

Choice and control: social care must not disable people with intellectual disabilities

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*People with intellectual disabilities should not have to prove their abilities in independence skills before having the right to live the life they want, argues **Val Williams**. Policy should allow for a [personalised focus](#) on the identity of an individual, with personal assistants able to step back and facilitate choice. Inclusive research helps build up this attention to detail in a relationship and can highlight how shifts might occur from being mutually supportive to becoming defensive, judgemental or even abusive.*



Disabled people should not be divided into the ‘cans’ and ‘cannots’. Choice and control are not all-or-nothing characteristics, but can be nurtured through the (extra)ordinary skills of those who take up roles as personal assistants or support workers. By looking at how these relationships play out in real life, people with intellectual disabilities themselves can help us learn more about how to manage practices in respectful ways – and to avoid practices which become neglectful or abusive.

[Inclusive research](#), where people take active roles within a project, is in itself a way of achieving ‘choice and control’. And just like with direct payments or personal budgets, inclusive research works best when there is good support from other people who will listen to you, and help you decide things for yourself. In light of the frequent scandals in English social and health care, it may seem more important to protect and safeguard people with intellectual disabilities, rather than to understand their rights to decision-making. However, we need to pay detailed attention to their everyday lives. Otherwise, we are at risk of assigning them to a special sub-category of disabled people whose life chances depend on consumerist models of care.

This theme about making decisions with others is reflected [in a recently published study](#) about the process of support planning, in which we tried to unravel the blanket of assumptions which sometimes prevent people with intellectual disabilities from enjoying their rights to ‘choice and control’. With the implementation of the new [Care Act](#) the principle of ‘wellbeing’ lies at the heart of both assessments and support planning. Yet a personal budget user tends to be treated in practice either as someone who ‘can’ do it for themselves, or as someone whose family and carers will protect them from making the wrong decision.

[Our research](#) about support planning asked people with intellectual disabilities themselves about their experiences with personal budgets. Their words led us to believe that people can grow more confident in managing their relationships with others, and that increased self-confidence will mean a better chance of being in control of their lives. Three important areas of focus stood out:

- **Identity matters:** People in this study demonstrated in their interviews how they relied on praise and encouragement, and when this was not forthcoming, they became anxious or unsure of themselves.
- **People in your life:** One woman in our study said: *‘I’ve got control. You know, me and [my personal assistant] can sort of sit down and we’ll work out dates and that.’* However, there was a tendency to see oneself as always at fault, as morally unworthy, and certainly as a constant learner. The phenomenon of ‘control’ was not seen as an individual accomplishment, but as something that was enacted together with others, and some spoke of the professional staff who supported them by first name, and considered them to be potential friends and people to trust with problems.

- **Personal budget processes:** When it came to the actual processes involved in a personal budget, our participants showed considerable confusion. They generally liked the idea of ‘meetings’, but relied on others telling them what would happen in those meetings which seemed a little like oral One man whose review meeting was coming up said: *‘I’ll just listen to what they say. Just wait and see...I don’t know until I get there’*. Despite all this, several people spoke about the value of trust in relationships they enjoyed with friends and peers in self-advocacy groups, with their personal assistants, and other practitioners. They all wanted an approach which was truly personalised, and they cared about the small details in their day-to-day living and in taking action to give something back to the community.

What does all this mean then for policy? One of the key points is that functional ability and skills should not be confused with the right to choose, with ‘autonomy’. People should not have to prove their abilities in independence skills, before having the right to live the life they want. This shift towards a [personalised focus](#) on the identity of an individual is the meat of person-centred planning.

Equally, with the trust placed in one’s own supporters, the skills of a personal assistant to step back and *facilitate* choice are very much at the heart of a successful personal budget. More attention to the detail of personal assistant practices and relationships will help us to see how they can get stuck, how support practices can move from being mutually supportive towards becoming defensive, judgemental and even abusive.

Conversely, of course, we can also look at these relationships to see how positive facilitation and support takes place. This is what our new research is doing, with a focus on understanding social practices in ways that help us to make changes, on the terms of people with intellectual disabilities themselves. ‘[Getting Things Changed](#)’ is planned and carried out in co-production with disabled people, and one of the strands of this project is working with a local drama group, [The Misfits](#), to help us understand the way in which young people with intellectual disabilities learn those ways of being more confident in themselves, in interaction with a personal assistant.

Please [get in touch](#) with the author if you want to know more or take part in this further research.

About the Author

Val Williams is a Disability Studies researcher at the University of Bristol. Her key interests are ways of conceptualising change in policy and practice, on the terms of disabled people themselves. She is executive editor of the international journal [Disability & Society](#) and Head of the [Norah Fry Research Centre](#).

