

# Exploring the Relationships between Choice and Independence: Experiences of Disabled and Older People

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## Abstract

Extending choice and control to the users of publicly funded services is a cornerstone in the personalisation agenda. It is assumed that giving service users greater choice and control will promote users' independence. As service users are increasingly given the responsibility to determine their support, social work practitioners need to work differently with service users in order to provide personalised support in exercising choice. This requires practitioners having a nuanced understanding of people's concepts of independence, how people make choices about support services and how those choices can impact on their perceived independence in the longer term. This paper reports new findings from a longitudinal qualitative study of choice and control over the life course in England. Semi-structured interviews were carried out with fifty adults and older people experiencing fluctuating support needs and/or a sudden deterioration in health. The paper discusses the relationships between choice and independence as experienced by disabled and older people. The findings show that independence is not a fixed concept, but is relative and multidimensional. There are multiple relationships between the choices people make and the consequences of those choices for people's subjective views of their independence. The paper concludes by highlighting the implications of findings for the role of social work practitioners.

**Keywords:** Choice, independence, disabled people, older people, longer term, social care

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## Introduction

Extending choice and control to the users of publicly funded services is a cornerstone in the personalisation agenda, which was central to the previous Labour government's policies in England (Department of Health, 2006, 2008; HM Government, 2007) and is supported by the current Coalition government. Measures to increase choice and control in social care include Direct Payments and Personal Budgets. The development of such schemes has been largely driven by the demands of the disability movement for increased independence and control (Morris, 2006; Barnes, 1993). More recently, In Control has actively promoted greater choice and control on behalf of people with learning disabilities. It is assumed that, by giving service users greater choice and control over the way in which their needs are met, services help maintain users' independence (Department of Health, 2005). In the Cabinet Office Strategy Unit's report, *Improving the Life Chances of Disabled People* (Cabinet Office, 2005), the government committed itself to bring about an improvement in disabled people's life chances over the next twenty years, which later led to the development of the Independent Living Strategy in 2008 (HM Government, 2008). The approach adopted in that report supports the idea that, without choice and control, autonomy, self-determination and citizenship cannot be achieved.

Research shows that choice is a highly problematic concept with multiple challenges for many disabled people (Beresford and Sloper, 2008; Lent and Ardent, 2004). While it can be argued that having choices in itself is good for people's welfare, disability writers have promoted choice as having viable options and control over personal support and not simply as consumer choice promoted by current policies. Linking the concepts of choice, control and independence, Morris points out that, by increasing opportunities for individuals to exercise choice, they will be able to exercise control over the services and support they need to live independently—which may, in turn, facilitate the exercise of choice in other areas of daily life (Morris, 2006). Giving people choices in social care, personal support and similar services is also argued to be central to conceptions of independence among older people (Parry *et al.*, 2004).

Similarly, the concept of independence is contested. Care researchers have been alleged to view disabled (and older) people as passive recipients of care, unable to exert choice and control, making it impossible to promote an independent life (Brisenden, 1989; Corbett, 1989; Morris, 1993). As Morris points out, the perception of disabled people as powerless suggests that one cannot have 'care *and* empowerment' (Morris, 1997, p. 54, emphasis in original). Challenging this notion of 'care', disability writers have argued that what impacts upon disabled people's sense of independence are the structural and attitudinal barriers that society imposes on

them and not the physical and mental limitations of individual people (Oliver, 1989; Barnes, 2004).

Oliver claims that, in advancing the idea of independence, professionals and disabled people have not been talking about the same thing. Professionals tend to define independence in terms of self-care activities and measure it against skills in relation to performance of these activities (Oliver, 1989). Disabled people, however, define independence not as being self-reliant, able to care/perform activities for oneself without assistance, but as being able to make decisions about one's life and exercise control over whatever help is required in order to achieve chosen goals and objectives (Brisenden, 1989; Oliver, 1989; Morris, 1993; Barnes, 1991). So independence is viewed as 'a thought process not contingent upon physical abilities' (Barnes, 1991, p. 129).

For older people, a similar distinction is made between the process of making decisions and the ability to implement, operationalise and carry them out independently (Collopy, 1995). Boyle (2005, p. 734) distinguishes between 'decisional' and 'executorial' autonomy and suggests that, for frail older people, mental ill health is more likely to be associated with constraints on the capacity to make decisions than with restrictions on the capacity to execute those decisions independently (Glendinning, 2008). This means that 'someone may continue to exercise a substantial level of decisional autonomy, which maintains a sense of self and personhood intact, even though the execution of those decisions may involve others' (Fine and Glendinning, 2005, p. 610).

Others have argued that the dependence/independence dichotomy is misleading and should be replaced with the notion of 'interdependency' based on the idea that mutual dependence is the central concern for all human beings and not just disabled or older people (Tronto, 1993; Sevenhuijsen, 1998). Reindal (1999) defines independence in terms of 'partnership' and a two-way responsibility and not solely an individual ability. Similarly, Shakespeare argues that the language of dependency should be replaced by the notion of human interdependency, as the notion of dependency is both 'individualising' and 'excluding' (Shakespeare, 2000). Supporting the argument for interdependency, Barnes has pointed out that the same person can be a care-giver and care-receiver, either at the same time or at different times (Barnes, 2006, pp. 142 and 143). This is said to be the case for many disabled women who themselves have care responsibilities (Morris, 1993).

At a more practice level, research shows that measures to increase choice and control have the potential to transform the organisation and delivery of adult social care and improve the lives of people using public services (Glendinning *et al.*, 2008). However, for a choice-based system to reach its full potential in achieving desired outcomes, social work practitioners may need to play a distinct role in supporting people to make choices based on their preferences and aspirations. This, in turn, requires

practitioners to understand people's concepts of independence and consider how choices they make about support services can impact on their perceived independence in the longer term.

The expectation that personalisation would affect social work roles and some of the challenges for the social work practitioners in that process is documented in existing research (Glendinning *et al.*, 2008; Manthorpe *et al.*, 2011; Newbrunner *et al.*, 2011). However, less attention has been paid to the training that might be necessary to transform social workers' current roles and practices, or to the evidence on which that training is based (Manthorpe *et al.*, 2009). There is evidence that, sometimes, practitioners are unsure of what managers expect from them (Parley, 2001) or they consider that the choices people make about services may be at odds with their professional expectations and expertise (Kilbane and Thompson, 2004) or with their training and beliefs (Todd, 2002). While evidence suggests that some staff have welcomed the principles underlying the new approach (Glendinning *et al.*, 2008), others have been alleged to be more resistant to change because they believe they lack professional skills to work within the new system (Duffy, 2007).

Moreover, despite growing policy interest to promote choice and independence for older and disabled people, much of the existing literature relating to independence has been either written from theoretical perspectives or has been specific to issues concerning people with learning difficulties (Nota *et al.*, 2007; Arvidsson and Jonsson, 2006) or limited to specific settings (Rock, 1988; Boyle, 2004). Another gap in the existing evidence base is the lack of longitudinal research looking at the relationships between choice and independence over time, as research to date has been largely cross-sectional and based on 'snapshots' in time. The key strength of longitudinal qualitative research is that it captures the fluidity of experiences and the dynamic nature of people's lives (Saldana, 2003; Leisering and Walker, 1998) and explores connections between events that are widely separated in time (Hakim, 1987).

Given such gaps in the existing evidence base, it is still not clear whether independence means the same thing to everybody and how choices disabled and older people make about support services impact on their perceived independence in the longer term. The purpose of this paper is to fill in this gap. It does this by focusing on not only choices relating to health and social care, but also choices made within other domains such as employment, transport and housing. Particular attention is given to how those relationships can fluctuate over time and what factors might affect them. The findings are highly relevant to social work practice because, without such knowledge and understanding, social work practitioners may not be able to offer the appropriate support that people need in order to exercise choices—across a wide range of domains—that optimise independence in the face of changing needs and circumstances.

## Methods

This paper draws on findings from fifty disabled and older people who took part in a qualitative, longitudinal study exploring choice-making in the context of changing circumstances. Multicentre NHS research ethics approval for the study was obtained.

Thirty-two participants were aged between twenty-five and sixty-four years; eighteen were aged sixty-five or over. Sampling was theoretical; participants were selected purposively to include people whose conditions were likely to change over time, meaning that they had to make repeated choices, and those with sudden onset of support needs making welfare-related choices for the first time. Thirty adults and older people had fluctuating support needs (AF & OF) and twenty had recently experienced the sudden onset of a disabling condition (AS & OS). A pre-defined sampling quota aimed to ensure diversity within each of these groups of participants in terms of gender, ethnicity and household composition. About a third of those under sixty-five lived with dependent children. One of the adult participants had limited speech and was interviewed using 'talking mats' (Murphy, 1998), a visual framework using symbols. Two participants were interviewed through interpreters.

Participants were recruited from user-led specialist/condition-specific voluntary organisations and support groups; hospitals; social services; minority ethnic community groups; an independent recruitment agency; and 'snowballing' from other study participants. An advisory group representing disabled adults and older people was involved in the development of the topic guides and commented on the study findings.

The types of information the study sought included respondents' perceptions, subjective feelings and lived experiences. Consequently, semi-structured interviews were used for data collection to generate qualitative data. Each participant was interviewed three times between 2007 and 2009. Participants were asked in the first two interviews to discuss in detail a recent important choice they had made about support services, including factors they took into account and the outcomes of the choice. In addition, in part of the second interviews, participants were asked about their views on independence, particularly what independence meant to them and if/how the choices they had discussed in the first and second interviews were related to the issue of independence. In the subsequent interviews, participants reflected back on the choices discussed in earlier interviews and anticipated future potential choices. This paper is based on data from all three rounds of interviews.

Interviews were digitally recorded and transcribed. The data were analysed by a process of data reduction and display, conclusion drawing and verification (Miles and Huberman, 1994). The research team read a sub-sample of transcripts to identify emergent themes and then agreed a

framework for analysis. A computer-assisted qualitative package (MAXqda2) was used to code the data. A series of charts was devised addressing issues relevant to individual rounds of interviews as well as longitudinal themes from different rounds. Conclusions were verified by checking transcripts and through ongoing discussions within the research team.

## The meanings of independence

The findings from this study show that independence is not a fixed and 'given' concept, but is highly relative, conditional and multidimensional. The meanings participants associated with independence varied from person to person. The following are some of the main features that participants used to define what independence meant to them:

- being able to do things on your own;
- being in control and able to make decisions;
- freedom of movement to go where you want to go and do what you want to do;
- being self-sufficient, as in not being reliant on anything and anybody;
- ability to maintain personal mobility;
- the confidence and the ability to be who you feel you are;
- having financial security and control over your money; and
- being able to live in your own house.

However, for many participants, independence had multiple components and it was not simply the case of either being 'dependent' or 'independent'. They often regarded themselves as being more or less independent in different areas of their lives (e.g. being financially dependent but able to take care of their personal care) and in relation to how they were affected by their condition at any one time (e.g. becoming more dependent on others during relapses). Whatever the participants' perceptions of their own independence, most people associated the loss of their independence with being forced into making a particular 'choice' because there were no realistic alternatives and/or support to make choices:

To me independence is that what I want is what happens . . . if I can get into the supermarket then I can shop . . . but if somebody takes my disabled parking space then they've taken my independence, because I no longer can exercise that choice (AS125).

The longitudinal analysis of the data revealed some differences between participants with fluctuating conditions and those who had recently acquired a disabling condition. The first group, particularly those whose

conditions had significantly deteriorated over time, reported that they had reached a point at which they were not anymore able to physically do things for themselves but they were still able to make decisions and that was very important to them. Hence, they had redefined their views of independence from being able to do everything for themselves to being in charge and having control over their life. Whether or not they were able to do things for themselves became less important to them. However, many participants noted that it would be no good making decisions if they did not have the support they needed to implement them.

In contrast, a couple of participants who had recently acquired a disabling condition seemed hopeful to regain at least some of their reduced/lost capacity and this was apparent in how they viewed their independence. For them, independence would only be possible if they were able to resume 'normal' activities of daily living (e.g. washing, dressing) for themselves without help.

The difficulties with coming to terms with an impairment and the desire to avoid any stigma felt to be associated with being 'disabled' or 'old' had prevented some participants from asking for help when they felt they needed it. Several people said that they were 'forced' to accept advice and ask for help when they realised that their physical independence was being 'stripped away' and that using aids and adaptations would enhance their feeling of independence. A number of participants who had longer experience of living with an impairment said that what was important to them was to know how to maintain a balance between doing things and asking for help. For people with dependent children, the added pressure to ask for help came from the understanding that whatever decisions they made were not just about them, but impacted on their children, too:

I have got that stubborn ignorance to say, come on, you can do it . . . . But then another part of me says, you can't be mummy and daddy at the same time and, when you are down you're down and you're gonna have to ask for help to get up . . . (A single mother—AF122).

## Relationships between choice and independence

### *Making choices to maintain independence and possible barriers*

Maximising/maintaining independence, however participants viewed it, was a major factor in almost all choices that participants talked about in this study: for example, choices relating to equipment, housing/adaptations, transport (e.g. having an adapted car) made to maintain/maximise physical mobility; and decisions about social care arrangements made to maintain choice and control over the support that participants received. Many people made choices relating to employment (e.g. reducing hours at work), to safeguard their financial independence in the longer term. Other choices were made to protect people's health (e.g. having an



operation or having time off work for ill health). While these choices were not directly driven by independence issues, they were nevertheless reported to have had indirect consequences for participants' subjective view of their independence (e.g. taking time off work due to ill health could threaten one's employment opportunities and jeopardise their financial security). Choices that were likely to increase participants' dependence on others or limit their control over their lives were often viewed negatively, even when they were at the expense of potentially positive outcomes such as improving their own health.

In line with other research (Lock *et al.*, 2005), the findings reveal that choices that would enhance independence for disabled and older people were often constrained by structural difficulties, attitudinal barriers and the way support services were organised. As Morris (2004) has pointed out, such restrictions help maintain dependency rather than promote people's independence. For example, several participants said that eligibility criteria for services had limited their choices and undermined their independence. One person explained that, while she could still manage at home without using a wheelchair, she felt unsafe to go out without one, which meant that she did not go out on her own. She applied for an electric wheelchair, which she could use independently, and the response she had was:

... even though ... you medically need it, you have to be a full time wheelchair user to get an electric wheelchair, and ... if you're not using it in the house then you're not a full time wheelchair user (AS125).

Consistently with other research (Priestley *et al.*, 2007; Glasby, 2005), participants using Direct Payment in this study felt that these arrangements had enhanced both their decisional and executional autonomy. Direct Payments made people feel more in charge in terms of what to get done, how to get it done and when to get it done. However, as Arksey and Baxter (2011) have reported, participants using Direct Payments in this study were frustrated by a lack of continuing support and clear guidance on the use of Direct Payments and felt that it was important for the advisers to draw attention to potential longer-term consequences of using the scheme at the outset, as well as providing information about issues of immediate relevance.

### *A dynamic relationship*

The examination of participants' experiences over time shows that there are multiple relationships between choices made and the consequences of those choices on people's subjective views of their independence. In some circumstances, the choices made were straightforward, with immediate effects on people's independence, such as choosing an adapted car, bath seat or walking frame promoted physical independence. However, in the majority of cases, the relationships between choices and subsequent independence were much more complex, often requiring multiple choices being made in



different areas of life before any of these choices had a chance to impact on people's sense of independence. For example, for some people, choices made in relation to equipment precipitated further choices in relation to housing, employment and transport.

People with deteriorating conditions had to make a series of choices over time to maximise their independence as their health deteriorated. For example, one person who had recently started to use a wheelchair had to have some adaptations in her house to make it wheelchair accessible. A year later, she had to have further changes made to install a wet room. In two years' time, she said her condition had deteriorated to the extent that some of the original adaptations were no longer useful; instead, she needed to have hoist tracks. In hindsight, she said she wished she had hoist tracks installed at the time of building work because having it done later would be more costly, difficult and disruptive, but no one had given her any advice on that earlier. This raises an issue about 'future-proofing' decisions and the need for information about potential impacts on independent living in the longer term. However, not all participants wished to make long-term trade-offs between choices aimed at maximising independence. Some prioritised choices that maintained their sense of independence in the shorter term, even at the potential risk of their future independence.

### *Choices and unanticipated consequences for independence*

Some choices were made with the aim of safeguarding independence but had unanticipated consequences or proved less effective in maintaining independence than anticipated. For example, a participant who had experienced a sudden onset of a disabling condition decided to make an early return to work because she wanted to prove to herself and to others that she was still capable of working. At the time of her first interview, she was working two days a week, intending to increase to full time. A year later, she was working four days a week and still happy to have made the decision, even though she said her health had deteriorated and she had been financially worse off, to begin with, because she had lost her Incapacity Benefit. However, reflecting back on her decision, at her third interview, she was not sure whether, health-wise, she had taken the right decision because doing the job had meant that she was not able to keep up all her doctor's appointments and that had damaging consequences for her health.

While some choices helped people achieve independence in one area of their life, they unexpectedly created dependency in another area/s over time. For example, a participant with a fluctuating condition who had recently started to use a wheelchair moved into a bungalow to accommodate her manual wheelchair. The move increased her independence, but the deterioration of her health between the first and second interviews

meant that she was no longer able to manage her manual wheelchair without help. She got an electric wheelchair to maximise her independence. The unexpected consequence of using the electric wheelchair was that she lost the opportunity of using her local taxi company independently (for health and safety reasons), as she was told that the only way she could do that was if she had somebody accompanying her. In retrospect, she was not convinced that relocating to the bungalow had much improved her independence. Neither did she think that there was a particular advantage in her having an electric wheelchair. She thought the wheelchair was going to be her freedom but she was beginning to feel like a prisoner in her own house.

The ability to live in their own home was highlighted by several people as an important aspect of their independence. The fear of moving to a residential care home had prompted some participants to make choices about having some adaptations in the house:

... now I've got a stair lift, there's not a risk, hopefully, that they can put me into care, because this is what's happening. They're putting people into care, and that's what most people absolutely dread (OF200).

However, the findings support other research (Boyle, 2004) that receiving care at home does not always enable older people to have greater choice and control in their everyday lives than those living in residential care. Physical/environmental barriers can significantly constrain choice and independence for many older and disabled people. One participant who was looking forward to being discharged from hospital felt that, by going home, he lost a great deal of the physical independence he had experienced in the hospital:

Once you get home it's totally different ... I used to say 'I wish I were back in hospital' ... they wheeled you to a sink and I could shave half me face and clean me teeth, wash a bit of me face, wash me chest and me arms, but here of course there's no sink to go up to. So they wash me ... laid in bed, and you think well I'm not doing anything ... you're back to where you started when you're at home 'cos there's no facilities for that, you know (AS115).

### *Choice, independence and family relationships*

Supporting the argument for the notion of interdependency, the findings reveal that choices relating to independence were not made in a social vacuum, but were more often than not shaped by the contexts of care-giving and family relationships, with knock-on effects on others. For some, choices made to maximise independence focused on their ability to give care. Many participants had made choices to be near their sons and daughters, not only to have their support, but also to support their families, such as by looking after their grandchildren. A number of participants made choices about medication that they would have otherwise considered risky, in order to speed up their recovery so they could look after their elderly parents.

For participants with dependent children, maintaining a sense of independence sometimes necessitated making huge trade-offs between outcomes for themselves and for their children over time. For example, a single mother with multiple sclerosis (MS), who had a fierce ambition to be financially independent, mentioned on her first interview that she had been 'forced' to give up the nursing course, which she thought would have secured her future financial independence, because her disabled child was having a severe episode with his condition. A year later, although her son's and her own condition had improved, she was feeling depressed for relying on welfare benefits. This had made her feel that she had failed to achieve both as a mother and as a woman. So she decided to change her career option and settle for a part-time vocational training, which she thought was more suitable to her circumstances. At the time of her third interview, she had taken up a flexible job on 'as and when you come' basis. In hindsight, she thought that, even though she was not making a lot of money, the choices she had made had some positive outcomes, as they had enabled her to provide her child with the support he needed.

Choices made sometimes created 'enforced dependency' on a partner or a relative with a view to maintaining personal independence. For many, relying on family carers was considered to be the only viable option that could help maintain their independence. People with fluctuating support needs felt that the lack of access to flexible support was the main reason for their dependency on family carers. For example, one participant who was in full-time employment explained that she had to rely on her husband for the support she needed because she was not able to have paid carers at times that enabled her to get to work and maintain her financial independence.

However, dependency on a partner or a relative sometimes limited disabled people's choices in some areas. Moreover, the increased independence generated by family carers could sometimes be at the cost of carers' own independence. For example, one participant said that her husband left his job to become her designated carer, knowing full well that going back to work would not be easy for him. The decision to leave his work affected his career prospects as well as his social life:

... he didn't go out with his friends for three months ... He was very conscious ... he felt he wasn't a man cos he wasn't working ... and that's why he had to get back to work quickly ... to give him some pride back ... so that he could go back to feeling like he, he was a person, you know, he, he wasn't just a skiver (AF131).

Dependency on partners could also alter the 'balance' and the power dynamics of the relationship. While one person felt that dependency on her partner had brought them closer to each other, most others said that they had more arguments. A couple of people said they had even considered splitting up at one stage. Participants who had relied on family carers for

support thought it would have been helpful if practitioners had provided more information at the outset on the short and longer-term implications of involving family members in their care arrangements.

Other people made choices to maintain their independence from their families and turned to formal services for support. Sometimes, those choices had negative consequences for the disabled person's own independence due to the inadequacy of appropriate support from formal services. For example, a participant with multiple impairments (including communication impairments) who lived with his mother decided to go into a care home to give his mother some freedom. Reflecting back on his move two years later, they both felt that the move had given his mother some of her freedom back, but it had limited the son's decisional autonomy and control over his life, as the staff in the care home were not able to communicate with him.

## **Discussion and conclusions**

This paper fills a gap in current research evidence by providing new empirical longitudinal evidence to show what independence means to disabled and older people and to explore the relationships between the choices these people made about support and related services and their subjective views of independence over an extended period of time.

The in-depth qualitative insights extend our understanding of the multi-dimensional nature of the concept of independence. In contrast to the views that define independence in terms of self-care skills or ability to make decisions, the findings reported in this paper demonstrate that independence is highly relative, conditional and subjective and not 'fixed' or 'given'; therefore, it can mean different things to different people. For some, independence is more about being able to do things on their own; others feel what is more important for them is being in control of their lives and being able to make decisions. Some people feel independent if they are able to live in their own house. Others feel independence is more about having self-confidence and the ability to be themselves. However, the findings illustrated that choices do not always lead to independence and being forced into choices because of lack of knowledge about available alternatives can compromise independence.

The findings also reveal that independence is variable. So, rather than regarding themselves as 'dependent' or 'independent', most participants felt they were more or less independent in different areas of their lives, and this balance was subject to change, depending on their circumstances at any one time and how these affected their support needs. The longitudinal analysis of the data showed that some participants redefined what independence meant to them over time, from being able to do everything for themselves to having control over their lives. Nevertheless, being able to

make choices was still central to feelings of independence for people whose conditions had gradually deteriorated over time.

The experiences of participants in this study illustrated that there is a clear link between choice (and control) and independence (however defined). In general, people made choices about support arrangements that would maintain their independence for longer, or help minimise their dependence on other people. However, the findings show that the relationship between choice and independence for disabled and older people is not always as simple and linear as choice policies assume, but it is often complex. Choices can involve trade-offs between different outcomes, and those trade-offs can be short-term or long-term: some choices are viewed negatively even at the expense of other potential positive outcomes; other choices might be viewed positively at one time but negatively at another time.

The longitudinal nature of the study provided a unique opportunity to explore the relationships between choice and independence as a dynamic process over the time. Sometimes, participants had to make a series of choices in different domains before any of these choices could begin to have an actual impact on their sense of independence. Sometimes, choices made at one time precipitated other related choices being made later to maintain people's independence as their health deteriorated. Other choices had unexpected consequences for people's own independence and that of their close family members. Concerns about independence also affected the timing of choices; some participants delayed making choices in order to maximise their current levels of felt independence. For others, sustaining independence in one aspect of life created dependency in other domains or formed 'enforced dependency' on a partner/relative.

The findings reported in this paper have important implications for social work practice. They highlight the importance of social work practitioners understanding the great variation of individuals with whom social work is engaged and the contexts in which people make choices as their circumstances change. The variability in individual concepts of independence means that practitioners need to have a broad view of independence rather than assuming that it means the same thing to everyone. Equating independence with doing things 'on your own' and assessing it against the physical capacity of individuals to perform activities fails to recognise the potential to be independent for people who can use help to make decisions and/or perform daily tasks.

Furthermore, changes in people's support needs and circumstances over time suggest that there is a need for regular reassessment and recognition that people may choose to compromise current independence for future independence and vice versa. It is therefore crucial for social work practice that assessments and responses to needs are timely, flexible and based on

individual circumstances and not determined by the priorities of existing services, if they are to have a real impact on people's lives.

The findings also demonstrate the importance of practitioners' role in supporting people not only in terms of immediate needs, but also in thinking about future possible needs and, wherever possible, the longer-term consequences of choices they make. This requires both the availability of timely information and the ability to support people through the whole process of choice-making.

As shown in this paper, independence can involve a wide range of services and not just social care. This requires effective partnerships and co-ordination of multiple service inputs as well as a holistic approach to assessment. However, while partnership and multi-agency working are key drivers of the government's health and social care policies, evidence from this study shows that professional and agency boundaries still appear to constrain choices that can enhance independence for disabled and older people.

Finally, as the findings indicate, 'independence' may include both being responsible for others as well as being dependent on others within the family context. This highlights the importance of social work practitioners' role in adopting a holistic family approach: recognising the care and support that people give to others, while at the same time paying attention to roles and responsibilities of informal carers to ensure that maximising independence through dependence on those carers does not disproportionately jeopardise their independence.

The findings reported in this paper are of direct relevance for social work practitioners, particularly in the context of the widespread implementation of self-directed support arrangements. They highlight the importance of offering disabled and older people appropriate support in exercising choice if they are to benefit from the changed agenda for social care. The findings also indicate the critical importance of understanding what independence means to individual disabled or older people, and how these meanings may change over time. A nuanced and flexible understanding is essential if practitioners are to help service users maximise the opportunities for exercising choice and control as new self-directed support arrangements are rolled out across adult social care.

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