

Experiences of physically disabled young adults seeking choice and control over managing their care and support

The transition to adulthood demands a lot from any young person. For young adults with physical disabilities, including complex degenerative health conditions, there is the additional challenge of taking on greater responsibilities around managing care and support arrangements. Our innovative study explores the issues and identifies user-endorsed good practice for this group of adult service users.

In Britain, we know quite a lot about how young people with learning difficulties make the transition towards adulthood and how adult social care services can support this process. Much less is known about how physically disabled young people, including those with chronic, complex or degenerative health conditions, begin to take charge of their own care and support arrangements.

‘Take, for example, an 18-year-old man with a neuro-muscular degenerative disorder such as, Duchenne muscular dystrophy who is hoping to go to university’, explains Dr Wendy Mitchell, part of a research team aiming to fill this knowledge gap.

‘If he has chosen to have a personal budget, he will have a lot to consider and organise in advance. And once at college, there is the responsibility of managing and maintaining his support arrangements and the carers he is employing. Until now, the

young man may have lived at home with family providing lots of support and advocating for him. So, as a young adult, having a personal budget can be daunting. It also raises the issue of perhaps finding a third party to manage the personal budget, sorting out tax and national insurance or possibly acting as a broker for all the bits of care he needs and wants, so basically organising the whole package for him.’

Dr Mitchell and her colleagues from the University of York’s Social Policy Research Unit (SPRU) are looking at the things that can help physically disabled young adults gain the choice and control they want as well as barriers they can face.

‘Some young adults may embrace the opportunity to assume responsibility for their care and support arrangements, others may not want to assume that level of responsibility but still feel that they have choice and control over arrangements.’



'We are talking about physically disabled young adults who want to be as independent as possible but have extensive care and support needs arising from their impairments and health condition. They have a lot to juggle and it can feel scary but also exciting – if proper support is there.'

Dr Wendy Mitchell, researcher

'We want to explore the role of statutory services and also voluntary organisations and private sector companies that have moved into the personalisation market. In the past, statutory services would have organised young adults' care but now because they have a personal budget they should have more choice and control, if they want it.'

The study will include interviews with between 20 and 32 physically disabled young adults from 4 English local authorities. A smaller sample of parents will be interviewed too.

'Young people at this age can have lots of ambitions and aspirations,' says Dr Mitchell. 'They may want to work, get a job, go out with friends and have an independent social life. Those coming back from college may not want to go back to the family home – they may want

to have their own house. We need to hear how or if these young adults are getting the support they want and feel they need.'

The team will also be speaking to managers in adult social care and transition teams and front line staff. These interviews will explore experiences of supporting this particular group of adult social care users, including any issues unique to this group and the extent to which they have found they need to adapt their approach and practice. The role of voluntary and private sector support providers will also be explored.

The aim of the study is to inform practice about how adult social care and transition support services can best help physically disabled young adults achieve the level of choice and control they want over their care and support arrangements.

Project: Taking On and Taking Over: physically disabled young adults and their care and support arrangements

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