

Taking on choice and control in personal care and support : the experiences of physically disabled young adults

MITCHELL, Wendy, BERESFORD, Bryony, GLENDINNING, Caroline, BROOKS, Jennifer <<http://orcid.org/0000-0001-7735-3718>> and MORAN, Nicola

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/12201/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

MITCHELL, Wendy, BERESFORD, Bryony, GLENDINNING, Caroline, BROOKS, Jennifer and MORAN, Nicola (2017). Taking on choice and control in personal care and support : the experiences of physically disabled young adults. *Journal of Social Work*, 17 (4), 413-433.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

**Taking On Choice and Control in Personal Care
and Support: The Experiences of Physically
Disabled Young Adults**

**Wendy Mitchell*, Bryony Beresford*, Jenni Brooks*,
Nicola Moran* and Caroline Glendinning***

Social Policy Research Unit, University of York, UK*

Corresponding Author:

Wendy Mitchell

Social Policy Research Unit

University of York

York, UK

Email: wendy.mitchell@york.ac.uk

Telephone: +44 (0)1904 321951

Taking On Choice and Control in Personal Care and Support: The Experiences of Physically Disabled Young Adults

ABSTRACT

Summary

Research on self-directed care has focused on older people and adults with learning disabilities or mental health difficulties. This paper reports physically disabled young adults' experiences of self-directed care. Such work is important because young adults are a 'minority' group within adult social care. This, and their still developing life skills and lack of life experience, may have a bearing on their experiences of self-directed care and associated support needs. An exploratory qualitative study using semi-structured interviews investigated this issue. Participants were aged 19-29 years with a range of congenital and acquired impairments.

Findings

Many aspects of interviewees' experiences of self-directed care appeared to be influenced by their limited life experience, the fact they are still developing life skills and are a minority group within adult social care. Interviewees

identified their lack of life experience and self-confidence as making them cautious in assuming responsibility for their care arrangements and, typically, their desire for on-going parental support. They also believed their age and life stage contributed to difficulties managing carers and PAs. Preferences around the characteristics of carers/PAs were influenced by their age and desire to integrate into mainstream activities. Information provided by statutory services did not (fully) acknowledge that some users were young adults.

Applications

Compared to other physically disabled users of adult social care, young adults' under-developed life skills and lack of life experience influences their experiences as users, and the support they needed to assume control of their care arrangements. Tailored information and support for this 'minority group' is required.

KEYWORDS: self- or consumer-directed support; personalization; adult social care; physical disability; young adults; transition

Taking On Choice and Control in Personal Care and Support: The Experiences of Physically Disabled Young Adults

INTRODUCTION

Self- or consumer-directed care is a core element of adult social policy in many OECD countries and England is no exception (Alakeson, 2010; Ottman, Allen & Feldman, 2013). As with many of the countries adopting self-directed care approaches (Alakeson, 2010), the core element of its current strategy are personal budgets (PBs) which to enable service users to arrange and purchase support to meet their individual needs and preferences (Department of Health, 1996; HM Government, 2007). Thus, following assessment, the 'budget' available to an individual from which to meet their social care needs is set. Currently in England personal budgets are delivered either in the form of a cash payment (Direct Payment (DP)) paid directly to the individual or a third party (e.g. family member), alternatively, the individual can request their local authority assumes responsibility for managing their PB.

In England, research into self-directed care has, so far, centred on the groups constituting the greatest proportion of users of adult social care: adults with learning disabilities, mental health problems and older people. Findings from

these studies in terms of user outcomes and experiences paint a mixed picture (Sims & Cabrita-Gulyurtlu, 2014). There is growing evidence that DPs, or self-directed care approaches more generally, are associated with increased user choice and control ~~(have increased user independence~~ Leece & Bornat, 2006; Powers, Sowers & Singer, 2006; Glasby & Littlechild, 2009; Egan, 2010) though the extent of positive outcomes may differ between user groups, with some evidence suggesting mental health service users and working age adults may benefit more than older service users (Netten et al, 2012; Alakeson, 2010; Newbronner et al, 2011). Studies have also found that financial/administrative responsibilities and managing staff can impact on user satisfaction and willingness to pursue self-directed care (Bewey & McCulloch, 2004; Powers et al., 2006; Glendinning et al., 2008; Glasby and Littlechild, 2009; Norah Fry, 2010; Social Care Institute for Excellence, 2011; Evans, 2012; Arksey & Baxter, 2012). Again, there is some evidence that the extent to which these act as barriers to opting for self-directed care varies between user groups, with older people less willing to engage (eg Newbronner et al., 2011). Perhaps not unexpectedly, this pattern of findings is similar to that of research conducted in other countries (Powers et al., 2006; Alakeson, 2010). Factors hindering positive outcomes and experiences have also been identified by a number of studies in this and other countries and include: a

dearth of accessible and informative information, support and advocacy services, limited training opportunities and problems recruiting personal assistants (PAs) (e.g. Arksey & Baxter, 2012; Manthorpe et al., 2011).

Young adult service users

In the UK, physically disabled young adults are a minority¹, but growing, population of users of social care. Improvements in the care and treatment of childhood diagnosed complex health conditions (e.g. Duchenne muscular dystrophy) means children are now surviving into adulthood (Fraser et al., 2012). Self-directed care is a highly relevant issue for this group; assuming responsibility for their care and support arrangements is a realistic aspiration and accords with the shift towards independence associated with late adolescence and the early twenties. Indeed, this is in line with what is known more generally about the groups most likely to be using direct payments: namely adults aged 18-64 with physical disabilities (Health and Social Care Information Centre, 2013a). However, whilst there is some evidence about

¹ During 2012/13, less than in five physically disabled users of statutorily provided social care services were aged 18-64 years, with the majority (82%) being 65 years of older (Health and Social Care Information Centre, 2013a, p.37). More fine-grained breakdown by age is not available; however, it is important to recognise that physically disabled young adults (18-30 years) will only represent a proportion of this 'working age' age group (Health and Social Care Information Centre, 2013a, p.37). We also know that across all users of adult social care, young adults age 18-24yrs, followed by those aged 25-34 years, are the smallest groups (numerically) of service users compared to other, older, age bands (Health and Social Care Information Centre, 2013b)

working age physically disabled adults' use and experiences of PBs (Leece & Bornat, 2006; Glasby & Littlechild, 2009), almost nothing is known about the particular needs and experiences of physically disabled *young* adults.

Physically disabled young adults include both individuals who have transferred from children's services and those who have had no previous contact with social care. There is an expectation in England that disabled young people transferring from children's services will be prepared for, and supported in, this move (DOH, 2008, 2013). These young people and their families will have experience of 'dealing with' services, albeit services working to a family-centred ethos (Mitchell, 2012). Other physically disabled young adults will not have used children's services. This includes young adults with some types of degenerative conditions, where there is a gradual onset of physical impairment and who may not have been eligible for, or needed support from, children's services. In addition, as with any age group, there are those with acquired disability resulting from accidents (e.g. spinal injury) and sudden onset health conditions (e.g. stroke, meningitis).

Young adulthood as a developmental stage

The late teenage years through to mid-to-late twenties are increasingly regarded as a distinct developmental phase (Arnett, 2000, 2001, 2004) with

cognitive, psychosocial and physical maturation still occurring. This phase has been described as 'emerging adulthood': a term which usefully highlights this group as different to the wider population of working age adults in terms of life skills and life experience as well as engendering a sense of on-going development. In making his argument, Arnett drew on evidence from a number of academic disciplines. Changes in terms of the age at which individuals in many Western societies achieve the so-called milestones of adult (e.g. employment, leaving the family home) are significantly later than was the case in the past. Increased access to further and higher education, and economic factors, have played their role and societal expectations have shifted in response to this. In terms of cognitive development, neuropsychologists report substantive evidence of on-going development and 'consolidating' of neural pathways in the brains of twenty-plus year olds in areas where higher level cognitive functions (eg. emotion-regulation; rationale decision-making) are located (Johnson, Blum and Giedd., 2009). Importantly, young adults do not typically perceive themselves as 'adults', something they define as a state of autonomy and self-sufficiency (self-responsibility, independent decision-making) rather than the milestones of leaving the family home, employment and so on (Arnett, 2001).

Personalisation and young adults

The personalisation agenda in social care seeks to increase choice and control for service users, with self-directed care as a key plank of this approach. However, it brings with it unfamiliar roles and responsibilities. For young adults with physical disabilities this can be a considerable undertaking. Indeed, it is one which even older working age adults may find daunting. However, although studies may have included physically disabled young adults in their samples (e.g. Manthorpe et al., 2011), the authors have not been able to identify any research studies which have looked specifically at the experiences of young adults with physical disabilities within the context of the personalisation agenda. Given the policy drivers for personalisation, including self-directed care, in children's (Department for Education, 2013) and adults' services in England (Care Act, 2014), it is essential that professionals have access to evidence to inform their practice when working with this group.

This paper reports findings from a study on self-directed care and young adults with physical disabilities. A key objective was to hear the experiences of young adults who have assumed (greater) responsibility and control of their care and support arrangements, particularly PBs and DPs. It is this element

which we report in this paper. Other aspects of the study are reported elsewhere (Mitchell et al., 2015).

METHODS

Findings reported here are drawn from a larger qualitative study on the topic of self-directed care and physically disabled young adults which involved semi-structured interviews with young adults, parents and staff in statutory and voluntary sector organisations.

Four authorities in England were chosen as research sites. They were selected to represent different models of transition support and organisational type. Fieldwork was conducted January to September 2013. A project advisory group, including physically disabled young adults and parents, met twice over the course of the project and provided advice and support on an *ad hoc* basis in between meetings. Young adults unable to attend advisory group meetings were visited by a member of the research team.

Recruitment

The study set out to achieve a sample size of around 24 young physically disabled adults, recruited across the four research sites. Within each site a

social care manager was asked to identify individuals from caseloads against the study's inclusion criteria, namely aged 18-30 years², physical disability but no learning disability; experience of using PBs or DPs. Each manager sent recruitment packs (comprising a letter of invitation and project information sheet) to potential participants and this was followed up with a phone call by a member of staff. At the end of this call, young adults interested in participating in the study agreed for their contact details to be passed to the research team.

The sample achieved using this approach did not reach the required size. In response, the research team recruited voluntary sector service providers within the research sites to assist with recruitment, In addition, some participants were recruited through snowball sampling (Robins-Sadler, Lee, Seung-Hwan, Lim & Fullerton, 2010) via young adults already participating in the study, see Table 1. The final sample size was 23.

Insert Table 1 about here

The interviews

² This age range was chosen to reflect to study's focus on young adulthood (see Introduction), with the upper age limit extended slightly beyond the mid-/late twenties to ensure that some of the sample had extended experience of managing their care and support arrangements.

A semi-structured topic guide, informed by previous research on disabled young people, transition and choice-making (e.g. Mitchell, 2012a; 2014) was developed. It covered the following: current care and support arrangements, the role of social care and transition services, practitioners and other people helping young adults plan and prepare for taking on more control, personal reflections of this help and future plans to assume more (or less) control of their care and support arrangements. Two pilot interviews were undertaken and the topic guide amended accordingly.

Interviews lasted 60-90 minutes. The majority were conducted in the young adults' homes though two young adults chose to be interviewed by telephone. All interviews were audio-recorded. Three young adults chose to have a personal assistant (PA) or family member present to facilitate communication.

Consent was gained at the start of the interview. This took the form of either a signature on the consent form or audio-recorded verbal consent.

Data analysis

The Framework method (Ritchie & Lewis, 2003) was used to analyse the data. A thematic framework was developed through a process of reading transcripts and detailed interview summaries and discussions within the team. The framework included a priori themes (reflected in the topic guide) and emergent themes. The data was then summarised under these themes on a series of charts (one per theme) and indexed back to the location in the raw data. (This system allows efficient access to verbatim quotes and to test emerging findings within the wider context of the interviews.) Each row on a chart was used exclusively for one research participant and the far left hand column on each chart was used to record background information about participants.

FINDINGS

The sample

Nine young men and fourteen young women aged 19 to 29 years were recruited, see Table 2. Congenital conditions, a third of which were degenerative or progressive (e.g. muscular dystrophies), and acquired disabilities resulting from accident or illness were represented. Twenty participants received a DP, with almost half having DPs for more than two years. Three were using local authority managed PBs.

None of those with acquired disabilities had had prior contact with social care services. For some with degenerative conditions, family support had sufficed when they were younger and their first contact with social care was with adult services. Almost two thirds lived, at least part of the year (e.g. at college), independently.

Insert Table 2 about here

The questions put to the data

Our approach to analysing the data was to examine whether the experiences and issues encountered by young adults, as they assumed (greater) control of their care and support arrangements, appeared to be influenced by their age, or developmental life stage, and/or the fact that they are a minority group within a larger and predominantly older group of service users.

A number of issues or themes were identified which appeared to be unique or which have a particular meaning for this specific group of adult service users.

These were as follows (note: the order below is pragmatic and does not reflect priorities, strength of opinion etc):

- individual differences in assuming responsibility and control
- in control but involving others
 - parents
 - services and professionals
 - other DP users
- preferences around accessing peer support
- the role of transition preparation and planning work
- suitability of information provided by statutory services
- 'staff' management issues
- preferences around characteristics of PA

The following sections describe and discuss each of these in turn.

Individual differences in assuming responsibility and control

Almost all the young adults we interviewed had welcomed the opportunity to take on (greater) responsibility for managing their care and support arrangements. Importantly, however, there was considerable variation in how they wanted to achieve this and the pace at which it happened. Thus, within our sample a minority did not currently feel ready to take on DPs and were happy to have an authority managed PB, but with the aim of moving to DPs in the future.

Two separate, but linked, factors were associated with a reluctance to directly assume full control over support arrangements at the outset of using adult social care: concerns about becoming an employer and its associated responsibilities and a perceived lack of life experience, or 'readiness', to assume and successfully manage this responsibility.

I didn't feel ready ... I just didn't feel ready cos, you know, I was only young and had just left university. (YA17)

Even among those who were successfully using DPs, anxieties about the responsibilities they shouldered remained. However, this was outweighed by the independence and/or flexibility it afforded.

It feels good, I've finally got some power, yeah, but no, I do worry in the sense that I want to get it right and I don't want to like con my employees or pay them less than they're due or anything. (YA11)

In control but involving others

Almost all the young adults described actively involving others to support and enable them to assume responsibility for their care and support arrangements. This included parents predominantly, but also professionals. These individuals were being used by the young adults as sources of practical, administrative, informational and/or emotional advice and support. At the same time, it was very clear that the young adults were choosing which tasks or roles to hand over, and when to draw on the support and advice of others. For example, recruitment of PAs was an area where the young adults consistently wanted to make the final decision. Some young adults reported involving other people in the selection process (e.g., inviting parents (especially mothers) and/or a current PA to attend interviews). Here, the knowledge and experience parents and/or PAs could draw on and the emotional reassurance gained from talking through ideas and preferences was valued.

I might use another PA to sit in on the interview panel, not to coordinate or control the interview cos at the end of the day it's my decision that counts but like I just want to bounce an idea off them afterwards or just ask for their interpretation of what they thought.

(YA21)

Parents

For some young adults life-stage changes, especially leaving school and moving onto further/higher education, presented an opportunity to take more control of their care and support arrangements and for parents to 'let go'. Others simply described it as feeling the 'right time' to be more independent. Parents were specifically identified by over half our interviewees as playing a role in helping them to have the confidence to take this step. Parents' positive attitudes regarding greater independence and self-sufficiency were highly valued and often this reflected the 'can do' approach which parents had adopted from the point of diagnosis:

My mum has always championed me being as independent as possible and me achieving what I want to achieve. (YA6)

My parents were very supportive, you know, they've always been the ones ... to inspire me, push me forward ... so I think that kind of gave me confidence to go and do it [university and DP]. (YA17)

There was little evidence in the young adults' accounts of parents being discouraging or overly protective, although an initial reluctance around independent living was noted by one or two. Indeed, some young adults described being aware that their parents, particularly mothers, had found it difficult to 'let go', especially handing over self-care to 'strangers'. Nevertheless, this reticence had not been accompanied with a discouraging attitude.

There was also clear evidence that the majority of interviewees welcomed and wanted parents' on-going involvement to support them as they assumed control of their care and support arrangements. Roles assumed by parents included those which the young adult was dis-interested in assuming such as, the everyday administration of their DP, particularly organising and completing PA timesheets. In addition, for most interviewees, parents were a key source of advice and support when difficulties occurred. Common examples were advice, support, sometimes, direct intervention around managing a difficult situation with a PA (see earlier/later sections).

Only a small minority of young adults reported positively choosing to exclude their parents. This appeared to arise from a prior experience of parents taking over decision-making in, for example, the selection of PAs.

Services and professionals

Most of the young adults were not managing the everyday financial aspects of their DP, especially PA pay, tax and national insurance. Those who were using payroll services were generally pleased with this arrangement. DP support services were also viewed very positively by the young adults. They valued the personalised nature of the service, including home visits, and the availability of ongoing support from a clearly identified adviser

She [DP adviser] explained it all [employing PA] to me. When I was going to start it, she explained the system ... and every time I've employed someone if I have any questions I've asked her. (YA11)

Other DP users

Other DP users were regarded as an important source of information and support and offered something which parents or professionals could not provide. Specifically, they had 'real life' knowledge and experience to share.

Some had friends or peers (for example at college/university) who were in a similar situation and with whom they shared information and experiences. Whilst talking to DP users of a similar age was helpful, greater priority was sometimes given to learning from DP users with a similar disability, as one person explained,

... the network for my condition, SMA [spinal muscular atrophy], and the support from that network. (YA9)

Internet based DP forums, such as those on disability specific websites were helpful to find other DP users. We return to the use of social media in a later section.

Preferences around accessing peer support

Some young adults reported speaking to friends and acquaintances, both in terms of accessing information about DPs/PBs and also for support during decision-making. Social media was sometimes used to facilitate this contact.

So it was mainly personal networks that helped me, you know, understand what was going on ... I'm lucky enough to be able to speak with them on social media and talk it through. (YA18)

However, a number of interviewees also voiced the wish for more opportunities to 'meet' other DP users, both via social media and face-to-face, regardless of their age. Importantly, as well as being in touch with their peer group, contact with others with the same condition was valued. Organising more locally based DP user support groups and creating more DP forums on easily accessible social media websites, such as Facebook, were suggested.

The role of transition planning and preparation work

Some of the young adults we interviewed, such as those with degenerative conditions where deterioration was relatively limited during childhood and those who had acquired their disability as young adults, had not been users of children's social care. Others had used children's services (e.g. short breaks), including some who had received Direct Payments, albeit managed by parents.

For those who had used children's services, we were interested to find out whether work around planning for the transition to adult social care had helped to prepare or equip the young adults to assume greater control over their care and support arrangements. A number reported positive and

encouraging support from their social worker during this time which had helped them achieve their aspirations. For example, negotiating and facilitating arrangements associated with moving away to college or university. However, others expressed frustration with their social workers' lack of knowledge about relevant adult services and, particularly, DPs. A further barrier to planning for adult social care was infrequent contact with social workers during the transition years. This was typically attributed to staff changes and unfilled posts. Finally, interviewees suggested that offering opportunities to 'try out' working with and beginning to manage a PA would be a valuable addition to transition support.

Suitability of information provided by services

Among the young adults we interviewed, over a quarter specifically reported not receiving enough written information about DPs and felt this had been problematic, especially, when initially deciding whether or not to take on a DP. Young adults also reported it was difficult to find information due to poor signposting, particularly on the internet. For example, a couple of the young adults described feeling overwhelmed when they started off searching, unsure how or where to begin looking for information. Assistance from parents was once again welcomed. Two inadequacies were identified regarding the

information provided by statutory social care services and care agencies. First, information was not tailored, or did not acknowledge, that some DP users had physical impairments, as opposed to learning disabilities. Second, there was little recognition of the fact that, young adults as well as older people, may be interested in care agency services.

When you do look at agencies' information [care agencies] they're filled with pictures of old people being cared for and then there's just a little bit at the bottom, 'we also provide care for young people'. (YA12)

'Staff' management issues

'Person-management' issues associated with being cared for by PAs or carers provided by an agency were consistently reported as the most difficult and stressful aspect of assuming responsibility for care and support arrangements. Two types of difficulties were encountered: poor performance or unsatisfactory care, and establishing boundaries in relationships with PAs/carers. Importantly, most of the young adults explicitly reported feeling ill-equipped and even at a loss as to how to deal with these issues. They identified their lack of life skills and experiences of work as hindering their ability to manage these situations.

... because I've never worked, because I don't know what it's like to work because I can't put myself in their shoes, I find it difficult to say what's right and wrong [to PAs] ... (YA18)

This, in itself, was perceived by some as increasing their vulnerability to carers 'taking advantage' over things such as poor timekeeping (e.g. not arriving at allotted shift times),

I find the day-to-day stuff really hard ... I had a PA who always without fail was late and I didn't know how to deal with that. (YA17)

In addition, some believed their age and lack of experience (as an employer and/or using paid carers) had been the reason underlying a lack of respect or disinclination to take instruction on the part of carers.

I had an agency person and she kept saying 'I'm 26 years old; I'm 5 years older than you. I've been doing this job for so long, don't tell me I don't know how to do my job'. (YA19)

Developing appropriate skills to address situations such as these was challenging. Some described it as a process of learning through experience. Indeed, it is important to note that finding their own solutions could be an empowering experience, reinforcing feelings of personal control and self-respect from other people. Just under a quarter of the young adults reported instances in which they drew in other people, such as their mother or a care agency manager.

I'll get my Mam to talk to them [PAs], I don't really like saying it to them [PAs] cos I always feel a bit awkward. (YA20)

As well as believing others were more skilled to deal with such situations, involving a third person was also viewed as useful in instigating a more formal or professional relationship between the young adult and their paid carer. Some had found a written personal care plan was a helpful tool in terms of setting out how they wanted their PA/carer to meet their care and support needs,

I have a list of ground-rules now that I give to people about what I will and won't tolerate ... I do a little 'about me' section because I do have

preferences ... some of my appalling experiences in my first year have now made it into the hypothetical situations that I give to people in interviews so then, I can tell whether they think that's [care and respect expected] acceptable or not. (YA19)

Finally, many young adults described their relationships with one or more of their PAs as a friendship: indeed this was perceived as one of the positive outcomes being able to choose PAs and carers (see section below: Preferences around the characteristics of PAs). However, this led to ambiguity in employer/employee roles and boundaries, something which could then make performance management issues very difficult situations to address and manage.

I think I've learned over time, at first I struggled with it, I didn't quite know how to be professional; even now it's difficult cos you are so close to people and you become good friends ... (YA9)

Although learning from experience was inevitable and important, the young adults also wanted more information and training opportunities.-They rued the

lack of information, or even training, particularly in terms of 'person management' and employer/employee relationships. A couple of our interviewees had received some useful advice from DP support service staff on 'person management' but it was brief, specific to a particular problem or situation and had been actively sought by the young adult rather than routinely and proactively provided. Relevant and easy to understand training was wanted around the practical and emotional aspects of being an employer from people with 'real' (i.e. employers; DP users) rather than just 'text book' experience. Interviewees also suggested a set of 'how to' guides would be a useful resource. Preferences varied from generic guides to young adult specific resources covering topics such as, DPs, PA management and moving towards independent living. None reported seeing such material whilst planning and/or choosing to have DPs. However, one young adult noted that he himself had, sometime later, found an accessible guide to having a PA (Vasey, 2000) and felt it would have been very helpful. In fact, he continued to regard it as an important resource:

... it's like a bible really because it's written by a group of disabled people who employ PAs, probably years ago but it's got some great

tips and advice, information and guidance. So, if I ever get stuck, I always just read that. (YA21)

Preferences around the characteristics of PA's

Drawing on past experience of PA/carer selection, face-to-face interviews with potential PAs/carers was regarded as important in order to 'check out' candidates, particularly their interests and attitude to caring. 'Getting on' with PAs was also important and, in this respect, the young adults believed having PAs of a similar age helped. For example, shared music interests were especially important to one young adult as she liked to go to music festivals and concerts. Others noted how PAs of a similar age were more likely to be perceived as a friend rather than carer when out and about in public spaces; this was important to them. Finally, expectations around acceptable job-related demands were more likely to be aligned. For instance, staying out late was unlikely to be viewed as problematic by PAs who were young adults themselves:

So if I come in at two in the morning, that's fine with them. (YA7)

Gender was important to young women; they wanted female PAs, especially for personal care support. The young men we interviewed appeared less concerned about this.

Discussion

This paper reports physically disabled young adults' experiences of personalisation in adult social care in England; particularly, their experiences of using DP or managed PBs. One of the key research questions was whether practice to help support physically disabled young adults assume greater control over their care and support arrangements needs to be different in some way to the support given to other physically disabled adults or other groups using PBs or DPs. Our argument was that young adults are a 'minority group' among users of adult social care and that this, and the notion that they are still developing into adulthood, may have a bearing on their experiences and support needs. Current evidence points to the benefits of self-directed care compared to traditional models of providing social care; furthermore, as a user group, it would appear there is great potential to achieve high levels of control and independence. Together these make a strong case for the importance of ensuring young physically disabled adults are adequately supported to assume responsibility for their care and support arrangements.

It is important to recognise that many of the experiences described by the young adults who participated in this study (eg. concerns around administrative/financial burdens, person management, lack of information) have been reported by other groups of service users (Arksey & Baxter, 2012; Manthorpe et al., 2011). These are, therefore, clearly problems that can impede all service users, irrespective of age or disability, from taking on more control of their support. However, whilst recognising this, it is important to highlight that the young adults themselves attributed their (difficult) experiences to their age, lack of life experience and life skills, and their 'minority status' within the adult PD population. In addition, the (desired) on-going involvement of parents added to the unique-ness of their experiences. Both these issues have implications in terms of ways of working.

Almost all the young adults we interviewed welcomed the personal control over their care and support arrangements that DP offered and, to a lesser extent, managed PBs. The importance of service users achieving control has been reported by other studies (Lepidus et al., 2007; Bennett, 2009). However, in this study there was a clear sense from many interviewees' accounts that, for them, a personalised approach to managing their care

placed significant demands on them, some of which were particularly challenging. Whilst administrative and financial tasks could be handed over (to parents, payroll agencies, the local authority), it was the management of PAs and agency carers which caused greatest concern. Whilst difficulties managing PAs are also reported by studies with other groups of service users (Glasby, 2011; Manthorpe et al., 2011), the young adults specifically identified their age, limited life experience (particularly in the world of work) and the desire to have PAs/carers who were their age (and hence 'socially invisible' but which carried the risk of the blurring of employee/employer boundaries) as both increasing the risk for 'person management' issues to arise, and their (perceived) ability to effectively manage such situation. Importantly, 'person management' issues were, perhaps, the most difficult problem for a young adult to handover to someone else without it engendering a sense of dependency.

It was also concerning to report instances where young adults believed their age and/or inexperience had resulted in carers/PAs taking advantage in terms of poor-timekeeping or being dis-inclined to adhere to instructions. We know that other user groups may have similar concerns and experiences (Glasby & Littlechild, 2009; Carr, 2010; Manthorpe et al., 2011) though there is no

consistent evidence that self-directed care increases, or decreases, the risk to the quality of care (Ottman et al, 2013; Lundsgaard, 2005). However, the *perceived* causes for poor quality or disrespectful care among our sample had additional, or different, dimensions to those of other user groups. Finding effective ways to address the information/training needs around preventing and/or managing difficult employer-employee situations certainly emerges as a crucial issue to address, as does the need to address such training/information to the particular issues and vulnerabilities different groups of service users may face. It is worth noting here the effective way in which some interviewees had used personal care plans to pre-empt or overcome some of the 'people management' difficulties associated with using PAs or agency carers. Although the process of support planning and writing a user-led support plan is important within personalisation in England (DH, 2008), our findings also highlight the importance of personal care plans which clearly set out wishes and preferences in terms of how day-to-day care and support needs should be met.

It is also important to draw attention to individual differences in the young adults' aspirations to assume control of their care arrangements and the pace at which this happened. Figures on take-up suggest a range in willingness

among adults' to use PB/DPs (Craston, Thom & Spivack, 2013). However, it could be argued that for *young adults* their lack of life experience and life skills is an additional factor that must be recognised as contributing to their readiness, or preparedness, to assume control of their care and support arrangements. This aligns with other research which argues that these individual differences reflect important differences among others, in life skills and experience, personality and availability of support (Mitchell, 2012)

Another key theme, and related to the young adults' views and experiences of the demands of self-directed care, was the active involvement of others in supporting them to manage their care and support arrangements. Whilst practitioners were identified as having particular, and typically rather limited roles, parents emerged as a key source of support for many of the young adults we interviewed. Sometimes this was particularly in the early days, for others, parents continued to be actively involved and assumed a range of roles. Despite this however, there was a clear sense that the young adults were in control of the involvement of others and that they welcomed the support others could offer them. For a minority, unwanted interference (from parents) had resulted in parents being subsequently excluded, although an

issue of concern, the young adults did not choose to discuss this in detail during their interview.

The active involvement of parents in young adults' lives, particularly at the interface with adult services, is something which provokes mixed responses. Past literature has suggested that parents of disabled young people find it hard to 'let go' and encourage independence (e.g. Bowey, McGlaughlin & Claire, 2005). However, generic research on young adulthood has found that young adults generally want and value parents' on-going involvement in their lives (e.g. Arnett, 2000; Arnett, 2001; Schoeni & Ross, 2004). It is, in a sense, the developmental and cultural norm. These findings are also replicated in research specifically with physically disabled young adults (Abbott & Carpenter, 2010; Maddison & Beresford, 2012; Mitchell, 2012a & 2014). One explanation for the on-going involvement of parents is that the majority of young adults have not 'replaced' their parents' support with support from a long-term, committed partner. Another reason given by young adults with significant health conditions for the continued involvement of parents in their health care, and which may also apply with regard to social care, is the young adults condition is something they are used to managing as a family. Hence, parents expertise was valued (Beresford & Stuttard, 2014). Therefore, a key

issue for adult services, and particularly, practitioners who typically deal with older working age adults, is to accommodate and work with this difference in the source of significant support used by young adults compared to that used by other service users.

This issue also raises questions about support for those whose parents are unable or unwilling to provide support or for those young adults who do not want to involve their parents (Maddison & Beresford, 2012). In our study, a minority preferred not to involve their parents and had found other sources of emotional and decision-making support, for example, other DP users and trusted PAs. These alternative sources of support emerged as particularly important as contact with social workers appeared absent or limited for many of our interviewees. This was partly the result of a lack of prior contact with social services (see below), but also because self-directed care reduces, more generally, the role of social workers in service user care management.

The extent to which transition support equips young adults for personalised approaches within adult social care was something we were also keen to explore. Here, a couple of issues worth noting are. First, physically disabled young adults vary in terms of their prior experiences of services. Young adults

who have used children's services, whilst potentially more 'savvy' about statutory services, may be hindered in the way they adapt to adult social care practices because their expectations are informed by experiences in children's services (Beresford & Stuttard, 2014). At the same time, those with no prior contact of social care services will typically have a very low level of knowledge of the way services are organized and the options available to them. Indeed, the possibility of 'service invisibility' (Abbott & Carpenter, 2010) for those who had not used children's services became apparent during recruitment for this study. All four authorities struggled to identify physically disabled young adult service users. This reiterates the importance of joint working between health and social care practitioners, especially information sharing (Beecham et al., 2008).

We know from other studies (e.g. Beresford et al, 2013) that young adults with newly emerging care and support needs may not be aware of their entitlements to statutory support. This is, perhaps, particularly the case for those with a degenerative condition where there is no acute event to trigger contact with services, or services' awareness of them. Second, our findings question the extent that current transition planning and preparation practice equips young adults to assume control of their care and support

arrangements. There would appear to be some scope to develop ways by which young people can have some (gradual) experience of managing their care and support arrangements.

The value of peers – particularly as sources of information and social support – has been consistently identified in research (Leece & Bornat, 2006; Social Care Institute for Excellence, 2011; Manthorpe et al., 2011; Callaghan, 2012; Griffiths, 2012). In terms of enabling *young adults* to access such support, this may differ from older service users because of their preferences for and/or ease with using social media. However, it is also useful to note that shared experiences of a health condition may be prioritised over age or situation. This may, in part, reflect and be accentuated by a sense of isolation which individuals with rare conditions frequently report (Abbott & Carpenter, 2010; Beresford et al, 2013). However, this prioritisation of shared health experiences may challenge assumptions, including practitioner assumptions, about ‘who’ young adults would prefer to make contact with and discuss their situation and concerns.

Limitations

This study was, we believe, the first in England to tackle the topic of physically disabled young adults experiences of self-directed care. As is the case with research on a 'new' issue, the purpose was to explore and describe the range of views and experiences. The difficulties we faced with recruitment, partly due to needing to rely on professionals identifying potential participants and passing on recruitment materials and our resort to snowball sampling (Robins-Sadler et al., 2010) may be seen as compromising the study. Certainly, we would not claim to have captured the complete range of experiences physically disabled young adults may have as they use DPs or PDs. However, a relatively diverse sample, and with a range of different aspirations and experiences, was achieved. A key element of this study has been to test whether young adults differ in their needs and experiences compared to other service user groups. We did not have any other populations represented in this study; however, we have drawn on the relatively substantial existing evidence to make these comparisons. We have also drawn on the growing field of theory and research on emerging adulthood (e.g. Arnett, 2000) to analyse and explain the data. Finally, we recognise that presence of a parent/carer in three of the interviews may have influenced responses. However, assistance facilitating young adults' participation and communication was felt to outweigh concerns of bias.

In conclusion, the insights provided by this research into the experiences of physically disabled young adults as they seek to assume greater control and responsibility for their care and support arrangements suggest their experiences may, at least to some extent, be similar to other groups of service users. However, the *perceived* reasons behind difficult experiences and challenges, their sources of support (that is, the role of parents), and their own perceived abilities to address and overcome difficulties are grounded in young adults' perceptions of themselves as distinct and different to other (working age) adults and older people. Finally, the findings from this project flag up the need for tailored, or 'young adult-centred' practice and support, particularly in terms of information provision and 'training', whilst also facilitating the supportive role family and peers frequently play. Increasing awareness of the needs and experiences of this 'minority group' among practitioners who work with physically disabled adults is therefore important. To this end another output from this project has been a freely available multi-media resource for practitioners (<http://youtu.be/n8RiE9sPWEU>).

Ethical Approval

Ethics approval was given by the Social Care Research Ethics Committee, REC Number 12/IEC08/0043.

Acknowledgements

The authors would like to thank the young adults who participated in the study.

Funding acknowledgement

This work was supported by the NIHR School for Social Care Research. The views expressed in this publication are those of the authors and not necessarily those of the National Institute for Health Research (NIHR) School for Social Care Research or the Department of Health, NIHR or National Health Service. This article presents independent research commissioned by the NIHR School for Social Care Research.

References

Abbott, D. & Carpenter, J. (2010) *Becoming an adult: Transition for young men with Duchenne Muscular Dystrophy*. London, UK: Muscular Dystrophy Campaign.

Alakeson, V. (2010) International Developments in Self-Directed Care. *Issues in International Health Policy: publication number 1370, Volume 78*. New York, US: The Commonwealth Fund.

Arksey, H. and Baxter, K. (2012) Exploring the temporal aspects of direct payments, *British Journal of Social Work*, 42, 1, 147-164.

Arnett, J. (2000) Emerging adulthood: a theory of development from late teens through the twenties. *American Psychologist*, 55, 469-480.

Arnett, J. (2001) Conceptions of the transition to adulthood: perspectives from adolescence through midlife. *Journal of Adult Development*, 8, 133-143.

Arnett J. (2004) *Emerging adulthood: the winding road from the late teens through the twenties*. New York: Oxford University Press.

Beresford, B., Moran, N. and Clarke, S. (2013) *My Life: Growing up and living with Ataxia-Telangiectasia*. York, UK: Social Policy Research Unit, University of York.

Beresford, B. & Stuttard, L (2014) Young adults' experiences of adult health care. *Clinical Medicine*, 14, 4, 404-408.

Beecham, J., Snell, T., Perkins, M. & Knapp, M. (2008) After transition: health and social care needs of young adults with long-term neurological conditions, *PSSRU Research Summary 48*, Bristol, UK: PSSRU.

Bowey, L., McGlaughlin, A. & Claire, S.(2005) Assessing the barriers to achieving genuine housing choice for adults with learning disability: the views of family carers and professionals. *British Journal of Social Work*, 35, 1, 139-148.

Callaghan, L., Netten, A., Brookes, N. & Fox, D. (2012) *Personalisation of services scoping study*. Research Findings. London, UK: NIHR School for Social Care Research.

Carr, S. (2010) *Enabling risk, ensuring safety: Self-directed support and personal budgets*. London, UK: Social Care Institute for Excellence
(<http://www.scie.org.uk/publications/reports/report36/files/report36.pdf>)

Craston, M., Thom, G. & Spivack, R. (2013) *Evaluation of the SEND Pathfinder Programme: process and implementation*. Research Brief. London, UK: Department of Health and SQW.

Department of Health (1996) *Community Care (Direct Payments) Act*. London, UK: Department of Health.

Department of Health (2010) *A vision for adult social care: capable communities and active citizens*. London, UK: Department of Health.

Department of Health (2014) *Care Act*. London, UK: HMSO.

Department for Education (2013) *The Children and Families Bill*. London, UK: HMSO.

Egan, D. (2010) *2GoDirect – The experience of two people using direct payments to employ a personal assistant*. The Independent Living Institute. Retrieved from <http://www.independentliving.org/2GoDirect>.

Evans, C. (2012) *The self-defined training needs of people who use direct payments and personal budgets in Wiltshire in 2011*. Unpublished report. Wiltshire, UK: Centre for Independent Living.

Fraser, L., Miller, M., Hain, R., Norman, P., Aldridge, J., McKinney, P. & Parslow, R. (2012) Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*, 129, 923-929.

Glasby, J. & Littlechild, R. (2009) *Direct payments and personal budgets. Putting personalisation into practice*, Bristol, UK: Policy Press.

Glasby, J. (2011) *Whose risk is it anyway? Risk and regulation in an era of personalization*. York, UK: Joseph Rowntree Foundation

Gleeson, H., McCartney, S. & Lidstone, V. (2012) Everybody's business: transition and the role of adult physicians. *Clinical Medicine*, 12, 6, 561-566.

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York, UK: Social Policy Research Unit, University of York.

Health and Social Care Information Centre (2013a) *Community Care Statistics: Social Services Activity, England, 2012-13 Final Release*. London, UK: National Statistics.

Health and Social Care Information Centre (2013b) *Personal Social Services Adult Social Care Survey, England, 2012-13 Final Release*. London, UK: National Statistics.

HM Government (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*. London, UK: HM Government.

Johnson, A., Blum, R. & Giedd, J. (2009) Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *Journal of Adolescent Health* 9, 45, 216–221

Leece, J. & Bornat, J. (Eds.) (2006) *Developments in direct payments*. Bristol, UK: Policy Press.

Lepidus Carlson, B., Foster, L. Dale, S. & Brown, R. (2007) Effects of cash and counselling on personal care and well-being. *Health Services Research* 42, 1 Part 2, 467-487.

Lundsgaard, J. (2005) *Consumer direction of choice in long-term care of older persons, including payments and informal care*, OECD Working Paper 20, Paris: OECD publications.

Maddison, J. & Beresford, B. (2012) Decision-making around moving on from full-time education: the roles and experiences of parents and disabled young people with degenerative conditions. *Health and Social Care in the Community*, 20, 5, 477-487.

Manthorpe, G., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Gray, B. (2011) *Self-Directed Support: A Review of the Barriers and Facilitators*. Edinburgh, Scotland: Scottish Government Research

Mitchell, F. (2012) Self-directed support and disabled young people in transition (part 1). *Journal of Integrated Care*, 20, 1, 51-61.

Mitchell, W (2012a) Perspectives of disabled young people with degenerative conditions on making choices with parents and peers. *Qualitative Social Work*, 11, 6, 621-643.

Mitchell, W. (2014) Making choices about medical interventions: the experiences of young people with life-limiting Conditions. *Health Expectations*, 17,2, 254-266.

Mitchell, W., Brooks, J., Beresford, B., Moran, N., and Glendinning, C. (2015) *Taking On and Taking Over: Choice and control for physically disabled young adults: SSCR Research Findings*. London: NIHR School For Social Care Research

Social Care Institute for Excellence (2011) Learning from the experiences of older people and their carers. Personal Budget Briefing 40, London, UK: Social Care Institute for Excellence.

Netten, A., Jones, K., Knapp, M., Fernandez, J-L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. and Wilberforce, M. (2012) Personalisation through individual budgets: does it work and for whom?, *British Journal of Social Work*, 42, 8, 1556-1573.

Newbrunner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. and Glendinning, C. (2011) *Keeping Personal Budgets Personal: Learning From the Experience of Older People, People with Mental Health Problems and their Carers*. London, UK: Social Care Institute for Excellence.

Norah Fry Research Centre (2010) *'It's all about respect': people with learning disabilities and personal assistants*, Bristol, UK: Norah Fry Research Centre.

Ottman, G., Allen, J. & Feldman, P. (2013) A systematic narrative review of consumer-directed care for older people: implications for model development. *Health and Social Care in the Community*, 21, 6, 563-581.

Powers, L., Sowers, J. & Singer, G. (2006) A cross-disability analysis of person-directed, long-term services. *Journal of Disability Policy Studies*, 17,2, 66-76.

Ritchie, J. & Lewis, J. (Eds.) (2003) *Qualitative research practice: a guide for social science students and researchers*. London, UK: Sage.

Robins Sandler, G., Lee, H-C., Seung-Hwan Lim, R. & Fullerton, J. (2010) Recruitment of hard-to-reach population groups via adaptations of the snowball sampling strategy. *Nursing and Health Sciences*, 12, 369-374.

Schoeni, R. & Ross, K. (2004) Material assistance received from families during the transition to adulthood. In R. Settersten; R. Furstenberg & R. Rumbaut (Eds.), *On the Frontier of Adulthood: Theory, Research and Public Policy*. Chicago, IL: University of Chicago Press.

Sims, D. & Cabrita Gulyurlu, S. (2014) A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health and Social Care in the Community*, 22, 1, 13-21.

Timonen, V., Convery, J. & Cahill, S. (2006) Care revolution in the making: a comparison of cash-for-care programmes in four European countries. *Ageing and Society*, 26, 3, 455-474

Vasey, S. (2000) *The rough guide to managing personal assistants*. London,
UK: National Centre for Independent Living.

Table 1: Number of information packs sent and young adults recruited

| <i>Local authority</i> | <i>Information packs sent by:</i> | | | <i>Young adults recruited</i> |
|------------------------|-----------------------------------|--|--------------------|-------------------------------|
| | <i>Local authority</i> | <i>Other – voluntary organisation, snowballing</i> | <i>Total packs</i> | |
| LA1 | 20 | 15 | 35 | 0 |
| LA2 | 20 | 4 | 24 | 6 |
| LA3 | 20 | 17 | 37 | 6 |
| LA4 | 20 | 0 | 20 | 4 |
| Other | Not applicable | 8 | 8 | 7 |
| Total | 80 | 44 | 124 | 23 |

Table 2: Young adults – Characteristics and type of personal budget*

| <i>Identity</i> | <i>Age(years)</i> | <i>Gender</i> | <i>Cause of physical Disability</i> | <i>Type of PB</i> | <i>Period of time with PB (approximate, in years)</i> | <i>Support prior to PB</i> |
|-----------------|-------------------|---------------|-------------------------------------|------------------------|---|--|
| YA1 | 26 | Female | Congenital | Direct Payment (DP) | Awaiting decision | Family |
| YA2 | 24 | Male | Congenital (progressive) | DP | 6 | Family and limited short-break care |
| YA3 | 26 | Female | Congenital (progressive) | Authority managed (AM) | 3 | Family |
| YA4 | 20 | Male | Congenital | DP | 1.5 | Family and friends |
| YA5 | 22 | Female | Congenital | DP | unsure | Family and regular short-break care |
| YA6 | 28 | Female | Congenital (progressive) | DP | 1.5 | Family, care agency backup as required |
| YA7 | 20 | Female | Acquired | AM | 2 | None required |
| YA8 | 22 | Female | Congenital | DP | 1 | Family and regular short-break care |
| YA9 | 25 | Male | Congenital (progressive) | DP | 7 | Family and regular short-break care |

| <i>Identity</i> | <i>Age(years)</i> | <i>Gender</i> | <i>Cause of physical Disability</i> | <i>Type of PB</i> | <i>Period of time with PB (approximate, in years)</i> | <i>Support prior to PB</i> |
|-----------------|-------------------|---------------|-------------------------------------|---------------------|---|-------------------------------------|
| YA10 | 26 | Female | Congenital | DP | 8 | Family and limited short-break care |
| YA11 | 26 | Female | Congenital(progressive) | DP | <1 | Family |
| YA12 | 26 | Female | Acquired | AM | 2 | None required |
| YA13 | 19 | Female | Acquired | DP | 4 | None required |
| YA14 | 24 | Male | Acquired | DP AM previously | Recent (1.5:AM) | None required |
| YA15 | 22 | Female | Congenital | DP. | 4 | Family and limited short-break care |
| YA16 | 29 | Female | Congenital | DP | Unsure | Family |
| YA17 | 26 | Female | Congenital | DP | 7-8 | Family, small DP mother managed |
| YA18 | 23 | Male | Congenital | DP | | Family and friends |
| YA19 | 24 | Female | Congenital | DP | 6 | Family |
| YA20 | 28 | Male | Congenital (progressive) | DP | 7 | Family, small DP mother managed |
| YA21 | 24 | Male | Congenital | DP | 7 | Family |

| <i>Identity</i> | <i>Age(years)</i> | <i>Gender</i> | <i>Cause of physical Disability</i> | <i>Type of PB</i> | <i>Period of time with PB (approximate, in years)</i> | <i>Support prior to PB</i> |
|-----------------|-------------------|---------------|---|-------------------|---|---------------------------------|
| | | | (progressive) | | | |
| YA22 | 26 | Male | Congenital | DP | 3 | Family |
| YA23 | 21 | Female | Congenital | DP | unsure | Family, small DP mother managed |

*At time of each young adult's interview