are more disadvantaged in adopting this option and exercising the accompanying choice and control (Malbon et al., 2019). The rapid roll-out of the scheme has outpaced the capacity of the disability market to evolve, leaving participants with potentially nothing to buy particularly in areas with 'thin markets' and unresolved questions about the government's role to steward new markets (Carey et al., 2018a). Moreover, interface issues, particularly between the NDIS and health system, pose a risk to NDIS sustainability and quality of

funded supports if major responsibility disputes are not resolved (Productivity Commission, 2017). At the organisational level, research from Foster *et al.* (2021) shows the struggle with personalisation where there is stronger marketisation. Specifically, the shift in financial control has simultaneously created a heightened sense of disconnection and a greater need for collaboration between providers.

Whereas the UK combines disability and aged care in a single adult social care system, these are dealt with separately in Australia, with the latter comprising multiple funding models and programs. Consumer Directed Care (CDC) has its origins in *The Aged Care (Living Longer Living Better) Act 2013*, and Home Care Packages Program created in 2013, which aimed to support older people to live at home and have choice of services and supports through a sustainable market-based system (Jorgensen and Haddock, 2018). Further legislative amendments in 2016 transferred financial control from providers to consumers, ensuring that by 2018 all home care packages were consumer-directed (for further information see Hodgkin *et al.*, 2020; Moore, 2021). Described as a 'tiered system that provides greater levels of support according to an individual's assessed care needs' (Hodgkin *et al.*, 2020: 378), home care is means tested (unlike the NDIS), and sometimes may require co-contributions (My Aged Care, n.d.). Not only are there budget caps, but the overall number of home care packages available Australia-wide for eligible older people is capped (Australian Government, 2021), both of which present persistent and contentious problems (see Moore, 2021) due to long wait times and increased vulnerability of older Australians. Once in receipt of a home care package, consumers can choose from a list of government approved providers only.

Like the NDIS, market limitations are also challenging for older people. The Royal Commission into Aged Care (Commonwealth of Australia, 2021b: 201) reported 'a clear absence of market management by the Australian Government', with a drift towards very large providers and an over-concentration in big cities. The recommendations highlighted the centrality of personalisation and collaboration to the future vision of improved aged care in Australia: 'Based on assessed need, it should provide an entitlement to care at home with a personalised budget which allows for a coordinated and integrated range of care and supports' (Commonwealth of Australia, 2021a: 100). However, unlike the UK where there are forms of structural integration between health and social care, this is less the case in Australia despite care coordination being the focus of many reforms.

A lack of willingness to adopt more integrated cross-sectoral funding models continues to thwart attempts to coordinate services and supports for older Australians (Mann *et al.*, 2019) and for Australians with disability (Productivity Commission, 2017). We can see therefore that for both older and disabled people in Australia, personalisation and collaboration remain key aspirations but that progress to date has been very limited.

Discussion and conclusion

Reviewing the literature on personalisation and collaboration in Australia and the UK, it is clear that in both countries these twin initiatives remain at the heart of long-term ambitions. Progress towards both of them is incomplete, and this is of course no surprise given the implementation challenges of reforming complex systems (Carey *et al.*, 2019; Needham *et al.*, 2022). Covid-19 has been a further disruptive factor with devastating consequences for many people living with disability or age-related frailty (see e.g. Daly, 2020; Kavanagh *et al.*, 2021). The collaboration agenda may have been advanced

through the pandemic as local stakeholders worked closely together to ensure continuity of support (Comas-Herrera *et al.*, 2020). However, personalisation and flexibility of provision may have become less of a feature given the limits on service access associated with recurrent lockdowns and shielding by many disabled people (Yates *et al.*, 2021). The extent to which Covid-19 will have reconfigured care services in the long-term remains to be seen.

We could therefore apply a temporal lens and argue that collaboration and personalisation need longer to embed and mature (on the other side of the pandemic). Providers require time to develop the skills and networks in order to join-up services around the person in a way that delivers both personalisation and collaboration. However, a second explanation is that these agendas, although pursued in tandem, contain contradictory impulses that will continue to undermine each other (see Allen *et al.*, 2022 in this themed section). More collaboration between organisations risks closing down choice and control for the person using services; alternatively, the move to individualised funding fragments care markets in such a way that collaboration is harder than ever.

Future research could usefully explore the extent to which some types of collaboration and of personalisation are easier to combine than others. It may be that the structural integration attempted in the UK is particularly ill-suited to fostering the kinds of choice and control that personalised care necessitates. The approach taken in the NDIS to collaborate around the person offers scope for support that is both tailored and seamless. However, Foster *et al.*'s article in this themed section highlights that there are aspects of the current design that militate against this, particularly in heavily privatised care markets. Future research could also move beyond care and support services to consider how far the same fragmenting versus integrating conflicts are evident in other welfare services. For example, 'welfare to work' arrangements often promise to deliver support that is both tailored and holistic (Considine *et al.*, 2011; Rees *et al.*, 2014), usually with disappointing results on both elements. There are broader questions here about the primacy of choice and markets as a goal in welfare systems over alternative dynamics of relational and holistic support (Cottam, 2018). Is the most important aim of a welfare system to maximise the choice and control of the people using services, or to join up services around them in a way that improves efficiency and outcomes? Such value conflicts and ambivalences are not unusual in welfare systems, as Hoggett (2006: 179) argues. Rather than being resolved he suggests that they must be 'lived out' at the frontline:

[I]t is often at the level of 'operations' that unresolved value conflicts are most sharply enacted, public officials and local representatives finding themselves 'living out' rather than 'acting upon' the contradictions of the complex and diverse society in which they live.

Missing from Hoggett's account of public officials and local representatives are the people with lived experience of using social services. They in particular must 'live out' the value conflicts within the welfare state. Services that are either tailored or seamless remain well beyond many people's experiences as closed residential institutions endure or are remade in overly controlling and functional community support systems (Fox, 2018). Finding a way to advance personalisation and collaboration, and understanding which to prioritise when they are in tension, must be a co-productive endeavour with the people who have most at stake.

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