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"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 welfare reform in the UK.

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Points of Interest

- This study investigates the daily living experiences of adults with intellectual disabilities in the context of personalisation and funding cuts in social care provision.

- Some people with intellectual disabilities want more independence and control in their lives, but these are not realistic goals for everyone.

- Barriers that make it harder for people with intellectual disabilities to gain independence and control include limited education and employment opportunities and harassment in the community.

- Social support networks are important for the wellbeing of people with intellectual disabilities. Some social support networks have been lost with the closure of specialist services.

Adults with intellectual disabilities and personalised social care

Introduction

In the United Kingdom there have been major shifts in disability related health and

social care public policy over the past half century. In the 1970s, scandals regarding the

quality of long stay hospital care came to light; concurrently 'normalisation' ideologies

emerged in North America and Scandinavia (Hamlin and Oakes 2008), influencing the

advent of 'community care' policies in many countries. In the UK, large institutions

were closed and replaced with locally commissioned community based services, with

the overarching aim of supporting people to remain in their own homes and

communities. Individuals were assessed by social workers within local government

authorities and if eligible, would be offered services funded by that authority, which

were often provided to large groups and were criticised for failing to meet individual

needs or offer substantial choice (Sims and Gulyurtlu 2014). The past two decades have

seen a further shift towards the delivery of more personalised social care services in the

UK and these ideas have underpinned reform of adult social care under successive

governments (DH 2005, 2010; HM Government, 2007) and are embedded in recent

health and social care legislation (Health and Social Care Act 2012; Care Act 2014).

Personalisation is described as a re-conceptualisation of the public sector,

'starting with the person rather than the service' (Carr 2010, p.67). Ideas central to

personalisation are mirrored in policy specifically aimed at people with intellectual

disabilities, which has been driven by the principles of rights, independence, choice and

inclusion (DH 2001, 2009). The personalisation agenda attempts fundamentally to

change the relationship between the individual and the state. Personalised health and

social care services aim to move away from a system with values rooted in institutional

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care (Duffy, Waters and Glasby 2010; Needham 2014; Power 2014), in which

professionals identified the needs of individuals who, as passive recipients, were given a

'one size fits all' service (Boxall, Dowson and Beresford 2009). Instead, a personalised

system is influenced by the human rights and social justice ideologies of the

independent living movement (Glasby and Littlechild 2009; Sims and Gulyurtlu 2014);

individuals contribute to the identification of their needs, and local government

authorities devolve their purchasing responsibility to individuals so that they can

choose, purchase, and manage their own care in the form of a personal budget or direct

payment (Slasberg and Beresford 2014).

Several commentators have argued that the appropriation of vocabulary of the

independent living movement is rhetorical, masking an underlying neo-liberal policy

agenda designed to reduce state welfare spending (Ferguson 2007; Lymbery 2012;

Beresford 2014). This signals a departure from the themes of citizenship that the

welfare state purports to be founded upon (Rose 1999). Opponents of the

personalisation agenda point out that individuals change from passive recipients to

active consumers (Houston 2010), which some may not be prepared or equipped for

(Morris 1997). Moreover, it has been argued that personalisation favours those who are

better educated and more articulate (Clarke et al. 2007; Ferguson 2007), potentially

exposing those who have difficulty in exercising and acting upon their choices to

vulnerability and inequality (Scourfield 2007; Lymbery 2010).

In the intellectual disabilities literature, concerns are raised about individuals'

ability to manage the complexity of a personal budget (Abbot and Marriot 2012) and to

fulfil the role of employer, which requires comprehension of employment law (Sims

and Gulyurtlu 2014). One area in which most people with intellectual disabilities would

like more control is the choice of 'personal assistants' (Poll et al. 2006). However, the

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potential for exploitation associated with employing unregulated staff has been

highlighted (Hall 2011; Abbot and Marriot 2012).

Outcomes of personalisation

Evidence for improved service user outcomes associated with personalised social care is

mixed. In a critical review of the personalisation model as implemented in the UK,

Slasberg, Beresford, and Schofield (2012) question research findings indicating positive

outcomes of personal budgets, on the basis that the samples used in many studies over-

represent those people most likely to enjoy better outcomes (e.g. direct payments

recipients). In contrast, the authors conclude that there is no evidence of improved

outcomes, and that the implementation process is costly and unpopular. Similarly, a

study using RCT and interviews to evaluate the outcomes and cost-effectiveness of

personal budgets reported mixed findings for people with intellectual disabilities

(Glendinning et al. 2008). Overall, those receiving a budget reported feeling more in

control, with most benefits seen in those who were more able, and who already had care

arrangements and good support networks in place. However, the majority reported

finding the process of managing budgets stressful. Personal budgets were found to be

cost-neutral, and their cost-effectiveness for people with intellectual disabilities was less

clear than in other service user groups, due to higher costs associated with the care

planning and assessment process.

Sims and Gulyurtlu (2014) reviewed evidence relating to personalisation and

outcomes, outlining studies that report an increased lifestyle satisfaction in people with

intellectual disabilities following a personalised approach (e.g. Poll et al. 2006; Hatton

et al. 2008). However, the participants in Hatton et al.'s (2008) study also reported areas

of low satisfaction: 29% reporting satisfaction related to safety and security, 36% to

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economic wellbeing and 47% to health and wellbeing. It is important, therefore, to gain

a clearer understanding of the impact of personalisation on the daily lives of people with

intellectual disabilities.

Personalisation and austerity

Several commentators have cautioned that the personalisation agenda emerged when

spending in the UK was historically high, and may be compromised under current

government spending cuts (Henwood and Hudson 2008; Needham 2014). The initial

vision for personalisation highlighted four domains thought to be essential to its

success, namely universal services, early intervention and prevention, social capital, and

choice and control. However, at a local level there has been a narrower focus on the

implementation of personal budgets (Slay 2012) with local authorities placing

restrictions on what the money can be spent on (Duffy, Waters, and Glasby 2010).

Since the global financial crisis in 2008 several nations, including the UK, have adopted

economic austerity measures, which have reduced available spending for health and

social care (Slay 2012; Power 2014). The combination of reduction of budgets and

increasing pressure on intellectual disability services caused by the increasing numbers

of people with intellectual disabilities (Emerson and Hatton 2004, 2008) has resulted in

many local authorities tightening eligibility criteria in order to manage resources

(McInnis et al. 2011).   Thus, in many areas statutory services have been available only

to individuals classified as having 'critical' or 'substantial' support needs (Sully and

Bowen 2012), despite evidence that 'limiting access by raising eligibility has only

modest and short term effects on expenditure' (DH 2010, 6). Abbot and Marriot (2012)

suggest that in the next decade it will likely be only those with complex needs who will

receive funded support.

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Sully and Bowen (2012), on behalf of the Learning Disability Coalition,

surveyed people with intellectual disabilities, local authorities and service providers.

They highlighted that, during the preceding year, 17% of people with intellectual

disabilities had experienced a reduction in support, 13% had been given less money to

spend on support, 18% had seen their service charges increased and 2% had had

services withdrawn due to changes in eligibility criteria. Mencap (2012) reported that

almost one in three local authorities have closed specialist day centres, with no

alternative offered in many areas. Needham (2014) argues that these closures have been

framed as a positive consequence of personalisation, while the financial imperatives

underlying reduction in specialist services have been underplayed. Several agencies

have raised concern about the impact of tightened eligibility criteria and the decrease in

specialist services (Henwood 2012; Mencap 2012; Sully and Bowen 2012). It is

suggested that without early intervention for those with low or moderate needs, there is

increased risk of escalation to crisis, which is more costly (Parish 2011; Beresford and

Andrews 2012).

Slay (2012) suggests that future research could usefully examine the effect of

changes in welfare and public spending on individuals who use services and their

carers. Despite these suggestions, the impact on those classified as having mild or

moderate needs is currently under-researched. Those most likely to be assessed as

having low or moderate needs are those with mild/moderate intellectual disabilities,

who are ironically the group most able to benefit from managing their own budgets

(Glendinning et al. 2008).

The current study

This study therefore focuses on a sample of individuals with mild/moderate intellectual

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disabilities and their support workers, who were accessing care provision at the time of

data collection, but may be at risk of 'falling between the cracks' of service eligibility.

The study aims to explore their experiences of daily life in the context of the

introduction of personalisation and social care budget cuts.

Method

Participants

Ethical approval for the study was obtained from the York St John University Ethics

Committee. We used purposive sampling to recruit adults with mild to moderate

intellectual disabilities, and representatives of support agencies, to the study. As a first

step, we contacted local authority-led and third-sector organisations by email, giving

details of the aims and scope of the research.   Where representatives of these agencies

expressed interest in taking part, we followed up with telephone calls, during which we

requested that they disseminate information about the study to adults using their

services. Arrangements for a focus group with all consenting individuals within each

organisation were then made, either at the organisation's premises or at the university,

according to the participants' preference.

Twenty-six adults with intellectual disabilities (19 male and 7 female) and 13

support workers (6 male and 7 female) were recruited to the study. All participants

were aged between 23 and 60 years, and were resident in a city in the north of England

and surrounding area, living either in family homes or in assisted living

accommodation. The majority of participants (38 of 39) were of white British of

ethnicity; one participant was black British. Systematic data on comorbidities were not

collected; however, the sample included people with intellectual disabilities with co-

occurring physical disability, visual impairment, autism and mental health difficulties.

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Data collection and analysis

We conducted seven focus groups, each of which included between two and nine

participants. Initially, we allocated between six and ten people to each focus group,

reasoning that this would allow varied contributions to the discussion, while avoiding a

crowded and potentially intimidating environment. However, two focus groups were

conducted with lower numbers, either due to the preferences of the participants, or

because invited members did not attend. Each focus group included at least one support

worker.

Previous research indicates that focus groups are an appropriate method for

eliciting the views of people with intellectual disabilities, because interaction with peers

in a group setting allows experiences to be collectivised and contributions validated by

peers (Cambridge and McCarthy 2001; Nind 2008). Furthermore, small groups with

familiar others can reduce anxiety about taking part in research and facilitate discussion,

since participants may have knowledge of each other's situations and share common

experiences (Barr, McConkey, and McConaghie 2003; Fraser and Fraser 2004).

At the outset of each group discussion, an accessible information sheet

(formatted in easy-read with visual aids) was given to each participant and read aloud

by one of the authors.   Care was taken to ensure that everybody understood the aims of

the research, and their rights of withdrawal, confidentiality and anonymity, before

participants were asked to sign consent forms.

To guide the discussions, we used a semi-structured question schedule, which

asked participants to describe their daily living experiences (or those of people for

whom they provided support) in terms of care and support needs assessments, housing,

transport, finances, employment, education, health and socialising. Two of the authors

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acted as facilitators at each focus group, and care was taken to allow each member of

the group to contribute to the discussion. The presence of support workers who were

familiar with the participants with intellectual disabilities was helpful, as on occasion

they could interpret contributions where speech was unclear. Focus group discussions

lasted for an average of 70 minutes (range 53-106) and were video-recorded and were

subsequently transcribed in full verbatim.

In analysing the data, we took a critical realist approach, aiming to report the

reality of people's experiences and the meanings attached to these experiences, while

acknowledging that this reality can only be captured in a partial and imperfect way

(Willig 1999). Our research question, which was refined through the analytic process,

was 'Are adults with mild to moderate intellectual disabilities able to live their lives in

the way they want to in the context of personalisation and funding cuts in adult social

care?'

In order to identify patterns within the data corpus, we utilised the thematic

analysis protocol outlined by Braun and Clarke (2006, 2013). As data collection

proceeded, we familiarised ourselves with the data through multiple readings of the

transcripts, noting and discussing initial ideas. At the first stage of coding, two of the

authors highlighted features of interest within the data; the codes generated were

discussed and refined before the coded data were collated into working themes. We

reviewed the thematic structure iteratively as new focus group data were added to the

corpus.

Findings and Discussion

For clarity, participants with intellectual disabilities are referred to as 'participants',

while representatives of support organisations are referred to as 'support workers'

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throughout the excerpts cited; all speakers are given pseudonyms.

Independence and Agency

Issues relating to in/dependence and the extent to which individuals are able to assume autonomy within their lives were discussed frequently within the focus groups. We present three sub-themes relating to independence and agency: (a) desire for independence; (b) prioritisation of needs; and (c) contextual constraints on independence and agency.

Desire for independence

Many participants expressed the desire to live independent lives. For example, participants described plans or ambitions to move out of the family home: 'I don't know, in the future I would like to live on my own. I don't know how I would cope yet' (**Helen, participant**). While Helen expresses doubt about managing the transition to independent living, Mary had recently moved into assisted living accommodation and described the period in which she was waiting to be allocated housing as a frustrating time: 'I was so desperate to move to get my own independence' (**Mary, participant**). Thus moving out of the family home was viewed by some participants as a key factor in achieving independence. Another recurring motif was the desire to enter (paid) employment; participants often cited financial stability, occupation and opportunities for social contact as reasons:

> **Steve (participant):** I feel as though there's erm, with me being out of
> employment, you know like a hole in my life. I feel as though it needs filling first
> before I can get going. But that's really difficult to do.
>
> ----

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Robert (participant): Yeah I've got enough of money, but I need a little job. I'm OK, about three or four pounds a day whatever, to get me out doing things. I'm hoping to do things with my hands.

There was a common concern among participants that taking a paid job would jeopardise benefits payments, leaving them financially disadvantaged. Participants tended to be unsure about where to find information and seek support with navigating the transition to employment. Those who were already in employment (unpaid or nominally paid in all cases) tended to express satisfaction in their work: 'I work at [*workplace*]. I don't get paid but I enjoy working at [*workplace*].' **(Joe, participant**). The goals of independent living and paid employment expressed by these participants mirror the principles of personalisation.

However, some participants in the current study noted "independence", if defined in terms of normative goals such as living alone and entering paid employment, to be the goal of services rather than their own. This is demonstrated by the experiences described by an older, male participant with complex needs, including intellectual disability, recently-diagnosed autism, and mental health difficulties. This man was living alone, but was seeking more support and expressed a clear sense of frustration when this was not provided, as illustrated in the following two excerpts:

Michael (participant) – excerpt 1: I'm erm extremely unhappy with things at the moment … because I feel I'm having difficulties with my anxiety and I can't cope very well and- and I've been begging the social services to help me and they've done an assessment on me recently … I've been saying I want to go into a residential care home because I feel like I can't cope any more and they just ignoring- ignoring this and they've said as well I can't go into a care home but I can't have a support worker either.

 Michael, excerpt 2: …on appearances I seem to be functioning well in the community, I seem to be doing things. [*The assessment*] didn't take into account at

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all how I felt inside or how distressed or how unhappy or how upset I was feeling

inside, that didn't matter. … And again the way I see it is just that they're trying

to stretch people as far as they can without spending any money to give people

support.

For individuals like Michael, the drive for independence underlying

personalisation could be critiqued as simply a way to reduce dependence on the state, as

opposed to offering real choice about the amount and type of support offered. Michael

noted that health professionals working with him were also arguing for increased

support. He expressed the view that he would not get any support until he had reached

crisis, something that has been highlighted in the literature as a likely costly outcome of

failure to provide early intervention to those with mild and moderate needs (Parish

2011; Beresford and Andrews 2012). As the criteria for access to care services have

become limited to people with critical or substantial need over recent years (Sully and

Bowen 2012), there exists a growing number of people who have limited opportunities

both of entering the mainstream social spaces and of accessing care. Hall and McGarrol

(2012) argue that, in the Scottish context, supported employment opportunities are

limited to the most "able", while social care is increasingly restricted to the most

"disabled", leaving a group of people who fall into neither category and are left

excluded both from mainstream and care communities. Cases such as Michael illustrate

the potential mismatch between the narrative of empowerment underpinning the

personalisation agenda and individuals' views of their needs (Hall 2011). There is a

risk that the language of the independent living movement may be mobilised to justify

reducing or eliminating funding for social care support; in fact, many individuals with

complex needs such as Michael require support from services, which requires sufficient

funding, in order to live independently.

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Prioritisation of needs

There were several examples of participants describing agency and choice in how they

spent their time, which in line with experiences of employment detailed above, was

often described with satisfaction:

> **Terry (participant):** Yeah I go to work … I do things on my own and I do get
> buses, I get bus on time, … but I don't do anything in town. But I generally decide
> what I do independently on my own and things.

In contrast, some participants described experiences in which the needs of others

were prioritised over individuals' own choices. In the following excerpt, a support

worker explains how family carers' preferences can affect outcomes for people with

intellectual disabilities:

> **Mark (support worker)**: It's a strange one the process that people go through to
> get supporting living … because they need the backing of the family and there's a
> huge waiting list …. And you'll become a high priority if … say the family … are
> 100% behind that and don't want them to live at home any more. … but if the
> family aren't 100% convinced about them going into supported living that person
> then will be at the bottom of the pile. That person might want to- really like have
> that independence and live somewhere you know supported living or wherever it
> might be, but if the parents aren't backing that they'll just be (*motions hand to
> height just above floor*). That's something that's happened quite a lot. … that
> individual is saying "I want to live on my own" but the parents are saying "no you
> can't" and they're gonna be at the bottom of the pile. I don't think that's right; if
> that person wants to then they should be.

The importance of family members as a source of 'bonding social capital'

(Putnam 2000) for people with intellectual disabilities has been highlighted by other

authors (Tilly 2013; Walker and Ward 2013). However, it is important to recognise that

the goals of individuals and their family members are not always well aligned. In a

previous study, empowerment talk was invoked by family carers of people with

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intellectual disabilities as an 'ill-considered, politically correct professional idea'

(Jingree and Finlay 2012, 416), and the drive towards increased independence and

choice constructed as irresponsible, and often counter to the needs of their family

members with intellectual disabilities. Where individuals desire greater independence,

it may be that the voices of family members are heard more clearly than the voices of

individuals, compromising the agency and choice that personalised welfare seeks to

promote.

Similarly, participants discussed instances when they felt that their needs had

been secondary to the timetables of their personal assistants.

> **Jim (participant):** And it's also difficult when you have got personal assistants
> sometimes, I know it has happened to me, you feel as though you're fitting in with
> their lives. They'll ring up and say "oh well, um I can't come at this time today but
> I'll be in at that time." Do you know what I mean? And sometimes you may want
> to do something on say a Saturday or a Sunday and then they'll ring you up and say
> "well I can't do this at this time but I can come in for a couple of hours" and then
> after a couple of hours you know you're by yourself.

The difficulty for some individuals of taking on the management of their own

care services under the personal budget system was highlighted in focus group

discussions. There was a perception that individuals were not well supported in taking

on the role of employers of personal assistants (PAs): 'And when you sort of get onto

direct payments, we're the employers. I mean there doesn't seem to be any training for

people who are gonna be employers or the PAs themselves' (**Sarah, participant**).

Graham, who is visually impaired, illustrates how self-directed support does not always

meet the needs of the individual, describing an occasion on which he had found it

difficult to 'manage' his PA:

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Graham (participant): It's difficult y'know because I am the employer and I am trying to be a bit more assertive... Because if they're coming into your house when you're not there and then, like I got back at about just after three and she said "oh well I've done your tea, I've done the hours, I'm off now." And I was like, "but I've hardly seen you! Y'know since I've got back I've hardly seen you to say what you have done or what you haven't done" and y'know I was a bit well shell-shocked actually.

Jill (support worker): They can't assist you when you're not there, can they?

Taking on the role of 'employer' under the personal budgets system was experienced as stressful by some individuals, and relationships with PAs were sometimes felt to be unsatisfactory as a result. This finding supports concerns regarding the ability of people with intellectual disabilities to fulfil the role of employer without adequate support, and the potential for exploitation (Hall 2011; Sims and Gulyurtlu 2014). A report on financial issues for people with intellectual disabilities in the UK highlighted how direct payments can increase autonomy and control, but that significant support is required to help individuals manage their personal budgets (Williams et al. 2003). In our study, participants indicated that they did not have access to such support; the situation described by Graham above illustrates how the quality of personalised care can be compromised as a result of a lack of training and support in employing PAs under the personal budget system.

Contextual constraints on independence and agency

Several contextual factors that limited individuals' agency within their lives emerged from the focus group discussions. The restricted range of activities, educational and employment opportunities available to adults with intellectual disabilities was often cited as a constraint on choice: 'There ain't a lot of things out there for people to do' (**Jim, participant**). Support workers voiced frustration at the range and quality of

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education available to individuals: 'We have a joke about people with learning

difficulties are always taught to make buns' (**Laura, support worker**). The same

support worker went on to discuss how the "intellectual disabilities" label can affect

educators' expectations of students:

> **Laura**: The thing about education is that there's no assumption that people with
> learning disabilities are still learning. … Maybe enough people in education don't
> really know very much about people with learning disabilities … Jim might not
> learn in the same way some people you know but get to know Jim, how does he
> learn? He's just been Romeo, he had to learn bloody long speeches for that! How
> did he do that? Because he wouldn't have done it before, it was about- it was a bit
> about self-esteem … and pride in himself.

With government funding cuts falling heavily on the adult education sector

(Association of Colleges 2014) it is unlikely that educational opportunities for people

with intellectual disabilities in the UK will improve in the near future. Limited access

to education acts a barrier to agency, independence and inclusion within this population

(Stonier 2013). In a similar vein, participants discussed how negative perceptions of

disability can impede access to employment: **'**I feel as though there's a lot of

resistance, because of disabilities, there's a lot of resistance from employers.' (**Steve,**

participant). The exchange below between a support worker and participant concerns

a mutual acquaintance, who performed well during an unpaid period of work experience

in a café, but was not able to progress to paid work:

> **Laura (support worker):** There was one young woman in particular-
> **Jim (participant):** She was fantastic!
> **Laura:** She should have been the manager, because she was much better at the job
> than the person that was employed to support them! And she was never given a
> chance. Why? … because she's got a learning difficulty.

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Stereotypes about the capabilities of people with intellectual disabilities limit the range of choices that individuals can make; reflected in the fact that in 2011-12 only 7% in the UK were in paid employment (Emerson et al. 2012). People with intellectual disabilities are also disproportionately represented in victims of bullying and hate crime, and are among the least likely groups to receive support from the criminal justice system (Macdonald 2015). The discrimination, prejudice and harassment often experienced by people with intellectual disabilities constitute a further constraint on agency, as illustrated by Robert's experience:

> **Robert (participant):** I use the bus now. Now I've got my confidence back I use the bus. When I used to go to [*place*] on my own, I got the number [*X*], sit there, loads of kids behind me got a pencil or something sharp and stabbed it in my back, so I wondered what it was, then the kids poking the pencil through the seat. So I then said I'm not going on the bus.
> **Jenny (support worker):** I mean there are- you're not an isolated incident, I mean there's hate crime on buses.
> **Robert:** No, when before I used to go for a walk, I've been stopped at the … bridge. I were on the bridge … here trying to get over it, loads of lads tried to stop me saying "you're banned from over here". …. Tell me I am, so we phoned the police and police said no I'm not banned, take no notice, you can do whatever you want.

In summary, participants described several factors that impinge on the degree of autonomy they have within their daily lives, including a limited range of educational opportunities, resistance from employers, and experiences of harassment within local communities. It is interesting to note that most viewed independence as an aspirational goal even in the face of these contextual barriers. For personalised social care to deliver reduced dependence and enhanced agency for people with intellectual disabilities, however, these barriers need to be acknowledged and addressed.

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Social capital and wellbeing

Participants frequently discussed their social networks of friends, family members and

support workers; the quality of these networks was central to participants' perceived

wellbeing. We present three sub-themes in relation to social capital and wellbeing: (a)

interdependent social networks; (b) fragmentation of social networks; and (c) isolation

and exclusion.

Interdependent social networks

Many participants emphasised the importance of regular opportunities to socialise with

friends for quality of life: 'You want to go out, socialise, do everything that everybody

else does.' **(Sarah, participant)**. Voluntary-sector organisations play a key role both in

providing a context for individuals to make and maintain relationships with peers, and

in supporting individuals to access activities within their wider local communities. The

desire of many people with intellectual disabilities to have access to such '"semi-

institutional" spaces within mainstream communities' has been highlighted by Hall

(2011, 592); these communal spaces can provide an invaluable source of bridging social

capital (Bates and Davis 2004; Kendall and Cameron 2013). The following exchange

between two young women and a support worker illustrates how relational support

networks might facilitate agency for individuals:

> **Rachel (participant)**: I want to go to that [*name of dance group*] night.
> **Mark (support worker)**: So more social groups?
> **Rachel**: Yeah.
> **Jane (participant)**: I want to go on a [*name of dance group*] night as well.
> **Mark**: Yeah, you two are the same, you want to go to more like social groups,
> don't you, and sort of meet new people?
> **Jane**: Yeah, new people.
> **Mark**: You two are good friends as well and you see each other on a Friday.

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> **Jane:** (puts arm around Rachel) We're good friends, aren't we?
>
> **Rachel**: Yeah.

Through this exchange, Rachel and Jane's common interests and goals are established, a process facilitated by the quality of the support worker's relationship with the two participants. Social networks of family, friends and voluntary-sector organisations act interdependently to affect individuals' quality of life (Hall 2011). Rachel had recently made the transition to adult services and was living in the family home. When asked what would help her attend the dance group, she said:

> **Rachel**: Well I'd need some transport there, but my mum would like to come for the first time and my sister … would like to go as well. Talked about it and my mum said if you don't want to go you don't have to … I said I really want to go and she said we'll see.
>
> **Mark**: Yeah we're trying to get your mum to sort of erm-
>
> **Rachel**: Let me have my wings.
>
> **Mark**: Yeah! Exactly, just let you go really. ….
>
> **Rachel**: I can't actually go see my friends that live down my street. I could see them but I can't, my mum won't let me go.

Rachel's family home provided her with a safe and caring environment, but also constrained her ability to interact with people outside the family. Her relationship with Mark within the context of a voluntary-sector organisation provided her with an opportunity to challenge these constraints and develop her independence as a young adult.

Fragmentation of social networks

All of the participants in our focus groups were recruited via voluntary-sector organisations, which meant that they had access to at least one community of social support outside the home. Concerns were expressed in several focus groups about

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people with intellectual disabilities in the area who were not accessing voluntary-sector

organisations for support, socialising and participation in activities, particularly in the

light of the closure of specialist day services:

> **Emma (support worker)**: And then these places closed and people weren't given
> contact details for people they'd lived with for years and years. So their friends
> just kind of disappeared off the edge of a cliff it felt like I think.

The move away from specialist services under personalised social care reform

has led to concern about the potential impact on the social networks of people with

intellectual disabilities, particularly people with less severe disabilities who may no

longer be eligible for access to statutory care services (Mencap 2012; Kendall and

Cameron, 2013). This concern is borne out by the experiences of some participants,

illustrated in the two excerpts below:

> **[Excerpt 1] Michael (participant)**: I want to get out and have something to do
> and meet people and have something to do because there's such a shortage of day
> services and things and to just let people – it seems a bit – with not enough services
> you know and day services and things and it's difficult sometimes finding
> voluntary work and I just wanted to do it because it would give me something to do
> and keep me occupied and I'd meet people and it would be a good thing you know.

> **[Except 2] Laura (support worker):** It's like as well isn't it, I remember you
> talking about when people move into a residential unit-
> **Sarah (participant):** Oh yes.
> **Laura**: Nothing goes with them. It takes us a long while to find out where they've
> gone.
> **Sarah**: Like a couple of my colleagues disappeared didn't they and we asked the
> care manager at the time, 'oh we don't know'.
> **Laura**: Well we made- yeah. With this care manager, we asked and we weren't
> able to get where this person had gone, they just disappeared one day, they went to
> [*place*] or somewhere like that. … But I mean, that was the attitude, we don't
> know if this lady's dead or alive y'know.

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Support workers expressed particular concern for individuals who lived alone, without family members to source information about voluntary-sector organisations, to provide links to the community outside the home, and to advocate for them in times of difficulty:

> **Mark (support worker):** [*to Helen (participant)*] You've got a support network there but erm people that don't have families then they're the ones, the guys that erm probably struggle more because like they don't have that. They rely on their care manager to make decisions for them.

People with intellectual disabilities are among the least likely groups of people with disabilities to have sources of bridging social capital, including non-disabled friends (Robertson et al. 2001; Bates and Davis 2004). Against a backdrop of restricted access to statutory care and cuts to day service provision, individuals who lack family support networks are at particular risk of isolation and exclusion from local communities. Social networks are fundamental to the quality of life of people with intellectual disabilities (Hall 2011); nevertheless, support workers felt that current statutory assessments tend to prioritise basic living needs at the expense of social needs:

> **Amanda (support worker)**: They have to see progression and progression to the council is often the practical things, are they keeping up with their housing? You know sometimes you have to work maybe a year with someone to get that relationship, to maybe then be able to go into their house and help them with that kind of thing but you've got to go in with someone's interests and build the relationship that way to build their confidence around going out and doing social things. It's kind of deemed as not important.

Another factor contributing to the perceived fragmentation of social networks for people with intellectual disabilities was the high turnover of staff in PA roles, which

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made it difficult for some participants to form meaningful relationships with the people

supporting them in their daily living.

> **Robert (participant):** It's OK if I know which one I have. Sometimes I click with
> someone, know which number to phone, then about a week after he say "Oh I'm
> leaving, it'll be our last day the next day". Oh, have to get a new one to come, then
> new one comes in, have her for a couple of weeks or something, then they say "oh,
> I've got bad news, I'm leaving", you have to have another one.

Overall, several contextual factors which can inhibit individuals' access to social

capital were discussed during the focus groups, including the closure of specialist day

services, high turnover of care staff and a limited focus on social needs during statutory

assessments. The fragmentation of social networks described by participants and

support workers has negative implications for the wellbeing of people with intellectual

disabilities with mild to moderate support needs, who may be ineligible to access

statutory services, particularly in the absence of family support.

Isolation and Exclusion

While many participants in our study had strong, interdependent networks of social

support through families, friends, voluntary-sector organisations and local communities,

there were also examples of individuals who were currently experiencing, or who had

experienced in the past, extreme marginalisation and isolation from communities. For

example, Robert described his lifestyle before he started to attend a social group

organised by a support organisation:

> **Robert (participant)**: Before I used to come here, I used to be at home twiddling
> my thumbs, watching TV, drinking about, you ever seen a coke? A three-litre
> bottle of coke? I used to drink three bottles of these a day. … I lived with my mum
> before and then I said 'nobody wants me', I drink myself loads of things, I have a
> bottle of vodka, big massive bottle of vodka on own and drink it. I said "nobody

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wants me". Went for a job round town, a woman turned me down, she said "I

can't have you". "Why?" "You can't speak".

The association between diminished financial resources, isolation and mental

health issues in people with mild or moderate learning disabilities was discussed further

by Robert's support worker during the same focus group:

> **Jenny (support worker):** I also know from [*name of organisation*] when I was
> working there, that a lot of them who were borderline [*to Robert (participant)*] a bit
> like you, who lost benefits over the years and their health deteriorated a lot because
> they weren't meeting people, getting out, they weren't engaging in activities any
> more, which meant that they lost skills as well. And also the fact that they didn't
> have any routine created agitation and anxiety for a lot of people.

Mental ill-health is known to be prevalent among people with intellectual

disabilities, and is associated with inequalities in access to health information and

services (Emerson et al. 2011). It is therefore of serious concern that some adults with

mild to moderate intellectual disabilities experience increased isolation and loneliness,

due in part to reduced access to social care services and the associated fragmentation of

social support networks. Michael, who experiences anxiety and depression, talked of

his sense of isolation and limited access to sources of support within the local

community:

> **Michael (participant):** I just have to rely on [*name of fellowship community*] at
> the moment, that's all I've got. And I have to go … to the drop-in support session
> on a Wednesday. But the only problem with that is it's only on a Wednesday so
> that's the only support I've got really at the moment. I've just got to rely on that,
> there's nothing else.

Furthermore, limited social capital acts as a further constraint on individuals'

independence and agency, which was vividly illustrated by one participant:

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> **Susan (participant):** There's a lot of places I would like to go and things that I
> would like to do and I don't have anyone that I can go with and I would never go
> by myself.
> **Amanda (support worker):** And it's almost like the learning through practice
> thing, if you did it ten times with a support worker you'd know what to do.
> **Susan:** You could get coached.
> **Amanda**: Yeah and then you'd start to maybe try things on your own and it can
> take a long, long time for people to build up the confidence to do that.

Though by no means universal within our sample, such experiences of isolation

and exclusion in people with intellectual disabilities are a major cause for concern.

People cannot be empowered to work towards normative outcomes, such as paid

employment and independent living, if they have such limited social capital and

minimal access to the wider community. When excluded from mainstream society to

such a degree, it is also unlikely that these individuals' voices can be heard in the debate

about the effectiveness of personalisation for people with intellectual disabilities.

Limitations and Conclusions

This study has several notable limitations. The sample included in the current study was

small and recruited from one local authority area; the issues raised in the analysis are

therefore specific to the regional and national social care context. Moreover, the

participants with intellectual disabilities who took part in the focus groups were all

accessing at least one voluntary-sector support group, and so the experiences of the

most socially isolated were potentially not represented in the discussions. Future studies

focusing on the experiences of adults with intellectual disabilities should seek to recruit

individuals with mild-to-moderate support needs who do not access voluntary-sector

support. However, the findings shed light on the complexity of experiences of people

with intellectual disabilities, and we interpret them in terms of theoretical

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generalisability, rather than statistically generalisable trends (Sim 1998).

The reported findings suggest that, while many people with intellectual

disabilities embrace the principles of the personalisation agenda, there remain

significant contextual barriers to achieving greater independence and agency within

their lives. Participants described experiences of limited educational opportunities,

employers' reluctance to engage people with intellectual disabilities in the workplace,

and difficulty moving into independent living spaces associated with long waiting lists

and resistance from family members.   Moreover, managing PAs can be particularly

challenging for people with intellectual disabilities, and participants highlighted the lack

of support available for this task. The move towards personalisation in social care has

coincided with unprecedented cuts to the social care budget, and both of these factors

have influenced local authority decisions to close specialist day services. A

consequence of these closures, discussed by our participants, has been the fragmentation

of important social networks, leading to an increased risk of isolation and exclusion

from communities. While voluntary sector organisations provided an invaluable source

of social capital for our participants, many were concerned about other individuals who

were not accessing either statutory or voluntary-sector services.

Importantly, the drive for increased independence under personalisation should

not be interpreted as a justification for discontinuation of social care funding and

removal of sources of support. Several participants in the current study described living

in isolated circumstances, having negative experiences of interactions with support

agencies, and often poor mental health. For these individuals, reduced access to

services (because of restricted eligibility criteria and/or closure of day services)

diminishes the likelihood of early intervention and increases the risk of difficulties

escalating to the point that crisis care is needed. Advocates of personalisation

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acknowledge that a 'one-size-fits-all' approach to social care is not fit for purpose; it is

important that individuals are supported to achieve desired levels of independence and

agency in their lives, without 'falling between the cracks' of reduced statutory care

services.

Finally, this study adds to the relatively small literature focusing on the voices of

people with intellectual disabilities, which are often unheard in policy development. It

is paramount that evaluations of the outcomes of personalisation in adult social care

include these voices to inform service development in the future.

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