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Does personalised social care meet the needs of adults with mild to moderate intellectual disabilities?

Lorna Hamilton & Sue Mesa

This article is a summary of a paper delivered at the North-east of England Branch Annual Conference in September 2015. The presentation reported findings from a qualitative focus group study with adults with mild to moderate intellectual disabilities and representatives of community organisations providing support for people with intellectual disabilities (PwID). An overview of key findings is presented here, highlighting: (a) instances in which the personalisation agenda in social care, with its drive to reduce dependence and promote individual responsibility, can be at odds with the needs of PwID, and (b) some contextual constraints on agency and social inclusion within this population.

Abbreviations

PB = Personal Budget

PwID = People with Intellectual Disabilities

The personalisation agenda in social care

The drive towards personalisation has underpinned adult social care reform in the UK under governments of all colours during recent years (DH, 2007; Health and Social Care Act, 2012). The personalisation agenda emphasises making universal services accessible to all (in preference to specialist services for particular groups), reducing dependence, and promoting agency and choice through 'self-directed support' (Duffy, Waters, & Glasby, 2010). For example, individuals assessed as having eligible support needs are allocated a personal budget (PB), which can be managed by the local authority, by carers, friends or family members in a trust, or as a 'direct payment', administered by individuals themselves ("Money – personal budgets", n.d.). A key aim of such initiatives is to place control over social care provision as close to the individual as possible.

The personalisation narrative mirrors the language of the disability movement in its emphasis on empowerment, independence and choice. However, some commentators have argued that the

appropriation of the vocabulary of the disability movement masks an underlying agenda to cut social care provision, often to the detriment of the most vulnerable members of society (Roulstone, 2015). Indeed, changes in eligibility criteria under Fair Access to Care Services (DH, 2010) have meant that, in many regions of the UK, statutory services are available only to individuals classified as having critical or substantial support needs (Sully & Bowen, 2012). The impact of these changes on PwID classified as having mild or moderate needs is under-researched; however, concern has been raised about the impact of tightened eligibility criteria and the decrease in specialist services on PwID by a number of agencies (Joseph Rowntree Foundation, 2011; Mencap, 2012; SCIE, 2012).

There is also concern that personalised welfare support favours those who are better informed, more assertive, and/or have stronger social support networks (Walker & Ward, 2013). PwID are among the least likely groups to manage their own PBs and, when they do, often report that they find the process stressful (Hall, 2011). While evidence from randomised control trials suggests that, overall, P are cost-neutral in comparison to local authority-controlled care provision (Jones et al., 2013) their cost-effectiveness for PwID is less clear. It is plausible that difficulties with managing PBs, in combination with restricted access to services, could lead to an increase in need for crisis care, including emergency admissions to hospital.

Social care policy also foregrounds social inclusion as a key goal for PwID. Inclusion is often conceptualised from a normative perspective, as the integration of people with disabilities into mainstream occupations and social spaces, such as independent living and paid employment. Studies that incorporate the voices of PwID report that some individuals' goals can be quite different from those associated with inclusion in its normative sense. For instance, an interview study reported that some participants discussed their need for places of safety and strong, supportive social networks over and above normative goals related to independence, thus highlighting the potential mismatch between key outcomes of personalisation (such as entrance into the workplace) and individuals' needs. Further, Hall and McGarroll (2012) argue that, in the Scottish context, supported employment opportunities are available only to the most 'able', while social care is increasingly restricted to the most 'disabled', leaving a group of people with significant needs who fit neither profile and are thus excluded from both mainstream spaces and care communities.

The current study

This study aimed to explore the daily living experiences of people at risk of 'falling between the cracks' of social care and inclusion into mainstream social spaces, i.e. adults with mild to moderate

intellectual disabilities. Our research question was “Are PwID able to live their lives in the way they want to in a time of personalised welfare reform?”

Methodology

Twenty-six PwID and 14 representatives of community organisations supporting PwID from the York area took part in seven focus groups, each of which included between two and nine participants. Participants ranged in age from 19 to 60. Previous research has indicated that focus groups are an effective means of eliciting the views of PwID, since they allow experiences to be collectivised and validated by peers, potentially reducing anxiety about participating in research (Nind, 2009). Information on the study was provided in an accessible format and read aloud by the focus group facilitator, before participants gave written consent to take part in the study. The semi-structured question schedule covered topics including experiences of support needs assessment, housing, transport, finances, employment, education, health and socialising. Focus group discussions were video recorded and subsequently transcribed in full verbatim.

In analysing the data, we took a critical realist approach, aiming to report the experiences described by focus group participants, and the meanings attached to these experiences, while acknowledging the constraints of contextual factors on experience (Willig, 1999). We used the thematic analysis protocol outlined by Braun and Clarke (2006) in order to identify patterns in the dataset, reviewing the emerging thematic structure iteratively, and searching for confirming and disconfirming examples of each theme.

Findings and Discussion

A full analysis, including illustrative data excerpts, is presented in a forthcoming paper. Here, the key points emerging from the thematic analysis are summarised. For clarity, PwID are referred to as ‘participants’; representatives of support agencies are referred to as ‘support workers’.

Independence, Agency and Choice

The participants in our study discussed a broad range of daily living experiences. Several of the participants aligned themselves with the goals of personalisation, identifying aspirations to achieve greater independence within their lives, for example by moving into supported living accommodation or by entering paid employment. Many of those who already lived independently

expressed satisfaction with their housing arrangements and their ability to manage their day-to-day lives. While none of the participants had jobs that were paid at or above the minimum wage level, those who undertook regular voluntary or nominally paid employment also talked about the importance of this work in terms of occupation, developing skills, and building a social network outside the home. Participants who were not in employment often expressed a desire to enter the workplace, one young man describing his lack of employment as a “hole in his life”. However, he also recounted a long history of unsuccessful job applications, and his perception that employers tended not to see past his diagnosis.

However, there were also examples within the dataset of participants for whom greater independence was not a goal. One middle-aged, male participant with complex needs, including mental health problems, intellectual disability and recently-diagnosed autism, voiced his frustration at his long-standing difficulty in accessing care services. He lived independently and did not have a local family support network. In the focus group, he acknowledged how, on appearances, he could be perceived to be functioning well in the community, but went on to describe how his mental health difficulties left him feeling isolated and unable to cope living in his own home. His experience of statutory assessment had been negative, he did not have access to a support worker, and he expressed a clear sense of voicelessness in his interactions with social care services. For some, the drive to reduce dependence can be unrealistic and exclusionary, potentially exacerbating mental health difficulties and leading to an increased demand for crisis care services.

Contextual Constraints on Agency

A number of participants described busy weekly schedules, largely made up of activities run by community-based voluntary sector organisations, which provided an important source of ‘bonding social capital’ (Putnam, 2000) for many individuals. These participants expressed satisfaction in feeling in control of how they spend their time, and having adequate support (through family members, personal assistants and voluntary sector agencies) to take part in a range of activities through the week.

However, several contextual factors that limited individuals’ agency within their lives also emerged from the focus group discussions. First, there were instances of others’ needs being prioritised over those of PwID. A striking example was provided by an older male participant, who is visually impaired. He recounted an occasion on which he returned home to find his personal assistant (employed by him via his PB) on the point of leaving, saying she had prepared a meal for him but had other commitments to fulfil. This participant described how difficult it was for him both to monitor

the work that had been done in his home, due to his visual impairment, and also to form a meaningful social relationship with his assistant, due to limited opportunity to spend time together. Other participants also discussed the challenges of taking on the role of 'employer' under the PB system, and noted the lack of training available for people to develop the necessary skills to manage personal assistants effectively.

Second, several participants and support workers talked about the limited opportunities available to PwID. For example, one support worker voiced frustration at the range and quality of educational courses open to PwID, and at how the 'intellectual disabilities' label can affect educators' expectations of students: 'there's no assumption that people with learning disabilities are still learning'. In one focus group, participants described a running joke that PwID are always taught to make buns. With government funding cuts falling heavily on the adult education sector ("Further very late cuts", 2015) it is unlikely that educational opportunities for PwID will improve in the near future. Limited access to education acts a further barrier to agency and independence within this population.

Third, bullying and discrimination directed at PwID act as another constraint on individuals' agency. Survey research indicates that PwID continue to be at higher risk of experiencing hate crime in their communities, and are less likely to receive support from the criminal justice system, than people with other conditions (Macdonald, 2015). Our dataset contained several examples of participants recounting occasions on which they had been victims of threatening behaviour and harassment within their local community. One participant described in some detail how repeated experiences of bullying while on public transport had, at one time in his life, led to his becoming almost house-bound. People cannot achieve agency within their lives if they do not feel safe in their homes and local communities.

Finally, the reduction in day services has, in some cases, led to the fragmentation of important networks of social support for PwID. In the focus groups, support workers expressed concern that, following the closure of specialist facilities for PwID, 'their friends just kind of disappeared off the edge of a cliff'. Similarly, when people are moved into residential care outside the local area, it can be very difficult for existing friends to access their new contact details. Networks of bonding social capital are extremely important for mutual support, advocacy and wellbeing in PwID (Hall, 2005), and the reform of care services can have the unintended consequence of breaking up these networks; this is reflected in the experiences of isolation and loneliness described by a minority of our participants.

Conclusions

The personalisation agenda sets out to avoid a 'one size fits all' approach to adult social care, an aim which is desirable for many people with PwID. However, the experiences described by our participants suggest that current provision risks promoting a new incarnation of 'one size fits all', in which the drive to reduce dependence and promote agency can leave some individuals, for whom these may not be appropriate goals, further excluded and isolated. Many PwID do aspire to, and often achieve, greater independence in their lives, through supported living, entering the workplace, or being active members of their communities. However, the needs of PwID are many and varied, and it is of real importance to hear the voices of individuals when evaluating the effectiveness of social care reform. There is a potential mismatch between the personalisation agenda in social care and the needs of some individuals with intellectual disabilities, and a risk that these needs are unheard in the face of increasingly restrictive criteria for access to services. We, as a society, must make sure that we are listening.

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