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Taking On and Taking Over: Choice and control for physically disabled young adults

KEY POINTS FROM THE RESEARCH

- While welcoming the opportunities afforded by personalised approaches within adult social care, almost all the young adults described feeling daunted by the associated responsibilities.
- Key sources of practical, informational and emotional support were parents and other Personal Budgets (PBs) users, especially, those using Direct Payments (DPs) (a PB managed by the person/family themselves), those at the same life stage and/or those with the same or similar condition. Social networking sites could be useful in making contact with peers.
- Managing Personal Assistants (PAs)/carers was consistently identified as the most difficult aspect of having a DP. Most young adults felt ill-equipped to deal with issues such as poor performance, and establishing employer/employee boundaries.
- Young adults found information from statutory services was typically targeted at other audiences, for example, older people.
- Among the young adults who participated in this study, only a minority believed transition planning/support services had played a significant role in preparing them for taking on a PB.
- Young adults had clear views about the types of PAs/carers they preferred to use.

This study looked at ways of supporting physically disabled young adults to achieve their preferred levels of control over care and support arrangements:

- What are physically disabled young adults experiences of managing their care and support arrangements?
- How can they be better supported?

- Professionals with limited experience of working with young adults with physical disabilities typically assumed that issues faced by this group, as they took on greater control of their support arrangements, were similar to those of other groups with whom they worked.
- Social workers with more experience of working with young adults identified specific issues that need to be accommodated including: young adults' relative lack of life skills and experience; young adults' preferences regarding parental involvement; and addressing parents' support needs.

PRACTICE IMPLICATIONS

Study findings suggest that physically disabled young adults have specific support needs and/or require particular ways of working which acknowledge and address their life-stage, patterns of parental involvement, and potentially, their relative immaturity and inexperience.

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Approaches to meet these specific needs may include:

- offering a staged approach to assuming control and responsibility of support arrangements;
- incorporating low risk opportunities within transition planning and preparation processes to begin experiencing control and responsibility;
- information, training and support around avoiding and dealing with 'staff-management' issues;
- recognition of, and working with, family patterns of support and involvement;
- opportunities to access peer support via social media, written information and face-to-face encounters;
- information from and about statutory and other social care services which reflects the fact that some service users may be physically disabled young adults;
- training within adult social care on young adulthood and the sorts of conditions young adults with physical disabilities may have is needed to ensure practice is not based on assumptions about, or stereotypical views of, young adulthood.

BACKGROUND

Assuming responsibility for their own care and support arrangements is a realistic aspiration for many physically disabled young adults. However, there are a number of potential barriers to achieving this. For example, as a minority group amongst users of adult social care, social workers may have little experience of working with physically disabled young adults and the health conditions they typically have.

In addition, compared to other user groups, young adults themselves may have more limited life skills and experiences. This study explored physically disabled young adults' experiences of taking on greater control and responsibility for their care and support arrangements. The views and experiences of parents, social care managers and front-line social workers were also investigated.

FINDINGS

Young adults' experiences and perspectives

Almost all the young adults who took part in the study welcomed the independence and control afforded by taking on (greater) responsibility for managing their support arrangements.

It feels good! I've finally got some power.

However, the routes by which this had been, or was being, achieved varied. At the time of being interviewed, a minority had chosen a 'staged' approach with their PB being managed by the local authority. However, all planned to move on to DPs in the future. Many had taken the route of DPs from the outset. However, in some cases this had been a gradual process in which DPs were initially used to fund some, but not all, aspects of their support arrangements.

Concerns and sources of support

Anxiety about assuming responsibility, and a perceived lack of life skills/experience needed to successfully assume control, were common themes in the young adults' accounts:

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

... but 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.

Parents were typically identified as the predominant source of practical, administrative, informational and/or emotional support and advice. Importantly, parental involvement was sought by young adults rather than imposed by parents.

Another key source of information and advice was other DP users. This included both peers of the same age, and/or others with the same or similar condition, including those who had already achieved independent control of their support arrangements. Many voiced a desire for more opportunities for face-to-face contact with peers. Some had used social media to access such support:

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.

The role of transition planning and preparation processes

The extent to which transition planning and preparation had included work around preparing to use, or support accessing, DPs or PBs varied considerably.

Some young adults found children's services staff had limited knowledge of personalisation arrangements and practice in adult social care. Others, however, specifically identified their social worker during transition as playing an important role in enabling them to assume responsibility for their support arrangements once they moved to adult services. This was both in terms of a 'can do' attitude and providing information, advocacy and/or administrative support.

Managing PAs/carers was consistently reported by young adults as the most difficult aspect of assuming responsibility for support arrangements. Poor performance or unsatisfactory care and establishing boundaries in relationships with PAs/carers were consistently identified as the two most difficult situations to deal with. The majority of young adults in the study believed a lack of confidence and life experience hindered 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] ...

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.

In addition, some believed their relative immaturity made it more likely that staff-management issues would arise:

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'.

Parents and peers were typically identified as key sources of help in this area. Many young adults expressed a desire for more 'training'

and proactive input from social care staff on pre-empting and dealing with issues associated with employing carers/PAs.

The characteristics of PA and carers

As with any person, the young adults wanted their PAs/carers to recognise and respect their interests, preferences and priorities. Some noted that carers who were used to working with other age groups could be inflexible in what they were prepared to do. Typically, PAs/carers of around the same age were preferred. Key reasons given were, first, the carer/cared for relationship was less apparent in public situations, and, second, there were more likely to be shared interests and a willingness to support the young adult in the activities they wanted to do:

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

However, having PA/carers of a similar age can create difficulties in establishing and maintaining boundaries in the employer/employee relationship.

The young women interviewed were adamant about the importance of having female PAs, especially for personal care. Preferences around gender were less marked among the young men interviewed.

Suitability of information provided by services

The suitability or acceptability of information available from adult social care services and care agencies was questioned by many of the young adults. They reported that most was tailored to other user groups (for example, older people, or those with learning disabilities), with little or no reference to the fact that some users may be young adults:

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'.

Professionals' perspectives

Many of the adult social care managers and social workers interviewed reported having little experience of working with physically disabled young adults. These staff tended to

view physically disabled young adults as similar to other groups of service users they worked with. In contrast, staff with experience of this age group believed that the age and life-stage of these young adults raised particular issues, as discussed below.

Parental involvement

Social workers were typically aware that parents were often a significant source of practical and emotional support, and that this was vital in ensuring young adults successfully achieved the level of control they desired over their support arrangements. Ascertaining how the young adult wanted their parent(s) involved and establishing a good working relationship with parents was therefore important.

Limited life skills and experience

Some social workers highlighted the need to adjust practice or ways of working to accommodate young adults' likely relative lack of experience, skills and confidence. These were regarded as affecting decision-making as well as young adults' abilities to take lead responsibility for support arrangements.

Strategies reported by practitioners to address this included: allocating young adults more time and support than might be offered to other service users when making decisions about their support arrangements, and allowing a gradual approach to assuming control. The latter could be achieved by a young adult initially managing a small part of their PB until they had gained the skills and confidence to take on full responsibility, or, staging the process of assuming independence (for example, successfully moving away from home before taking on management of a DP).

Social workers also noted the benefit to parents when young people had opportunities to experience some control and responsibility

ABOUT THE STUDY

The study took place between July 2012 and January 2014 and involved semi-structured interviews with young adults, parents and social care professionals.

Professionals were recruited from four English local authorities. Young adults and parents were recruited from these authorities and through a process of snowball sampling. Twenty-three physically disabled young adults (19 to 29 years) and the parents of nine of these young adults participated. Telephone interviews were conducted with 17 physical disability and transition service managers, while twenty-eight practitioners took part in focus groups.

The study was approved by the Social Care Research Ethics Committee.

The research team comprised Wendy Mitchell, Jenni Brooks, Bryony Beresford, Nicola Moran and Caroline Glendinning from the Social Policy Research Unit at the University of York.

Further information for social work staff can be found at <http://bit.ly/totop> (checklist) and <http://bit.ly/sptoto> (video) or contact wendy.mitchell@york.ac.uk, 01904 321 971.

for their support arrangements prior to transition. It appeared to help relieve parents' anxieties and enable them to support their son/daughter's desire to assume greater control and responsibility for this aspect of their lives.

Staff training

Social workers reported having had no specific training in working with this group. Many also felt that they were not sufficiently informed about condition-specific, third sector, and/or mainstream services for physically disabled young adults. Some stated they would welcome examples of creative use of PBs by this group.