

Article

Personalisation policy in the lives of people with learning disabilities: a call to focus on how people build their lives relationally

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Abstract

Social care provision across high-income countries has been transformed over the last ten years by personalisation - a policy agenda to give people with eligible support needs more choice and control over their support. Yet the ideological underpinnings of this transformation remain highly mutable, particularly in the context of reduced welfare provision that

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has unfolded in many nations advancing personalisation. How the policy has manifested itself has led to an expectation for people to self-build a life as individual consumers within a care market. This article draws on a study exploring how people with learning disabilities in England and Scotland are responding to the everyday realities of personalisation as it is enacted where they live and show the relationality inherent in their practices. We propose that the personalisation agenda as it currently stands (as an individualising movement involving an increasing responsibilisation of individuals and their families) ignores the inherently relational nature of care and support. We propose that social care policy needs to recognise the relational ways in which people build their lives and to advocate a redistribution of responsibility to reduce inequalities in the allocation of care.

Key words

austerity, intellectual disability, personalisation, relationality, social care

Introduction

In many countries in the Global North, ‘personalisation’ has become the core principle in the provision of social care and support (Carey et al., 2019; Hamilton et al., 2017). This principle emerged from demands in the 1990s by the disability rights movement for a redistribution of power, more choice over community-based support, and crucially control of the funding that went with it (Power et al., 2015). For people with learning (intellectual) disabilities, person-centred support emerged as a parallel agenda based around a care and support plan to enable individuals to exercise more choice and control in their lives and recognition of inclusion and empowerment as the foundations of support provision. These guiding principles gained international recognition through the UN Convention for the Rights of People with Disabilities (2006), prompting many governments to enshrine legislation offering individuals personal budgets in place of block-funded care; in the UK, the touchstone policies in relation to learning disability were ‘Putting People First’ (Department of Health, 2008) in England, and ‘Keys to Life’ (Scottish Government, 2013) in Scotland.

While person-centred support initially gained policy attention internationally, it became gradually constrained and undermined in the UK by inadequate funding and training, and inflexible and disempowering support in the community and in residential care (Joseph Rowntree Foundation, 2011). By contrast, personalisation took centre stage in the UK and internationally including Sweden, Australia, and the US. Needham (2011) credits its success to being like a story with a unifying and compelling theme and a dominant,

emotionally resonant narrative across public services. Yet despite growing policy adoption, the concept and associated rhetoric has been critiqued as hollow, ambiguous and open to other forms of inscription (Ferguson, 2007; Pykett, 2009; Spicker 2012). These critiques have highlighted how personalisation has always been an ideology rooted in self-determination, but that this has become inflected with a neoliberal agenda. Consequently, it has been enacted as a mechanism involving an increasing responsibilisation of individuals, where disabled people are expected to operate as consumers of care and support services in local care 'markets' (West, 2012; Roulstone and Morgan, 2009; Mladenov et al., 2015). The socio-political context underpinning this transformation is discussed below. How it has manifested has been critiqued as detracting from (and closing) collective and relational forms and sites of care and support (Hall, 2011). This concern has been heightened as the scope of the welfare state has reduced with a tightening of eligibility criteria, meaning fewer people can access benefit payments and care funding. Austerity has accelerated these existing developments, putting additional pressures on family care and limiting the development and sustainability of new initiatives (Manji, 2018).

Amid the transforming policy terrain and critique, disabled people, including people with learning disabilities, and their designated carers, are increasingly being required to take on responsibility for arranging daytime care and activities within a social care market comprising multiple actors (across the voluntary and private sector). We term this anticipated activity 'self-building a life', to refer to how people are being expected to respond to the assumptions of individual self and agency at the heart of the personalisation agenda. In contrast to this dominant narrative, we sought to explore how this 'self could be understood *relationally* to characterise how people are building meaningful daily lives in their communities (thereafter using the short-hand 'building a life'), through their own support networks, activities, and forms of learning, in relation to each other, and with family, friends, advocates, and support organisations.

Our perspective on how people are effectively building their lives is developed with recourse to relational thinking on selfhood. Our focus on the relational self is further informed by our interdisciplinary study (geography and education) of how people with learning disabilities are learning to build their lives in their local communities in England and Scotland. If personalised social care and support is to become more than an individualised consumption-focused project (West, 2012), and actively support people to build meaningful lives, social care policy needs to better understand and support the conditions necessary for people to do so relationally. Understanding how individuals and groups can be facilitated to build their own networks of support and learn to live in their communities within this context, is one of the key challenges for care commissioners, organisations and families.

The next section explores the conceptual underpinnings of personalisation and person-centred support, and the potential for adopting a relational perspective to critically examine what a personalised support landscape offers – and what it *could* offer if the right conditions are created. It then describes the study which underpins our critique. Finally, it examines the findings, drawing on a set of vignettes, and explores which conditions could enable people to build their lives meaningfully.

Narratives and critiques of personalisation

As noted above, the journey towards personalisation began with the disabled people's movement, in the USA and UK, demanding more control over the provision of care and support, and the direct funding to do so (Glasby and Littlechild, 2002). Transformation was arguably long overdue; services had become standardised, inflexible and unresponsive to people's needs, still framed by institutional notions of medically-defined provision and dependency.

For people with learning disabilities, person-centred support emerged later as a model to support them to achieve their aspirations and to become more included within their communities (Department of Health, 2001). Despite achieving initial policy interest, it evolved more slowly, as organisations led by people with learning disabilities were fewer in number and gradually became undermined through inadequate funding and training (JRF, 2011). This largely gave way to the more individualising approach we see in services today, such as the end of block grants and people purchasing slots in day services. Despite more people with learning disabilities taking up Direct Payments to pay for services and activities, this happens far less than for other disabled people (NHS Digital, 2018). Further, as eligibility criteria for accessing care and support funding have tightened, many people with mild and moderate learning disabilities are now deemed 'too able' to need support, leaving families, friends and community organisations to 'fill the gap' (Hall, 2011; Hall and McGarrol, 2013), thus generating other forms of inequality.

The early promise of personalisation was that it demanded 'thinking about public services. . . in an entirely different way, starting with the person rather than the service' (Carr, 2010: 67). Needham (2011: 1) identifies the five key themes that underpinned the initial success of the personalisation 'story-line':

- (1) personalisation works, transforming people's lives for the better; (2) person-centred approaches reflect the way people live their lives, rather than artificial departmental boundaries; (3) personalisation is applicable to everyone, not just

to people with social care needs; (4) People are experts on their own lives; and (5) personalisation will save money.

Needham (2011) traces how each theme evolved from policy evaluations backed up by powerful articulations of individual stories of transformation. However, the enacting of personalisation has been hugely variable, indeed the very ambiguity that made it a rallying point for reform has been the subject of critique (Manji, 2018; Pearson et al., 2018; Spicker, 2012). Roulstone and Morgan (2009) and Mladenov et al. (2015), for instance, argue that personalisation has developed within a dominant neoliberal discourse of cost-efficiency, market-led provision and individual consumption, and has become a vehicle for unchecked marketisation of social policy. Hall (2011) has argued that it has emphasised the individual to the detriment of more collective forms of support. Relatedly, Needham (2013) has argued that personalisation has been more effective in legitimising the closure of day centres for people with learning disabilities than stimulating the development of new opportunities and services in the local care market (see also Manji, 2018). Further, from the very beginning, local communities have been identified as the 'natural' sites for personalised lives to be supported and enabled; these 'imagined moral geographies' of communities that 'ought to care' of the early days of personalisation (Gleeson and Kearns, 2001), are amplified in the current rhetoric of 'asset-based' community provision (SCIE, 2017).

Within the ongoing context of significantly reduced social care funding, there is a widening gap between the aspiration and hopes of personalisation (summarised by Needham, 2011, above) and the harsh reality of budget cuts making it impossible to realise these hopes (West, 2012). 'Transforming Care' – a UK government initiative to reduce institutional care provision for people with learning disabilities (NHS England, 2012) – has effectively stalled. In some areas, the constraints have focused minds to develop personalised approaches; in others, there has been a retreat to provision of more standard provider-driven services to those most in need (Think Local Act Personal, 2019).

Personalisation is at a critical point in its narrative. Can its aspirations and the process of transforming care and support be achieved in a context of enduring austerity and an individualised consumption-based approach to provision? Can the responsibilisation of individuals ever be a reality for people with learning disabilities and arguably anyone? To answer these, we examine how people with learning disabilities are responding to the everyday realities of personalisation as it is enacted where they live (which might be quite different to how it is dominantly envisaged) in the actions they are taking in the building of their lives. We show that the personalisation agenda does not fully account for relationality inherent in care and support or address the inevitable inequities involved in responsibilising individuals and relying on their very different support networks.

Building lives relationally

Arguably one of the stumbling blocks for personalisation, alongside lack of funding, has been its prioritisation of individual subjectivities, aligned with discourses of unfettered autonomy, self-sufficiency and self-development, mediated by a culture of market-driven consumption (Springer et al., 2016). This is built on the assumption that agency is a property of the individual whose autonomy ('choice and control') will regulate the market. By contrast, the notion of self that was envisaged in person-centred support was a more collective endeavour based around a plan in partnership with family and local support services. The policy dominance of personalisation raises complex questions about how individual preferences are to be established and enacted, what conditions might be attached to choice and control, and how independence and autonomy are conceived. More widely, this individualisation has resulted in a 'redistribution of societal risk' with responsibility increasingly placed with individuals and communities regardless of their ability to absorb this (Asenova et al., 2015), or the capacity of local authorities to support them.

The 'self' that is understood as central to the personalisation narrative – informed and empowered to choose and determine their care and support – is an autonomous, detached, individualised entity free from constraints of standardised care provision. We argue that this is also a core reason for the crisis of personalisation, as it misses or denies the inherent relational connections that constitute people's lives. This connects with Mladenov's (2012) earlier critique of the liberal-individualist assertions of the personal assistance model as espoused by Independent Living advocates: that despite the advocates' assertions, their proposed model presupposes a distributed, relational understanding of human *being*.

Relational accounts of the self, autonomy and agency come from a range of perspectives, including phenomenology (Freeman, 2011), social psychology (Anderson and Chen, 2002), and of particular interest to our article, feminist ethics of care (Davy, 2019; Ward and Barnes, 2016) including within disability studies (Kittay, 2011) and cultural geography (Conradson, 2005). Such relational accounts, advocated by Greener (2002) and others, begin to unravel the dominant notions of self (noted above) long naturalised in Western thought. (Neo)liberal accounts of self misrepresent the ways in which identities are shaped within relations, accreting, unfolding and emerging within socio-cultural contexts over time, and in relation to intersections of gender, class, ethnicity, and dis/ability. In a relational model of self, the development and exercising of individuality and agency is a complex competence, requiring ongoing interpersonal, social and institutional scaffolding (Mackenzie, 2019). From this perspective, the aspiration of 'independence' (understood as being autonomous) – long central to the personalisation reform of social care (Care Act, 2014) – is arguably misconceived, diverting our attention away

from the relational ‘resources’ that could enable many more people to ‘activate’ their autonomy (Davy, 2015).

Davy (2015), drawing on a feminist conception of the relational self, advocates a ‘relational autonomy’ which recognises that vulnerability and need for support are intrinsic to our embodied human status. She argues that autonomy is achievable only when support, advocacy and enablement are collectively in place. Similarly, Nedelsky (1989: 12) argues that ‘what actually enables people to be autonomous . . . is not isolation, but relationships – with parents, teachers, friends, loved ones’. At the heart of this is a debate over recognising and valuing interdependence and care. Fudge-Schormans (2016) argues that the wider disability community (particularly people with physical or sensory disability) have sought to emphasise agency over care, rejecting the latter as implying vulnerability and (inter)dependence. This rejection has underpinned the male-dominated social model of disability criticised by disabled feminists like Morris (1991) and French (1994). Consequently, support and dependence on others and our understanding of how care is defined, experienced and practised in connection with people with learning disabilities have not been adequately explored (Fudge-Schormans, 2016). Here, Conradson (2005: 340) advocates using a formulation that explicitly acknowledges the connections between the self and the diverse ‘others’ that constitute a socio-spatial landscape:

Where possible, this framework should also attempt to specify some of the (admittedly complex) ways in which influence is transmitted through webs of connectivity . . . “significant others” have the potential to shape the contours of the self.

Inherent within Conradson’s approach is a commitment to *care-ful* conversations between disabled people and professionals (Ward and Barnes, 2016). We adopt this relational approach by drawing on the experiences of people with learning disabilities in a way that explicitly acknowledges their connections with ‘significant others’ that constitute their practices in building a life, to inform and advance this debate.

Researching relational building

To find out what people with learning disabilities are doing and learning in the process of remaking the landscape of support for themselves in the midst of personalisation policy (and austerity) we conducted research over two years (2018–2020). The study was designed to explore with people with learning disabilities and their allies their lived realities to inform a critical assessment of responses to a changing support landscape and to examine whether and

how creative forms of support were evolving. Ethics approval was given by the Universities of Southampton and Dundee. We obtained informed consent using easy-read information and consent forms, with an advocate present to assist in understanding where needed. The organisations and individuals have been anonymised. We adopted the advisory group model (Bigby et al., 2014) to ensure we conducted the research with respectful regard for the perspective of people with learning disabilities. We co-established three locally-based advisory groups (two in Scotland and one in England) so that people with learning disabilities could share their experiences of the issues and the locality, advise on the accessibility of the ideas and methods, support recruitment, monitor relevance, and inform the decision-making, analysis and dissemination processes.

The first phase comprised scoping community-based day support provision in each of four case-study areas, one urban and one rural in England and Scotland. These were selected to build on existing relationships and networks rather than for their typicality as cases, but they offered diversity and richness. We interviewed local authority commissioners in social care and worked with the local advisory groups to map activities and networks in their area. From this we interviewed 39 staff and volunteers from 29 organisations providing support and activities to fill the gap in community-based support (as formal social care and support was withdrawn) and we spent time at meetings and events at eight of them. Many of these were micro-enterprises and charities, some user-led organisations and some day centres in transition; they included voluntary work and training initiatives, community living support networks, self-advocacy and friendship groups.

The second phase involved people with learning disabilities more directly. We worked out from gatekeepers in community-focused support organisations in each area to recruit 43 people with learning disabilities to tell us about their experiences of building their daily lives. Participants were 24 men and 19 women, aged 18–70, two Asian British otherwise White British. We recognised that these would not be representative of the wider group of people with learning disabilities, many of whom would not be directing lives in the community and whom it is very challenging to reach. We began with focus groups so that participants could support each other and use others' experiences to prompt recall and reflection of their own. Each group met twice, following the advice of Nind and Vinha (2014), so that we could generate a picture of their lives collaboratively and iteratively. As such, the research process was itself inherently relational. Each focus group facilitator had spent time with the participants in their communities, chatting and observing, and this informed the mix of talk and activities they deployed in the focus groups. Activities included discussing photographs they took of their daily lives and creating a circle of people in their lives, a timetable of their typical week, and a collage of images of activities in which

they participated. We followed up with individual interviews to understand in more detail the contexts, decision-making, learning and agency involved for each person building their daily life.

We analysed the dataset in an iterative, deductive and inductive process using NVivo12 and sharing our emerging themes with our advisory groups. Initially, individual researchers focused either on exploring the landscape of care, the sustainability of voluntarism, the role of the state and support initiatives for building a life, the lived experiences of people with learning disabilities, or on the informal, community and lifelong learning evident. Then, *a priori* and emerging codes from this process were examined together and core themes were identified. The analytic process allowed us to identify the places people go and things they do, the roles they take up, the learning they engage in, and the issues that arise in building daily lives.

Encapsulating relational building

Our research is presented in a series of vignettes that encapsulate real life problems and solutions in people's efforts to build their daily lives. They are scenarios in which the full range of relational agency among the study participants can be seen; each vignette shows a different type of relational practice ranging from micro-agency through to taking control. This method of what Jeffries and Maeder (2005: 20) refer to as 'incomplete short stories' is used to communicate research findings and to encourage more nuanced discussions of potential solutions. As 'renderings of fieldnotes about social interactions' (Simmons, 2020: 30) and interviews, they invite dialogue on the wider issues.

Penny - a daily life stifled and unsupported

Penny is in her early sixties; she attends the *Better Together* day service three days a week and another local day service one day a week. Penny lives in a flat with her sister who also has learning disabilities. The managers at *Better Together* have known her for over three decades. She does not have any other close family or friends who support her, but she has maintained contact with friends at *Better Together* from when the premises housed a council-run day service (with the same managers). She has no other visitors and says of her and her sister 'that's all [the family] we got'.

Penny likes to knit and often has her knitting with her at *Better Together*, building a familiar rhythm of activity. She never has a hot meal; the carer who visits each morning makes her sandwiches to eat in the evening. Carers prepare for her a 'packed lunch' each day - mostly six mini chocolate bars and a yoghurt. Despite complaints from the *Better Together* centre manager she is not supported to make healthy food choices or prepare her own food.

We used a visual approach with pictures of activities to choose from so that Penny could tell us more about her interests. From this we understand that Penny likes music – any music – and dancing to it. She supports the local football club and loves to watch ‘Strictly Come Dancing’ on television. She travels to *Better Together* on a community transport minibus that stops at her house. We learn from staff that the morning carer does not stay for this, instead leaving the front door wide open for her to be collected, and leaving her potentially vulnerable (‘I wouldn’t want my front door being left open in that area of town’ – *Better Together* manager). Sometimes on Saturdays a carer takes her shopping. Penny says she loves to go and see the Christmas lights in town.

The picture that emerges is of a minimal standard of support. When we left Penny with a disposable camera to capture activities in her life, she returned a series of pictures of the inside of her flat in the dark, and one of her sister that she was very excited by. Despite the laminated instructions attached to the camera, nobody had supported her to take pictures at *Better Together* or within her home.

Penny has very little agency with no external family advocates and basic support. Her limited relational agency takes the form of the friendships (with staff and other people using the service) that she has forged over decades. Staff are probably her strongest advocates and provide stability, but the open spaces to make choices are small – the carers ‘know what she likes’ and her agency is limited to choosing knitting or dancing.

The *Better Together* premises were once part of a set of traditional, local authority run day centres. This centre (unlike others that were closed in the town) transitioned to a Community Interest Company in 2016 through the leadership of the original day service managers. The management has remained top-down with no user-led component, though the managers explain that ‘we ensure the service users have regular opportunities for feedback . . . we’ve had surveys on what activities people like, on what things they’d like to do’. The re-brand and shift to a Community Interest Company has not changed the feel and features of a traditional day service. The managers who saved it from closure have introduced a wide array of activities, visitors and fundraisers to ensure continuity for many of the (mostly aged 50+) people involved. The legacy of the old day centre is the people, commitment and long-held, valued relationships, together with the ‘client and service user’ mentality that inhibits relational autonomy and growth rather than safety and continuity.

Leonard - making small inroads into building a life

Leonard, a white British man in his thirties, became involved in the research because of his participation in *Gardening Activities*, which had been a traditional, charity-run day care scheme, but was undergoing transition to a community-focused enterprise. Leonard therefore, along with his peers, was caught up in changes in the organisation, largely a passenger rather than

steering this ship. He, though, was tuned into change and creating small opportunities to have some control.

Leonard had lived in his small town in a rural area nearly all his life. After the death of his mother and incapacity of his father two years previously, he lived independently very close to the homes of his sisters. He speaks of his 'large supportive family' and when mapping the people in his life Leonard includes his parents (still present for him), his sisters and their families, people from *Gardening Activities*, Jim his neighbour ('he's important'), and church. In sharing with us the pattern of his week, Leonard's two sisters feature strongly as people who support him at home and give him lifts, providing practical support, alongside the home carers who visit to help with meals and the occupational therapists and physiotherapists who support his mobility.

Gardening Activities has been a major part of Leonard's week for sixteen years, linking to his dad's interest in gardening. Along with attending a local social club once a month, this has provided continuity. Leonard has experienced 'good changes' during the day care transformation, so that 'now you do other things'. His activity there has expanded from gardening to spending time in the café and shop and doing cooking. He takes part in the community-based activities offered now too, a weekly social club and sport in mainstream venues. No longer required to attend five days a week, Leonard dropped his Friday at *Gardening Activities* to do a life skills course and he keeps Tuesdays for food shopping and appointments. He explains that he tried a different gardening scheme but did not like it. With new people and new roles Leonard has a new sense of himself, reflecting with laughter about going alone to do food shopping, 'Well I didn't know I could do it'.

The scope for Leonard to build his daily life is limited as there is no bus locally, and he cannot think of things at *Gardening Activities* that he wants to change. Nonetheless, Leonard goes to church and the pub on his own and he has built a critical social link for himself. On evenings when he is not with his sisters or elsewhere, he goes around to see his neighbour, Jim. He seems unsure whether to tell us that Jim is 77, having observed that the age gap breaks a social more, but he explains that he likes talking to older people. Jim is the reason, he says, that he does not get lonely in his bachelor pad. They both enjoy the company as they watch television together and this shared time is something Leonard both drives and values. It is his own inroad into a slither of community life. Any risks taken here are set against a backdrop of considerable continuity of people and place.

Eve -building a life driven by frustration with constraints

Eve became a familiar face when we observed *Friendship Meetups* events run by a self-advocacy organisation, always attending with David, with whom

she had recently begun a relationship, and both agreed to participate in our focus group. A white British woman in her late 40s, Eve has lived in a small town all her life, attending a day centre for most of her adult years until she decided to give it up very recently. She explained, 'I know my mother wasn't too happy about it but I said well I'm old enough to make my own mind . . . she doesn't like me changing.' Eve's mother lives locally, as do her half-sister and half-brother, and with intermittent support from social workers, they help Eve to manage her personal finances.

Though Eve has been attending two local disability social groups in the town for several years, the opportunity to get a lift in David's car has enabled her to get to the nearby town and one further away to participate in *Friendship Meetups* and other evening social events. She and David also attend a speaking up group, held monthly. Formerly staff-facilitated, this has recently become exclusively user-led, supported by volunteers in administrative roles only. Previously cut off by a limited evening bus service, access to these activities has transformed Eve's social life.

Eve spoke candidly of the members of her local groups who have higher support needs: 'I've had always, had disabled people around me' and despite joining the steering groups of both groups in recent years, she expressed frustration at the limited opportunities and the reluctance to change. In contrast, the *Friendship Meetups*' network provided both Eve and David access to peers with more shared interests and outlooks. Just prior to the focus groups, they and a small group of friends had also begun independently arranging to meet up at weekends for drinks and pub lunches. Both were keen to stress that these were not formal *Friendship Meetups*' events, but they acknowledged the role the network had played not only in bringing them all together, but also in motivating them and giving them the confidence and social skills to make their own autonomous arrangements. Soon after the interviews, *Friendship Meetups* began promoting these weekly meetings for others to join. While we can assume this was done at the request of the members themselves, it is interesting that after an informal and spontaneous demonstration of agency, they chose to defer to more formal arrangements for its continued momentum.

Eve has worked part-time all her adult life, volunteering at a café and, until recently, a kitchen in a local arts centre. She readily recognises her own skills (well organised, good at remembering things) and hints that her years of experience afford her a certain status among work colleagues – she has seen many changes in staff and co-workers. But she admits the work is repetitive (mainly washing up) with little opportunity for progression or paid work. She is open to other types of work but there seems to be little encouragement or support from others to look into opportunities. Eve considers herself sociable and dependable; she admitted, 'I have never put myself first until the end of last year, it's been very difficult to do it but . . . I'm getting there slowly'.

The key change in Eve's life in recent years (access to a new social life outside her hometown) may have happened primarily through the agency of her partner, but there seems to be an impetus with her newfound confidence. When pushed on what has contributed to this, she quickly acknowledged her relationship with David, her access to new social activities, and her new group of friends. Eve's agency is inexorably interlinked with, and to an extent dependent on, her relationship with her partner, but is also transitional, as she continues to placate the relationship with her mother: 'it's very hard for me to tell her that I've got a life outside'. Her half-sister has been more encouraging of the changes, but Eve indicated how little she confides in her family and she outlined plans she had discussed with David to move to a nearby town with him and look for other work.

Amy - the driving force behind building a life

We were first introduced to Amy, a white British woman in her 50s, at a *Your Voice* meeting. *Your Voice* is a small self-advocacy group based in Amy's rural hometown. Going to *Your Voice* has helped Amy to be more confident in talking about issues and it has been an important place for her to make and meet friends. Amy is the treasurer for the group and manages its finances. The other members of the group all acknowledge that Amy is 'in charge of the money' and affectionately describe her as 'the boss', commenting on the money that 'she rules it with an iron fist'. Managing money is something that Amy is now very good at, and she takes care of her own finances with some help: 'I do my finance myself. And my support worker checks that I did it right'. Amy appears confident, fun loving and fiercely independent and she describes herself as someone who is in control of decisions made about her life, 'I do it by myself [...] my choice . . . I'm the boss'. Others agree with Brendan (advocate and friend) laughingly commenting, 'to be honest I don't think anybody dare tell Amy what she's going to be doing'.

Amy lives in her own home, with a friend, in the grounds of a care home, and she is supported by the staff there. She sometimes goes up to the 'big house' in the evenings to watch television with the residents but is free to come and go as she pleases. She loves having her own place and is keen to stress that it was 'her choice' to live there. Amy gets some support (a couple of hours a week) and she says the support worker mainly helps her with filling in forms. Amy volunteers at a local charity shop on Mondays, and on Tuesday mornings she works at the local council office, doing general administration such as filing and photocopying. She used to do this in a voluntary capacity but is now paid for this work. This is something that she fought for, with the support of Brendan.

Amy is a member of a Special Olympics club dedicated to helping people with learning disabilities in the area to achieve their sporting potential. She

plays Boccia with the club every Thursday evening. She is active in her community, has a good network of friends and a sister who lives nearby whom she sees regularly. She says that there is nothing she would change about her life because she is very happy.

In building her life, Amy is clearly the driving force; she demonstrates high levels of agency, choice and control over where she lives and works, who she spends time with and the places that she goes. Equally important though, are the support networks that she had been able to cultivate throughout her life, which are as much to do with her strength and tenacity as a person as they are about formal social care structures. Indeed, Amy's friends and advocates speak very highly of her and she is described as someone who people admire and respect – and inevitably feel drawn to. Crucially, it is through these strong and enduring networks of social support that Amy is able to develop her own agency and autonomy.

Discussion and conclusion

The vignettes presented in this article were selected to represent the range of relational networks that we encountered among participants in the research and the broader constraints inherent in contemporary social support. In each case, these individuals had differential access to support workers, advocates, family members, partners, and peers. Their experiences highlight how building a life was based on sociable, reciprocal, supported efforts. In some cases, this support was more established and long-standing, and bolstered people's capacity to develop their own agency. Each case was therefore a collective story, or in Penny's case, an absence thereof. The cases help show that people can only effectively build a life (and sustain the creativity required to do so) if the opportunities, infrastructures and capacity are there within their networks. As we discovered, these opportunities are geographically variable, with significant variation evident in the ethos, availability and capacity of the local individuals and support organisations that underpin people's networks, and in some cases, enable them to build their own. The context and situations that people live in also shape the opportunities and constraints they experience (e.g., housing, transport links, local work opportunities).

From the vignettes, three aspects can be distilled which enable people to build lives and, as such, should underpin social care policy. Firstly, building lives is a relational process; it requires relational agency (as opposed to solely individualised autonomy); for example, Amy's skills and confidence in becoming treasurer were enabled through the opportunities facilitated by an advocate and her peers recognising her abilities. Secondly, building lives is productive and emergent; it is about developing and expanding one's learning and networks and not primarily about consuming or participating in sets

of activities. As such, building lives relationally can be transformative. For Leonard this was in part about initiating and developing new friendships. Thirdly, building lives requires an environment that is conducive to creativity and gives people the tools to both challenge negative and fearful attitudes and bolster more encouraging ones; in Penny's case, the context she spent much time in was not encouraging or creative, so stifling her opportunities for choice. A stimulating environment can unlock the energy that drives people to build their lives successfully.

The experiences illustrated in our vignettes demonstrate how building a life is dependent on the availability and contribution of 'significant others'. Yet, their experiences are situated within the broader personalisation policy landscape in which this distribution of care fails to be sufficiently recognised, thus potentially placing undue demands on those involved. The Care Act (2014) focuses on the person *requiring* support and a single carer, the person who is eligible for Carer's Allowance (the main welfare benefit to help carers in the UK). By channelling funding only to these individuals, personalisation policy holds them responsible for outcomes they cannot control – that depend on factors within their social networks and local area, and on wider social structures, policies and attitudes. In this way, policy fails to recognise adequately the socially shared dimension of care and support, as advocated within a feminist ethics of care framework (Davy, 2015; Mackenzie, 2014; Ward and Barnes, 2016). The depth of these inherent tensions serves to continually undermine these three aspects of care - relational, productive and creative - that underpin building a life. As such, the ideological basis of personalisation ensures that support for building a life will continue to remain precarious, potentially not sustainable, and contradictory.

The insights from a learning disability perspective offer the potential to inform a critique of the form of atomised autonomy typically inscribed in the personalisation narrative. Further, recognising a feminist ethics of care enables a different type of inscription which sees relationships of care and inter-dependency as preconditions for agency and self-determination, which should be reclaimed as positive concepts, a point advocated by Henderson and Forbat (2002). Such a model recognises that self-representation, like all representation, is mediated, situated within power relations and enmeshed with other subjectivities, and that 'individual autonomy without care, for most if not all of us, is tantamount to abandonment' (Davy, 2019: 110).

Davy (2015) and Fudge-Schormans (2016) note how the position and concerns of people with learning disabilities, their families and carers, have been excluded from philosophical thinking about autonomy, understood as marginal exceptions to the norm of rational independence and autonomy (and hence their exclusion from early developments of personalisation; Hall, 2011). Significantly, within learning disability (see Goodley, 2000) and learning literature (Billett, 2006), there has been a greater willingness to acknowledge a

relational self, highlighting the limited relevance of policy such as the Care Act (2014), and its guiding principle of independence, to many people with learning disabilities. This provides crucial insights for our own focus on people with learning disabilities and how self and agency is learnt in active relation to others and contexts.

The notion of 'building a life' (as a shorthand for the relational practice of people co-constructing their daily life in their communities in a way that is meaningful to them) is a helpful and accessible tool for thinking and discussing with others some of the challenges of the personalisation agenda, prompting questions such as: What are the building blocks for building a life? What care, planning and support is needed up front? What makes it worth doing? And, critically, is 'self-building' (to characterise the assumed autonomous self in this building practice) achievable for everybody, and if not, what are the alternatives to personalisation for those not included? This final question is particularly relevant when considering how personalisation may be failing some groups (e.g., people with higher support needs or without networks). In raising these questions, we sought to further open up 'personalisation' to critical examination and particularly to identify the inherent relationality in the actions that characterise people's everyday lives. In short, we argue that personalisation has failed on the terms under which it has operated, because the policy and ideology which underpins it do not recognise and value the relational (rather than individualistic) actions and responses of people, social groupings and organisations. We propose that social care policy needs to challenge the way personalisation has manifested itself and recognise the relational ways in which people build their lives. In doing so, perhaps it can reclaim one of the fundamental principles of person-centred support; to achieve people's aspirations and become more included within their communities (Department of Health, 2001).

It is important to consider whether there is scope for helping to advance relational understandings of personalisation more widely, including in other nations that have advanced individualised approaches, and to do this in a way that relates to other groups – all disabled people, older people etc. Without such an advancement, personalisation will arguably continue to obscure alternative understandings 'of what care might be, the forms it might take, how and by whom it might be provided, and how it might be experienced differently' (Fudge-Schormans, 2016: 3). We argue that the prospects for such a politics do exist but must be teased out to ensure isolated examples can coalesce into large-scale change. We see the acceptance of explicitly relational forms of autonomy as essential to framing an inclusive agenda for social care; one that admits the significance of the range of people implicated in personalised lives, so that (inter)dependence does not need to be disavowed. A model of the self as necessarily founded in relationality, and of autonomy as always based in enabling relationships (that are themselves supported), might help to bring about a more coherent and sustainable rationale for policy in social care.

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References

- Anderson SM and Chen S (2002) The relational self: An interpersonal social-cognitive theory. *Psychological Review* 109(4): 619–645.
- Asenova D, Bailey S and McCann C (2015) Managing municipal austerity: Mitigation of social risks. *Local Government Studies* 41(1): 1–19.
- Bigby C, Frawley P and Ramcharan P (2014) Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disability* 27(1): 3–12.
- Billett S (2006) Relational interdependence between social and individual agency in work and working life. *Mind, Culture, and Activity* 13(1): 53–69.
- Carey G, Crammond B and Malbon E (2019) Personalisation schemes in social care and inequality: Review of the evidence and early theorising. *International Journal for Equity in Health* 18(1): 170.
- Carr S (2010) *Personalisation: A Rough Guide*. London: Social Care Institute for Excellence.
- Conradson D (2005) Landscape, care and the relational self: Therapeutic encounters in rural England. *Health & Place* 11: 337–348.
- Davy L (2015) Philosophical inclusive design: Intellectual disability and the limits of individual autonomy in moral and political theory. *Hypatia* 30(1): 132–148.
- Davy L (2019) Between an ethic of care and an ethic of autonomy: Negotiating relational autonomy, disability, and dependency. *Angelaki* 24(3): 101–114.
- Department of Health (2008) *Putting People First*. London: Stationery Office.
- Ferguson I (2007) Increasing user choice or privatizing risk? The antinomies of personalization. *British Journal of Social Work* 37(3): 387–403.
- Freeman L (2011) Reconsidering relational autonomy: A feminist approach to self-hood and the other in the thinking of Martin Heidegger. *Inquiry* 54(4): 361–383.
- French S (1994) The disabled role. In: French S (ed.) *On Equal Terms: Working with Disabled People*. Oxford: Heinemann, pp.47–60.
- Fudge-Schormans A (2016) People with intellectual disabilities (visually) reimagine care. In: Barnes M, Brannely T, Ward L and Ward N (eds) *Ethics of Care: Critical Advances in International Perspective*. Bristol: Policy Press.
- Glasby J and Littlechild R (2002) *Social Work and Direct Payments*. Bristol: Policy Press.

- Gleeson B and Kearns R (2001) Remoralising landscapes of care. *Environment and Planning D: Society and Space* 19(1): 61–80.
- Goodley D (2000) *Self-Advocacy in the Lives of People with Learning Disabilities*. Buckingham: Open University Press.
- Greener I (2002) Agency, social theory and social policy. *Critical Social Policy* 22(4): 688–705.
- Hall E (2011) Shopping for support: Personalisation and the new spaces and relations of commodified care for people with learning disabilities. *Social & Cultural Geography* 12: 589–603.
- Hall E and McGarrol S (2013) Progressive localism for an ethics of care: Local area co-ordination with people with learning disabilities. *Social & Cultural Geography* 14: 689–709.
- Hamilton LG, Mesa S, Hayward E, Price R and Bright G (2017) ‘There’s a lot of places I’d like to go and things I’d like to do’: The daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom. *Disability & Society* 32(3): 287–307.
- Henderson J and Forbat L (2002) Relationship-based social policy: personal and policy constructions of ‘care’. *Critical Social Policy* 22(4): 669–687.
- Nind M and Vinha H (2014) Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities* 42(2): 102–109.
- Jeffries C and Maeder DW (2005) Using vignettes to build and assess teacher understanding of instructional strategies. *The Professional Educator* 27(1&2): 17–28.
- JRF/Joseph Rowntree Foundation (2011) *Supporting People: Towards a Person-centred Approach*. London: JRF.
- Kittay EF (2011) The ethics of care, dependence, and disability. *Ratio Juris* 24(1): 49–58.
- Mackenzie C (2019) Relational autonomy: state of the art debate. In: Armstrong A, Green K and Sangiacomo A (eds) *Spinoza and Relational Autonomy: Beings with Others*. Edinburgh: Edinburgh University Press, pp.10–32.
- Manji K (2018) ‘It was clear from the start that [SDS] was about a cost cutting agenda.’ Exploring disabled people’s early experiences of the introduction of Self-Directed Support in Scotland. *Disability & Society* 33(9): 1391–1411.
- Mladenov T (2012) Personal assistance for disabled people and the understanding of human being. *Critical Social Policy* 32(2): 242–261.
- Mladenov T, Owens J and Cribb A (2015) Personalisation in disability services and healthcare: A critical comparative analysis. *Critical Social Policy* 35(3): 307–326.
- Morris J (1991) *Pride against Prejudice: Transforming Attitudes to Disability*. London: Women’s Press.
- Nedelsky J (1989) Reconceiving autonomy: Sources, thoughts and possibilities. *Yale Journal of Law and Feminism* 7(21): 32–36.
- Needham C (2011) Personalization: From storyline to practice. *Social Policy & Administration* 45(1): 54–68.

- Needham C (2013) Personalization: From day centres to community hubs? *Critical Social Policy* 34(1): 90–108.
- NHS England (2012) *Transforming Care*. London: NHS England.
- NHS Digital (2018) *The Proportions of Users and Carers receiving Self-directed Support, and Self-directed Support via Direct Payments*. London: NHS Digital.
- Pearson C, Watson N and Manji K (2018) Changing the culture of social care in Scotland: Has a shift to personalization brought about transformative change? *Social Policy and Administration* 52(3): 662–676.
- Power A, Lord J and Defranco A (2015) *Active Citizenship and Disability: Implementing the Personalisation of Support*. New York: Cambridge University Press.
- Pykett J (2009) Personalisation and de-schooling: Uncommon trajectories in contemporary education policy. *Critical Social Policy* 29(3): 374–397.
- Roulstone A and Morgan H (2009) Neo-liberal individualism or self-directed support: Are we all speaking the same language on modernising adult social care? *Social Policy & Society* 8(3): 333–345.
- SCIE (2017) *Asset-based Places: A Model for Development*. London: SCIE.
- Scottish Government (2013) *Keys to Life Strategy: Improving Quality of Life for People with Learning Disabilities*. Edinburgh: Scottish Government.
- Simmons B (2020) Exploring the situated social being of children with profound and multiple learning difficulties across educational contexts: A study of belonging. In: Nind M and Strnadova I (eds) *Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion*. Abingdon: Routledge, pp. 27–40.
- Spicker P (2012) Personalisation falls short. *British Journal of Social Work* 43(7): 1259–1275.
- Springer S, Birch K and MacLeavy J (eds) (2016) *Handbook of Neoliberalism*. Abingdon: Routledge.
- Think Local Act Personal (2019) *Self-directed Support: Getting Past Stuck*. TLAP Conference, 24 September 2019. London: Coin Street Neighbourhood Centre. <https://www.thinklocalactpersonal.org.uk/Events/Self-Directed-Support-Getting-past-stuck-24-September-19-09-24/>
- Ward L and Barnes M (2016) Transforming practice with older people through an ethic of care. *British Journal of Social Work* 46: 906–922.
- West K (2012) The grip of personalization in adult social care: Between managerial domination and fantasy. *Critical Social Policy* 33(4): 638–657.

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Recent publications: Eastham and Kaley (2020) ‘We’re talking about you, not to you’: Methodological reflections on public health research with families with young children, *Qualitative Health Research* 30(12): 1888–1898; Kaley, Hatton and Milligan (2019) Health geography and the ‘performative’ turn: Making space for the audio-visual in ethnographic health research. *Health and Place* 60(7).

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Nind, Coverdale and Croydon (2020) Learning from each other in the context of personalisation and self-build social care. *Disability & Society*.