

## RESEARCH

# Personalisation and the Promise of Independent Living: Where Now for Cash, Care and Control for Disability Organisations Across the UK?

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Personalisation has dominated social care across OECD countries over the past 20 years. UK policy evolved from the efforts of disabled peoples' organisations (DPOs) to secure the availability of cash payments as part of a wider drive to enable independent living. Implementation of personalisation across the UK has seen significant divergence in how governments have developed their own responses, but in each country the DPOs' role and impact has shifted from campaigning and promoting the voices of disabled people to a more muted focus on service provision and limited policy engagement. This article draws on a series of interviews with DPOs and leading disabled activists. It highlights concerns raised related to themes around austerity, changing relationships with local government and the role of co-production in developing policy. We conclude the article by discussing the future directions for personalisation and developments in light of the COVID-19 pandemic.

**Keywords:** personalisation; social care; direct payments; disability

## Introduction

When we were talking about direct payments, I felt ... like disabled people and disabled people's representatives ... had full ownership ... The drive for Self-Directed Support has come very much from [devolved government] ... So ... we have lost ownership of it.

(DPO, Northern Ireland 2017)

In 2017, we undertook a small study to examine how personalisation in social care was being implemented in the four UK jurisdictions, interviewing some of the main DPOs, including those active in campaigning for the original direct payments legislation (Pearson 2000). We were interested to see how the personalisation of social care – a policy promoted across OECD countries – reflected the goals and priorities of DPOs. One of the quotes that summed up the general mood of these interviews is set out above. It highlights how the shift from direct payments – or cash for care – to personalisation has brought with it a change in the nexus of control between DPOs and governments. Personalisation has been presented as a radical and transformative policy and is the driving force for much UK public service reform. Put simply, it is about giving people choice and control over the way public bodies work and the services they provide. This can be in the way services are designed and delivered through individualized assessments and tailored responses or as a means to reflect user preferences, rather than being based solely on assessment (Department of Health [DoH] 2008). Policies across the UK administrations appeared to link in with the principles of direct payments and indeed became one of a number of options for users – whereby cash was allocated to users as an alternative to directly provided services. Unlike personalisation, direct payments emerged from grassroots activism of local groups of disabled people and featured in care systems across the UK, Sweden, Norway, Canada and key US states, from the late 1990s onwards (Evans 2002). However, by the early 2000s successive OECD governments became interested in using many of the principles underpinning cash for care to develop more widespread systems of personalisation in social care. As these policies have become embedded in provision, we set out to further examine the views and roles of DPOs in this changing policy context. We began this process in 2017–18 through 5 initial interviews with DPOs. These were revisited in 2020 through an additional 14 interviews with the leading DPOs, activists and allies across the UK disability movement. This article draws on these interviews and highlights the key issues raised around the changing values promoted in each of

the UK personalisation policies, how they have impacted on the wider goals of DPOs and the promotion of independent living. We conclude by discussing future roles of DPOs, both in terms of personalisation and in recognition of the fundamental challenges ahead – particularly amidst the onset of the COVID-19 pandemic.

Debates framing personalisation in social care have increasingly masked its origins as a radical policy tool promoted for over 40 years by global networks of disability activists. Campaigns for direct payments – cash-based alternatives to directly provided services – eventually led to the development of distinct legislative pathways, underpinned by a drive to facilitate independent living for disabled people in each part of the UK. From the outset, the policy has been a key demand for many disabled people and a growing network of DPOs, including centres for independent/integrated living (CILs) in a number of mainly urban areas across the UK. Yet as personalisation has become engrained, the legacy and influence of DPOs has been eroded from policy. As with the original direct payment schemes (Pearson 2000), our research found that there remain pockets of good practice but DPOs and allied groups have found their influence weakened and policy discourses around choice, control and independent living lessened. Through our interviews, we therefore examine how personalisation is impacting on social care and question where the promise of cash, care and control at the centre of the drive to independent living features in current policy environments.

Legislation underpinning social care delivery across the four UK nations has been operating in an arena heavily influenced by austerity introduced by the Coalition Government in 2010. Whilst social care is a devolved issue, under the control of the administrations of Wales, Scotland and Northern Ireland, funding levels are set by Westminster. Between 2010 and 2015, UK-wide social care funding was cut by 13.5% from £22.5bn to £20.6bn (Burchardt et al. 2015) and although by 2019 it had risen to £22.2bn, it is still below the level of 2010.

As our interviews show, this has led to loss of innovation and flexibility in support packages, with a shift away from the global demands for independent living set out in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (Pearson 2019) and towards subsistence in an individual's home.

The paper then moves on to a more detailed appraisal of the role of cash-based payments. For many in the disability movement, these are the focal points of disabled peoples' independence. Yet they remain little more than a marginal feature of personalisation in each part of the UK and – as we found – many local authorities remained resistant to promoting them. Findings revealed a push back from discourses of choice and control in many areas of England and Scotland, with the appearance of council-led initiatives such as pre-paid cards. By contrast, legislation in Wales has promoted the role of user-led co-operatives as an alternative to cash-based support. In line with Norway and Sweden (Christensen 2016; Clevnert & Johansson 2009), we examine how this approach has been developed as part of local care markets in Wales. Given the shifting parameters of policy, the final interview theme focuses on the position of DPOs. Despite the changing policy focus in personalisation, the premise of co-production has featured strongly in legislation. We examine how this has been utilised in practice in relation to the views and roles of DPOs. Before doing this, we turn to set out how personalisation in social care has been framed across the UK.

### Pathways to Personalisation Across the UK

Driven by a desire for more control in their lives and in the way care and support are delivered, the disability movement took a leading role in the campaigning for new forms of cash-based support. In the UK, one of the first global policy directives came through the adoption of legislation for Direct Payments under the Community Care (Direct Payments) Act 1996 (Pearson & Ridley 2017). Whilst popular with those who opted to receive care via direct payments, take up across the UK was limited and they failed to become mainstream (Priestley et al. 2010). There was also variation between and within the nations, with much lower number of users in Scotland, Wales and Northern Ireland compared to England (Riddell et al. 2005). From 1997 to 2003, attempts were made by the respective devolved administrations to reignite policy, but uptake was never more than marginal (Priestley et al. 2010). Policy development at this time also recognized a more prominent role for disabled people and publication of the strategy document *Improving the Life Chances of Disabled People* (Cabinet Office 2005) included leading disability activists in its authorship.

However despite direct payment's low uptake, a growing political will to implement personalisation emerged (Riddell et al. 2005). Under the Labour Government (1997–2010) many of the themes that linked direct payments to the Conservative's broader agenda of marketization were developed through a focus on personalisation in social care. Initially in England. Leadbeater argued that personalisation could be as influential as privatization was in the 1980s and 1990s in re-shaping public provision (Leadbeater 2004). By exploring how services could be modernized through direct participation of users in service delivery, he took the concept away from the original direction proposed by the disabled people's movement with links to independent living and instead focused on promoting a model of consumerism. This placed users in the role of budget holder, alongside an emphasis on related rights and entitlements. Leadbeater argued for what he called 'deep' personalisation, whereby users engage as co-designers of services, in contrast to 'shallow' personalisation, which offered only modest modifications. A central tenant of deep personalisation is therefore about moving people from service consumers to giving them the power to redesign solutions from the ground up and develop new strategies for self-management and self-organisation.

Although the overarching theme of personalisation has been endorsed by all four UK jurisdictions, there has been divergence in implementation. Key to personalisation has been the relationship between the state and the markets set in place by the interpretations of the UK-wide National Health Service and Community Care Act 1990. In England,

this established the role of quasi-markets in social care (Le Grand 1991), whereas in Scotland, Wales and Northern Ireland, allegiances to public sector provision remained much stronger. After devolution in the late 1990s, Scotland and Northern Ireland gained legislative freedom on welfare issues and Wales secured these in 2011 – although a common social security policy throughout the UK has constrained major divergence. Changes set out in the 2016 Scotland Act enable further disparity between Scotland and the rest of the UK, as some of the social security powers impacting on disabled people, have now been devolved.

In England personalisation was formalized in 2007 and is now firmly established within social care through the Care Act 2014. This repealed much of the existing statutes and created a single legislative adult social care framework. By 2014, 81 per cent of all people receiving community-based services were supported by Personal Budgets (PBs) or Personal Health Budgets (PHBs) (ADASS 2014). These are monies allocated to individuals to support their health and well-being needs, planned and agreed between the person and their local NHS team. PBs or PHBs are provided as an ‘upfront’ allocation of resources (calculated using a resource allocation system) and are intended to provide an approximate indication of the costs involved in meeting a person’s needs. The allocated PB or PHB may be taken in three forms: a direct payment; an ‘indirect payment’ held by the local authority or an individual service fund held by a third party or organisation. In contrast to the rest of the UK, social care in England has rested on promotion of the market since the early 1990s when the NHS and Community Care Act came into force. Critically, this required 85 per cent of services to be purchased from the independent sector. Since the early 2000s, there have been a number of significant policy statements which have promoted social enterprise roles (see for example, DoH, 2008) and the Social Enterprise Investment Fund was introduced in 2007 to simulate growth in this area (Hall et al. 2012).

The picture of personalisation in England has become more complex with shifts to deliver greater powers over health and social care integration to English regions through devolution (McKenna & Dunn 2015). The Care Act 2014 underlined the increasing importance of integration, stating that local authorities must promote it with health provision where it enhances wellbeing of adults, contributes to prevention and improves the quality of care (DoH 2014). For example, in 2015, Greater Manchester local authorities and Clinical Commissioning Groups took control of £6bn in health and social care funding, whilst five London boroughs became pilot sites from the new London Health Devolution Agreement. Each of these deals makes provision for health and social care in different ways and so personalisation and integrated health and social care are likely to develop according to region-specific demands and priorities. This presents a much more flexible approach to personalisation in England, when compared with elsewhere in the UK.

Scotland has traditionally been slow to embrace the market in social care and was largely sceptical of direct payments (Pearson 2004). The Scottish Government (SG), led by the Scottish National Party, employed its own version of personalisation – the Social Care (Self-directed Support Act) (SDS) (Scotland) Act 2013 – which introduced SDS into the mainstream of social care. This offered users four different options for SDS – ranging from a direct payment to support arranged through the local authority, a third sector or a mixture of these. The principles of co-production were placed firmly at the heart of the SDS strategy in Scotland, with DPOs involved in the drafting legislation and an emphasis on collective agreement from users and practitioners at all service development stages (SG 2010). Yet research to date shows that SDS is yet to have a transformative effect on social care in Scotland (Audit Scotland 2017; Pearson et al. 2018), with low uptake of direct payments and near identical proportions of users using existing providers. Whilst PHBs are not available in Scotland, implementation of new legislation to integrate health and social care services has influenced the policy environment for SDS, with health assuming a more dominant role in service planning (Authors 2018).

In Northern Ireland, Scotland’s model of SDS has been adopted as the basis of the policy framework, although no specific legislation is in place. The drive to adopt personalisation emanated from the *Transforming Your Care* (TYC) programme (Health and Social Care Board 2011), which emphasised broad support for increased individual control over budgets across health and social care reform. In June 2015, phased implementation of SDS began across the five health and social care trusts. Unlike Scotland, health and social care have been integrated since 1973, but TYC identified integrated care (alongside personalisation) as one of the 12 principles for change. This included a pledge to set up 17 new Integrated Care Partnerships in Northern Ireland in an attempt to join up a full range of health and social care services in each area. In 2016, a new model of health and social care was set out in the Bengoa Report as part of a 10-year strategy (DHSSPS 2016). The report is strongly centred on health provision, acknowledging the social care role mainly through its impact on hospital admissions (Birrell 2016). However, progress with developing health and social care policies in Northern Ireland has been slow, with the suspension of devolved government (2017–2020) significantly limiting policy discussion.

Whilst principles of choice and control remain central to Welsh legislation, the terms ‘personalisation’ and ‘self-directed support’ are notably absent. Instead Welsh policy aims to deliver what are termed ‘citizen centred services’ (CCS) through the ‘involvement of persons for whom care and support and preventative services are to be provided in the design and operation of that provision’ (National Assembly for Wales 2014). A new single statute – *Social Services and Well Being (Wales) Act 2014* – replaced a swathe of Welsh and UK legislation and enshrined CCS in law. In both Wales and Scotland, local authorities have explicit duties to engage and promote non-profit service providers. This requirement is consistent with the Welsh Government’s stated eschewal of market forces and the preference for these organisations suggests new models of care and support may follow (Clements 2016). There is also a focus on community and less emphasis on choice and consumerism compared to England.

There is undoubtedly an ideological tension at the heart of personalisation, with the consumerist ideals of freedom conflicting with the collective impulses of social justice. Early advocates of personalisation within the disabled peoples' movement appealed to market efficiencies to evidence their calls for choice and control and secure legislation for direct payments (Zarb & Nadash 1994). Whilst personalisation is partly a response to collective grassroots activism and early developments in personalisation were built upon collective responsibility for individual rights (Morris 1997), little is known about its potential to act as a conduit for civic participation and deliberative public policy development. As we discuss here, the emphasis on social enterprises in Wales and Scotland suggest that personalisation may mean that UK jurisdictions have the potential to pursue the type of approaches to user-led co-operatives seen in Norway and Sweden. Critically, this implies new and diverse roles for DPOs. However a shift to a more varied provider market in personalised social care requires a major cultural shift in service provision. In the rest of this paper, we draw of a series of 20 interviews with key voices from across the UK disability movement, to assess the key issues for DPOs in the development of personalisation in social care. Before doing this, we outline the background to this study and detail the empirical research used.

## The Study and Method

A total of 20 interviews (19 by telephone and one by email) were carried out between March 2017 and March 2020 with representatives from the leading disability organisations across the UK (see **Table 1**). This included CILs, organisations of disabled people and one of the main organisations working on behalf of disabled people. Four DPOs (two in Scotland, one in England and one in Wales) were interviewed in both 2017 and 2020 and in 2020 we widened our interviews to include a number of leading disability activists/consultants. These were individuals who had previously worked and campaigned for DPOs and/or in the social care sector and had been active in the ongoing push to secure independent living, but were now either retired or self-employed. Whilst some of our interviewees were concerned about possible implications for speaking out against local authorities or national governments, the individual activists felt much less restricted. It was therefore very useful to have this range of voices of disabled people, which a rich experience and commitment to the themes we were pursuing. The sample does not purport to be representative and instead is purposive. In some parts of the UK it was easier to secure interviews than others. Notably, given the size difference across the four nations, a greater number of interviews were secured in England and we were able to use long-term links in Scotland to speak to a range of people and clarify any issues over the course of the study.

We chose to use telephone interviewing as our main data collection tool because it is both user-friendly and cost effective (Ward et al. 2015). One interview was conducted face-to-face at the interviewee's request. The research questions focused on the following themes: the impact of the personalisation of social care on disabled people (including discussion around austerity); key local issues; impacts on DPOs; provider markets (including the private sector and co-operatives) and political and/or campaigning roles (including co-production). A summary of respondents is shown in **Table 1**.

Ethical and research governance approvals were received for the research from the [College of Social Science, University of Glasgow, Ethics Committee, Reference: 400190075]. All interviewees gave verbal informed consent prior to the interview – the consent form was emailed to them and then read out for agreement. Interview themes and preliminary questions were also made available. For the reasons set out above, participants have been anonymised by the generic term 'DPO' and the countries where they were located. Interviews lasted a maximum of 60 minutes, were audio taped and fully transcribed. The data were read independently by members of the research team and coded manually, looking for emerging themes (Bryman 2015). A joint coding framework was devised as a basis for analysis, developing more detailed coding as themes and sub-themes emerged.

The next sections of this paper explore the themes raised in the interviews in more detail. This begins by a focus on the impact of austerity.

## Personalisation and the Impact of Austerity

As detailed elsewhere (Pearson & Ridley 2017; Pearson et al. 2018), the aftermath of the financial crisis of 2008 led to the onset of an austerity programme across the UK and other OECD economies. In the UK, austerity disproportionately targeted support for disabled people and coincided with key phases of the implementation of personalisation in social care across different parts of the UK. As Mladenov et al. (2015) argued, personalisation provided an ideological cover for austerity measures, as a means of achieving more with less.

**Table 1:** Details of interviewees.

Role of interviewee	Location	Number of interviews
DPO	England, Scotland, Wales, Northern Ireland	5 (2017)
		7 (2020)
Organisation for disabled people	England, Scotland, Wales	3
Disability activist/consultant	England, Scotland	5



DPOs across the UK spoke of a 'loss of innovation' (DPO England) and the difficulties of embracing the values of the legislation amid severe financial restraints:

What you end up with is ... a less personalised service where the service user ... often doesn't know that they've got a personal budget, they don't know what that budget is ... it ends up as a list of services that they're going to put in while the social worker then closes the case and moves onto the next customer.

DPO (England 2020)

I think the ... implementation of the Act has coincided with austerity and cuts in services. So part of the mantra with the Act, the implementation of this is like no cost or low cost.

DPO (Wales 2020)

Since the [SDS] Act has commenced, it seems to be driven by financial considerations ... The message that there is no money is so overpowering – or disempowering ... There is no space to create flexibility and creativity around the person.

DPO (Scotland 2020)

SDS ... is clearly motivated to save money rather than in the best interests of recipients.

DPO (Northern Ireland 2020)

Others in England spoke in more acute terms, suggesting that the social care system was close to 'collapse' (DPO England). This had a profound effect on providing support in local areas.

It was clear from across the interviews that the focus of personalisation had moved abruptly from support to facilitate independent living, to more restricted subsistence in a home setting. As one of the Scottish DPOs commented, 'the care packages are much smaller ... its really about making sure that the person is fed, dressed and put to bed ... rather than supporting [them] to move forward and live an independent life'. This raised broader issues about how personalisation has been reframed through austerity. Slasberg and Beresford (2019) question whether austerity has indeed been the real cause of the broader retreat from independent living. They argue that cuts to the numbers of people supported by social care is considerably more than the resource cuts. Given the extent of social care package reductions and the reframing of boundaries at which support access can be gained, Slasberg and Beresford (2019) argue that the level of resources available to each service user should in fact be greater, not less. We will return to this contention later in the article.

As detailed earlier, the cost efficiencies associated with direct payments in the UK were used as a persuasive tool by the disability movement in securing policy change (Zarb & Nadash 1994). The following section explores how this part of the personalisation agenda has developed and how DPOs and their allies view this role.

### **Cash for Care and Personalisation: The Cornerstone of Policy or a Marginal Interest?**

The importance of cash-for-care to facilitate independence has been pivotal for the global independent living movement over the past 40 years (Campbell & Oliver 1996; Westberg 2010; Christensen 2016). For many disability commentators, personalisation differs significantly from direct payments in its focus on marketization, economic efficiency (Morris 2011) and its implementation across welfare systems as a 'top-down' policy. This contrasts with the evolution of a global grass-roots support for direct payments from groups of disabled people.

Whilst UK disability policy has seen a shift over the past 20 years from its own cash-based model of direct payments to the broader remit of personalisation, each of the devolved administrations have set out a specific focus on how direct payments can be used. Welsh Government guidance is unequivocal, stating that direct payments can 'no longer viewed as a secondary consideration but as an important means ... to meet a person's need for care and support' (Social Services and Well-being (Wales) Act 2014 – Part 4: Sections 50–53). The English Care Act 2014 goes further in suggesting that direct payments are 'the Government's preferred mechanism for personalised care and support' (Care Act 2014, Statutory Guidance, para. 12.2).

By contrast SDS guidance in Scotland and Northern Ireland, sets out direct payments as one of four options with no preference indicated as to which should be favoured (SG 2014: para 2.12; Health and Social Care Board 2013). This therefore remains an important difference to the demands of the international disability movement.

Indeed our interviews revealed concerns as to a broader reframing of personalisation and erosion of the direct payment option. A former CIL employee, now working as an independent consultant, expressed disquiet at what he had observed:

I did some work with a disabled peoples' organisation in [north of England] and [it] was like stepping back in time ... they didn't have anybody as far as I could see on a PB that was real ... Everybody had managed services through their social worker, whether they wanted it or not.

Disability consultant (England 2020)

This was reiterated by a representative from one of the leading organisations for disabled people in England, who commented that:

... it's surprising how many qualified social workers you see who ... see no difference between assessment, support plan and review ... They think they're there to tell them what they can and can't have on a functional basis. We don't do house cleaning, we don't do socialising anymore because we can't afford that ... what we do is help you to the toilet, help you to eat ... very functional tasks. And that's why some of it's gone back 30 odd years.

Disability organisation (England 2020)

Uptake of direct payments in Scotland ('option 1') has also remained consistently low since implementation of SDS – at around 10 per cent, compared with 70 on directly provided services ('option 3') (Authors 2018). This was reiterated by one of the representatives from the Scottish DPOs, who commented that 'we're finding ... people are increasingly steered in not very subtle ways, towards options 2 and 3, rather than being given the opportunity to make informed decisions about which option suits them'. Direct payments were widely available in Northern Ireland, but were often used as a last resort when alternative packages had failed. One of our contacts in Wales stated that direct payment uptake there was amongst the lowest in the UK at around 8 per cent.

The position of direct payments in Wales was therefore seen in the context of a more diverse care market. This appeared to integrate a more varied role for service providers and potentially DPOs:

The Social Services Act does actually place a duty of local authorities to be more pro-active around promoting direct payments ... There's [also] a duty on local authorities to promote co-operative social enterprises and user-led services.

DPO (Wales 2017)

This provision in the legislation had initiated new projects, one of which, *Citizen Directed Co-operatives Cymru* (CDCC), developed a direct payment co-operative run by users from Disability Wales and Wales Co-operative Centre (funded by the Big Lottery's Innovation Fund until March 2018). This was the first co-operative of its type in the UK, with the other major international examples appearing in Norway and Sweden over the last 40 years (Christensen 2016; Clevnert 2007). The user-led co-operative model has offered a clear alternative to both privatized social care services and full state control, thereby enabling significant potential to empower disabled people and foster social inclusion and solidarity in local communities (Roulstone & Kwang Hwang 2015). Whilst a co-operative had been developed that brought together direct payment users in South Wales, there was a push in other areas to bring together other kinds of social care co-operatives. In these examples, a wider variety of interested parties had been involved, including employee or family members working on behalf of disabled people who needed support and therefore it was difficult to maintain a user-led ethos.

Elsewhere in the UK, there have also been some attempts to integrate co-operatives into social care provision. The SG pledged to support the development of more user-led DPOs 'to build capacity and standing within the localities they operate' (SG 2016: 8) and there was some progress was made through the *Innovation Fund*. This was a £1.2 million initiative funded by the SG to enable third sector organisations to 'promote culture change [to] enable more flexible and creative social care support (SG 2016: 10). However, only two out of the 21 funded projects were user-led. In England government support for co-operatives is more tenuous and is largely reliant on local innovation. Research by Fisher et al. (2012) on the DoH's pilot programme found that despite government support for small localized social care providers, these type of organisations were slow to become established and did not have resources to compete with larger providers. More recently, it has become clear that much of the user-involvement and engagement work established by DPOs in England has moved to non-user-led charities and private sector organisations (Pring 2018). The implications of this will be returned to later in this article.

In Northern Ireland, the social care market is much more limited than elsewhere in the UK with little provider diversity. The DPO we spoke to told us that under SDS there had been an understanding that 'option 2' (managed budget) would facilitate development of community resources so that people could access alternatives to the more traditional social care from the trusts. However, health and social care trusts have been unable to offer this beyond the existing organisations that already have private contracts. We were told that, 'the scope and desire for the private sector to provide social care is huge in Northern Ireland but essentially the money does not exist to fund it'. (DPO Northern Ireland 2020).

Whilst direct payments are clearly not suited to everyone as a means of receiving support, arguably they – and access to other cash-based models – have been very important in global campaigning for independent living. Their apparent retreat as a policy option in some areas was therefore a source of real concern. Examples in Scotland and England were given where local authorities had replaced direct payments with prepaid cards. Whilst many local authorities may argue that this shift removed problems around accountability for users, this was viewed cynically by the DPOs we spoke to.

The increased use of pre-paid cards was also often seen as part of a broader deterioration in local authority relationships. As one of the Scottish DPOs recounted, the policy change was developed without any meaningful consultation:

It's caused a huge amount of work for us ... because it was introduced without really listening to us ... You'd think you'd run a pilot, learn from it and introduce the rest. But no ... it has huge access issues for people.

DDPO (Scotland 2020)

This was re-iterated by one of the other English DPOs, who highlighted how pre-paid cards had emerged as part of a broader narrowing of support packages:

It's really hard to get anything that's not about personal care. You've got pre-payment cards, very prescribed things, it's not about kind of funding outcomes, hasn't been for years.

DPO (England 2020)

This type of policy shift and its impact on working practices was indicative of broader movements in relationships between DPOs and local authorities. It also reflects a longer-term problem in partnership working between some local authorities and DPOs (Pearson 2000; 2004). This saw many local areas from the late 1990s onwards resist attempts to implement direct payments and engage meaningfully with DPOs as part of this process. The next section details the impact of some of these shifts.

### **Turning the Clock Back?: Shifting Power Relations with Local Authorities**

For organisations working across different local areas, contrasting policy approaches were strongly apparent. This suggests that the picture of direct payments as a 'postcode lottery' across the UK (Riddell et al. 2005) nearly 20 years ago remains firmly in place. As one of the respondents commented, 'Each local authority has huge discretion on how it manages ... and every local authority is therefore different' (Disability consultant, England).

One example of innovation and good practice in England was mentioned in several of the interviews and stood out from the wider commentary. As one DPO commented, 'it's amazing good practice ... everyone should know about it'. This referred to the London borough of Hammersmith and Fulham, which had become the first council in England to abolish care charges and had set up an enquiry on independent living led by disabled people and in line with the principles of Article 19 in the UNCRPD. In addition, all staff – including frontline practitioners and councillors – had undertaken disability equality training. The changes had come about through the actions of a small group of disabled people in the area, firstly working with the then opposition Labour Party to successfully challenge the charging policy and then being brought in by the new Council administration to work in partnership and establish an independent living strategy. Hammersmith and Fulham's transformative approach to social care, when compared with the broader experiences of other local authorities across the UK, raises wider questions as to how this could be achieved. As one of the leading DPOs in London acknowledged, this was being discussed in the wider area:

Well they made different political ... choices and I think ... they're suffering from austerity like anybody else. I mean now that there's a growing demand from other groups of disabled people in other boroughs to say 'why can't you do what's happening in Hammersmith and Fulham?'

DPO (England 2020)

However, examples given of deteriorating local authority relationships were more common. One respondent in England described this as 'social work reasserting its power' (Disability consultant, England 2020). In Scotland, one of the DPOs highlighted a broader problem in establishing a meaningful working partnership with the local authority:

Local authorities are really still working silos ... the commissioning and procurement departments are not supporting the implementation of successful SDS ... We have a [support] contract ... which says that we should support people before assessment ... and that there was space to work with them ... But there hasn't been any communication or [it's] been ... very confusing communication about our role as an organisation to the social workers, to the OTs [occupational therapists]. So the social workers, the OTs are not referring people to us.

DPO (Scotland 2017)

In England, we were told about a number of cases which suggested a fundamental retreat from policy discourses around choice and control. At its most acute, examples were given where it would appear that the entire independent living philosophy had been rejected by individual local authorities:

You'll get some directors [of social care] who were very anti-self-directed support who believe that it's their duty to have people in residential homes ... They absolutely believe that that's the right thing to do and we just need to make them better quality ... giving money to people is back-door privatisation, as far as they're concerned.

Organisation for Disabled People (England 2020)

This apparent deterioration in relationships between local authorities and DPOs was exemplified in some of their changing support roles. This presents a conflict between their traditional site as campaigning forces and their integration into the social care system as service providers. As we examine these changing positions, the next section asks where DPOs now fit in.

### Where Do DPOs Fit In? Co-Production, Co-operation and Personalisation

Support for a network of user-led service provision for disabled people in the UK has been somewhat muted since the commitments set out in *improving the life chances of disabled people* (Cabinet Office 2005). This policy document – devised under the Labour administration (1997–2010) – and in partnership with many leading UK disabled commentators, stated that every local area should have a user-led organisation by 2010. Despite cross-government commitment, the pledge disappeared without enforcement after the 2010 general election. Since then, the focus on user involvement in personalisation has been framed largely through a discourse of co-production. Co-production describes a particular approach to partnership between those reliant on services and the people and agencies providing them (Hunter & Ritchie 2007) and has featured strongly in the legislation across the UK jurisdictions (see Care Council for Wales 2017; DoH & Social Care 2018; SG 2014). Despite the inclusion of user groups as partners in the policy development process, concerns were expressed throughout the DPO interviews as to the effectiveness of this role. In England, it was suggested that, ‘it [had] sometimes lost its meaning’ and in Northern Ireland it was largely dismissed as ‘tokenism’. This apparent disconnect between policy discourse and disability groups was set out in more detail by one of the Scottish DPOs, who described how the terms of reference for co-production had shifted:

DPOs have worked with the Scottish Government, and there has been some kind of co-production ... In the meantime, locally ... some organisations, like ours, managed to work with local authorities, and develop some stuff. But then, once the Act commenced ... local authorities do not have the time to engage with people in organisations like ours. They think they've done it ... So since the Act has started, I would say, no longer are we as involved as we should be.

DPO (Scotland 2017)

A more acute example of the changing relationships between DPOs and local authorities was described in one of the English areas we interviewed, where the CIL had lost the contract to provide support for around 3000 disabled people in receipt of PBs, resulting in the council taking the role in-house. As detailed below, their work in advocating on behalf of PB users or campaigning against service cuts, was increasingly seen in conflict with the local authority:

Social workers were actively making comments, and really viewing the organisation in a very, very negative way ... Comments [like] ‘well it's difficult to work with you when you're standing outside, protesting, when I come into work’ ... Since then, we've had meetings with councillors, where they've gone, ‘well we're funding you, why are you protesting against us?’ And that became very, very difficult ... The Board ... had to sit down and go ... how do we do this? Do we want to be an advocacy organisation? Do we want to be a service provider, or do we want to be a campaigning organisation? And they have never really ... managed to square that circle.

DPO (England 2020)

In Scotland, it was acknowledged that the DPOs had to be ‘really careful’ about any criticism of the local authorities they supported as their role was seen as critical to disabled people:

If we weren't here and they [the local authority] just decided either to take in support in-house or use somebody else ... then I honestly believe people would get a much worse service from people who have a very different set of principles and values. So we have to take that all into account.

DPO (Scotland 2020)

This type of closer relationship between DPOs and local authorities provoked a more critical line from some of the other activists interviewed, who had previously worked both in social care and had a prominent role in disability activism. At this stage, they were able to speak more freely as they no longer had a working relationship with local or national government and expressed concerns that leading DPOs were ‘hand in glove with the [Scottish] government’ (Disability activist, Scotland 2020). Whilst co-production had been effective in allowing the voices of disabled people to feature in the development of SDS legislation, it was argued that this had removed critical voices from on-going policy negotiations. Similarly at local level, contractual arrangements between DPOs and local authorities limited other key roles in representing the needs of disabled people:

There is no voice you trust of disabled people at the local level, and that is a real bugbear that needs to be developed. Not only do disabled people need a greater voice in the assessment process, they need it in the resource



allocation process. They also need a bigger voice in the management and policy development of social care at the local level, and that is missing.

(Disability activist, Scotland 2020)

### Discussion, Concluding Comments and the Challenge of COVID-19

DPOs' position across the UK has become increasingly challenged through the shift to personalisation in social care. What began as a global grassroots' campaign to facilitate independent living, has been subsumed by a reforming agenda in each of the devolved administrations. Whilst this may differ across the nations, the voices of disabled people have been diminished. Social care provision has been residualised and with it, the values and ideals of the Independent Living Movement. Restrictions have been placed on DPOs and many feel unable to act as a campaigning force if they are contracted as service providers. Blame for this has often been placed on either austerity and/or neoliberalism (Ferguson 2012; Grover 2019). Slasberg and Beresford (2019) have argued that this is too simplistic and that rather than being the cause, austerity has been used as an excuse and cover to reconfigure disability support. It is, they argue, a political decision. The case of Hammersmith and Fulham highlighted above supports this assertion. Where there is a will to change social care support and to provide services that empower and enable, it can be done. These lessons can be drawn from the original campaigns for independent living in the 1990s, which relied on grassroots activism and co-production with allies in the local council. It was these that enabled a framework for disability-led support to emerge and it is this approach that is working in Hammersmith and Fulham.

One of the aims of direct payments was to improve disabled people's participation, both in decisions about their own personal care and also in the wider democratic process. There is little evidence that this has happened in the UK and in the data we present above it is clear that the shift to marketisation, introduced under the guise of personalisation, is damaging this further. As Fraser (2013) has argued, policies introduced to empower and promote social justice have been used to legitimate state retrenchment. We have seen a shift from the macro to the micro, with a focus on the individual rather than the structural and the paternalism that previously surrounded the provision of disability support, has been replaced by a market-led response.

There have also been attempts in different parts of the UK to counter this and to develop a co-operative model of support, the type of which has previously been most prominent in Norway and Sweden. Whilst Wales has offered the most innovative example of this, it has clearly been difficult to maintain a user-led ethos. Without sustained government investment in this area and recognition of the advantages of peer support, it is difficult to envisage a major reconfiguration of social care. Likewise, Scotland and Northern Ireland's attempt to bring in co-operatives through SDS has been especially muted.

At the time of writing this article, the COVID-19 pandemic emerged and governments across the world locked down the main areas of economic, social and civic life. Alongside the immediate heightened danger of the virus to many disabled people, the UK government's strategy for dealing with the outbreak raised profound concerns for DPOs and the wider social care system. This centred on implementation of the emergency legislation – the Coronavirus Act – which suspended social care legislation across the UK, removed the automatic right to Special Educational Need and changed mental health legislation.

The need for governments to implement emergency legislation during the pandemic raises broader questions about compliance with the requirements set out both nationally, in for example the Single Equality Act (2010) and internationally, in the UNCRPD. We need to make sure that any future social care settlement post COVID-19 does not fail to accommodate the original values and ideals. We cannot let COVID be used in the same way as austerity as a stalking horse for further challenges to the right to independent living.

### Competing Interests

The authors have no competing interests to declare.

### Author Contributions

Charlotte Pearson was responsible for framing the article, a number of the interviews and the majority of the writing. Richard Brunner and Tom Porter completed interviewing and contributed to the writing. Nick Watson contributed to writing and editing.

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